

UCLA

UCLA Electronic Theses and Dissertations

Title

Invisible Bodies: Representing Gender and Gender Variance in Medical Records and Health Data

Permalink

<https://escholarship.org/uc/item/0nq6j6np>

Author

Wynholds, L. A.

Publication Date

2018

Peer reviewed|Thesis/dissertation

UNIVERSITY OF CALIFORNIA

Los Angeles

Invisible Bodies:

Representing Gender and Gender Variance in Medical Records and Health Data

A dissertation submitted in partial satisfaction of the requirements for the degree

Doctor of Philosophy in Information Studies

by

L. Wynholds

2018

© copyright by

L. Wynholds

2018

ABSTRACT OF THE DISSERTATION

Invisible Bodies:

Representing Gender and Gender Variance in Medical Records and Health Data

by

L. Wynholds

Doctor of Philosophy in Information Studies

University of California, Los Angeles, 2018

Professor Anne J Gilliland-Swetland, Chair

Prior to 2010, there was virtually no population-based health data on trans and gender variant populations at the federal, state, or local level in California. This population was completely invisible in health data. This research project took the formation of such an odd silence in the data as the motivation to form a qualitative approach to studying how gender has been encoded in medical records and health data in California. The project focused on identifying which aspects of gender were able to be recorded and what aspects were not able to be represented within the affordances observed in the recordkeeping structures. The research materials documented practices in public health and medical recordkeeping contexts at a critical historical juncture, when practices were in flux, both locally and nationally, focusing on three research sites in California: in San Francisco, Los Angeles, and Sacramento. All of the

sites were directly engaged with recordkeeping questions around how gender is encoded for trans and gender variant populations, working collaboratively to develop the information structures for representing gender and gender variance in their recordkeeping systems.

The analysis produced documentation of the information structures encoding gender at each of the sites and concluded that there are six (6) major functional information recordkeeping elements conflated under the current system of binary gender markers, including elements of gender identity, social gender (pronouns), medical gender, legal gender, organ lists and sex assigned at birth. Several of these elements operate in unrelated fields of policy discourse, such as those around identity documents (legal gender) versus medical diagnoses (medical gender). These overlapping policy environments often conflict in reality, yielding uncountable populations of trans and gender variant persons attempting to access care with unresolvable incongruence between the legal, medical and social records of gender.

Disparities around recording individual instances of gender variance created systemic disparities in medical systems built upon the statistical aggregation of evidence. This observation suggests that system designers need to better account for edge effects in data structures. These populations who are poorly represented within data structures, especially as these recordkeeping systems are scaled up to include the entire general population writ large. Many patients still withhold gender identity information from healthcare systems, which suggests that conflicts in recordkeeping practices cannot be resolved without first addressing basic safety and data security issues for trans and gender variant populations.

The dissertation of L. Wynholds is approved.

Leah A Lievrouw

Jonathan Furner

Sharon J Traweek

Anne J Gilliland-Swetland, Committee Chair

University of California, Los Angeles

2018

INVISIBLE BODIES:
REPRESENTING GENDER AND GENDER VARIANCE IN MEDICAL RECORDS AND HEALTH DATA

TABLE OF CONTENTS

0: Title	i
Abstract.....	ii
1: Introduction	1
Purpose of Research	3
Research Questions.....	5
Project Description.....	7
Motivation.....	10
Significance	15
Cited References (Introduction).....	17
2: Historical Background	20
Sub-chapter table of contents	20
Cited References (Background).....	59
3: Literature Review	66
Sub-chapter table of contents	66
Cited References (Literature Review)	123
4: Methods.....	140
Sub-chapter table of contents	140
Cited References (Methods)	161
5: Descriptions of Research Data	163
Sub-chapter table of contents	163
Cited References (Data Descriptions)	203
6: Analysis	204
Sub-chapter table of contents	204
Cited References (Analysis).....	270
7: Discussion.....	275
Sub-chapter table of contents	275
Cited References (Discussion).....	285
8: Conclusion.....	286
Social Aspects.....	286
Recordkeeping Structures.....	288
Future Work	289
Final Thoughts.....	291
9: Appendixes.....	292
Appendix I: Historical Timeline	292
Cited References (Appendix I).....	301
Appendix II: Explanation of Types of Research Materials.....	302

LIST OF FIGURES

page

Chapter 1

Figure 1: Data cycle showing data dependencies between knowledge systems..... 4

Chapter 3

Figure 2: Bar graph showing gender distribution in California, 2010..... 100

Figure 3: Gendered hormone sample distribution 102

Chapter 4

Figure 4: Sample participant interview questions..... 156

Chapter 5

Figure 5: Summary of research data source types and their geographical breadth..... 167

Figure 6: Summary of research data source types across research sites..... 169

Figure 7: Summary of Gender Identity Data Elements..... 174

Figure 8: Summary of Data Elements for Pronouns..... 175

Figure 9: Summary of Data Elements for Sex Assigned at Birth..... 176

Figure 10: Summary of Data Elements for Legal Gender..... 177

Figure 11: Summary of Organ Registry Data Elements.....178

Figure 12: Summary of Data Elements for Hormone Status..... 179

Figure 13: Questions tested in CHIS pilot study.....183

Figure 14: Sample text from Gender Health Center Patient Intake Form..... 187

Figure 15: Gender Health Center Intake Form,
Transgender Health History, Supplemental Form..... 188

Figure 16: Lyon Martin patient update form, February 2014..... 191

Figure 17: excerpt from UCSF Center of Excellence in Transgender Health's 2011
data collection recommendation..... 193

Figure 18: Lyon Martin patient demographic intake form (Feb 2016),
excerpt from pg 2..... 194

Figure 19: Lyon Martin patient demographic intake form (Feb 2016),
excerpt from pg 1..... 194

Figure 20: Excerpt from Lyon Martin Trans Intake Form
(acquired Feb 2016, form dated 2007)..... 195

Figure 21: Bay Area Reporter news story on Lyon Martin, January 2011..... 201

Chapter 6

Figure 22: Summary of Major Recent Health Policy Changes in California..... 218

Figure 23: Word cloud showing themes developed during coding process..... 221

Figure 24: Summary of coding terms developed for themes..... 223

Figure 25: TransLine Poster from WPATH/USPATH conference at UCLA (2017)..... 269

Chapter 7

Figure 26: Summary of Recommendations for Data Elements..... 284

ACKNOWLEDGEMENTS/PREFACE

Because this research project is situated at an interdisciplinary intersection of post-modern methods and observational theory, I had to address some basic epistemological questions prior to writing a dissertation. Throughout the process of designing the research, selecting methods, positing a focal point for the inquiry, and preparing a manuscript, I had to face a number of bigger questions: How do I know if these methods are appropriate to my research questions? How do I know that this method of data collection will yield the intended level of insight for the analysis? How will I ascertain the validity of the research? At what granularity does it make sense to study this problem? How does one interact with and relate to multiple granularities of evidence and data simultaneously? How do I know whether I've selected a meaningful time frame and time increments for the trends I'm observing? At every juncture, I've been enormously lucky to have an educational environment that provided meaningful feedback and encouraged working through these types of epistemic questions.

As I dug into these questions and began writing about the topic, I found that I had to re-examine some of my very basic assumptions about research and academic writing. I had to establish a perspective, a voice from which to establish authority in describing the materials and research. While it sounds simple, the question derived from practical concerns about whether one could draw valid conclusions and productive dialogs from such disparate and heterogeneous evidentiary traditions, academic discourses and functional vocabularies. Over the course of writing the manuscript I have aimed to articulate presentations of evidence without underplaying these limitations of perspective. I have attempted to speak

authoritatively of what I have observed without totalizing the experience or underplaying the enormity of the parts which are unknowable. If I am to speak about the problem of tunnel vision and blind spots within a structure of medical and public health records, I needed to be confident that I too would not be blindsided by the complexity of the topic and by limitations in the data. While any errors in this research are entirely my own, any successes have been the result of the legacy of generosity in the formative intellectual instruction I have received.

Dissertations, in general, are written to demonstrate independent mastery of a detailed course of research including a demonstration of well-formulated mode of inquiry. But this manuscript is equally the product of a specific set of discussions fostered by a generative educational environment. None of this would have been possible without a decade of support, feedback and encouragement of my family, my colleagues, my faculty committee and especially my chair, Professor Anne Gilliland. I have benefitted beyond words from their instruction and research mentorship. I am equally indebted to the dozens of educators, researchers and professionals who took the time to share their experiences with me during my data collection efforts. I am also indebted to the majesty of the National Park System and the Angeles National Forest, where much of this manuscript was conceived and written.

-lw

November, 2018

Sacramento, California

VITA ***L. Wynholds***

EDUCATION: MASTER OF LIBRARY AND INFORMATION SCIENCES, MAY 2009
University of Wisconsin, Madison
B. S. IN ENVIRONMENTAL & RESOURCE SCIENCES WITH HONORS, DECEMBER 2002
B. A. IN GERMAN WITH HONORS, DECEMBER 2002
University of California, Davis

PAPERS:

- Wynholds, L. (2014, July 17) Invisible Bodies: Information Structures for Representing Gender and Gender Variance in Medical Record-keeping Systems. Presented at the 2014 Archival Education and Research Institute (AERI), Pittsburgh, PA
- Sands, A., Borgman, C. L., Wynholds, L., & Traweck, S. (2014, February). "We're Working on It:" Transferring the Sloan Digital Sky Survey from Laboratory to Library. Presented at the 10th International Digital Curation Conference, San Francisco, CA
- Wynholds, L. (2012, October). *Temporalities of Mobility: When to assemble a sensor network and when to assemble a network of data. (In the session: Promises and perils of sensor networks)*. Presented at the Annual Meeting of the Society for the Social Studies of Science, Copenhagen, Denmark.
- Wynholds, L., Wallis, J. C., Borgman, C. L., Sands, A., & Traweck, S. (2012). Data, data use, and scientific inquiry: two case studies of data practices. In *Proceedings of the 12th ACM/IEEE-CS joint conference on Digital Libraries* (pp. 19–22). New York, NY, USA: ACM. doi:10.1145/2232817.2232822
- Wynholds, L., Fearon Jr., D. S., Borgman, C. L., & Traweck, S. (2011). When Use Cases Are Not Useful: Data Practices, Astronomy, and Digital Libraries. Presented at the Joint Conference on Digital Libraries, Ottawa.
- Wynholds, L. (2011). Linking to Scientific Data: Identity Problems of Unruly and Poorly Bounded Digital Objects. *International Journal of Digital Curation*, 6(1), 214-225.
- Borgman, C. L., Fearon Jr., D. S., Wynholds, L., & Traweck, S. (2010). *When Use Cases are Not Useful: A Working Paper for the Data Conservancy IRD IS/CS Retreat* (White Paper). Pittsburgh, PA: Data Conservancy.
- Wynholds, L. (2008). Public monies, privatized words, and the pace of technology: The struggle to provide scholarly access in the face of rising costs and budget shortfalls. Presented at the The Culture of Print in Science, Technology, Engineering and Medicine Conference, Madison, WI.
- Marsh, C., Schmitz, E., & Wynholds, L. (2008, June). A User's Guide to the NBII Wildlife Disease Information Node. *The Wildlife Professional*, 2(2), 41-43.

CONFERENCES:

- Wynholds, L. (2013, March 15). Following the Data: An Evolving Constellation of Artifacts, Records and Tacit Knowledge. Poster presented at the Curate Thyself Workshop, Chapel Hill, NC.
- Borgman, C. L., Sands, A., & Wynholds, L. A. (2013, January 8). *Astronomy: On the Bleeding Edge of Scholarly Infrastructure*. Poster presented at the American Astronomical Society, Long Beach, CA.

CONFERENCES: (cont'd)

- Sands, A., Borgman, C. L., Wynholds, L., & Traweek, S. (2012, October 29). *Follow the Data: How astronomers use and reuse data*. Poster presented at the ASIS&T 75th Annual Meeting, Baltimore, MD. Retrieved from <http://www.asis.org/asist2012/abstracts/341.html>
- Wynholds, L., Fearon Jr., D. S., Borgman, C., & Traweek, S. (2011, February). *Awash in stardust: data practices in astronomy*. Poster presented at the iConference, Seattle, WA.
- Wynholds, L. (2010, December). *Linking to Scientific Data: Identity Problems of Unruly and Poorly Bounded Digital Objects*. Presented at the 6th International Digital Curation Conference, Chicago, IL. [Best Student Paper Award]
- Borgman, C. L., Fearon Jr., D. S., Traweek, S., & Wynholds, L. (2010, October 24). *Curators to the Stars*. Poster presented at the ASSIST Annual Meeting, Pittsburgh, PA.
- Borgman, C. L., Fearon Jr., D. S., Traweek, S., Wynholds, L., & Fidler, B. (2010, February 3). *Embodying Research Methods into Fields and Tables: A Process of Informed Database Design*. Poster presented at the iConference, University of Illinois at Urbana-Champaign.
- Discussion Panel: *The Contested Language of Description and Access*, 33rd Annual Wisconsin Women's Studies Conference and 4th Annual LGBTQ Conference, Madison, WI April 2009
- Discussion Panel: *(un)intentional community: queer zines in an institutional context*, GLBT Archives, Libraries, Museums and Special Collections (ALMS) Conference, New York, NY, May 2008
- Discussion Panel: *Using Open Source Software in Digital Archives*, Annual General Meeting, Society of California Archivists, Long Beach, CA May 2007

PRESENTATIONS AND WORKSHOPS:

- Using Zotero*, Knowledge Infrastructures Research Group, UCLA, February 3, 2012
- Trans Histories and Archives*, Gender Justice LA Leadership Institute, West Hollywood, CA November 19-20, 2011
- An Introduction to Citation Management Software: Zotero*, Global Studies Undergraduate Research Seminar, UCLA, October 2011, October 2012, and October 2013
- Data Identity and Identifiers*, with Jillian Wallis, Data Curation Course (Borgman IS 289), UCLA, May 5, 2011
- An Introduction to Linux*, Open Source Open House, LITA Student Chapter, Madison, WI October 2008
- An Introduction to Zine Making and Alternative Print Culture*, People's Networking Convention, Madison WI, August 2008
- An Introduction to Creative Commons*, Open Source Open House, LITA Student Chapter, Madison, WI November 2007
- An Introduction to Wikis in the Library Environment*, with Phoebe Ayers, Carlson Health Sciences Library, Davis, CA March 2007.

CHAPTER 1: INTRODUCTION

Access to health care is a fundamental human right that is regularly denied to transgender and gender non-conforming people...Transgender and gender non-conforming people frequently experience discrimination when accessing health care, from disrespect and harassment to violence and outright denial of service ... Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room, or other medical setting and 2% of the respondents reported being physically attacked in a doctor's office...If medical providers were aware of the patient's transgender status, the likelihood of that person experiencing discrimination increased...Nineteen percent (19%) had been refused treatment by a doctor or other provider because of their transgender or gender non-conforming status.

National Transgender Discrimination Survey Report on Health and Health Care¹, 2010

Until recently, neither state nor federal health agencies had the capacity to record the number of trans or gender variant bodies receiving services in the United States. From the 1950s until late in the 2000s, gender identity and gender variance information were not included in any basic US healthcare records or health demographic information surveys. Currently, most health and medical recordkeeping systems still lack the capacity to record information about transgender and gender variant populations. While population-based data on gender variance in the US have been lacking², recent targeted datasets have indicated a

¹ Jaime M Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care" (National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010), http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.

² Randi Ettner, Stan Monstrey, and A. Evan Eyler, *Principles of Transgender Medicine and Surgery* (New York: Haworth Press, 2007); Randi Ettner, Stan Monstrey, and Eli Coleman, *Principles of Transgender Medicine and Surgery* (Routledge, 2016).

higher incidence of gender variance than previously anticipated³, bringing the US population estimates to over 1 million⁴ and making the arguments about the danger of data blind spots even more pressing. However, these recent studies also indicate that there are still many valid reasons for patients to withhold gender variance information from healthcare systems and their highly bureaucratic administrative practices⁵. Since the HIV epidemic of the 1980s, the silences and erasures of queer bodies within bureaucratic systems have been central to discussions of marginalization and healthcare disparities for LGBTIQ populations⁶.

As the provision of healthcare to trans and gender variant persons has become more normalized in US healthcare operations in recent years, awareness of the information disparities around data collection have become more acute⁷. The disparities for trans bodies in US healthcare had become so extreme that the NIH and other federal funding agencies have invested in developing data collection practices for gender identity information. While there are many anecdotal, snowball sample, or small-n community surveys demonstrating healthcare disparities across the LGBTIQ community, there is a near total invisibility of trans and gender variant bodies within population-based and longitudinal healthcare datasets.

³ Madeline B. Deutsch, "Making It Count: Improving Estimates of the Size of Transgender and Gender Nonconforming Populations," *LGBT Health* 3, no. 3 (June 2016): 181–85, <https://doi.org/10.1089/lgbt.2016.0013>.

⁴ Katy Steinmetz, "This Is How Many Americans Identify as Transgender," *Time*, June 30, 2016, <http://time.com/4389936/transgender-americans-statistic-how-many/>.

⁵ Judith Bradford et al., "Experiences of Transgender-Related Discrimination and Implications for Health: Results from the Virginia Transgender Health Initiative Study," *American Journal of Public Health* 103, no. 10 (2013): 1820–1829.

⁶ Greta R Bauer et al., "'I Don't Think This Is Theoretical; This Is Our Lives': How Erasure Impacts Health Care for Transgender People," *The Journal of the Association of Nurses in AIDS Care: JANAC* 20, no. 5 (October 2009): 348–61, <https://doi.org/10.1016/j.jana.2009.07.004>.

⁷ "Lesbian, Gay, Bisexual, and Transgender Health - Healthy People 2020," accessed January 15, 2014, <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>.

1.1 Purpose of Research

Trans and gender variant populations suffer from a lack of inclusion in health data collection efforts⁸ in a number of key areas⁹. Trans populations suffer from multiple barriers to accessing and receiving healthcare¹⁰. The paucity of data includes a paucity of basic demographic information such as how many trans people are in the general population, where they are, what income brackets they fall in, whether they have health insurance. However, the paucity of data also includes health-related disease demographics (e.g. what are the rates of different diseases in the community, what side effects are common with various medical interventions), and most importantly, population based data to support evidence-based treatment. This research seeks to document and explore the role that information structures play in the information voids found in health data and medical record-keeping practices. This research focuses specifically on structures for encoding gender into health data and medical records and follows questions of how gender variance can become invisible in the records.

This research project focuses on questions of how information structures may produce and reproduce disparities for marginalized communities. Information disparities are common in marginalized communities, but become particularly acute around medical information needs. There is a critical information dependency within the relationship between the information collected about specific health conditions and the development of evidence-based practices for treatment of these conditions. Complex health conditions often require very large datasets

⁸ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives."

⁹ Viviane Namaste, "Making the Lives of Transsexual People Visible: Addressing the Politics of Social Erasure," *Rethinking Society in the 21st Century: Critical Readings in Sociology*, 2008, 94.

¹⁰ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care."

and/or studies with very long time scales in order to fully evaluate treatment paradigms. As such, medical record and health data contribute broadly to critical scientific and policy decision-making processes, such as establishing standards of care, evaluating evidence based medicine, evaluating health policy, and advocating for public health funding. Limitations in medical recordkeeping and health data collection practices can thus result in substantial blind spots in the downstream materials produced from such data, such as in standards of care, evidence based medicine, health policy, and health funding.

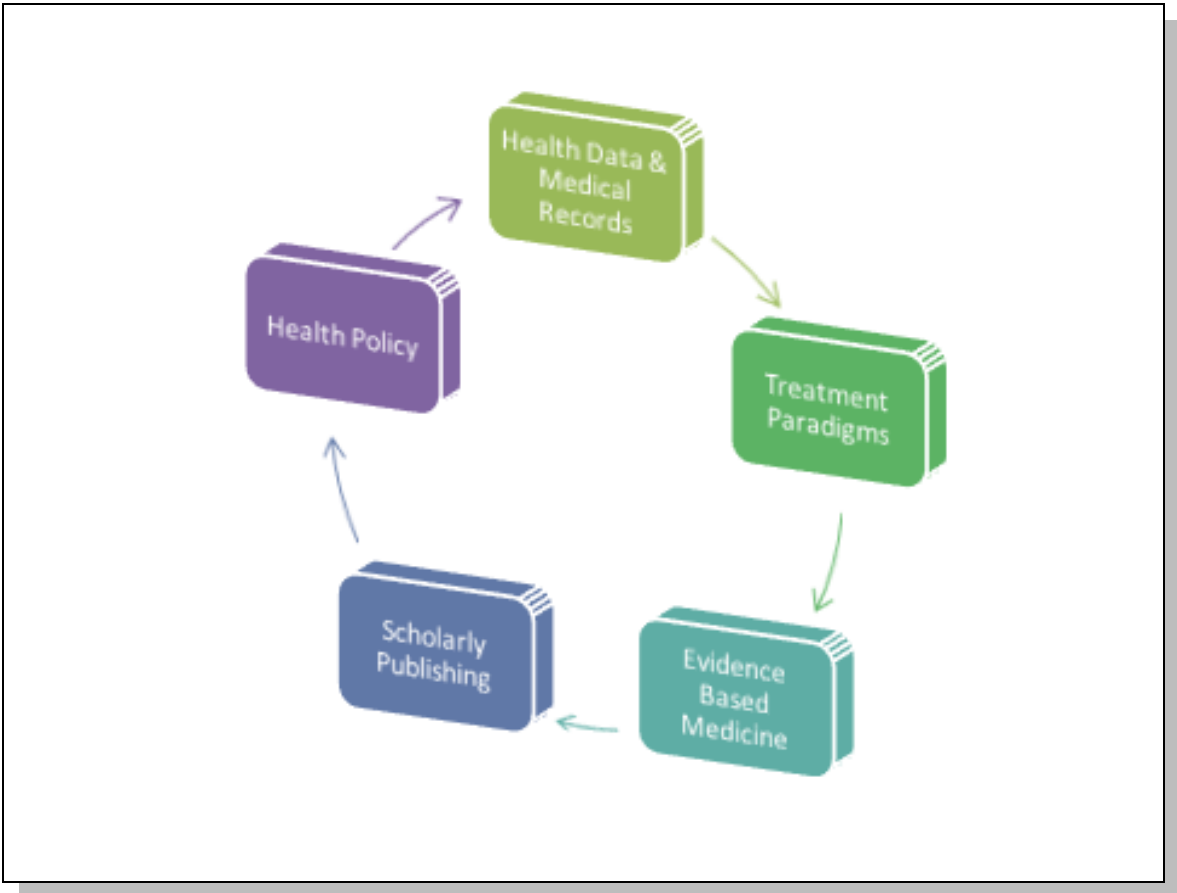


Figure 1: Data cycle showing data dependencies between knowledge systems

Transgender and non-normatively gendered populations confront a number of challenges in accessing and using healthcare systems¹¹ while simultaneously negotiating a system that has failed to record medical evidence to inform their treatment. Figure 1 shows a representation of data flows between various knowledge systems that act systemically to contribute to healthcare practices. There has been a well-documented lack of longitudinal health studies and public health data¹² for transgender and gender variant patients in the US¹³. This lack of population-based health data and longitudinal health studies is referred to herein as a ‘data void’. If one examines this data void in relation to the systems that are dependent upon the data (see Figure 1), one can see how the void propagates through the dependencies of the knowledge systems, resulting in a situation where none of the systems have adequate data to represent the population in question. In other words, the less information that is collected in studies and records, the less data driven the medical treatments are, and the more likely that providers will have to rely on social norms and anecdotal experiences to provide medical services for trans and gender variant patients.

1.2 Research Questions: Gender Labels and the Long Tail of Gender Variance

The major guiding questions for this research are:

¹¹ Rebecca Sussman et al., “Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles” (Los Angeles, California: St. John’s Well Child and Family Center, 2015), <http://www.wellchild.org/sjwcfinalthpwhitepaper.pdf>.

¹² Kerith J. Conron et al., “Sex and Gender in the US Health Surveillance System: A Call to Action,” *American Journal of Public Health* 104, no. 6 (June 2014): 970–76, <https://doi.org/10.2105/AJPH.2013.301831>.

¹³ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*.

1. How is gender and gender variance represented in electronic medical records and public health datasets? What functions do gendered categories perform within recordkeeping systems? For whom do these categories perform functions, social or otherwise? How are gender categories constructed, maintained, practiced and evolved over time? How is gender variance represented when it is included in the records? What is the role of temporal fluidity in the face of static categorical structures?
2. How do trans populations manage to remain uncoded in the massive volume of health data currently available for evidence based medicine? How did substantial numbers of trans bodies come to be invisible under existing gender and diagnostic categories? What role to metadata structures, categorization and data structures play in the invisibility of trans and gender variant populations in California's health care systems?
3. What does it mean for large health information datasets to contain populations that are structurally invisible due to artifacts of the category construction? What does it mean for these datasets when they fail to represent marginalized populations?
4. How do these information disparities affect the recordkeeping activities and abilities of institutions? Is it possible to observe secondary and tertiary effects of these information disparities? What kinds of outcomes are observable from the recordkeeping problems generated by strict binary categories of gender? Who bears the costs and to whom go the benefits?

5. How do these information and metadata structures relate to the provision of trans healthcare services and/or the lack thereof?

1.3 Project Description: Finding Invisible Bodies in the Records

This dissertation research project explores the ways in which the information structures that can render trans bodies invisible within health information systems. The research revolves around the unusual silences of the medical recordkeeping systems which are responsible for capturing information about the practice of transgender medicine in the US. This population has had access to medical services such as hormones, surgery and other medical interventions for over 50 years, and yet there are virtually no medical studies of these interventions. From 1950 to 2000, there was no census data, no population data, no health outcome statistics, and no US based longitudinal studies of trans and gender variant populations. For more than fifty years these types of surgeries were labeled as experimental due, in part, to the lack of data available on the outcomes of the procedures.

This research project explores how gender is encoded and the resulting silences of the data in the records around gender variance. This project was conceived to explore the relationships between these silences and the question of whether the paucity of data is a result of the failure of records and information structures or an artifact of the social systems of marginalization in play, or both. The project seeks to better understand the complexity and dependencies of the relationship between records of the gender and information system structures. The project explores the blind spots in recording gender variance and looks into

the relationship between the affordances of records/data structures and the bodies represented in the information systems.

The project approaches these data structures as historical artifacts of the social dynamics present. However, the ethnographic and socio-historical based observation of trans and gender variant populations necessitate addressing complex and multi-faceted histories of social marginalization. These histories include polarizing terms for gender variance as well as overlapping and conflicting terms used in assigning gender, the performance of gender roles and the expression of sexuality. In both historical and current usage, terms of sex, gender and sexuality have often been conflated, particularly when these terms are used in the context of cultural norms of gendered interactions. Moreover, many of the key figures and historical events associated with LGBTIQ communities were deeply entangled in complex intersections of self, identity, social responsibility and community, such as seen in the entanglement of gay liberation with the civil rights struggles of the 1960s.

Because of these complex and poorly documented histories, an additional background section (Chapter 2) presents key aspects of intersecting histories of racialized, sexualized, and gendered bodies that contributed to the current state of affairs for representing gendered bodies in medical records. These background materials include close readings of selected historical figures, movements, and moments. These readings engage with the materials with the question of a) what the successes were, b) what the failures were, and c) what limitations constrain interpretations of materials. The background section also introduces the historical context of the records development environment for gender variance, focusing on California

primarily, but also including references to larger national and international trends affecting the issue. It includes a brief historical summary of the evolution of gender categories, gender markers, trans bodies, billing regimes, and record keeping systems in US healthcare systems.

The literature review has been divided into two parts, both focusing on theoretical discourses relevant to the project. The first part of the literature review aggregates the theoretical discourses around information theory, information infrastructures, data structures, category theory, enunciative modalities and issues of representational marginalization within data structures. The second part of the literature review provides context for how expectations of binary gender are manifested in the material and literal fixity of the data and record keeping systems, how the literal fixity of the records naturalizes the expectation of binary gender, and how something as complex as gender has come to be manifested exclusively in binary categories of 'M' vs 'F'.

The research project problematizes the notion that trans bodies are 'unnatural' or 'out of place' from a 'natural' gender binary by inverting the frame of analysis and focusing the research materials on the frictions and functionality of information infrastructures for gender for healthcare purposes. The qualitative methods, data collection rubrics and epistemic stance are described in detail in Chapter 3, titled 'Methods'. The research materials span a wide variety of types and content media and are described and summarized in detail in Chapter 4, titled 'Data Descriptions'. The analysis traces the erasure of gender non-conforming bodies as they become essentialized into binaries of M or F by data and record keeping systems. In problematizing the 'natural' state of an exclusive gender binary, the analysis chapter engages

with interpreting observations of social construction of categories, the gendering of social expectations, the kinds of work that categories do, and the positionality/subjectivity embedded in the construction of data structures, gender markers and medical records. The research pays special attention to cases of generalized constructs, which can lead to a great deal of mental efficiency in categorization tasks, but as the scale and nature of the tasks change, the generalized constructs are also caught in a process of breakdown and repair.

1.4 Motivation: Silences in the Data and Data Voids

Medical systems in the US have long struggled with ethical questions around how to best serve trans and gender variant populations with histories of social stigma and marginalization¹⁴. The development of medical information structures around gender and gendered health records reflect complex historical tensions between safety and visibility, between transparency and exposure, between information disclosure and information erasure¹⁵. The effects of silences in the data for trans and gender variant bodies are often multifaceted, from the individual¹⁶ to the aggregate population¹⁷. The invisibility of the population is evident on many levels¹⁸. Within the LGBTIQ community, the lack of data on

¹⁴ Bradford et al., "Experiences of Transgender-Related Discrimination and Implications for Health."

¹⁵ Toby Beauchamp, "Artful Concealment and Strategic Visibility: Transgender Bodies and US State Surveillance After 9/11.," *Surveillance & Society* 6, no. 4 (2009).

¹⁶ Viviane Namaste, *Invisible Lives: The Erasure of Transsexual and Transgendered People* (University of Chicago Press, 2000).

¹⁷ Mona Chalabi, "Why We Don't Know The Size Of The Transgender Population," *FiveThirtyEight Life* (blog), July 29, 2014, <http://fivethirtyeight.com/features/why-we-dont-know-the-size-of-the-transgender-population/>.

¹⁸ Meredith Temple-O'Conner, Elizabeth Wehr, and NIH LGBT Research Coordinating Committee, "Response to the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals," accessed March 8, 2014, http://report.nih.gov/UploadDocs/LGBT%20Health%20Report_FINAL_2013-01-03-508%20compliant.pdf.

their communities is well known and often viewed as an issue of systemic invisibility and erasure:

*LGBTI people are well-aware of the health disparities taking hold and stealing lives in their communities, but are being excluded from data collection efforts. As a result, LGBTI communities are rendered invisible and therefore unable to make a convincing case for health financing to address their needs.*¹⁹

The lack of data around transgender and gender variant populations is particularly striking in comparison to the amount of data collected annually in California within medical records and health data collection efforts. Despite 50+ years of specialist surgeries and related medical interventions, there have been virtually no longitudinal studies on the health outcomes associated with these medical interventions in transgender and gender variant populations²⁰.

Until the early 2010s, US-based providers relied on data and medical evidence stemming from Canadian²¹ and European (Netherlands²², Belgium²³) health care centers to inform their treatment practices with trans and gender variant patients. US-based providers were forced to rely on Canadian and European health care practices because the US lacked data on these populations and outcomes. Not only was there a well-known paucity of data on health outcomes from medical interventions, prior to 2010 there was no population-based data from health surveys at the local, state, or federal levels. The lack of data has been considered by

¹⁹ "Agenda 2030 for LGBTI Health and Well-Being," 203, accessed July 20, 2017, https://www.outrightinternational.org/sites/default/files/sdg2030_05052017_0.pdf.

²⁰ Sam Winter et al., "Transgender People: Health at the Margins of Society," *The Lancet* 388, no. 10042 (July 23, 2016): 390–400, [https://doi.org/10.1016/S0140-6736\(16\)00683-8](https://doi.org/10.1016/S0140-6736(16)00683-8).

²¹ Kailey Willetts, "Transgender Health Program," *Visions Journal* 6, no. 2 (2009): 32–34.

²² Lisette Kuyper and Ciel Wijsen, "Gender Identities and Gender Dysphoria in the Netherlands," *Archives of Sexual Behavior* 43, no. 2 (February 1, 2014): 377–85, <https://doi.org/10.1007/s10508-013-0140-y>.

²³ Eva Van Caenegem et al., "Prevalence of Gender Nonconformity in Flanders, Belgium," *Archives of Sexual Behavior* 44, no. 5 (July 1, 2015): 1281–87, <https://doi.org/10.1007/s10508-014-0452-6>.

LGBTIQ health care advocates to be a major barrier for research, health policy, advocacy, evidence based medicine, and funding purposes²⁴.

Despite the mounting evidence of a sizeable (US) gender variant population numbering in the millions²⁵, there has been a long standing paucity of population based data available on transgender and gender variant persons (or their medical outcomes). Moreover, the paucity of data has historically been used to justify the denial of medically necessary care as untested, experimental and/or cosmetic²⁶. As such, the lack of data cannot be understood outside of the social and historical context of these populations. For much of the 20th century, basic safety concerns necessitated gender variant persons living in stealth and passing as cisgendered in order to achieve minimal access to health care, housing, and employment²⁷. Because the medical profession operates under an ethos of ‘do no harm’, recording gender variance has operated under limitations of safety. Health professionals would often consider it if they could be confident that the patients would benefit from the disclosure of the information. Aside from a small handful of actively engaged advocates, very few providers in California have started recording any information about gender variance for their patients.

As a result of the culture of invisibility and the lack of representation in the data, it has historically been quite difficult to assemble data to reflect the gender variant population size,

²⁴ Deutsch, “Making It Count.”

²⁵ Steinmetz, “This Is How Many Americans Identify as Transgender.”

²⁶ Daphna Stroumsa, “The State of Transgender Health Care: Policy, Law, and Medical Frameworks,” *American Journal of Public Health* 104, no. 3 (2014): e31–e38.

²⁷ Tarynn M. Witten and A. Evan Eyler, “Hate Crimes and Violence against the Transgendered,” *Peace Review* 11, no. 3 (1999): 461–468, <https://doi.org/10.1080/10402659908426291>.

healthcare outcomes and healthcare needs²⁸. Identifying trans and gender variant persons in medical information systems has been like trying to track ghosts in the machine, with key pieces of information being sliced between incommensurate categories and rendered in such a way as to make trans or gender variant status completely uncountable in aggregate. Some researchers and activists view this invisibility as a form of informational and institutional erasure²⁹. However, this invisibility can also be situated in a larger socio-historical context of invisibility, misrepresentation and discounting the existence of gender variance. On the one hand, invisibility can be viewed as a risk reduction tactic deployed by medical providers and patients alike to increase personal security in social environments with high levels of mistreatment, harassment and social violence.

Historically, many trans and gender variant persons managed the risk of social violence by omitting or obscuring information in their records that carried the risk of being delegitimized by social stigma. However, the lack of data and representation in the records also perpetuates the social erasure of a population with a long history of being driven by social violence to live in the shadows³⁰. Many trans and gender variant communities have colloquial terms to refer to omitting or obfuscating their gender status/history such as ‘living in stealth’ or ‘passing’ and terms that negatively refer to being identified such as ‘being clocked’, ‘being read’, and ‘being outed’. Collecting legible data on this population requires trans and gender variant persons to

²⁸ Scout, “Déjà Vu: National Surveys Leave Trans People Behind,” *Huffington Post* (blog), June 13, 2013, http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html.

²⁹ Bauer et al., “I Don’t Think This Is Theoretical; This Is Our Lives.”

³⁰ E.A. Armstrong and S.M. Crage, “Movements and Memory: The Making of the Stonewall Myth,” *American Sociological Review* 71, no. 5 (2006): 724–751.

be willing to identify themselves, which cannot be done successfully without addressing the risk of violence. The 2010 Report from the National Transgender Discrimination Survey explained:

*Every day, transgender and gender non-conforming people bear the brunt of social and economic marginalization due to their gender identity. Advocates who work with transgender and gender non-conforming people have known this for decades as they have worked with clients to find housing, to obtain health and partnership benefits, or to save jobs terminated due to bias. **Too often, policy makers, service providers, the media and society at large have dismissed or discounted the needs of transgender and gender non-conforming people in their communities, and a paucity of hard data on the scope of anti-transgender discrimination has hampered the struggle for basic fairness.***³¹ [emphasis added]

Dean Spade (2011) wrote about the challenges of getting past cultural assumptions to include gender variance in statistical representations, population based data and other records of gender, writing:

*These decisions about what constitutes a proper data element/manner of classification and what does not rarely appear as controversial political decisions because people who find the commonly evoked societal norms used in the classification familiar and comfortable tend to take these classification systems as neutral givens in their lives.*³²

Classifications of gender are a facet of social classification systems that most people take for granted, as neutral apolitical givens. It is a part of the invisible infrastructure of the psycho-social fabric of human interaction that underlies public space and political discourse³³. It becomes visible in the friction created around trans and gender variant bodies, but is otherwise taken for granted as if it were entirely objective, neutral and natural. It behaves like

³¹ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care," 2.

³² Dean Spade, *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law* (South End Press Cambridge, MA, 2011), 140–41.

³³ Raine Dozier, "Beards, Breasts, and Bodies: Doing Sex in a Gendered World," *Gender & Society* 19, no. 3 (2005): 297–316.

infrastructure, only becoming visible upon breakdown of the health data and medical recordkeeping procedures that fail to address trans and gender variant populations.

1.5 Significance

Medical records are at the intersection of several facets of social structures: medical research; government social services; business conventions within doctor's practices, insurance groups and hospitals; medical education; big data; and personal privacy. Transgender, transsexual and gender variant groups have often suffered from complete invisibility within medical record keeping and public health data systems. Many medical record keeping systems have not historically included record keeping affordances to represent trans or gender variant persons. As a result, their records have been indiscernible and/or invisible in aggregate. Most insurance companies, HMOs and providers have not had the ability to collect data that includes how many trans people they are serving. The problem of representing trans populations became a major topic of discussion across federal health and medical research funding agencies during the period that the study was conducted.

While there are many studies documenting the information voids and information disparities around trans people and medical care, none have examined the recordkeeping system structures. None have looked at how records and metadata structures may render trans bodies invisible and untraceable within current health data. Community members and LGBTIQ advocates have innumerable anecdotes documenting the assertion that trans populations are invisible and suffer from institutionalized prejudices. However, population based data has remained elusive for trans and gender variant populations and the healthcare

that relies on it. Addressing structural disparities within recordkeeping practices is of major importance as electronic medical recordkeeping systems become ubiquitous in health care environments.

CITED REFERENCES (INTRODUCTION)

- “Agenda 2030 for LGBTI Health and Well-Being.” Accessed July 20, 2017.
https://www.outrightinternational.org/sites/default/files/sdg2030_05052017_0.pdf.
- Armstrong, E.A., and S.M. Crage. “Movements and Memory: The Making of the Stonewall Myth.” *American Sociological Review* 71, no. 5 (2006): 724–751.
- Bauer, Greta R, Rebecca Hammond, Robb Travers, Matthias Kaay, Karin M Hohenadel, and Michelle Boyce. “‘I Don’t Think This Is Theoretical; This Is Our Lives’: How Erasure Impacts Health Care for Transgender People.” *The Journal of the Association of Nurses in AIDS Care: JANAC* 20, no. 5 (October 2009): 348–61.
<https://doi.org/10.1016/j.jana.2009.07.004>.
- Beauchamp, Toby. “Artful Concealment and Strategic Visibility: Transgender Bodies and US State Surveillance After 9/11.” *Surveillance & Society* 6, no. 4 (2009).
- Bradford, Judith, Sari L. Reisner, Julie A. Honnold, and Jessica Xavier. “Experiences of Transgender-Related Discrimination and Implications for Health: Results from the Virginia Transgender Health Initiative Study.” *American Journal of Public Health* 103, no. 10 (2013): 1820–1829.
- Caenegem, Eva Van, Katrien Wierckx, Els Elaut, Ann Buysse, Alexis Dewaele, Filip Van Nieuwerburgh, Griet De Cuypere, and Guy T’Sjoen. “Prevalence of Gender Nonconformity in Flanders, Belgium.” *Archives of Sexual Behavior* 44, no. 5 (July 1, 2015): 1281–87. <https://doi.org/10.1007/s10508-014-0452-6>.
- Chalabi, Mona. “Why We Don’t Know The Size Of The Transgender Population.” *FiveThirtyEight Life* (blog), July 29, 2014. <http://fivethirtyeight.com/features/why-we-dont-know-the-size-of-the-transgender-population/>.
- Conron, Kerith J., Stewart J. Landers, Sari L. Reisner, and Randall L. Sell. “Sex and Gender in the US Health Surveillance System: A Call to Action.” *American Journal of Public Health* 104, no. 6 (June 2014): 970–76. <https://doi.org/10.2105/AJPH.2013.301831>.
- Deutsch, Madeline B. “Making It Count: Improving Estimates of the Size of Transgender and Gender Nonconforming Populations.” *LGBT Health* 3, no. 3 (June 2016): 181–85.
<https://doi.org/10.1089/lgbt.2016.0013>.
- Dozier, Raine. “Beards, Breasts, and Bodies: Doing Sex in a Gendered World.” *Gender & Society* 19, no. 3 (2005): 297–316.

- Ettner, Randi, Stan Monstrey, and Eli Coleman. *Principles of Transgender Medicine and Surgery*. Routledge, 2016.
- Ettner, Randi, Stan Monstrey, and A. Evan Eyler. *Principles of Transgender Medicine and Surgery*. New York: Haworth Press, 2007.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jody L Herman, Jack Harrison, and Mara Keisling. "National Transgender Discrimination Survey Report on Health and Health Care." National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- Kuyper, Lisette, and Ciel Wijzen. "Gender Identities and Gender Dysphoria in the Netherlands." *Archives of Sexual Behavior* 43, no. 2 (February 1, 2014): 377–85. <https://doi.org/10.1007/s10508-013-0140-y>.
- "Lesbian, Gay, Bisexual, and Transgender Health - Healthy People 2020." Accessed January 15, 2014. <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>.
- Namaste, Viviane. *Invisible Lives: The Erasure of Transsexual and Transgendered People*. University of Chicago Press, 2000.
- . "Making the Lives of Transsexual People Visible: Addressing the Politics of Social Erasure." *Rethinking Society in the 21st Century: Critical Readings in Sociology*, 2008, 94.
- Scout. "Déjà Vu: National Surveys Leave Trans People Behind." *Huffington Post* (blog), June 13, 2013. http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html.
- Spade, Dean. *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law*. South End Press Cambridge, MA, 2011.
- Steinmetz, Katy. "This Is How Many Americans Identify as Transgender." *Time*, June 30, 2016. <http://time.com/4389936/transgender-americans-statistic-how-many/>.
- Stroumsa, Daphna. "The State of Transgender Health Care: Policy, Law, and Medical Frameworks." *American Journal of Public Health* 104, no. 3 (2014): e31–e38.
- Sussman, Rebecca, Felix Vargas, Aydin Kennedy, Shom Dasgupta, and Jim Mangia. "Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles." Los Angeles, California: St. John's Well Child and Family Center, 2015. <http://www.wellchild.org/sjwcfcfinalhpwhitepaper.pdf>.
- Temple-O'Conner, Meredith, Elizabeth Wehr, and NIH LGBT Research Coordinating Committee. "Response to the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals." Accessed March 8, 2014.

http://report.nih.gov/UploadDocs/LGBT%20Health%20Report_FINAL_2013-01-03-508%20compliant.pdf.

Willets, Kailey. "Transgender Health Program." *Visions Journal* 6, no. 2 (2009): 32–34.

Winter, Sam, Milton Diamond, Jamison Green, Dan Karasic, Terry Reed, Stephen Whittle, and Kevan Wylie. "Transgender People: Health at the Margins of Society." *The Lancet* 388, no. 10042 (July 23, 2016): 390–400. [https://doi.org/10.1016/S0140-6736\(16\)00683-8](https://doi.org/10.1016/S0140-6736(16)00683-8).

Witten, Tarynn M., and A. Evan Eyler. "Hate Crimes and Violence against the Transgendered." *Peace Review* 11, no. 3 (1999): 461–468. <https://doi.org/10.1080/10402659908426291>.

CHAPTER 2: HISTORICAL BACKGROUND

Background: 21

 In/visibility in the Records 25

 Terminologies of Gender: 29

 1930s-1940s: Early Sexologists and WWII 38

 1950s: Post War Period (1950s)..... 43

 1960s & 1970s: The Professional Gaze and Social Unrest 44

 1980s: Conservative Pushback and Reagan Economics 50

 1990s: Legacies of Marginalization 51

 Conclusions: 55

Cited References (Background) 59

*Violence does not start
with the euthanasia of the sick.
It begins when one person says
"You are sick:
You must do as I say!"¹*

Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room, or other medical setting and 2% of the respondents reported being physically attacked in a doctor's office²

Some 30% of transgender Californians report that they have postponed care for illness or preventive care due to disrespect or discrimination from doctors or other health care providers.³

HISTORICAL BACKGROUND:

Trans and gender variant communities have a long history of being attacked⁴, stigmatized, objectified, discounted, discriminated against⁵ and disenfranchised in all aspects of public life in the US, health care included⁶. Gender variance in the 20th century was often approached as a manifestation of mental illness and used as a pretext to justify overt social

¹ Erich Fried, *Love Poems*, trans. Stuart Hood (New York: Calder Publications Limited; Riverrun Press, 1991).

² Jaime M Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care" (National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010), http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.

³ E. Hartzell et al., "The State of Transgender California: Results from the 2008 California Transgender Economic Health Survey" (San Francisco, California: Transgender Law Center, 2009), 3, http://transgenderlawcenter.org/pdf/StateTransCA_report_2009Print.pdf.

⁴ Talia Mae Bettcher, "Evil Deceivers and Make-Believers: On Transphobic Violence and the Politics of Illusion," *Hypatia* 22, no. 3 (2007): 43–65.

⁵ Lee M. Peterson, "Workplace Harassment against Transgender Individuals: Sex Discrimination, Status Discrimination, or Both," *Suffolk UL Rev.* 36 (2002): 227.

⁶ Kami Kosenko et al., "Transgender Patient Perceptions of Stigma in Health Care Contexts," *Medical Care* 51, no. 9 (September 1, 2013): 819–22.

exclusion⁷, physical violence, criminalization⁸ and denial of medical care⁹. In the 21st century, social violence has continued to be commonplace in interactions with trans and gender variant persons. The first national survey of trans health issues concluded, '*access to health care is a fundamental human right that is regularly denied to transgender and gender non-conforming people*'¹⁰. The report continued:

Transgender and gender non-conforming people frequently experience discrimination when accessing health care, from disrespect and harassment to violence and outright denial of service. Participants in our study reported barriers to care whether seeking preventive medicine, routine and emergency care, or transgender-related services. These realities, combined with widespread provider ignorance about the health needs of transgender and gender non-conforming people, deter them from seeking and receiving quality health care.

In examining classifications of gender within medical information systems, one cannot escape the ubiquity of social violence experienced by gender variant populations. Looking at the data structures in isolation ignores the practical politics¹¹ of social interactions for populations whose records are represented within medical information and medical recordkeeping systems. However, most scholars working in this domain have recognized that discrimination and discounting are mutually constitutive acts of socially normative behavior.

⁷ Kevin M. Barry et al., "Bare Desire to Harm: Transgender People and the Equal Protection Clause, A," *BCL Rev.* 57 (2016): 507.

⁸ Joey L. Mogul, Andrea J. Ritchie, and Kay Whitlock, *Queer (In)Justice: The Criminalization of LGBT People in the United States* (Beacon Press, 2011).

⁹ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care," October 2010.

¹⁰ Grant et al.

¹¹ G. C Bowker and S. L Star, "How Things (Actor-Net) Work: Classification, Magic and the Ubiquity of Standards," *Philosophia* 25, no. 3-4 (1996): 195-220.

This chapter presents relevant aspects of historical context of transgender and gender variant populations as they pertain to the development of classifications of gender in medical recordkeeping practices in California. Many different communities and constituencies overlap within the context of medical care for transgender and gender variant populations. Due to the multiple communities and educational backgrounds, the terminologies of gender and gender variance are multifaceted, overlapping, and non-interoperable between historical and geographic systems. Some governmental and health records systems use 'sex', some use 'gender', some use the two terms interchangeably. Most academic discourses building upon gender studies from the 1990s and 2000s tend to differentiate 'sex', which refers to biological or physical characteristics, from 'gender', which refers to social and behavioral characteristics. Even the technical terms used within the medical discourse have evolved, from sex change surgeries to sex reassignment surgeries (SRS), to gender confirming surgeries (GCS).

This work orients to constructions of gender in recordkeeping systems using gender variance because of the statistically based theoretical affordances developed in studies of population variance, namely dynamics of data point centrality, dynamics of outliers, dynamics of edge cases and the overviews of long-tail demographics. The concept of variance is used to frame the argument within a network of social and physical characteristics which play into encoding gender within current health care systems. Gender variance, in the context of this work, often overlaps with a constellation of more broadly used terms such as 'gender identity', 'gender presentation', 'gender non-conforming', and pronoun preferences. These terms are explained with more depth later in this chapter.

Because this chapter focuses on historical narratives and development of recordkeeping practices, it is important to begin by acknowledging that deterministic historical narratives of progress towards LGBT rights and social equality do not reflect the complexity of contestation and discourse around classifying gender in medical contexts. This chapter takes a more indeterminate historiographic approach, attempting to bring together multiple perspectives into a pluralistic narrative about the histories involved in the classifications of gender in medical information systems.

This work focuses on recordkeeping systems and practices in California for several reasons. First and foremost, the research sites are located in California and inextricably situated within the policy environment of the state. Healthcare policies and legal identity documents for transgender and gender variant persons vary greatly from state to state. As such, this chapter includes occasional descriptions of national events and developments that played key functions in forming functional classifications of gender in California.

During the study period, trans and gender variant persons have been largely excluded from federal protections from discrimination in public services, education, the workplace¹², and healthcare¹³. California, in contrast, has enacted a number of healthcare and legal protections for trans and gender variant persons, but the development of these legal protections and healthcare policies are incompletely documented in current publications. This is likely related to the fact that healthcare policy has seen dramatic changes during the study period (2013-

¹² M. V. Badgett et al., "Bias in the Workplace: Consistent Evidence of Sexual Orientation and Gender Identity Discrimination" (University of California, Los Angeles: Williams Institute, 2007), <https://escholarship.org/uc/item/5h3731xr.pdf>.

¹³ Kevin M. Barry, "Disabilityqueer: Federal Disability Rights Protection for Transgender People," *Yale Human Rights and Development Law Journal*, 2014, http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2084351.

2017). Healthcare provision, policies and access for trans and gender variant populations in California have changed dramatically in the last ten years.

This historical background is divided into two sections, one that gives an historical overview to contextualize the development of practices around the classification of gender (Background) , and one that presents a general timeline of important events that continue to structure classifications of gender and gender variant populations (Appendix I). The timeline (Appendix I) is geographically focused on historical contextual developments and structural frameworks in the medico-legal and academic arenas that continue to structure and/or affect current data practices around the classification of gender. This timeline was written to ground historical aspects of practices and policies that are not fully documented in the published academic literature. Because detailed analysis of the policies are lacking in the published literature, a summary overview is provided here for the purposes of grounding the research sites in their policy environments. The theoretical frameworks and various literatures that intersect around this topic are presented in the next chapter (Literature Review).

2.1 In/visibility in the Records

In the early 2010s, the lack of health data for trans and gender variant populations was the motivation for federal public health agencies¹⁴, health care organizations¹⁵, providers and

¹⁴ Committee on LGBT Health Issues and Research Gaps and Institute of Medicine (IOM), “The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding” (Washington (DC): National Academies Press, 2011), <http://www.ncbi.nlm.nih.gov/books/NBK64806/>.

¹⁵ Madeline B Deutsch et al., “Electronic Medical Records and the Transgender Patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group,” *Journal of the American Medical Informatics Association* : *JAMIA* 20, no. 4 (July 2013): 700–703, <https://doi.org/10.1136/amiajnl-2012-001472>.

research groups¹⁶ to convene meetings to discuss mechanisms to improve their data collection practices. A researcher associated with developing gender variance questions for the California Health Interview Survey explained¹⁷:

Until recently, no large-scale population-based health surveys have attempted to measure gender identity or transgender status, leading to a significant public-health knowledge gap for this population. Without population estimates of this group, basic facts about this unique and vulnerable population are lacking, despite ample evidence from other surveys that they are at increased risk for certain health and wellbeing outcomes.

This lack of data has been exacerbated by the historical underreporting of the incidence of transgenderism, often by 2-3 orders of magnitude¹⁸. The assertion that trans and gender variant populations constituted less than 0.001% of the general population (less than 1 in 100'000) was the basis for the claim that gender variant populations were too small to justify a revision of medical recordkeeping or health data collection practices. Only in the last 5 years have more representational data collection efforts indicated that the real incidence is most likely between 1 in 1000 and 1 in 100¹⁹, revising population estimates of trans and gender variant populations upwards of 1-2 million in the US and 30'000-50'000 in California. This suggests that gender variance is far more common than previously assumed. These newer estimates suggest that if we do not address the fundamental lack of inclusion in health data

¹⁶ "The Center of Excellence for Transgender Health: Counting Trans Populations," accessed February 15, 2013, <http://transhealth.ucsf.edu/trans?page=lib-trans-count>.

¹⁷ Kerith J. Conron et al., "Sex and Gender in the US Health Surveillance System: A Call to Action," *American Journal of Public Health* 104, no. 6 (June 2014): 970–76, <https://doi.org/10.2105/AJPH.2013.301831>.

¹⁸ Lindsay Collin et al., "Prevalence of Transgender Depends on the 'Case' Definition: A Systematic Review," *The Journal of Sexual Medicine* 13, no. 4 (April 1, 2016): 613–26, <https://doi.org/10.1016/j.jsxm.2016.02.001>.

¹⁹ Sam Winter et al., "Transgender People: Health at the Margins of Society," *The Lancet* 388, no. 10042 (July 23, 2016): 390–400, [https://doi.org/10.1016/S0140-6736\(16\)00683-8](https://doi.org/10.1016/S0140-6736(16)00683-8).

collection practices, these same practices will disadvantage millions as standardized electronic recordkeeping software becomes ubiquitous in medical and health data contexts.

While trans and gender variant persons are not unique in their experiences of discrimination and social violence, they often face multiple complex stigmas and stereotypes related to the intersectionality of their gender, race²⁰, socio-economic status, ability to pass and legibility in their gender presentation. Healthcare providers and patients alike have responded to the risk of social violence in different ways. In some cases, providers and patients have pushed back against systemic problems, forming advocacy and education campaigns. However, in situations where the provider and/or patient could not be confident that the non-normative gender status would be safeguarded, they often responded by obfuscating or omitting information about gender variance from the medical records.

The tensions between widespread experiences of social violence against trans and gender variant populations and the tenets of medical beneficence, e.g. the Hippocratic Oath and the principle of ‘do no harm’, often come into conflict for organizations that intend to broaden data collection to explicitly record the gender status of trans and gender variant populations²¹. Most medical providers in the US have received no training in LGBTIQ health care issues, much less training in transgender specific health care practices²². This is one of the

²⁰ Pooja S. Gehi and Gabriel Arkles, “Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People,” *Sexuality Research & Social Policy* 4, no. 4 (December 1, 2007): 7–35, <https://doi.org/10.1525/srsp.2007.4.4.7>.

²¹ Edward J. Callahan et al., “Eliminating LGBTIQ Health Disparities: The Associated Roles of Electronic Health Records and Institutional Culture,” *The Hastings Center Report* 44 Suppl 4 (September 2014): S48-52, <https://doi.org/10.1002/hast.371>.

²² Juno Obedin-Maliver et al., “Lesbian, Gay, Bisexual, and Transgender-Related Content in Undergraduate Medical Education,” *JAMA: The Journal of the American Medical Association* 306, no. 9 (2011): 971–977, <https://doi.org/10.1001/jama.2011.1255>.

reasons that gender variant patients have trouble navigating these health systems. Any change in the medical recordkeeping practices must also account for the lack of training that most medical providers receive on the topic²³. As the quote at the beginning of this chapter indicates, stories of overt discrimination and denial of care are commonplace in LGBTIQ communities. These negative experiences tend to foster distrust and anxiety around medical encounters of all types within these populations. Many healthcare professionals who specialize in providing services to transgender patients were galvanized to serve this population after witnessing the heartbreaking effects²⁴ of systemic violence firsthand²⁵.

Gender records have historically approached the encoding of gender with exclusively binary data regimes, e.g. they require everyone to be labeled as either male or female. Information systems have been in development whereby gender variance information can be entered into additional data fields, but this type of approach presents problems for aggregating data. Starting in the early 2010s, a number of major national and statewide public health agencies began working on developing information practices that would capture gender identity and sexual orientation. This study covers the period of methodological development and reports on its outcomes in the data analysis section.

²³ Edward J. Callahan et al., "Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience," *Academic Medicine* 90, no. 2 (February 2015): 154–60, <https://doi.org/10.1097/ACM.0000000000000467>.

²⁴ Tarynn M. Witten and A. Evan Eyler, "Hate Crimes and Violence against the Transgendered," *Peace Review* 11, no. 3 (1999): 461–468, <https://doi.org/10.1080/10402659908426291>.

²⁵ Randi Ettner, Stan Monstrey, and A. Evan Eyler, *Principles of Transgender Medicine and Surgery* (New York: Haworth Press, 2007), xxi.

The normative assumption that all persons should adhere to the gender binary dominated the data structures of medical records and medical information systems in California for the period of 1900-2000. The medical information systems have been built on top of historically situated social constructs that have enforced legal and medical norms of male and female, (and with no affordances for gender variance). A handful of countries outside the US²⁶ have been in the process of adding a third gender marker option (in addition to the binary of male/female). In July 2017 residents of Oregon could apply for a third gender option on their driver's licenses. In early 2017, legislation was introduced in California to allow for a third gender marker on state-issued IDs and government records. While these changes are generally seen as positive for trans and gender variant populations, these changes may result in additional challenges for the state to comply with the Federal ID requirements established by the REAL ID act²⁷. Like the federal identity and vital records systems, many medical information systems have legacy data structures that act as inertial weight to changing data structures.

2.2 Terminologies of Gender:

The story of the classification of gender for medical purposes in the United States is deeply entangled in a framework of social norms that govern how gender is constructed and enforced in social interactions. Moreover, the definitions of terms around gender have changed substantially over time. One researcher explained:

²⁶ Staff and agencies, "Australian Passports to Have Third Gender Option," *The Guardian*, September 15, 2011, sec. World news, <http://www.theguardian.com/world/2011/sep/15/australian-passports-third-gender-option>.

²⁷ "REAL ID | Homeland Security," accessed October 26, 2017, <https://www.dhs.gov/real-id>.

Because gender and sex are seemingly inexplicably connected in most aspects of social life, theorists have difficulty in retaining these delineations [of sex and gender] throughout their work. Intellectuals have been creating, critiquing, and advancing concepts of gender for the past 30 years. Generally, gender is defined as the socially constructed correlate of sex...Gender, then, is the concept that creates and defines sex differences.²⁸

Because sex and gender, as terms, have been used in multiple contexts and definitions, many researchers, including Labuski and Keo-Meier (below) described the challenge of operationalizing terms:

Sex and gender are profoundly unstable realities whose 'assumed concordance' is more ideological than material. And though our goal was to represent trans people in the most comprehensive and useful ways possible, we were acutely aware that such a project was riddled with complexity. Like any unit of scientific analysis, transgender is a category through which a wide variety of multidimensional individuals are gathered, many of whom have little in common aside from their gender- diverse bodies and practices²⁹.

Labuski and Keo-Meier also commented that the operationalization of the term presented definitional challenges:

A related problem was that the term transgender is variably defined and that, for many, this diverse nomenclature is a central feature of being trans. And though we were at pains to represent a category that we saw as both multiple and evolving, we were stymied by how to best render categorical resistance to an audience of demographers³⁰.

Rather than attempting to define transgender, this research engages with these epistemic challenges by locating transgender populations within the long tail of social, biological, and behavioral gender variance within and across populations. As such, the research is more

²⁸ Raine Dozier, "Beards, Breasts, and Bodies: Doing Sex in a Gendered World," *Gender & Society* 19, no. 3 (2005): 298.

²⁹ Christine Labuski and Colton Keo-Meier, "The (Mis) Measure of Trans," *Transgender Studies Quarterly* 2, no. 1 (2015): 13.

³⁰ Labuski and Keo-Meier, 14.

interested in observing commonalities in modalities of gender variability rather than creating operationalized definitions of the individual populations involved. Within the context of medical recordkeeping, the research focuses on what modalities of gender variability are able to be recorded and what modalities are unable to be recorded. With this type of openness in constructing observations of a long tail of gender variance, this research attempts to work within the complexity described by Labuski and Keo-Meier (below) without underestimating the importance of the epistemic artifacts thereof:

The degree to which we understand transgender in neurobiological, cultural, anatomical, behavioral, and/or psychological terms will determine the investigative angles and trajectories along which we trace and then establish a series of associations, hypotheses, findings, and even predictions, many of which will eventually articulate with public policy and popular media³¹.

Historians working within LGBTIQ topic areas have observed that social norms around the designation of gender have long been sites of social tension and cultural scapegoating³². These sites of social tension reflect deep epistemological conflicts around the nature of social stigma³³, discrimination³⁴, personal agency, bodily self-determination, and gender authenticity. These conflicts have also been reflected in medical contexts, such as the tensions around the question of which, if any, formal diagnoses of gender variance (e.g. intersex/DSD,

³¹ Labuski and Keo-Meier, 29.

³² E.A. Armstrong and S.M. Crage, "Movements and Memory: The Making of the Stonewall Myth," *American Sociological Review* 71, no. 5 (2006): 724–751.

³³ Brian L. B. Willoughby et al., "Who Hates Gender Outlaws? A Multisite and Multinational Evaluation of the Genderism and Transphobia Scale," *International Journal of Transgenderism* 12, no. 4 (March 2, 2010): 254–71, <https://doi.org/10.1080/15532739.2010.550821>.

³⁴ Tonia Poteat, Danielle German, and Deanna Kerrigan, "Managing Uncertainty: A Grounded Theory of Stigma in Transgender Health Care Encounters," *Social Science & Medicine* 84 (May 2013): 22–29, <https://doi.org/10.1016/j.socscimed.2013.02.019>.

transsexualism, transgenderism, transvestitism, GID, etc) should be classified as a disease-based pathology³⁵. For some, the contestations in the medical discourse revolve around questions of who determines whether population variance in gender presentation, gender identity, and biological sex constitutes evidence of psychological impairment, moral impairment or mental health problems³⁶.

This background section (and related appendixes) includes a survey of historical terms used in various classifications of gender. Many of the terms reflect tensions around changing social norms around gender and gendered behavior. One of the aspects of complexity stems from the historical interactions around terminologies of gender. Virtually all of the relevant terms used historically to describe gender and gender variance have been contested at one time or another³⁷ by populations both within California and across the nation. The relevant descriptive terminology for gender variance in US populations is fraught with questions of representation, authenticity, and authority when selecting terms to represent these populations³⁸. The descriptive terminology mirrors conflicts in a broader theoretical debate over the relationships between individual agency, authenticity, social norms, identity development, mental impairment, medical diagnosis and systemic violence.

³⁵ Kathy A. Gainor, "Including Transgender Issues in Lesbian, Gay and Bisexual Psychology," *Education, Research, and Practice in Lesbian, Gay, Bisexual, and Transgendered Psychology: A Resource Manual* 5 (2000): 131–160.

³⁶ American Psychological Association, "Guidelines for Psychological Practice with Transgender and Gender Nonconforming People.," *American Psychologist* 70, no. 9 (2015): 832–64, <https://doi.org/10.1037/a0039906>.

³⁷ Susan Stryker, Paisley Currah, and Leslie Jean Moore, "Introduction: Trans-, Trans, or Transgender?," *WSQ: Women's Studies Quarterly* 36, no. 3–4 (2008): 11–22, <https://doi.org/10.1353/wsq.0.0112>.

³⁸ C. J. Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients," *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505, <https://doi.org/10.1353/pbm.2007.0047>.

This research primarily relies on the terms ‘trans and gender variant’ to invoke the broader population of persons who challenge or otherwise fail to fit into traditional gender binaries, but also recognizes that there are many different kinds of communities and linguistic terms in use, both within and outside of these populations. The term ‘trans’ in the context of this research is intended to invoke trans*, transgender, transsexual, transvestite, gender non-conforming, genderqueer, and non-binary genders and gender identities. This approach follows and expands upon the one developed by the authors of the US Transgender Survey (USTS)³⁹:

The term “transgender” is often used to describe people whose gender identity or expression differs from what is associated with the gender they were thought to be at birth. Although this term has often been described as an “umbrella term” that encompasses the spectrum of identities and captures the diversity of transgender people, the authors recognize that one term cannot reflect each individual’s unique identity and some people prefer to use other terms to describe their gender identity.

The term ‘trans’ was chosen over ‘transgender’ to give implicit inclusion to the terms transgender, transsexual, trans women, trans men, and trans* persons. The project uses the term ‘trans and/or gender variant’ as an open umbrella term to aggregate various populations and communities that have struggled to align their experience of gender with their access to medical care and medical recordkeeping. ‘Gender variant’ is used as an umbrella term to group a varied population of variance around gender identity and biological development, which represents a long tail of gender variance that is poorly represented in the records including intersex populations, persons with disorders of sex development, non-binary persons, two-spirit populations, cross dressers, and other non-normative instances of gender identity and gender development. Gender variant, as a term, is used to include populations whose gender is

³⁹ Sandy E. James et al., “The Report of the 2015 U.S. Transgender Survey (USTS)” (Washington, DC: National Center for Transgender Equality, 2016), <http://www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF>.

not exclusively male or female, including those who identify as non-binary, as a gender other than male or female, or as more than one gender.

The historical context of gender markers overlaps with multiple social movements for equality in health care, public life, government policies, journalistic representations, and employment. The terms 'trans and gender variant' have been chosen to broadly include populations that are poorly represented records that rely on binary classifications of gender. The term 'gender variant' was chosen as a reflection of the statistical framing of the populations being discussed. The statistical framing was chosen as a foundational aspect to approach the representation of trans and gender variant populations because the inquiry includes research questions around how data structures impact data used for evidence based medicine, which in turn, relies on statistical approaches to analyze large volumes of data on the phenomenon of interest.

This project employs the language of population statistics to illustrate how data structures of medical recordkeeping systems are able to construct a binary view of gender wherein the lack of representation of gender variance results in a data collection blind spot that yields a dataset devoid of information about these populations. Within the terminology of population statistics, gender can be approached as a collection of traits that exhibit aspects of genetic and environmental variance both within and across categories of gender.

In the US, gender classifications have often relied on a framework of unspoken gender norms that are presented as scientifically based simplifying assumptions⁴⁰. Many researchers have looked at gender norms using the lens of gender variance. Dozier explained:

*Because transsexuals, transgendered people, and others at the borders of gender and sex are fish out of water, they help illuminate strengths and weaknesses in common conceptions of gender.*⁴¹

However, forming gendered classifications into a social expectation of a rigid gender binary benefits those who are served by the gender binary with an efficiency of simplification⁴² and disadvantages those who are not with a host of problems related to social marginalization.

In 2000, Kessler and McKenna summarized these common faulty assumptions:

*Over 20 years ago we wrote a book asserting that all aspects of gender, including the physical/biological aspects, which people refer to as "sex," are socially constructed. Our point was that **the male/female dichotomy is not essentially given in nature.***

In developing our argument, we analyzed the natural attitude toward gender. These taken-for-granted beliefs of the culture include:

- 1. There are two and only two genders. Apparent violations are not really violations. If you look long enough, ask enough questions, or do enough medical tests, the "real" gender will be revealed.*
- 2. Gender exists as a biological "fact" independently of anyone's ideas about gender.*
- 3. A person's gender never changes.*
- 4. Genitals are the essential defining feature of gender. That is, if you do not have the right organ between your legs, you cannot be what you say you are. You are not the "genuine article," even if you have everything else. (That is why transsexuals, at least historically, were not really*

⁴⁰ Virginia M. Miller, "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?," *American Journal of Physiology - Heart and Circulatory Physiology* 306, no. 6 (March 15, 2014): H781–88, <https://doi.org/10.1152/ajpheart.00994.2013>.

⁴¹ Dozier, "Beards, Breasts, and Bodies: Doing Sex in a Gendered World," 297.

⁴² Kim A. Case, Briana Stewart, and Josephine Tittsworth, "Transgender Across the Curriculum: A Psychology for Inclusion," *Teaching of Psychology* 36, no. 2 (2009): 117–21, <https://doi.org/10.1080/00986280902739446>.

*the gender they claimed until they had surgery, and that is why intersexed infants are required to have genital "reconstructive" surgery.)*⁴³

Many researchers have referred to such simplifying assumptions of a socially constructed gender binary as 'biological reductionism'⁴⁴.

One of the most contested arenas of medical terminology stems from the historical models of gender that characterize variance from the above assumptions as pathological in nature. The assertion that gender variance is pathological is often rooted in the assumption that non-conformity with social norms is socially disruptive and cannot be considered benign. However, these assumptions are almost always supported with moralistic arguments rather than evidence or observations. At the heart of these assumptions is a definition of gender that structurally denies the legitimacy of anything that falls outside the gender binary, which defines gender variance to be such a taboo transgression that only someone who was mentally ill would willingly associate with it. These circular definitions and assumptions are the basis for many scholars and researchers referring to this gender binary as being socially normative (proscriptive) rather than descriptive (or evidence based).

Historically, medical and demographic records of sex have been encoded as an exclusive binary⁴⁵, as either male or female, never both, never neither. Biological sex is considered a basic element of demographic and identifying information for both governmental and health

⁴³ Suzanne Kessler and Wendy McKenna, "Who Put the 'Trans' in Transgender? Gender Theory and Everyday Life," *International Journal of Transgenderism* 4, no. 3 (2000), <https://web.archive.org/web/20070927183856/http://www.symposion.com/ijt/gilbert/kessler.htm>.

⁴⁴ Walter O. Bockting, "Biological Reductionism Meets Gender Diversity in Human Sexuality," *The Journal of Sex Research* 42, no. 3 (August 1, 2005): 267–70.

⁴⁵ Kay Siebler, "Transgender Transitions: Sex/Gender Binaries in the Digital Age," *Journal of Gay & Lesbian Mental Health* 16, no. 1 (January 2012): 74–99, <https://doi.org/10.1080/19359705.2012.632751>.

records. As such, practices for assigning sex for birth certificates, identity documents, health insurance, and other vital records have been in development since the establishment of a medicalized model of gender. The characterization of gender assignment as a medicalized model of gender refers to the participation (and gatekeeping function) of medical providers in establishing and attesting to the sex or gender of an individual for the purposes of medical records and identity documents.

In the early part of the 20th century, gender and sex were often conflated and used interchangeably in various contexts. Semantic slippage between concepts of sex, gender and sexual orientation continued into the late 20th and early 21st centuries. The slippage between these concepts has resulted in substantial conflation between these terms in the historical literatures. Later, as researchers began to tease apart the physical aspects of gendered bodies from gendered behavior and identity, they argued that sex should be used to refer to physiologic aspects of sex, which include physical characteristics such as hormone levels, organs, chromosomes and secondary sex characteristics. These researchers argued that the term gender should be used to refer to the gender the person identifies with and presents socially. These aspects of gender are often referred to as gender identity and gender expression, respectively. These distinctions between sex and gender have been widely adopted by most academic researchers and medical disciplines since the 1990s⁴⁶ and have contributed

⁴⁶ Miller, "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?"

substantially to the ability to conduct medical research with trans and gender variant populations⁴⁷.

2.3 Early Sexologists and WWII (1930s and 1940s)

The medicalization of gender variance has roots in the formalization of social studies of sex and gender in the early 1900s, but surgeries and hormone replacement did not become widely available until the 1950s (and later)⁴⁸. In the 1910s and 1920s, as various medical and scientific disciplines began methodically to observe human sexuality and gender roles, many scholars and scientists assumed gender variance to be a form of pathology or psychosis. These assumptions and the associated cultural discourse around the morality of deviance played a foundational role in the development of information structures for recording gender information within the structures of medical information systems.

Magnus Hirschfeld was one of the first social science researchers to study gender variance and sexuality from an evidence-based perspective in 1920s pre-WWII Germany. He was considered a leading expert on homosexuality and a proponent of referring to homosexuals as having a third type of gender. Hirschfeld, in contrast to current approaches, considered all LGBTIQ persons as belonging to a third category of gender, or third sex, outside

⁴⁷ Canadian Institutes of Health Research (CIHR) and Institute of Gender and Health, "Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook" (Ottawa, Canada: Canadian Institute of Health Research (CIHR), 2012), <http://www.cihr-irsc.gc.ca/e/8673.html>.

⁴⁸ Dallas Denny, "Transgender Communities of the United States in the Late Twentieth Century," in *Transgender Rights*, by Paisley Currah, Richard M. Juang, and Shannon Minter (U of Minnesota Press, 2006), 171-.

the gender binary of male and female⁴⁹. He considered them to fall outside of the social expectations and norms assigned to male and female genders.

Many well-regarded early researchers, such as Magnus Hirschfeld⁵⁰, challenged the assumptions of gender as a rigid binary⁵¹. However, the socially conservative discourse around the morality of deviance resulted in his research being denounced by the Nazis and the contents of his research institute being denounced and publically burned. The stigmatizing assertion of gender deviance being associated with immorality and psychopathology dominated the political discourse for over a century⁵². Hirschfeld himself suffered from violence directed at homosexuals, leftists, and Jews in Nazi Germany during the 1920s and 1930s. He was attacked and badly injured as he was traveling to give public presentations of the results of his research. His library and research archive were completely destroyed during now infamous book burnings of 'degenerate' materials in 1933.

Christopher Isherwood, a popular novelist known for his novels about gay life in Berlin in the 1920s, visited Hirschfeld's Institute for Sexual Science in 1929. The institute studied sex and gender in every observable manifestation in Berlin. In his autobiography, Isherwood described his initial sense of horror in encountering Hirschfeld's normalization of gender variance, and yet by the end of his visit he came to honor Hirschfeld as a visionary:

⁴⁹ Magnus Hirschfeld, *Berlins Drittes Geschlecht* (Berlin: rosa Winkel, 1991).

⁵⁰ Hirschfeld.

⁵¹ Genny Beemyn, "A Presence in the Past: A Transgender Historiography," *Journal of Women's History* 25, no. 4 (2013): 113–21, <https://doi.org/10.1353/jowh.2013.0062>.

⁵² Barry et al., "Bare Desire to Harm."

*I remember the shock with which Christopher first realized that one of the apparently female guests was a man. He had pictured transvestites as loud, screaming, willfully unnatural creatures. This one seemed as quietly natural as an animal and his disguise was accepted by everyone else as a matter of course...During those early days, he found lunch at the Institute a bit uncanny.*⁵³

*Christopher giggled because he was embarrassed. He was embarrassed because, at last, he was being brought face to face with his tribe. Up to now, he had behaved as though the tribe didn't exist and homosexuality were a private way of life discovered by himself and a few friends. He had always known, of course, that this wasn't true. But now he was forced to admit kinship with these freakish fellow tribesmen and their distasteful customs.*⁵⁴

*Suddenly he loved Hirschfeld – at whom he himself had been sneering a moment before – the silly solemn old professor with his doggy mustache, thick peering spectacles, and clumsy German-Jewish boots... they were all three on the same side, whether Christopher liked it or not. And later he would learn to honor them both, as heroic leaders of his tribe.*⁵⁵

The horror around social deviance that Isherwood described above is strongly mirrored in Erving Goffman's conception of 'identity ambivalence'. His conception of 'identity ambivalence' is based on his studies of the identity management strategies of stigmatized individuals⁵⁶. Goffman described the deep ambivalence that his research participants felt when confronted with their "own kind":

The stigmatized individual may exhibit identity ambivalence when he obtains a close sight of his own kind behaving in a stereotyped way, flamboyantly or pitifully acting out the negative attributes imputed to them. The sight may repel him, since after all he supports the norms of the wider society, but his social and psychological identification with these offenders holds him to what repels him, transforming repulsion into

⁵³ Christopher Isherwood, *Christopher and His Kind* (New York: Farrar Straus Giroux, 1976), 15–16.

⁵⁴ Isherwood, 16.

⁵⁵ Isherwood, 17.

⁵⁶ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Simon and Schuster, 1963).

*shame, and then transforming ashamedness itself into something of which he is ashamed. In brief, he can neither embrace his group nor let it go*⁵⁷.

This ambivalence about associating with other visibly gender variant persons is common in descriptions of trans and gender variant communities during the 20th century and into the 21st century⁵⁸. During this period it was common practice in trans and certain other gender variant communities to go ‘stealth’, which is another term for hiding one’s gender history and gender identity. Within this practice, it has been common for these trans persons to avoid contact with other visibly transgender or gender non-normative persons so as to avoid being ‘clocked’, which is another term for being identified as transgender, gender variant, or gender non-conforming. Some researchers have asserted that this ambivalence should be considered a facet of internalized homophobia and/or transphobia, but regardless of the terminology, the ambivalence described has been a consistent feature in public life, the literature, and medical records for the time period.

The shadow of the Holocaust also affected the development of identity and community politics in the United States for decades thereafter. During the 1930s and 1940s, approximately ten thousand homosexual men, transgender women and gender variant (born male) persons were sentenced to imprisonment in concentration camps under Paragraph 175 during the Holocaust. These prisoners often faced the worst treatment within the camps. They were used for medical experiments. Many of them were worked to death. This group of persons assigned the pink triangle had the lowest survival rate of any of the designated groups sent to

⁵⁷ Goffman, 488–89.

⁵⁸ Heather Love, “‘ Spoiled Identity’: Stephen Gordon’s Loneliness and the Difficulties of Queer History,” *GLQ: A Journal of Lesbian and Gay Studies* 7, no. 4 (2001): 487–519.

concentration camps⁵⁹. It was not until after the close of WWII that research into sexuality and gender resumed in academic circles (with the work of Alfred Kinsey and others). However, it should be noted that the gay men and trans women who survived the concentration camps were not necessarily released nor cleared of their criminal sentences as the camps were liberated⁶⁰. After surviving the horrors of the concentration camps, many remained in custody, retained a criminal record, and/or had no right to petition for restitution from the German government (in contrast to the other groups forced into concentration camps). Their felony criminal convictions were upheld until 1994, when the German government formally repealed Paragraph 175 and apologized for maintaining the designation of these persons as felons after the close of the war.

Because there was such a long history of demonization and persecution of gender variance as criminal across Europe, the majority of the personal records of the men with the pink triangle had been lost by the time they were formally pardoned in the 1990s. Some records were rescued (by coincidental discovery) from garbage bins after the survivors had passed away. During the 1970s, LGBT activists began to organize around documenting and publicizing the histories stemming from LGBTIQ Holocaust survivors. Awareness of the systematic social marginalization particularly galvanized activists in the urban areas around San Francisco and New York⁶¹. The advent of the HIV epidemic during the 1980s was met with a cultural scapegoating of gays in the media. This scapegoating combined with a lack of concern

⁵⁹ Richard Plant, *The Pink Triangle: The Nazi War against Homosexuals* (New York: H. Holt, 1986).

⁶⁰ Plant.

⁶¹ Colin R. Johnson, "Feeling Our Way Toward a History of ACT UP," *GLQ: A Journal of Lesbian and Gay Studies* 17, no. 2 (June 4, 2011): 432–34.

exhibited by public health agencies generated a cohort of community organizers and activists in San Francisco, Los Angeles and elsewhere in California affiliated with the emblem of the pink triangle under the mantra 'silence = death'.

These histories galvanized a generation of US and international activists⁶², the legacy of which is seen in the proliferation of the pink triangle as a symbol during the 1970s and 1980s. San Francisco erects a highly visible pink triangle on Twin Peaks every June to honor the dead and celebrate the living. However, even in San Francisco these memorials have suffered from vandalism in recent years, a reminder that the social violence and discrimination has not yet become a thing of the past⁶³.

2.3 Post War Period of the 1950s

Pop culture representations of LGBT persons in the 1950s were characterized by sensationalized pulp novels where the protagonists were portrayed as deeply flawed and suffering greatly from their transgressive sexuality and/or gender identity. At this time gender variance was considered a moral defect and criminalized. In the 1940s and 1950s, anti-sumptuary and lewd conduct laws prohibited cross-dressing and same sex displays of affection. These laws were used to legitimize harassment and arrests of LGBT populations across California and the US. In Los Angeles in 1950, LAPD police chief William H. Parker declared them to be criminals guilty of "sex perversion" and made enforcement against them his

⁶² Plant, *The Pink Triangle*.

⁶³ "The Bay Area Reporter Online | Arson Hits Pink Triangle," accessed July 23, 2009, <http://www.ebar.com/news/article.php?sec=news&article=4037>.

department's top priority⁶⁴. The anti-cross dressing laws in LA required all persons to wear at least three items of clothing associated with their legal sex, e.g. men must wear at least 3 items of men's clothing and vice versa. These laws were used to justify the detention and strip-searching of LGBTIQ populations, with particular focus on populations further marginalized by race, education and class.

At the same time, the first widely publicized 'sex change' surgeries were performed (in Europe) on a former GI (named Christine Jorgensen) in the early 1950s. She became known internationally as having had a 'sex change'. Her autobiography was published in 1967. At this time, trans and gender variant persons began approaching providers with requests to access the hormones and surgery that Christine Jorgensen had received. At this time, Harry Benjamin and John Money became known as leading researchers on sex and gender in the US. Harry Benjamin, with the assistance of a wide variety of community members and healthcare providers, built up a professional network of healthcare providers for trans and gender variant persons that has developed healthcare practices for trans and gender variant patients in the United States. Reed Erickson, a wealthy patron of LGBT organizations and openly trans person, was also a key figure in building up an information network for healthcare providers in the 1950s and 1960s⁶⁵.

2.4 The Professional Gaze and Social Unrest of the 1960s and 1970s

⁶⁴ Lillian Faderman and Stuart Timmons, *Gay L.A.: A History of Sexual Outlaws, Power Politics, and Lipstick Lesbians* (Basic Books, 2006).

⁶⁵ A. H Devor and N. Matte, "ONE Inc. and Reed Erickson: The Uneasy Collaboration of Gay and Trans Activism, 1964-2003," *GLQ: A Journal of Lesbian and Gay Studies* 10, no. 2 (2004): 179.

In the 1960s, many universities opened gender clinics that worked towards making hormones and surgery available to trans patients. John Money worked at the clinic at Johns Hopkins. He performed studies where he experimented with children with disorders of sexual development (formerly called intersex and/or hermaphrodites in the literature) whereby the child underwent surgeries and were socialized into the gender chosen for them by the doctor. He believed these children could be successfully socialized as either boys or girls if the socialization was conducted seamlessly from birth. In most cases, the children were not informed of their sex development condition nor of the reasoning behind the surgeries. Later, several of these experimental studies were retracted based on ethical problems. A number of former child patients came forward to contest his conclusions and discuss the harm that they had experienced as a result of having their gender re-assigned without their knowledge or consent. Money, in defense of his research practices, insisted that he was trying to protect these children from the social violence leveled against non-binary manifestations of gender in this culture.

In the 1970s, cultural backlash against the rights movements of the 1960s also affected the gender clinics that had opened in the 1960s. Dallas Denny, in writing about the period explained:

*In 1979, Meyer and Reter published a study that purported to show 'no objective improvement' in male-to-female transsexuals who had undergone sex reassignment surgery. The effect of this publication was immediate and far-reaching. The Hopkins gender clinic closed in the furor which followed, and other clinics folded in its wake. Of the more than 40 university-affiliated gender programs in the U.S., only three survived.*⁶⁶

⁶⁶ D. Denny, "A Selective Bibliography of Transsexualism," *Journal of Gay & Lesbian Mental Health* 6, no. 2 (2002): 35.

Later studies from Europe showed that these surgeries resulted in substantially improved health outcomes and that less than 1% of patients had regrets about their surgery⁶⁷. However, the damage had already been done. At the crux of the problem with the Meyer and Reter studies were the definitions of ‘objective improvement’ and the question of whether the patient or the psychologist should determine the criteria of improvement. In 1979, the gender clinic at Johns Hopkins was also shut down and the culture of the institution towards trans and gender variant patients became more hostile in nature. Hopkins’ clinical psychologist, Paul R. McHugh, used similar studies to make unfounded claims that homosexual desire is ‘erroneous’ and that sex reassignment surgeries are ‘unsuccessful’ in treating the patients’ underlying psychological disorders. McHugh has continued to aggressively pursue these claims to this day, despite a conclusive amount of quantitative data (primarily from Europe) and qualitative data (from the US) refuting his claims. These various histories of marginalization and pathologization have left a powerful legacy of distrust between LGBTIQ communities and professional researchers in psychology, psychiatry, and mental health domains.

While a single researcher cannot determine the institutional culture of a medical institution, the following comment from 2005 from a patient attempting to access care illustrates how pervasive and disruptive these legacies can be:

⁶⁷ M. Landén et al., “Factors Predictive of Regret in Sex Reassignment,” *Acta Psychiatrica Scandinavica* 97, no. 4 (April 1998): 284–89.

I am transgender (female to male), and have been trying desperately to get into some sort of gender therapy for hormones and surgery. Unfortunately, most of the folks who I have dealt with in the medical community ... have no background, or do not want anything to do with my journey. [The psych evaluation] was nothing but pure hell. That group is very much anti-trans. ... I have never been so offended, or insulted in my entire life. ⁶⁸

The comment originated from a website written in the mid-2000s. The website is dedicated to advocating for the inclusion of trans women's voices in a dispute with clinical psychologists over whether anyone has the ability to determine the 'root cause' of a person's transgenderism or transsexualism. These clinical researchers dismissed the importance of listening to trans women's voices about their internal relationship to self and sexuality, designating them categorically as 'unreliable'. Unfortunately, there is no shortage of examples where trans women's experiences were marginalized, pathologized, or dismissed as unreliable. Similarly, there is no shortage of examples where legitimate objections to the characterizations applied to them in legal⁶⁹, scientific⁷⁰, historical⁷¹ and medical literatures⁷² have been dismissed and discounted without being adequately examined.

Many of the medical and mental health texts from the 1930s through the 1970s (focusing on gender and gender variance) were written by professionals limited in their

⁶⁸ "Johns Hopkins University: Anti-Trans Hotbed," accessed July 10, 2014, <http://www.tsroadmap.com/info/johns-hopkins.html>.

⁶⁹ Phyllis Randolph Frye, "International Bill of Gender Rights vs. the Cider House Rules: Transgenders Struggle with the Courts over What Clothing They Are Allowed to Wear on the Job, Which Restroom They Are Allowed to Use on the Job, Their Right to Marry, and the Very Definition of Their Sex, The," *Wm. & Mary J. Women & L.* 7 (2000): 133.

⁷⁰ Andrea James, "'Illegal Immigrants' vs. the Border Patrol of Sex and Sexuality: J. Micheal Bailey as the Border Patrol," *TSRoadmap.com*, 2012, <http://www.tsroadmap.com/info/bailey-immigrants.html>.

⁷¹ Susan Stryker, "(De) Subjugated Knowledges: An Introduction to Transgender Studies," in *The Transgender Studies Reader*, ed. Susan Stryker and Stephen Whittle (New York: Routledge, 2006).

⁷² Jane Fry, "Conclusion: On the Records," in *Being Different: The Autobiography of Jane Fry.*, ed. Robert Bogdan (New York: Wiley, 1974), 213–33.

experience of gender variance by their clinical interactions with populations of institutionalized patients (most of whom had multiple serious psychiatric issues). This exclusive focus on populations under treatment for concurrent mental health issues created conflation of behavioral and mental health problems in their definitions of gender variant populations from the 1950s-1970s⁷³. Transgender and gender variant populations in the 1960s and 70s were often represented in the popular media as monstrous, deceptive, evil or malignant⁷⁴.

In the 1960s and 1970s, gender variant persons were considered (by mental health providers) to be too mentally ill to participate in the professionals' discourse on sex and gender. (insert quotes from the Autobiography of Jane Fry) These problematic interactions tended to result in a strong insider-outsider social dynamic whereby gender variant populations felt judged, stigmatized, misrepresented and disenfranchised from the professionals who were responsible for their care and treatment. Around this time, medical recordkeeping and information systems adopted descriptive classifications of diseases that often included structural assumptions of moral degeneracy and psychopathology within the very definition of gender variance. Patients were often well aware that if they wanted to access care, they needed to conform to a specific narrative about gender and gender identity, regardless of whether they felt any affinity for the dominant narrative. These insider-outsider dynamics created substantial tensions between gender variant populations and medical providers, some of which are still creating substantial friction between these communities.

⁷³ Denny, "Transgender Communities of the United States in the Late Twentieth Century."

⁷⁴ Love, "Spoiled Identity."

1979 also saw the formation of the Harry Benjamin International Gender Dysphoria Association (HBIGDA) and release of the first edition of their standards of care. Later the group would rename itself the World Professional Association for Transgender Health (WPATH). The group was formed by medical and mental health professionals in order to support evidence based practices for treating trans and gender variant persons. They created a 'standards of care' practice manual for trans and gender variant persons in order to create a path for treatment for patients wanting to access hormones and surgery.

However, the creation of the standards was primarily in response to the backlash and contestations of identity described above, epitomized by the Argentinian doctor who was convicted of assault for performing what was called at the time 'a sex change operation'. This conviction gave a chilling effect on surgeries and gender clinics. The standards of care were created primarily as a framework of standards that would protect doctors and surgeons from legal challenges for being involved in prescribing hormones and/or performing surgeries. The standards of care were thus largely focused on creating a legally defensible modality of treatment for the providers.

Unfortunately, the standards resulted in the medical needs of transgender and gender variant patients becoming secondary to the protection of providers from medical liability. It created gatekeeping roles for doctors and mental health providers that added further complex tensions between patients and providers. On the one hand, the standards provide a pathway for trans people to navigate the medical system. On the other hand, it requires that patients to convince a mental health provider that they are mentally sound enough to give informed consent, something that is not required of any other population. To many trans people it feels

like the medical system treats them as insane and untrustworthy until proven otherwise. It creates an unspoken standard of regarding gender variant persons as ‘mentally ill unless proven otherwise’⁷⁵.

At that time, transgenderism and gender variance were considered direct evidence of a mental disorder⁷⁶. Current medical practice acknowledges that many of the negative mental health problems associated with gender variance result from trauma associated with social stigma and social violence rather than from the gender variance itself. The 1950s and 60s saw substantial build-out and innovation around medical interventions (such as surgery and hormones), but the 1970s saw a major cultural backlash that closed the majority of the gender clinics that had been established in the 1960s⁷⁷.

2.5 Conservative Pushback and Reagan Economics in the 1980s

During the 1970s, gender variant patients were often told by those in the mental health professions that they were suffering from a psychological disturbance and that sex reassignment surgeries would do nothing to treat their underlying psychological issues. Health care for trans-specific medical procedures became categorically excluded from insurance and governmental practices. Sex reassignment surgeries were labeled as experimental and the benefit of these surgeries were called into question. The practice of informed consent for surgery was rejected by adversarial psychologists on the basis of the assertion that anyone who

⁷⁵ Hale, “Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients,” 2007.

⁷⁶ Beemyn, “A Presence in the Past.”

⁷⁷ Dallas Denny, “Sex Certainly Did Change!,” *The Journal of Sex Research* 40, no. 3 (August 1, 2003): 316–17.

would want surgery must be mentally ill, and therefore cannot be considered competent to give informed consent. This same logic was applied to trans women who disagreed with certain psychologists' sexualizing their motivations for transitioning⁷⁸. The women were told that they were suppressing the real truth about themselves and that the psychologists 'knew better' than them. These disputes deepened the distrust and lack of confidence many trans populations felt around medical and mental health professionals.

Trans and gender variant populations responded to the cultural backlash and backsliding of access to medical care during the 1970s by going underground and developing information networks of transgender friendly providers in the 1980s and 1990s. Many found ways to access care while remaining invisible, passing as cisgender and erasing all evidence of their gender histories. Many began traveling internationally for surgery, seeking lower costs and lower barriers to care. Stories of medical providers refusing to treat trans and gender variant persons remain ubiquitous within trans and gender variant communities from the 1980s throughout the 2000s. In the 1990s and 2000s, medical providers and health analysts began to separate the effects of social violence from the effects of gender dysphoria. At that time, the medical literature began to recognize that the social violence constituted a major contributor to the mental health problems previously attributed to gender dysphoria⁷⁹.

2.6 Addressing Legacies of Marginalization in the 1990s

⁷⁸ Jaimie F. Veale, David E. Clarke, and Terri C. Lomax, "Male-to-Female Transsexuals' Impressions of Blanchard's Autogynephilia Theory," *International Journal of Transgenderism* 13, no. 3 (2012): 131–39, <https://doi.org/10.1080/15532739.2011.669659>.

⁷⁹ Kristen Clements-Nolle, Rani Marx, and Mitchell Katz, "Attempted Suicide among Transgender Persons: The Influence of Gender-Based Discrimination and Victimization," *Journal of Homosexuality* 51, no. 3 (2006): 53–69, https://doi.org/10.1300/J082v51n03_04.

In the 1990s, health care providers, LGBT community members, and researchers began to gain traction for moving away from categorizing and treating gender identity variance as a mental disease and pathology. However, the popular media continued to represent trans and gender variant persons as deceptive outsiders⁸⁰. For nearly 40 years, leading psychologists writing about trans and gender variant populations argued that these populations were actively engaged in psychotic forms of self-harm and therefore they could not be considered reliable sources of information about the nature of gender dysphoria⁸¹. They argued against medical interventions such as surgery and hormones, claiming that these interventions to be unfounded and misinformed⁸²:

"The ADA also excludes from coverage "transvestism," "gender identity disorders not resulting from physical impairments," and "transsexualism," but it does so for a very different reason. Unlike homosexuality and bisexuality, the ADA does not exclude these conditions under the theory that they are not medical "impairments." Instead, the ADA excludes transvestism, transsexualism, and gender identity disorder ("GID") because of the moral opprobrium of two senior U.S. senators, conveyed in the eleventh hour of a marathon day-long floor debate, who believed that all were "sexual behavior disorders" undeserving of legal protection."⁸³

In the 1990s gender studies, queer studies, and transgender studies began to form disciplines based on models of postmodern epistemology and critical inquiry. As such, a variety of researchers from a wide range of disciplines began to publish rich epistemic evidence against

⁸⁰ Randi Gressgard, "When Trans Translates into Tolerance-or Was It Monstrous? Transsexual and Transgender Identity in Liberal Humanist Discourse," *Sexualities* 13, no. 5 (2010): 539–561.

⁸¹ Elroi J. Windsor, "Accounting for Power and Academic Responsibility," *Archives of Sexual Behavior* 37, no. 3 (June 2008): 495–97, <https://doi.org/10.1007/s10508-008-9319-z>.

⁸² Paul McHugh, "Transgender Surgery Isn't the Solution," *Wall Street Journal*, May 13, 2016, sec. Opinion, <http://www.wsj.com/articles/paul-mchugh-transgender-surgery-isnt-the-solution-1402615120>.

⁸³ Barry et al., "Bare Desire to Harm," 510.

the argument that gender dysphoria was a destructive form of psychosis⁸⁴. Denny (2002) described the period:

*The collision of the psychomedical and postmodern models of transsexualism provided fertile ground for a paradigm shift. An alternative model had been proposed which changed the locus of pathology: transsexuals were not mentally ill men and women whose misery could be alleviated only by sex reassignment, but rather emotionally healthy individuals whose expression of gender was not constrained by societal expectations.*⁸⁵

Around this time period, many trans and gender variant populations began to chafe against the designation of gender variance as a disease in mental health diagnostic manuals such as the DSM-IV⁸⁶ and ICD-10⁸⁷. Spade comments on these assumptions when comparing the level of medical scrutiny required for FTM top surgery versus breast augmentation/implants⁸⁸. At the time, neither surgery was covered by health insurance, however, chest reduction surgery for FtMs required a letter of endorsement from a mental health professional; breast augmentation (implant) surgeries did not require any input from mental health professionals. Interestingly, the healthcare coverage and policy environment has changed dramatically since Spade's book was released in 2011.

⁸⁴ Walter O. Bockting, "Transforming the Paradigm of Transgender Health: A Field in Transition," *Sexual and Relationship Therapy* 24, no. 2 (May 2009): 103–7, <https://doi.org/10.1080/14681990903037660>.

⁸⁵ Denny, "A Selective Bibliography of Transsexualism," 36.

⁸⁶ Trevor A. Corneil, Justus H. Einfeld, and Marsha Botzer, "Proposed Changes to Diagnoses Related to Gender Identity in the DSM : A World Professional Association for Transgender Health Consensus Paper Regarding the Potential Impact on Access to Health Care for Transgender Persons," *International Journal of Transgenderism* 12, no. 2 (September 20, 2010): 107–14, <https://doi.org/10.1080/15532739.2010.509205>.

⁸⁷ "2016/17 ICD-10-CM Diagnosis Codes F64.* : Gender Identity Disorders," accessed November 1, 2016, <http://www.icd10data.com/ICD10CM/Codes/F01-F99/F60-F69/F64->.

⁸⁸ Dean Spade, *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law* (South End Press Cambridge, MA, 2011).

In the early 2000's most trans related medical interventions (e.g. surgeries, electrolysis, hormones, medications, etc) were categorically excluded from medical coverage by virtually all health insurance policies, both in CA and nationally. Trans and gender variant persons were paying for their treatment out of pocket as elective, informed consent procedures. Print records of the 2000's are full of references to fundraisers and parties to pay for surgeries and health care for community members. Spade's reference to top surgery as being elective is now somewhat dated. Now that California law mandates broader coverage of the most common medical interventions in California, more recent publications compared the process of elective mastectomy for women at high risk of breast cancer to the process of FTM top surgery. The surgery is a mastectomy in both cases, medically speaking. While both rely on a medical model of informed consent, the transgender variant also requires a letter of endorsement from a mental health professional based on up to a year of mental health evaluation.

The standards of care upon which this letter writing requirement was based was added as a requirement to the standards of care due to the risk of medical liability and malpractice for the providers⁸⁹. The letter requirement was primarily designed to protect medical providers from liability. The health care of the patients was secondary to the concern about medical liability. Later the approach was adapted to try to balance the patient's health and economic concerns with those of the providers. However, these letters are a unique model of healthcare provision compared to general medical practice in the US. If a provider is unfamiliar with WPATHs 'standards of care' and the medical model of gender that requires such letters, they

⁸⁹ C. J Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients," *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505, <https://doi.org/10.1353/pbm.2007.0047>.

are unlikely to write a letter of endorsement. Many providers are unwilling to provide an endorsement that is binding them to an unfamiliar legal framework of medical liability.

2.7 Conclusions:

Medicalized gatekeeping has a complex history of discrediting the voices of trans and gender variant persons and communities⁹⁰. Many psychologists have claimed that the conflict of gender identity between mind and body is fundamentally a mental disorder (and equate medical interventions with causing harm to the patient)⁹¹. Their argument rests on the claim that a mismatch between gender in the mind and gender of the body is the result of mental illness. This argument has been used repeatedly over the last century to disenfranchise trans and gender variant populations from having a voice in the professional discourse⁹². Others have noted that the mental health problems commonly observed in trans and gender variant populations result from exclusionary social practices based on normative expectations to conform to gendered social roles⁹³. Many trans and gender variant populations have voiced strongly worded criticism of medical, psychology and academic fields for treating them like lab rats. Their criticism revolves around using their bodies for research without giving them the

⁹⁰ Paisley Currah, "Expecting Bodies: The Pregnant Man and Transgender Exclusion from the Employment Non-Discrimination Act," *Women's Studies Quarterly* 36, no. 3/4 (October 1, 2008): 330–36; Alice D. Dreger, "The Controversy Surrounding The Man Who Would Be Queen: A Case History of the Politics of Science, Identity, and Sex in the Internet Age," *Archives of Sexual Behavior* 37, no. 3 (June 2008): 366–421, <https://doi.org/10.1007/s10508-007-9301-1>; Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients," 2007; Julia M. Serano, "The Case Against Autogynephilia," *International Journal of Transgenderism* 12, no. 3 (October 12, 2010): 176–87, <https://doi.org/10.1080/15532739.2010.514223>.

⁹¹ McHugh, "Transgender Surgery Isn't the Solution."

⁹² Barry et al., "Bare Desire to Harm"; Gainor, "Including Transgender Issues in Lesbian, Gay and Bisexual Psychology."

⁹³ Badgett et al., "Bias in the Workplace"; Judith Bradford et al., "Experiences of Transgender-Related Discrimination and Implications for Health: Results from the Virginia Transgender Health Initiative Study," *American Journal of Public Health* 103, no. 10 (2013): 1820–1829; Clements-Nolle, Marx, and Katz, "Attempted Suicide among Transgender Persons."

opportunity to represent themselves in terms that are based on their voices and lived experiences. The question of authenticity of gender (and who may determine whether a person's gender is authentic) is deeply fraught with the histories of these social conflicts around social deviance and belonging.

After decades of negative experiences, many trans and gender variant populations are deeply distrustful of the medical establishment and academia. With the increase in inclusion and protective language for gender identity, more trans and gender variant persons are allowing themselves to be identified in the records. However, their safety in disclosure cannot be assumed. Grant et al reported that "doctors' knowledge of a patient's transgender status increases the likelihood of discrimination and abuse. Medical professionals' awareness of their patient's transgender status increased experiences of discrimination among study participants *up to eight percentage points* depending on the setting⁹⁴" [emphasis added].

Establishing standards of gatekeeping for patients wishing to access surgery and hormones assumes that patients benefit from medical gatekeeping. However, gatekeeping is a highly complex interaction in health care contexts. Gatekeeping, in the context of standards of care, assumes that patients will have access to a functioning and appropriately educated mental health staff⁹⁵. Unfortunately, access to mental health services is problematic in most counties and most staff are poorly educated in working with trans and gender variant

⁹⁴ "National Transgender Discrimination Survey Report on Health and Health Care" (National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010), 6, http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.

⁹⁵ American Psychological Association, "Guidelines for Psychological Practice with Transgender and Gender Nonconforming People."; Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients," 2007.

populations. Most trans-specific health care procedures and medications were categorically excluded from insurance coverages until recent policy revisions forced changes in insurance practice. The lack of data allowed the surgeries to be labeled as experimental for over 50 years. During that period, trans people were paying out of pocket costs for a year or more of psychotherapy in order to be allowed access to hormones or surgery (\$5000-75000). After insurance companies were mandated by the state legislators to end exclusions for medically necessary trans specific health care, providers and insurance companies discovered they had no information in their index of providers that would allow them to refer patients to competent specialists for care.

As a result of the long history of complex problems of gender-based discrimination and social violence, few medical information systems have been able to record gender variance information effectively⁹⁶. These histories of marginalization and discrimination left deep legacies of distrust and trauma surrounding the power imbalances faced by a population struggling for fair representation within a system created by and for the majority⁹⁷. The question of gender markers and gender identity records have been a central point of concern for trans and gender variant health care advocacy and educational projects⁹⁸. It is striking the degree to which records and the management of the friction generated by those gender records cut across all other aspects of race and economic status. Transgender and gender

⁹⁶ Callahan et al., "Eliminating LGBTIQ Health Disparities."

⁹⁷ Spade, *Normal Life*.

⁹⁸ Susan Stryker, *Transgender History* (Berkeley CA: Seal Press, 2008).

variant populations suffer disproportionately from lack of representation⁹⁹ in medical records¹⁰⁰, health data¹⁰¹ and historical records¹⁰².

It remains unclear as to why most healthcare institutions have allowed these information disparities to develop and persist into such an extensive data void for trans bodies in the US. Some researchers posit trans bodies as intersecting in a no-man's-land of social tensions between evolving concepts of sex and gender. For many individuals during the 20th century, the risk of violence associated with being identified was more pressing than concerns about social erasure. The civil rights and social liberation movements of the 1960s and 1970s represented a widespread movement for visibility, equal rights and to collectively stand up against the violence. One argument suggests that the lack of data collection results from the lack of consensus around how to manage the security issues presented by the nature of the information. This chapter details tensions that intersect with the historical development of this data void.

⁹⁹ Sari L. Reisner et al., "Monitoring the Health of Transgender and Other Gender Minority Populations: Validity of Natal Sex and Gender Identity Survey Items in a U.S. National Cohort of Young Adults," *BMC Public Health* 14 (November 26, 2014): 1224, <https://doi.org/10.1186/1471-2458-14-1224>.

¹⁰⁰ S. L. Reisner et al., "'Counting' Transgender and Gender-Nonconforming Adults in Health Research: Recommendations from the Gender Identity in US Surveillance Group," *TSQ: Transgender Studies Quarterly* 2, no. 1 (January 1, 2015): 34–57, <https://doi.org/10.1215/23289252-2848877>.

¹⁰¹ Conron et al., "Sex and Gender in the US Health Surveillance System."

¹⁰² Paisley Currah and Lisa Jean Moore, "'We Won't Know Who You Are': Contesting Sex Designations in New York City Birth Certificates," *Hypatia* 24, no. 3 (August 1, 2009): 113–35, <https://doi.org/10.1111/j.1527-2001.2009.01048.x>; Scout, "Déjà Vu: National Surveys Leave Trans People Behind," *Huffington Post* (blog), June 13, 2013, http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html; Stryker, *Transgender History*; Alex Zimmerman, "Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research," *Pittsburgh City Paper*, December 12, 2013, Online edition, sec. Blogh, <http://www.pghcitypaper.com/Blogh/archives/2013/12/12/study-shows-just-01-percent-of-nih-funding-went-to-lgbt-research>.

CITED REFERENCES (HISTORICAL BACKGROUND)

- “2016/17 ICD-10-CM Diagnosis Codes F64.* : Gender Identity Disorders.” Accessed November 1, 2016. <http://www.icd10data.com/ICD10CM/Codes/F01-F99/F60-F69/F64->.
- American Psychological Association. “Guidelines for Psychological Practice with Transgender and Gender Nonconforming People.” *American Psychologist* 70, no. 9 (2015): 832–64. <https://doi.org/10.1037/a0039906>.
- Armstrong, E.A., and S.M. Crage. “Movements and Memory: The Making of the Stonewall Myth.” *American Sociological Review* 71, no. 5 (2006): 724–751.
- Badgett, M. V., Holning Lau, Brad Sears, and Deborah Ho. “Bias in the Workplace: Consistent Evidence of Sexual Orientation and Gender Identity Discrimination.” University of California, Los Angeles: Williams Institute, 2007. <https://escholarship.org/uc/item/5h3731xr.pdf>.
- Barry, Kevin M. “Disabilityqueer: Federal Disability Rights Protection for Transgender People.” *Yale Human Rights and Development Law Journal*, 2014. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2084351.
- Barry, Kevin M., Brian Farrell, Jennifer L. Levi, and Neelima Vanguri. “Bare Desire to Harm: Transgender People and the Equal Protection Clause, A.” *BCL Rev.* 57 (2016): 507.
- Beemyn, Genny. “A Presence in the Past: A Transgender Historiography.” *Journal of Women’s History* 25, no. 4 (2013): 113–21. <https://doi.org/10.1353/jowh.2013.0062>.
- Bettcher, Talia Mae. “Evil Deceivers and Make-Believers: On Transphobic Violence and the Politics of Illusion.” *Hypatia* 22, no. 3 (2007): 43–65.
- Bockting, Walter O. “Biological Reductionism Meets Gender Diversity in Human Sexuality.” *The Journal of Sex Research* 42, no. 3 (August 1, 2005): 267–70.
- . “Transforming the Paradigm of Transgender Health: A Field in Transition.” *Sexual and Relationship Therapy* 24, no. 2 (May 2009): 103–7. <https://doi.org/10.1080/14681990903037660>.
- Bowker, G. C, and S. L Star. “How Things (Actor-Net) Work: Classification, Magic and the Ubiquity of Standards.” *Philosophia* 25, no. 3–4 (1996): 195–220.
- Bradford, Judith, Sari L. Reisner, Julie A. Honnold, and Jessica Xavier. “Experiences of Transgender-Related Discrimination and Implications for Health: Results from the Virginia Transgender Health Initiative Study.” *American Journal of Public Health* 103, no. 10 (2013): 1820–1829.

- Callahan, Edward J., Shea Hazarian, Mark Yarborough, and John Paul Sánchez. "Eliminating LGBTIQ Health Disparities: The Associated Roles of Electronic Health Records and Institutional Culture." *The Hastings Center Report* 44 Suppl 4 (September 2014): S48-52. <https://doi.org/10.1002/hast.371>.
- Callahan, Edward J., Nicole Sitkin, Hendry Ton, W. Suzanne Eidson-Ton, Julie Weckstein, and Darin Latimore. "Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience." *Academic Medicine* 90, no. 2 (February 2015): 154–60. <https://doi.org/10.1097/ACM.0000000000000467>.
- Canadian Institutes of Health Research (CIHR), and Institute of Gender and Health. "Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook." Ottawa, Canada: Canadian Institute of Health Research (CIHR), 2012. <http://www.cihr-irsc.gc.ca/e/8673.html>.
- Case, Kim A., Briana Stewart, and Josephine Tittsworth. "Transgender Across the Curriculum: A Psychology for Inclusion." *Teaching of Psychology* 36, no. 2 (2009): 117–21. <https://doi.org/10.1080/00986280902739446>.
- Clements-Nolle, Kristen, Rani Marx, and Mitchell Katz. "Attempted Suicide among Transgender Persons: The Influence of Gender-Based Discrimination and Victimization." *Journal of Homosexuality* 51, no. 3 (2006): 53–69. https://doi.org/10.1300/J082v51n03_04.
- Collin, Lindsay, Sari L. Reisner, Vin Tangpricha, and Michael Goodman. "Prevalence of Transgender Depends on the 'Case' Definition: A Systematic Review." *The Journal of Sexual Medicine* 13, no. 4 (April 1, 2016): 613–26. <https://doi.org/10.1016/j.jsxm.2016.02.001>.
- Committee on LGBT Health Issues and Research Gaps, and Institute of Medicine (IOM). "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." Washington (DC): National Academies Press, 2011. <http://www.ncbi.nlm.nih.gov/books/NBK64806/>.
- Conron, Kerith J., Stewart J. Landers, Sari L. Reisner, and Randall L. Sell. "Sex and Gender in the US Health Surveillance System: A Call to Action." *American Journal of Public Health* 104, no. 6 (June 2014): 970–76. <https://doi.org/10.2105/AJPH.2013.301831>.
- Corneil, Trevor A., Justus H. Einfeld, and Marsha Botzer. "Proposed Changes to Diagnoses Related to Gender Identity in the DSM : A World Professional Association for Transgender Health Consensus Paper Regarding the Potential Impact on Access to Health Care for Transgender Persons." *International Journal of Transgenderism* 12, no. 2 (September 20, 2010): 107–14. <https://doi.org/10.1080/15532739.2010.509205>.

- Currah, Paisley. "Expecting Bodies: The Pregnant Man and Transgender Exclusion from the Employment Non-Discrimination Act." *Women's Studies Quarterly* 36, no. 3/4 (October 1, 2008): 330–36.
- Currah, Paisley, and Lisa Jean Moore. "'We Won't Know Who You Are': Contesting Sex Designations in New York City Birth Certificates." *Hypatia* 24, no. 3 (August 1, 2009): 113–35. <https://doi.org/10.1111/j.1527-2001.2009.01048.x>.
- Denny, D. "A Selective Bibliography of Transsexualism." *Journal of Gay & Lesbian Mental Health* 6, no. 2 (2002): 35–66.
- Denny, Dallas. "Sex Certainly Did Change!" *The Journal of Sex Research* 40, no. 3 (August 1, 2003): 316–17.
- . "Transgender Communities of the United States in the Late Twentieth Century." In *Transgender Rights*, by Paisley Currah, Richard M. Juang, and Shannon Minter, 171–. U of Minnesota Press, 2006.
- Deutsch, Madeline B, Jamison Green, JoAnne Keatley, Gal Mayer, Jennifer Hastings, and Alexandra M Hall. "Electronic Medical Records and the Transgender Patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group." *Journal of the American Medical Informatics Association : JAMIA* 20, no. 4 (July 2013): 700–703. <https://doi.org/10.1136/amiajnl-2012-001472>.
- Devor, A. H, and N. Matte. "ONE Inc. and Reed Erickson: The Uneasy Collaboration of Gay and Trans Activism, 1964-2003." *GLQ: A Journal of Lesbian and Gay Studies* 10, no. 2 (2004): 179.
- Dozier, Raine. "Beards, Breasts, and Bodies: Doing Sex in a Gendered World." *Gender & Society* 19, no. 3 (2005): 297–316.
- Dreger, Alice D. "The Controversy Surrounding The Man Who Would Be Queen: A Case History of the Politics of Science, Identity, and Sex in the Internet Age." *Archives of Sexual Behavior* 37, no. 3 (June 2008): 366–421. <https://doi.org/10.1007/s10508-007-9301-1>.
- Ettner, Randi, Stan Monstrey, and A. Evan Eyler. *Principles of Transgender Medicine and Surgery*. New York: Haworth Press, 2007.
- Faderman, Lillian, and Stuart Timmons. *Gay L.A.: A History of Sexual Outlaws, Power Politics, and Lipstick Lesbians*. Basic Books, 2006.
- Fried, Erich. *Love Poems*. Translated by Stuart Hood. New York: Calder Publications Limited; Riverrun Press, 1991.
- Fry, Jane. "Conclusion: On the Records." In *Being Different: The Autobiography of Jane Fry.*, edited by Robert Bogdan, 213–33. New York: Wiley, 1974.

- Frye, Phyllis Randolph. "International Bill of Gender Rights vs. the Cider House Rules: Transgenders Struggle with the Courts over What Clothing They Are Allowed to Wear on the Job, Which Restroom They Are Allowed to Use on the Job, Their Right to Marry, and the Very Definition of Their Sex, The." *Wm. & Mary J. Women & L.* 7 (2000): 133.
- Gainor, Kathy A. "Including Transgender Issues in Lesbian, Gay and Bisexual Psychology." *Education, Research, and Practice in Lesbian, Gay, Bisexual, and Transgendered Psychology: A Resource Manual* 5 (2000): 131–160.
- Gehi, Pooja S., and Gabriel Arkles. "Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People." *Sexuality Research & Social Policy* 4, no. 4 (December 1, 2007): 7–35.
<https://doi.org/10.1525/srsp.2007.4.4.7>.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster, 1963.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jody L Herman, Jack Harrison, and Mara Keisling. "National Transgender Discrimination Survey Report on Health and Health Care." National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- . "National Transgender Discrimination Survey Report on Health and Health Care." National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- Gressgard, Randi. "When Trans Translates into Tolerance-or Was It Monstrous? Transsexual and Transgender Identity in Liberal Humanist Discourse." *Sexualities* 13, no. 5 (2010): 539–561.
- Hale, C. J. "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients." *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505. <https://doi.org/10.1353/pbm.2007.0047>.
- . "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients." *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505. <https://doi.org/10.1353/pbm.2007.0047>.
- Hartzell, E., M. S. Frazer, K. Wertz, and Masen Davis. "The State of Transgender California: Results from the 2008 California Transgender Economic Health Survey." San Francisco, California: Transgender Law Center, 2009.
http://transgenderlawcenter.org/pdf/StateTransCA_report_2009Print.pdf.
- Hirschfeld, Magnus. *Berlins Drittes Geschlecht*. Berlin: rosa Winkel, 1991.
- Isherwood, Christopher. *Christopher and His Kind*. New York: Farrar Straus Giroux, 1976.

- James, Andrea. "‘Illegal Immigrants’ vs. the Border Patrol of Sex and Sexuality: J. Micheal Bailey as the Border Patrol." *TSRoadmap.com*, 2012. <http://www.tsroadmap.com/info/bailey-immigrants.html>.
- James, Sandy E., Jody L. Herman, Sue Rankin, Mara Keisling, Lisa A Mottet, and Ma’ayan Anafi. "The Report of the 2015 U.S. Transgender Survey (USTS)." Washington, DC: National Center for Transgender Equality, 2016. <http://www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF>.
- "Johns Hopkins University: Anti-Trans Hotbed." Accessed July 10, 2014. <http://www.tsroadmap.com/info/johns-hopkins.html>.
- Johnson, Colin R. "Feeling Our Way Toward a History of ACT UP." *GLQ: A Journal of Lesbian and Gay Studies* 17, no. 2 (June 4, 2011): 432–34.
- Kessler, Suzanne, and Wendy McKenna. "Who Put the ‘Trans’ in Transgender? Gender Theory and Everyday Life." *International Journal of Transgenderism* 4, no. 3 (2000). <https://web.archive.org/web/20070927183856/http://www.symposion.com/ijt/gilbert/kessler.htm>.
- Kosenko, Kami, Lance Rintamaki, Stephanie Raney, and Kathleen Maness. "Transgender Patient Perceptions of Stigma in Health Care Contexts." *Medical Care* 51, no. 9 (September 1, 2013): 819–22.
- Labuski, Christine, and Colton Keo-Meier. "The (Mis) Measure of Trans." *Transgender Studies Quarterly* 2, no. 1 (2015): 13–33.
- Landén, M., J. Wålinder, G. Lambert, and B. Lundström. "Factors Predictive of Regret in Sex Reassignment." *Acta Psychiatrica Scandinavica* 97, no. 4 (April 1998): 284–89.
- Love, Heather. "'Spoiled Identity': Stephen Gordon's Loneliness and the Difficulties of Queer History." *GLQ: A Journal of Lesbian and Gay Studies* 7, no. 4 (2001): 487–519.
- McHugh, Paul. "Transgender Surgery Isn't the Solution." *Wall Street Journal*, May 13, 2016, sec. Opinion. <http://www.wsj.com/articles/paul-mchugh-transgender-surgery-isnt-the-solution-1402615120>.
- Miller, Virginia M. "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?" *American Journal of Physiology - Heart and Circulatory Physiology* 306, no. 6 (March 15, 2014): H781–88. <https://doi.org/10.1152/ajpheart.00994.2013>.
- Mogul, Joey L., Andrea J. Ritchie, and Kay Whitlock. *Queer (In)Justice: The Criminalization of LGBT People in the United States*. Beacon Press, 2011.

- Obedin-Maliver, Juno, Elizabeth S. Goldsmith, Leslie Stewart, William White, Eric Tran, Stephanie Brenman, Maggie Wells, David M. Fetterman, Gabriel Garcia, and Mitchell R. Lunn. "Lesbian, Gay, Bisexual, and Transgender-Related Content in Undergraduate Medical Education." *JAMA: The Journal of the American Medical Association* 306, no. 9 (2011): 971–977. <https://doi.org/10.1001/jama.2011.1255>.
- Peterson, Lee M. "Workplace Harassment against Transgender Individuals: Sex Discrimination, Status Discrimination, or Both." *Suffolk UL Rev.* 36 (2002): 227.
- Plant, Richard. *The Pink Triangle: The Nazi War against Homosexuals*. New York: H. Holt, 1986.
- Poteat, Tonia, Danielle German, and Deanna Kerrigan. "Managing Uncertainty: A Grounded Theory of Stigma in Transgender Health Care Encounters." *Social Science & Medicine* 84 (May 2013): 22–29. <https://doi.org/10.1016/j.socscimed.2013.02.019>.
- "REAL ID | Homeland Security." Accessed October 26, 2017. <https://www.dhs.gov/real-id>.
- Reisner, S. L., K. J. Conron, Scout, K. Baker, J. L. Herman, E. Lombardi, E. A. Greytak, A. M. Gill, and A. K. Matthews. "'Counting' Transgender and Gender-Nonconforming Adults in Health Research: Recommendations from the Gender Identity in US Surveillance Group." *TSQ: Transgender Studies Quarterly* 2, no. 1 (January 1, 2015): 34–57. <https://doi.org/10.1215/23289252-2848877>.
- Reisner, Sari L., Kerith J. Conron, Laura Anatale Tardiff, Stephanie Jarvi, Allegra R. Gordon, and S. Bryn Austin. "Monitoring the Health of Transgender and Other Gender Minority Populations: Validity of Natal Sex and Gender Identity Survey Items in a U.S. National Cohort of Young Adults." *BMC Public Health* 14 (November 26, 2014): 1224. <https://doi.org/10.1186/1471-2458-14-1224>.
- Scout. "Déjà Vu: National Surveys Leave Trans People Behind." *Huffington Post* (blog), June 13, 2013. http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html.
- Serano, Julia M. "The Case Against Autogynephilia." *International Journal of Transgenderism* 12, no. 3 (October 12, 2010): 176–87. <https://doi.org/10.1080/15532739.2010.514223>.
- Siebler, Kay. "Transgender Transitions: Sex/Gender Binaries in the Digital Age." *Journal of Gay & Lesbian Mental Health* 16, no. 1 (January 2012): 74–99. <https://doi.org/10.1080/19359705.2012.632751>.
- Spade, Dean. *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law*. South End Press Cambridge, MA, 2011.
- Staff, and agencies. "Australian Passports to Have Third Gender Option." *The Guardian*, September 15, 2011, sec. World news.

<http://www.theguardian.com/world/2011/sep/15/australian-passports-third-gender-option>.

Stryker, Susan. "(De) Subjugated Knowledges: An Introduction to Transgender Studies." In *The Transgender Studies Reader*, edited by Susan Stryker and Stephen Whittle. New York: Routledge, 2006.

———. *Transgender History*. Berkeley CA: Seal Press, 2008.

Stryker, Susan, Paisley Currah, and Leslie Jean Moore. "Introduction: Trans-, Trans, or Transgender?" *WSQ: Women's Studies Quarterly* 36, no. 3–4 (2008): 11–22. <https://doi.org/10.1353/wsqs.0.0112>.

"The Bay Area Reporter Online | Arson Hits Pink Triangle." Accessed July 23, 2009. <http://www.ebar.com/news/article.php?sec=news&article=4037>.

"The Center of Excellence for Transgender Health: Counting Trans Populations." Accessed February 15, 2013. <http://transhealth.ucsf.edu/trans?page=lib-trans-count>.

Veale, Jaimie F., David E. Clarke, and Terri C. Lomax. "Male-to-Female Transsexuals' Impressions of Blanchard's Autogynephilia Theory." *International Journal of Transgenderism* 13, no. 3 (2012): 131–39. <https://doi.org/10.1080/15532739.2011.669659>.

Willoughby, Brian L. B., Darryl B. Hill, Cesar A. Gonzalez, Alessandra Lacorazza, Raymond A. Macapagal, Michelle E. Barton, and Nathan D. Doty. "Who Hates Gender Outlaws? A Multisite and Multinational Evaluation of the Genderism and Transphobia Scale." *International Journal of Transgenderism* 12, no. 4 (March 2, 2010): 254–71. <https://doi.org/10.1080/15532739.2010.550821>.

Windsor, Elroi J. "Accounting for Power and Academic Responsibility." *Archives of Sexual Behavior* 37, no. 3 (June 2008): 495–97. <https://doi.org/10.1007/s10508-008-9319-z>.

Winter, Sam, Milton Diamond, Jamison Green, Dan Karasic, Terry Reed, Stephen Whittle, and Kevan Wylie. "Transgender People: Health at the Margins of Society." *The Lancet* 388, no. 10042 (July 23, 2016): 390–400. [https://doi.org/10.1016/S0140-6736\(16\)00683-8](https://doi.org/10.1016/S0140-6736(16)00683-8).

Witten, Tarynn M., and A. Evan Eyler. "Hate Crimes and Violence against the Transgendered." *Peace Review* 11, no. 3 (1999): 461–468. <https://doi.org/10.1080/10402659908426291>.

Zimmerman, Alex. "Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research." *Pittsburgh City Paper*. December 12, 2013, Online edition, sec. Blogh. <http://www.pghcitypaper.com/Blogh/archives/2013/12/12/study-shows-just-01-percent-of-nih-funding-went-to-lgbt-research>.

CHAPTER 3: LITERATURE REVIEW

3.1 Representing Gender in Medical Records and Health Data	67
Terminologies of Recordkeeping Practices.....	70
Uncountable Bodies.....	71
Assigning Gender Markers to Records.....	74
Data Voids in the Age of Big Data	77
3.2 What are data? Do data structures matter?.....	81
Information as Evidence	84
Data as Representation.....	86
Recordkeeping Theory	89
The Language and Theory of Categories	92
Statistical Theory.....	98
Demography/Survey Theory.....	104
Scholarly Communication	109
3.3 Functional Exclusions and Representational Data Voids.....	110
Constituting measurements and metrics	112
Constituting records and data	115
Constituting evidence based medical studies and public health datasets.....	116
Constituting health care systems and health care policy.....	119
3.4 Concluding Thoughts: On the Records	121
3.5 Cited References (Literature Review).....	123

3.1 REPRESENTING GENDER IN MEDICAL RECORDS AND HEALTH DATA

Trans and gender variant communities have a long history of being attacked¹, stigmatized, objectified, discounted, discriminated against² and disenfranchised in all aspects of public life in the US, health care included³. Gender variance in the 20th century was often approached as a manifestation of mental illness and used as a pretext to justify overt social exclusion⁴, physical violence, criminalization⁵ and denial of medical care⁶. In the 21st century, social violence continues to be commonplace for trans and gender variant persons. The first major national survey of trans health issues concluded, *'access to health care is a fundamental human right that is regularly denied to transgender and gender non-conforming people'*⁷ and continued:

Transgender and gender non-conforming people frequently experience discrimination when accessing health care, from disrespect and harassment to violence and outright denial of service. Participants in our study reported barriers to care whether seeking preventive medicine, routine and emergency care, or transgender-related services. These realities, combined with widespread provider ignorance about the health needs of transgender and gender non-conforming people, deter them from seeking and receiving quality health care.

¹ Bettcher, "Evil Deceivers and Make-Believers."

² Peterson, "Workplace Harassment against Transgender Individuals."

³ Kosenko et al., "Transgender Patient Perceptions of Stigma in Health Care Contexts," September 1, 2013.

⁴ Barry et al., "Bare Desire to Harm."

⁵ Mogul, Ritchie, and Whitlock, *Queer (In)Justice*.

⁶ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care."

⁷ Grant et al.

Because of this complex history, a researcher cannot examine classifications of gender within medical recordkeeping systems without situating the ubiquity of social violence perpetrated against gender variant populations. Examining the data structures in isolation ignores the practical politics⁸ of classifying and standardizing gender for populations whose records are represented within medical information and medical recordkeeping systems.

Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room, or other medical setting and 2% of the respondents reported being physically attacked in a doctor's office...When respondents saw medical providers, including doctors, they often encountered ignorance about basic tenets of transgender health... Fully 50% of study respondents reported having to teach providers about some aspect of their health needs... Unfortunately, our data shows that doctors' knowledge of a patient's transgender status increases the likelihood of discrimination and abuse⁹.

The above research synopsis depicts a central tension in working with gender markers in medical recordkeeping¹⁰, namely tensions around invisibility, disclosure, access, stigma and safety. These tensions around gender in healthcare contexts reflect highly complex and problematic recordkeeping dynamics within complex and evolving social systems. Hence an understanding of the concepts and foundational information structures is required to engage with questions of structural limitations in representational abstractions and the perpetuation of functional blind spots within recordkeeping practices.

This chapter presents scholarly discourses around encoding gender in information structures and connects current recordkeeping practices to the historical disparities

⁸ Bowker and Star, "How Things (Actor-Net) Work."

⁹ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care."

¹⁰ Dykes and White, "Getting to Equal."

surrounding trans and gender variant bodies in US healthcare systems, including an introduction to the recordkeeping practices and theories of gender categories, gender markers, trans bodies, billing regimes, and record keeping systems that have regularly intersected in the provision of healthcare in California from the 1950s to 2010s. During this time period, transgender and gender variant populations were functionally uncountable in the recordkeeping systems of medical research and health studies, the lack of functional representation in these records forming a kind of 'catch 22' in documenting the problems facing these populations. As such, this chapter also introduces academic discourses around the silences, erasures, and loss of voice in the data.

Information studies scholars have researched health data and recordkeeping structures in a variety of fields and contexts, such as science studies¹¹, data practices research¹², archival studies¹³, scholarly communication, social science research, demography, survey research, evidence based medicine, research practices¹⁴, research design, sociology, infrastructure studies¹⁵, and other science and technology¹⁶ studies. These studies stem from a number of scholarly domains, including information theory, archival theory¹⁷, document theory, logic¹⁸,

¹¹ Shankar, "Recordkeeping in the Production of Scientific Knowledge."

¹² Hilgartner and Brandt-Rauf, "Data Access, Ownership and Control: Toward Empirical Studies of Access Practices."

¹³ Yakel, "Recordkeeping in Radiology."

¹⁴ Star, Bowker, and Neumann, "Transparency beyond the Individual Level of Scale: Convergence between Information Artifacts and Communities of Practice."

¹⁵ Shankar, "Order from Chaos."

¹⁶ Ribes and Bowker, "Between Meaning and Machine."

¹⁷ McKemmish, "Traces: Document, Record, Archive, Archives."

statistics, history of science¹⁹, sociological theory, medical anthropology²⁰, philosophy of science²¹ and critical theory. In bringing together a plurality of epistemic and research traditions involved in discourses around representational features of gendered data structures, a more detailed feature analyses of the functional landscape of data structures can emerge, itself requiring a detailed picture of the changing topographies of data policies, representational histories, data practices, invisible work, tacit knowledge²², blind spots, tunnel vision, data flows and data networks. The following sections introduce these concepts first as individual topics, and secondly by scale, from the micro level views of individual data structure interactions to the macro level views integrating multiple layers of interactional complexity.

Terminologies of Recordkeeping Practices

Because recordkeeping practices around gender markers stem from multiple research traditions and disciplines, including legal, governmental, academic, and health care records, there are many domain specific terms that are not adequately covered here. As such, this text generally attempts to avoid domain-specific terms of art in favor of more broadly used descriptive terms. Some terms are central to archival and recordkeeping practice and reflect canonical principles and are thus covered in more detail in this chapter. It is important to acknowledge that there is overlap and plurality in the terms and concepts present in the

¹⁸ Renear, Sacchi, and Wickett, "Definitions of Dataset in the Scientific and Technical Literature."

¹⁹ Knorr Cetina, *Epistemic Cultures*.

²⁰ Forsythe, "'It's Just a Matter of Common Sense.'"

²¹ Friedlander, "The Triple Helix."

²² Duguid, "'The Art of Knowing': Social and Tacit Dimensions of Knowledge and the Limits of the Community of Practice."

archival and recordkeeping literature that reflect specific areas of expertise that are beyond what can be covered herein. This section briefly introduces some basic aspects of recordkeeping practices with the understanding that these practices span multiple disciplines and discourses.

This research project anchors around the literature of recordkeeping practice, conducting a social science based approach to observations of records, recordkeeping systems, and the production of scientific analysis from records-based information systems. In this context, recordkeeping practice refers to the processes and professionals involved in the design²³, construction, instantiation, maintenance, and stewardship²⁴ of records and data. This type of research into recordkeeping practices²⁵ reflects complex in-person and human-computer interactions²⁶ at the intersection of several open-ended systems such as health care, research practices, scholarly publication, employment, professionalization, and social interaction.

Uncountable Bodies

To date, no US Census have recorded the number of trans, intersex or gender variant people living in the country, although recent estimates place these populations in the 1-2

²³ Anderson, "Representations and Requirements."

²⁴ Anderson, "Some Challenges and Issues in Managing, and Preserving Access to, Long-Lived Collections of Digital Scientific and Technical Data."

²⁵ Trace, "What Is Recorded Is Never Simply 'What Happened.'"

²⁶ Agre, "From High Tech to Human Tech."

million range²⁷. Earlier estimates varied widely²⁸ and were based on very limited data²⁹ with problematic sample sizes³⁰, but since the implementation of improved data collection mechanisms³¹ in recent years³², new data are now starting to accumulate. Prior to this, at virtually every level of data collection, from public health data to medical records to health care data systems, trans and gender variant bodies have been functionally invisible and uncountable³³. Gendered bodies that do not fit seamlessly into the essentialized encodings of binary gender became silently invisible to the representations of gender implemented in the recordkeeping environments³⁴.

The invisibility that has resulted from representational exclusions is also commonly referred to as erasure in some academic and research disciplines. Characterizing invisibility³⁵ as a form of erasure likely relates to the volume of well-documented forms of gender variance observed in population biology. This variance can be seen around primary and secondary sex characteristics commonly used to assign gender³⁶, whether speaking of chromosomes, sex

²⁷ Steinmetz, "This Is How Many Americans Identify as Transgender."

²⁸ Collin et al., "Prevalence of Transgender Depends on the 'Case' Definition."

²⁹ Green, "Transgender."

³⁰ Hartzell et al., "The State of Transgender California: Results from the 2008 California Transgender Economic Health Survey."

³¹ Herman, Wilson, and Becker, "Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey."

³² Deutsch et al., "Electronic Medical Records and the Transgender Patient."

³³ Callahan et al., "Eliminating LGBTIQ Health Disparities."

³⁴ LeBreton, "The Erasure of Sex and Gender Minorities in the Healthcare System."

³⁵ Namaste, *Invisible Lives*.

³⁶ Blackless et al., "How Sexually Dimorphic Are We?"

hormones, or reproductive organs. Issues of erasure and invisibility have been covered extensively in the scholarly discourses around trans health. Some studies have worked to characterize these issues, with one concluding:

Two key sites of erasure were identified: informational erasure and institutional erasure. How these processes work in a mutually reinforcing manner to erase trans individuals and communities and produce a system in which a trans patient or client is seen as an anomaly is shown. Thus, the impetus often falls on trans individuals to attempt to remedy systematic deficiencies.³⁷

Another facet of structural violence goes beyond erasure or invisibility to equating trans bodies with the intent to deceive or defraud³⁸. In the late 1990s, the presumption of deceit³⁹ in media representations of gender variance galvanized⁴⁰ trans and LGBT communities across the United States:

*Consistently, reports on the story of Brandon Teena are depicted as, at base, the story of "deception in the heartland," a story of how a young woman deceived others about her gender in the pursuit of her own desires. A cursory glance at the titles and subtitles of accounts of the case alone starkly makes this point. The subtitle of Aphrodite Jones' account is "A True Story of Sexual Deception and Murder in America's Heartland." The movie poster for the film, *The Brandon Teena Story*, called the film "A true story of love, hate, and revenge in the Heartland of America". A lengthy report in the *Omaha World Herald* was entitled "Romance, Deceit and Rage" while another in *The Des Moines Register* was "Charade Revealed Prior to Killings". The *Advocate* used the title "Heartland Homicide: Smalltown Nebraska Life was fine for a 21 year old man-until everyone discovered he was actually a woman" for its first major article on the case and entitled its shorter follow-up "Deception on the Prairie". A one act play that dealt with the case was named "Murder in the Heartland" and, finally, *Playboy* entitled its essay "Death of a Deceiver".⁴¹*

³⁷ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives."

³⁸ Serano, "The Case Against Autogynephilia."

³⁹ Sloop, "Disciplining the Transgendered."

⁴⁰ Hale, "Consuming the Living, Dis (Re) Membering the Dead in the Butch/FTM Borderlands."

⁴¹ Sloop, "Disciplining the Transgendered," 170.

Another academic commented, “The stereotype that transsexuals purposefully misrepresent themselves also feeds into the common presumption that what transsexuals say about their own gender identities and experiences need not be taken seriously⁴².” A number of historians have mentioned this type of dismissal as a common feature for trans and gender variant populations:

Under the epistemological regime that dominates the academy, the bodily situatedness of knowing is divorced from the status of formally legitimated objective knowledge; experiential knowledge of the effects of one’s own antinormative bodily difference on the production and reception of what one knows consequently becomes delegitimated as merely subjective⁴³.

Scholars have been articulating concerns that “LGBT health disparities, housing challenges, access to care problems, hate-crimes -- all the flotsam and jetsam of discrimination is effectively invisible if national surveys don't count us⁴⁴.” The existence of trans persons could not be recorded, accounted for, and not readily represented in the data until the climate around data collection improved⁴⁵ between 2010 and 2015.

Assigning Gender Markers to Records

This research approaches sex and gender as complex constellations of geographically and historically⁴⁶ situated social categories⁴⁷ which reflect social conflicts⁴⁸, structure social

⁴² Serano, “The Case Against Autogynephilia.”

⁴³ Stryker, “(De) Subjugated Knowledges: An Introduction to Transgender Studies,” 154.

⁴⁴ Scout, “Déjà Vu.”

⁴⁵ Conron et al., “Sex and Gender in the US Health Surveillance System.”

⁴⁶ Denny, “Transgender.”

⁴⁷ Currah, “Gender Pluralisms under the Transgender Umbrella.”

interactions⁴⁹, assign social value to bodies⁵⁰, enforce norms⁵¹ and define the social location of embodied experience⁵². Unfortunately, the assignment of gender markers within medical practice tends to be drawn into these highly complex levels of social interaction, which tends to result in many organizations avoiding the risk of engaging with a topic that is known to be difficult to navigate. For more than a century, public records, public health and medical recordkeeping practices were architected as a strict gender binary based on the following simplifying assumptions:

1. All people are either male or female.
2. No people can be both male and female.

Under these recordkeeping regimes, gender is managed as a static, concrete, and reliably identifiable personal characteristic. Moreover, within these recordkeeping practices, gender variance has no place. Gender variance is generally treated therein as an idiosyncratic and anomalous aberration⁵³ that must be handled on a case by case basis, if it is to be handled at all. One HIV research group explained⁵⁴:

⁴⁸ Fassinger and Arseneau, "I'd Rather Get Wet Than Be Under That Umbrella."

⁴⁹ Goffman, *Stigma*.

⁵⁰ Bettcher, "Trans Identities and First Person Authority."

⁵¹ Stryker, "Transgender History, Homonormativity, and Disciplinarity."

⁵² Califia, "Trashing the Clinic and Burning down the Beauty Parlor: Activism Transmutes Pitiable Patients into Fiesty Gender Radicals."

⁵³ Meyerowitz, "Sex Change and the Popular Press."

⁵⁴ Sausa et al., "Policy Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services."

At present, the way in which sex and gender are asked of clients and patients (if asked at all) is incomplete and results in discrimination against people who do not fall into this assumed binary of being only and always male or female. Today we know that sex and gender is more complex than originally assumed and that many people do not fit conveniently into binary systems.

In addition to ignoring gender variance, most recordkeeping regimes use gender markers as a permanent, static, externally identifiable characteristic, like name, eye color, height, weight or hair color. However, unlike hair color or weight, gender markers contribute to a person's legal identity, being included on legal identity documents such as birth certificates, passports, or driver's licenses. This framework of personally identifying information is the basis for the gender markers being used on identity documents, financial records, and insurance records, however, most of these legal identity frameworks ultimately draw gender information from medical frameworks of gender.

Unlike height, weight, or hair color, the policies of identity and medical recordkeeping systems have historically lacked procedural and records management mechanisms to address changes or ambiguity in gender markers. Gender ambiguity, gender fluidity, and gender variance in how biological traits are exhibited are not able to be recorded within these exclusively binary frameworks of recordkeeping. The existence of an individual with an unknowable gender is simply unthinkable in the logic of these recordkeeping systems.

Because recordkeeping systems have embodied tacit assumptions about gender via their procedures, functions and information structures, any individuals who exhibit any form of gender variance have historically been unable to be functionally represented by the records. The recordkeeping systems lack the mechanism to record individuals who would otherwise fall into a category of 'other/both/neither' when faced with gender as a binary. This lack of

functionality to discern gender variant populations due to exclusion from representation in the data structures is at the heart of historical discussions around invisibility, erasure, and marginalization seen earlier in the Background section of this dissertation. This functional exclusion of variance in the conception of gender creates a situation where it is virtually impossible to resolve the slippage and inconsistencies⁵⁵ between gender markers and the traits⁵⁶ used in medical and legal contexts as indicators of maleness or femaleness⁵⁷ for the purposes of assigning a gender marker⁵⁸. Unfortunately, the exclusion of variance⁵⁹ has often co-occurred within a social frame⁶⁰ that treated any form of variance as a monstrous⁶¹, dangerous⁶² or shameful⁶³ personal defect⁶⁴.

Data Voids in the Age of Big Data

While these descriptions of categories and the social co-construction of recordkeeping practices are relatively abstract, theoretical and intangible, the disparities⁶⁵ in the lives of trans

⁵⁵ Drescher, "Queer Diagnoses."

⁵⁶ Blackless et al., "How Sexually Dimorphic Are We?"

⁵⁷ Rosario, "Quantum Sex: Intersex and the Molecular Deconstruction of Sex."

⁵⁸ "What We Don't Know."

⁵⁹ Beemyn, "A Presence in the Past."

⁶⁰ Bettcher, "Evil Deceivers and Make-Believers."

⁶¹ Gressgard, "When Trans Translates into Tolerance-or Was It Monstrous?"

⁶² Beauchamp, "Artful Concealment and Strategic Visibility."

⁶³ Califia, *Sex Changes*.

⁶⁴ Fry, "Conclusion: On the Records."

⁶⁵ Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey."

and gender variant persons are readily apparent⁶⁶ to researchers working with these populations. As the provision of healthcare to trans and gender variant persons became normalized in US healthcare operations from the 1960s to present, the informational disparities around data collection have only become more acute⁶⁷. Despite the widespread provision of healthcare services for trans bodies for decades, there has been virtually no US-based data collection of evidence-based medical outcomes for trans healthcare⁶⁸. This research project refers to the resulting lack of information for these populations as a ‘data void’. The project uses the term data void to capture the duality of interaction where gender variant populations have been contributing records and health data, but relevant information about gender variance has not been functionally representable within these historical recordkeeping practices and structures, resulting in a situation where these populations have been invisible and uncountable.

Although surgeries have become more available since the 1950s, non-binary gender information was not included in any standardized healthcare records or health information surveys prior to 2000, which generated foundations for current electronic recordkeeping systems that are blind to gender variance, gender ambiguity, and any kind of gender changes. The silences and erasures of queer bodies within bureaucratic systems have been central to discourses of queer ecologies of erasure and healthcare disparities for LGBT populations since

⁶⁶ Bauer et al., “I Don’t Think This Is Theoretical; This Is Our Lives.”

⁶⁷ “Healthy People 2020 Transgender Health Fact Sheet.”

⁶⁸ Reisner et al., “‘Counting’ Transgender and Gender-Nonconforming Adults in Health Research.”

the 1980s⁶⁹. Also common are experiences of healthcare problems⁷⁰ resulting from functional incompatibilities⁷¹ in the conflation of legal, medical, and social gender within recordkeeping practices that assign gender markers⁷². For example, in the film, *Southern Comfort*, the experiences of a trans man with ovarian cancer demonstrate how deeply some of these recordkeeping issues can impair treatment. No hospital would agree to see him for a ‘female’ disease. He was unable to be seen by an oncologist at any of the hundreds of hospitals they contacted. The providers were unable to navigate the recordkeeping conflicts generated between his legal sex, his reproductive organs, his medical gender and the disease that was killing him⁷³. Unfortunately, this story is not unique among stories about the lack of access to care⁷⁴ and barriers to care⁷⁵ for trans and gender variant populations.

Connecting the current infrastructures of medical recordkeeping and public health data⁷⁶ to the disparities observed in these populations⁷⁷ requires navigating past the silences

⁶⁹ Kosenko et al., “Transgender Patient Perceptions of Stigma in Health Care Contexts,” September 1, 2013.

⁷⁰ Kitts, “Barriers to Optimal Care between Physicians and Lesbian, Gay, Bisexual, Transgender, and Questioning Adolescent Patients.”

⁷¹ Roberts and Fantz, “Barriers to Quality Health Care for the Transgender Population.”

⁷² Sussman et al., “Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles.”

⁷³ Ravishankar, “The Story About Robert Eads |.”

⁷⁴ Sussman et al., “Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles.”

⁷⁵ Bockting, “Transforming the Paradigm of Transgender Health.”

⁷⁶ Conron et al., “Sex and Gender in the US Health Surveillance System.”

⁷⁷ Grant et al., “Injustice at Every Turn: A Report of the National Transgender Discrimination Survey.”

and blind spots resulting from representational structures that functionally exclude⁷⁸ gender variance⁷⁹, such as in this blind spot demonstrated by one Massachusetts shelter system⁸⁰:

Homeless transgender people were sleeping on benches because the shelters, which were segregated by gender, didn't know what to do with them. As a result, transgender people weren't included in the city's assessment of who needed shelter.

Because the shelter system was segregated based on gender, and because the system could not parse transgender and gender variant persons into their strictly segregated system of shelter beds, these people were being invisibly barred from being able to use the shelter system.

Researchers, in many cases, have also contributed to these tensions by discarding data which exposes structural problems of binary designations:

We screened 645 individuals for eligibility, of whom, 586 (91%) were eligible. Of the eligibles, 523 (89%) completed the interview and HIV test. Eight intersexed individuals were excluded for this analysis because they could not be classified as either MTF [trans women] or FTM [trans men], resulting in a final sample size of 515⁸¹.

Narratives of exclusion and friction in administrative systems are ubiquitous in trans, intersex and gender variant populations⁸², but some communities have had modest successes in organizing to address problematic practices⁸³. Several urban areas in California, such as the San

⁷⁸ Spade, *Normal Life*.

⁷⁹ Miller, "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?"

⁸⁰ Chalabi, "Why We Don't Know The Size Of The Transgender Population."

⁸¹ Clements-Nolle, Katz, and Marx, "The Transgender Community Health Project."

⁸² Davidson, "Seeking Refuge under the Umbrella."

⁸³ Cartwright et al., "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy."

Francisco Bay area and the Los Angeles area⁸⁴, have long been recognized as hubs for marginalized⁸⁵ and displaced individuals within these populations⁸⁶. The above type of functional exclusion is a common experience within trans and gender variant populations⁸⁷, although policy changes have been improving the problem⁸⁸. As such, a deeper exploration of the interactions between representational abstractions and socio-technical infrastructure is warranted.

3.2 WHAT ARE DATA? WHY DO DATA STRUCTURES MATTER?

Before examining the specific record structures that encode gender in health data and medical recordkeeping, this chapter introduces the foundational concepts for encoding gender in health data and medical records⁸⁹. These foundational concepts have been in development in tandem with domain-based scientific and health recordkeeping practices used by healthcare providers and researchers both in California and nationally. But what are these concepts? How do they structure the data? How do data structures encode gender and/or similar demographic information in medical systems? Why do these structures matter for statistical analyses? This section introduces these data structures as a topic of inquiry and gives some examples of the

⁸⁴ Leigh, “Young People Exploring Nonbinary Gender Roles.”

⁸⁵ Gay and Lesbian Historical Society and Blackstone, “MTF Transgender Activism in the Tenderloin and Beyond, 1966–1975.”

⁸⁶ “This Tiny Clinic Is Fighting for Trans Patients Illegally Denied Medical Care.”

⁸⁷ Cruz, “Assessing Access to Care for Transgender and Gender Nonconforming People.”

⁸⁸ Gehi and Arkles, “Unraveling Injustice,” December 1, 2007.

⁸⁹ Carlson and Anderson, “What Are Data? The Many Kinds of Data and Their Implications for Data Re-Use.”

complexity of relationships between data and data structures. It includes an introduction to the tensions between medical evidence and the abstract representations thereof.

The combination of human-authored, text-based descriptive records in conjunction with the heterogeneity of record structures contribute to the assessment that health data and medical records can be some of the most complex datasets for scholars to work with⁹⁰:

[Using the dataset] assumes particular processes of translation by which data can be made visible in transportable and intelligible forms. It also requires mechanisms by which data quality and provenance can be trusted once “disconnected” from their producers. By analyzing the “life stages” of data in four academic projects, we show that these requirements create difficulties for disciplines where tacit knowledge and craft-like methods are deeply embedded in researchers, as well as for disciplines producing non-digital heterogeneous data or data derived from people rather than from material phenomena.

While these observations were written as a description of the research-oriented sciences studied by Carlson and Anderson, they can be applied equally to the practice-oriented health sciences and research-oriented medical sciences involved with the study of health data and medical records. The heterogeneous data structures and data collection practices presents challenges to health researchers and practicing health care providers, as each data element of a health record must be evaluated for the strengths and limitations of evidence presented by the data collection processes and structures prior to drawing meaningful conclusions from them⁹¹.

As these recordkeeping systems have reached the scale of millions of records, more and more of the systems processes have become automated:

⁹⁰ Carlson and Anderson, 635.

⁹¹ National Academy of Sciences, *Ensuring the Integrity, Accessibility, and Stewardship of Research Data in the Digital Age*.

Because of the huge quantities of data generated by digital technologies, an increasing fraction of the processing and communication of data is done by computers, sometimes with relatively little human oversight. If this processing is flawed or misunderstood, the conclusions can be erroneous. Documenting work flows, instruments, procedures, and measurements so that others can fully understand the context of data is a vital task, but this can be difficult and time-consuming. Furthermore, digital technologies can tempt those who are unaware of or dismissive of accepted practices in a particular research field to manipulate data inappropriately.

As these technological systems scaled up to support recordkeeping practices for millions of records in recent years, concerns about data disparities⁹², exclusions⁹³ and marginalization⁹⁴ have increased.

Despite the complexity and heterogeneity presented by health data and medical records, understanding the representational abstractions which structure records is foundational for understanding how they function, whether within healthcare organizations, within policy think tanks or within scholarly research groups⁹⁵. Perhaps the most critical aspects for understanding data as a representation of a phenomenon is the understanding that data presents only a partial snippet of the real world phenomenon being represented. Moreover, authoring such a representation involves not only the structuring of data collection, but also the opportunity to name⁹⁶ the representational features, categories, metrics, and abstractions used within the data. Because these records are finite and necessarily limited in scope, they have inherent limitations in their representation of evidence. The act of recording

⁹² Fallik, "For Big Data, Big Questions Remain."

⁹³ boyd and Crawford, "Critical Questions for Big Data."

⁹⁴ Burrell, "How the Machine 'Thinks.'"

⁹⁵ Kent, *Data and Reality*.

⁹⁶ Olson, "Assumptions of Naming in Information Storage and Retrieval."

data itself is a process of selection, distillation, characterization and abstraction⁹⁷ as the recording is not only finite, but also limited in scope by the data's structural affordances to represent and record evidence, discussed further in the following section on 'Data as Representation'.

Information as Evidence

While an overview of the scholarly discourses on information as evidence⁹⁸ yielded a dizzying mosaic of disparate disciplines, epistemologies and topics, they were surprisingly consistent in their emphasis of the structural dependencies created by the representational abstractions used during data collection and recordkeeping processes⁹⁹. This emphasis about the centrality of representational abstractions used different languages and terminologies, but was mentioned by scientists¹⁰⁰, digital archivists¹⁰¹, historians, archivists¹⁰², philosophers¹⁰³, health care providers¹⁰⁴, social scientists¹⁰⁵, anthropologists¹⁰⁶, legal ethicists¹⁰⁷, and policy

⁹⁷ Star, "The Politics of Formal Representations: Wizards, Gurus, and Organizational Complexity."

⁹⁸ Furner et al., "Conceptions of Information as Evidence."

⁹⁹ Scheiner, "Experiments, Observations, and Other Kinds of Evidence."

¹⁰⁰ Traweek, "Bodies of Evidence."

¹⁰¹ Groth, Miles, and Munroe, "Principles of High Quality Documentation for Provenance."

¹⁰² Trace, "What Is Recorded Is Never Simply 'What Happened.'"

¹⁰³ Furner, "What Is Documentation?"

¹⁰⁴ Deutsch, "Making It Count."

¹⁰⁵ Bauer et al., "Transgender-Inclusive Measures of Sex/Gender for Population Surveys."

¹⁰⁶ Farmer, "An Anthropology of Structural Violence."

¹⁰⁷ Spade, *Normal Life*.

analysts¹⁰⁸ in canonical instructional texts¹⁰⁹ and detailed case studies¹¹⁰ alike. Central to these discussions were questions of what the data represent, questions of what are excluded, questions of how the data represent evidence, questions of how the process of selection and exclusion was executed during the recordkeeping process, and questions of the limitations of the data. Thus digital representations of evidence have strengths and deficits that interoperate within the larger topographies of the data and records, in this case, the topographies of gender, medicine, demography, and health policy.

At their simplest, health data and medical records can be understood as physical and digital aggregations of formalized records of evidence of health management activities and metrics, as a form of documentation of practices and measures of health¹¹¹. It is important to recognize that health data and medical records operate in a highly heterogeneous socially-interactive context that includes complex histories of marginalization, including both human-authored, standardized textual records, but also information derived from physical procedures such as biopsies, blood draws, CT scans, MRIs, and more¹¹². These records may also include laboratory tests, provider notes, patient history descriptive information, diagnoses, medications, billing information, insurance information and identity¹¹³ verification information.

¹⁰⁸ "Why We Don't Know The Size Of The Transgender Population."

¹⁰⁹ Meier and Labuski, "The Demographics of the Transgender Population."

¹¹⁰ Herman, Wilson, and Becker, "Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey."

¹¹¹ Briet, *What Is Documentation?*

¹¹² Gregory, "Sorcerer's Apprentice: Creating the Electronic Health Record, Re-Inventing Medical Records and Patient Care."

¹¹³ Shrage, "Does the Government Need to Know Your Sex?"

These records increasingly contribute to long-lived¹¹⁴, personally identifiable¹¹⁵, highly regulated¹¹⁶, economically valuable¹¹⁷ records that are designed for producing evidence¹¹⁸ on managing individual (via individual medical records) and public health interventions (via public health datasets).

Data as Representation

The data collection practices of medical recordkeeping and public health data contribute foundationally to the formal, distributed epistemic project of evidence based medicine.

Evidence based medicine relies on this type of data to create the statistical analyses, scholarly publications, treatment paradigms, standards of care, metrics of health and metrics of disease which co-construct the state of medical knowledge about individual health conditions¹¹⁹.

Understanding how data structures may impact the quality of the representation is critical as the structure of the representation co-constitutes¹²⁰ the frame of analysis¹²¹ and because the data structures strongly affect the potential to reuse of the records outside their original

¹¹⁴ National Science Board, "Long-Lived Digital Data Collections."

¹¹⁵ Safran et al., "Toward a National Framework for the Secondary Use of Health Data."

¹¹⁶ Beauchamp, "The Substance of Borders Transgender Politics, Mobility, and US State Regulation of Testosterone."

¹¹⁷ Taylor, "Consumer Privacy and the Market for Customer Information."

¹¹⁸ National Research Council (U.S.), *A Question of Balance: Private Rights and the Public Interest in Scientific and Technical Databases*.

¹¹⁹ Kent, *Data and Reality*.

¹²⁰ Collins, "The Meaning of Data: Open and Closed Evidential Cultures in the Search for Gravitational Waves."

¹²¹ Lofland et al., *Analyzing Social Settings a Guide to Qualitative Observation and Analysis*.

context of creation¹²². Agre argued that these abstract representational functions are central to understanding the premise of data:

data isn't just numbers - it's also a way of thinking about the relationship between the abstract territory inside computers and the concrete territory outside them. Data has meaning - it represents the world. It can represent things inside computers, of course, but also represents things outside them: your age, the price of eggs, the number of cases of AIDS in New York, the predicted temperature in Brazil 10 years from now, how likely you are to buy a cubic zirconium ring¹²³.

These symbolic representational aspects are foundational to the logic of working with computers, whether speaking of software, hardware, or data practices. Edwards explained:

Computers are a medium for thought, like the English language or drafting tools. In order to think with a computer, one has to learn its language¹²⁴.

As such, the practical reality of studying information infrastructure in health recordkeeping contexts requires unpacking the black box of information structures in healthcare systems.

Suchman¹²⁵ spoke of these representational aspects in the context of invisible work and system design:

One central interest in representing work for purposes of system design is to create technologies aimed at the coordination and control of complex, distributed activities. Agre has developed an analysis of what he characterizes as the progressive (re)orientation of human activities to the requirements of designing and implementing such technologies. In this context, he argues that current wisdom in system design holds that the less of its user's behavior a system encodes, the less functionality it can provide. At the same time,

¹²² Star, *Ecologies of Knowledge: Work and Politics in Science and Technology*.

¹²³ Agre, "Living Data."

¹²⁴ Edwards, "The Army and the Microworld," 105.

¹²⁵ Suchman, "Making Work Visible," 59.

the more behavior is encoded by technical systems, the more technologies may come to prescribe human activities.

While Agre¹²⁶ was speaking to the tensions in representing evidence of multi-faceted complex real world phenomenon using computer systems, Suchman (above) was speaking to the tensions between fixity and fluidity in designing user interactions with technological systems.

The process of creating a record has been compared to making a map which uses visual symbols to represent the landmarks¹²⁷ and topographies of interest in the landscape¹²⁸. Using this metaphor, one can quickly see how a map is not a literal landscape unto itself, but rather a manufactured representation of a landscape. The process of mapmaking requires the author of the map to place bounds and constraints on the map, including scale, metrics, features, and objects to be included. Similarly, the process of recording data requires the author of the data to construct a sufficiently sound representation of the data landscape¹²⁹ that yields a record of the data features of the landscape with sufficient clarity to constitute sound evidentiary arguments.

In summary, understanding the construction of representational aspects of data is critical as the data structures reflect both the mindset of the system designers and of the data collector via the choices made of which aspects of the phenomenon to record, how to represent it, what to include in the representation, what to leave out, what to leave unspoken,

¹²⁶ Agre, "Living Data."

¹²⁷ Friendly and Denis, "Milestones in the History of Thematic Cartography, Statistical Graphics, and Data Visualization."

¹²⁸ Kent, *Data and Reality*.

¹²⁹ Kent.

and to what to call into question¹³⁰. Health data are thus the result of a complex process of system designers, recordkeeping practices and complex evolving representations of evidence¹³¹. Because each data structure is necessarily limited in its ability to represent only selected aspects of any given phenomenon, every dataset has limitations. The dataset can only represent the aspects of the phenomenon that the designers of the dataset have selected to be included in the representational structures¹³².

In terms of encoding gender for medical recordkeeping, the majority of datasets have a functional limitation which precludes recording atypical genders and gender variation. Each person is assigned into one of the two normative genders for their health records, usually at birth. Because the recordkeeping structures are incapable of encoding the gender of transgender and gender variant bodies, gender variance becomes invisible and uncountable in the data originating from the recordkeeping system. Many scholars refer to this functional exclusion¹³³ from the data collection and analyses as a form of social erasure¹³⁴.

Recordkeeping Theory

Archival and recordkeeping studies have contributed several important conceptual developments which inform data practices research generally and this research specifically.

¹³⁰ Nissenbaum, "How Computer Systems Embody Values."

¹³¹ Anderson, "Representations and Requirements."

¹³² Bowker, *Memory Practices in the Sciences*.

¹³³ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives."

¹³⁴ LeBreton, "The Erasure of Sex and Gender Minorities in the Healthcare System."

Five of the central principles contributing to archival work in digital recordkeeping environments also contribute to this research, namely the principles of the sanctity of evidence; respect des fonds, provenance, and original order; the life cycle of records; the organic nature of records; and hierarchy in records and their descriptions¹³⁵. Many health and vital records systems have assumed gender to be static, fixed and unchangeable¹³⁶ and thus have not been concerned about the need for recordkeeping practices around the changing of gender markers. Historical recordkeeping practices have encoded gender as a static entry which may have also contributed to the widespread socio-cultural assumption that gender markers are fixed at birth and should not be changed. Examining these principles exposes interesting tensions around encoding gender in medical records. Provenance is an interesting concept to discuss in relation to gender markers, as there is no consensus on updating of gender records, nor has the concept of provenance been included in discussions of standards such as the Meaningful Use Guidelines¹³⁷ for sexual orientation and gender identity¹³⁸.

There is a long history of trans voices becoming marginalized within the records¹³⁹. Throughout, the disparity between how people are represented and how they represent themselves, is a haunting reminder of erasure¹⁴⁰ and institutionalized structural violence:

¹³⁵ Gilliland-Swetland, *Enduring Paradigm, New Opportunities: The Value of the Archival Perspective in the Digital Environment*.

¹³⁶ Frye, "International Bill of Gender Rights vs. the Cider House Rules."

¹³⁷ Cahill et al., "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines."

¹³⁸ Baker, "Gathering Sexual Orientation and Gender Identity Data in Health IT."

¹³⁹ Beemyn, "A Presence in the Past."

¹⁴⁰ Makadon, "Ending LGBT Invisibility in Health Care."

"I know what I am. I like it...I am the only one responsible for what I do, and as long as I don't harm another human being mentally or physically, I'm being a good person."

--Jane Fry

"Mr. Fry displayed a psychotic profile evidenced by strong expressions of unconventional values, intense lack of self-acceptance, and a great need for more affection and support... He displays overt sexual inversion, is non-conforming and feels hurt if one doesn't pay attention to him."

--Jane Fry's medical record¹⁴¹

Examining the history of trans inclusion in healthcare and social movements presents a complex and often contradictory picture. LGBT persons who transgressed gender norms have been the most visibly queer, the most targeted¹⁴² and the least invisible¹⁴³. They were most often the ones targeted for arrest and social ostracism, from the anti-crossdressing ordinances of LA to the street queens of the Stonewall Inn¹⁴⁴.

Even in the relatively simple recordkeeping example of assigning a gender marker to a newborn infant, a number of physiological metrics and variables are implicated in being conflated, including, but not limited to, (1) external genitalia, (2) chromosomal make-up, (3) reproductive organs/internal genitalia, (4) endogenous hormones¹⁴⁵. However, even with the problems created by the conflation of multiple variables and types of gender within gender markers, many researchers have observed that gender and the conflated variables in question

¹⁴¹ Fry, "Conclusion: On the Records."

¹⁴² Frye, "International Bill of Gender Rights vs. the Cider House Rules."

¹⁴³ Gan, "'Still at the Back of the Bus': Silvia Rivera's Struggle."

¹⁴⁴ Stryker, *Transgender History*.

¹⁴⁵ Rosario, "Quantum Sex: Intersex and the Molecular Deconstruction of Sex."

are more accurately represented using statistical distributions rather than binary gender categories. If examined using principles of the sanctity of evidence, it becomes clear that binary gender categories as a representation of evidence do not adequately serve the full spectrum of the population as well as other representational structures.

Some scholars have argued that the relationship between meaning and text should not be considered as inherent to the recordkeeping system, but rather the result of multiple intersecting acts of authorship and interpretation which themselves enact a system of meaning via the structuring interactions of users within the system. Using the metaphor of networks of interactions in an ecosystem, Taborsky demonstrated multiple types of codal regimes in use in information and recordkeeping systems with varying levels of fixity, fluidity, sustainability, and divergence. The metaphor of ecosystems and networks of interactions is helpful to this research, as the records originate from a complex, multifaceted, and evolving landscape that is based on the open system dynamics of human activity and interaction. When seen from the perspective of both the terms and their users, one can more easily see how the construction of meaning from these abstractions and representations of gender bring complex socio-technical tensions of political, personal, social, legal, governmental, and familial interactions into recordkeeping practices.

The Language and Theory of Categories

Within the scholarly domain of information studies, classification and category structures have been a major topic of inquiry for more than a century¹⁴⁶, drawing at times from

¹⁴⁶ Buckland and Hahn, "Introduction."

additional domains such as mathematics, communication¹⁴⁷, documentation studies¹⁴⁸, signal processing, semiotics, philosophy and formal logic¹⁴⁹. These domains, with others, have contributed to the practice-based health recordkeeping systems of highly developed formal systems of text-based description, documentation, and standards to represent, aggregate, sort, protect, exchange and retrieve records. Many of these structures depend on systems of representation derived from linguistic-based cognitive¹⁵⁰ affordances for category structures derived from human communication. The study of gender as representation of social categories within medical recordkeeping systems draws necessarily from multiple discourses, vocabularies, frameworks and epistemologies. In one instance, Bowker and Star¹⁵¹ shared observations of how categories and classification systems function against complex backgrounds of standards, recordkeeping systems and technical infrastructures. They showed how interdependencies between cultural practices, recordkeeping structures and formal classifications created geographical differences in practices for recording the cause of death. Their arguments also illustrated the challenges of representing complex phenomena within open social systems¹⁵².

¹⁴⁷ Shannon, "A Mathematical Theory of Communication."

¹⁴⁸ Warner, "Semiotics, Information Science, Documents and Computers."

¹⁴⁹ Kristeva, "The System and the Speaking Subject."

¹⁵⁰ Lakoff, *Women, Fire and Dangerous Things—What Categories Reveal about the Mind*.

¹⁵¹ Star and Bowker, *Sorting Things Out*.

¹⁵² Bowker and Star, "Building Information Infrastructures for Social Worlds—The Role of Classifications and Standards."

Applying Bowker and Star's arguments to gender as a social category situates trans bodies within a history of contested social categories that are collectively function in a regime of gender that is imprecise, counterproductive and arbitrary¹⁵³. Dozier¹⁵⁴, in writing about the embodied experience of trans and gender variant populations, emphasized an important epistemic contribution to social discourses:

because transsexuals, transgendered people, and others at the borders of gender and sex are fish out of water, they help illuminate strengths and weaknesses in common conceptions of gender

People at the borderlands of sex and gender provide richer forms of evidence for this analysis, as they draw into focus the relative strengths and weaknesses of the representations of gender used in various health data and medical recordkeeping systems. For someone who fails to conform to the binary, the structural definition of the category itself precludes representation within the data, and they can provide a unique perspective of the frictions between the descriptive language and the lived experience, between the representation and the reality, between the landscape and the map¹⁵⁵.

Current recordkeeping practices in health recordkeeping systems typically use fixed categories for gender that are linked to legal identity gender markers. These records use a strict and exclusive binary, which is a type of nominal data structure. A person may only be recorded as either 'male' or 'female' with no affordances for outliers or other types of edge

¹⁵³ Mazur, "Arbitrary and Capricious: Six Inconsistencies Distinguishing Military Medical Policies for Transgender and Non-Transgender Personnel."

¹⁵⁴ Dozier, "Beards, Breasts, and Bodies Doing Sex in a Gendered World," 297.

¹⁵⁵ Kent, *Data and Reality*.

cases unable to fit coherently into one of the categories. This type of exclusive categorical structure lacks the affordances to represent those who are both or neither. The exclusive binary category structure excludes the possibility of recording variance, edge cases, or failure to fit into the category of genders within the current structure. This functional exclusion of variance is the primary reason that researchers have resorted to using secondary and tertiary indicators for identifying transgender and gender variant persons, using indirect indicators of gender such as diagnoses codes (e.g. transgenderism, gender dysphoria), prescriptions (hormone therapy), surgeries, preferred name, or pronoun preferences.

Category structures, abstractly speaking, have also been approached from a philosophical perspective, as a system of symbolic meaning which is reliant on to human language and communication¹⁵⁶:

Therefore, to suggest that the various 'mediums' of language, image, and gesture and the various organizational formulas of metaphor, metonymy, irony, and synecdoche; and other additional 'twists' such as paradigm and syntagm are structures separate from meaning ignores this basic fact that the codal actions are agential constructs of meaning¹⁵⁷.

In this text, Taborsky is arguing that categories and classifications cannot be disconnected from the author of the terms and the intended audience of active user(s). She referred to this type of symbolic system of communication as a codal regime, a structure of codes and encoding of information.

¹⁵⁶ Derrida, "Structure, Sign and Play in the Discourse of the Human Sciences."

¹⁵⁷ Taborsky, "Codal Regimes," 95–96.

In the above argument, the construction of meaning is inextricable from the act of interpretation, meaning that we cannot examine the encoding of gender in health systems without examining the interactions between the system, the authors/producers of the records and the users of the records. Taborsky argued that the encoding of information within language structures requires a person (aka agent) to construct meaning from the term, not only at the point of creating the data, but each and every time it is used to construct meaning. Hale, in critiquing media representations the lives (and deaths) of LGBTIQ populations, articulated some of the tensions around social erasure and creating meaning in border zones of social categories¹⁵⁸:

Disputes about contested category placement are one of the arenas in which contemporary categories and their boundaries are articulated. Such articulations, of course, have consequences for the living: they matter for decisions about who is included and who is excluded from contemporary categories, whether in accordance with or contrary to individuals' desires. More specifically, when a border zone denizen's corpse is claimed by those who are trying to live in the nearly unspeakable spaces created by overlapping margins of distinct categories. Border zone inhabitants infer reasonably that their lack of fixed location within categories is prohibited by the more firmly located, that such absence will be used as ground for subjecting them to multiple indiscriminate erasures, and that their sullen resistant silences and dissenting cries alike will be folded into the discourse of those with more solid categorical and thus social locations.

This act of authorship for categories and classifications is particularly relevant here, as the author of a label or descriptive term names the category and primes the discourse for the construction of meaning. These questions of gender categories used for legal and medical

¹⁵⁸ Hale, "Consuming the Living, Dis (Re) Membering the Dead in the Butch/FTM Borderlands."

purposes demonstrates how difficult it can be to disentangle the social¹⁵⁹, legal¹⁶⁰, personal¹⁶¹, political¹⁶², technical¹⁶³, medical¹⁶⁴, biological¹⁶⁵ and familial¹⁶⁶ elements.

This socially-dependent aspect of the assignment and interpretation of classifications is important to this research, in part because the current normative binary labels for gender fail to count transgender non-binary and gender non-normative persons, and in part because many social systems stigmatize and mischaracterize transgender and gender variant bodies. The importance of authorship of information structures also surfaces the limitations of computers and digital recordkeeping systems in making meaning with the records.

While these digital systems might appear to be the source of knowledge to a naïve bystander, the recordkeeping systems are limited to the gender structures as predetermined by system designers and recordkeeping practice. They are limited insofar as these digital systems are only able to modify records via execution of code, e.g. performing an instruction set authored by a system designer. Within these arguments, these digital systems do no interpretation of meaning themselves, but rather they are machines that reproduce meaning

¹⁵⁹ American Psychological Association, "Guidelines for Psychological Practice with Transgender and Gender Nonconforming People."

¹⁶⁰ Spade, *Normal Life*.

¹⁶¹ Bettcher, "Trans Identities and First Person Authority."

¹⁶² Shrage, "Does the Government Need to Know Your Sex?"

¹⁶³ Bauer et al., "Transgender-Inclusive Measures of Sex/Gender for Population Surveys."

¹⁶⁴ Koenig, "Distributive Consequences of the Medical Model."

¹⁶⁵ Ah-King and Nylin, "Sex in an Evolutionary Perspective."

¹⁶⁶ Frye, "International Bill of Gender Rights vs. the Cider House Rules."

via activities authored by system designers and records managers¹⁶⁷. This aspect of agency and authorship is particularly relevant as the inertia of the information infrastructures have resulted in a system with virtually no changes to gender markers in the last two centuries, even as other demographic variables, such as race, have undergone major naming and categorization revisions in social contexts¹⁶⁸, in government records¹⁶⁹, and in health records¹⁷⁰.

Statistical Theory

Statistical analyses of data and datasets has been of enormous value in the evaluation of evidence for medical and health sciences¹⁷¹. Because these same statistical analyses form the basis for algorithmic¹⁷² search and other record processing techniques¹⁷³, it becomes necessary to understand some of the statistical tools used in the evaluation of data structures¹⁷⁴. Medical and health sciences, as domains, typically rely on analyses of observational forms of data¹⁷⁵, but experimental data have also commonly played a role in some research domains¹⁷⁶. Both forms rely foundationally on statistical tools derived from the ‘normal’ distribution of probabilities,

¹⁶⁷ Star, “The Politics of Formal Representations: Wizards, Gurus, and Organizational Complexity.”

¹⁶⁸ Jacobson, *Whiteness of a Different Color: European Immigrants and the Alchemy of Race*.

¹⁶⁹ Prewitt, *What Is “Your” Race?*

¹⁷⁰ Mays et al., “Classification of Race and Ethnicity: Implications for Public Health.”

¹⁷¹ Blackless et al., “How Sexually Dimorphic Are We?”

¹⁷² Burrell, “How the Machine ‘Thinks.’”

¹⁷³ Kitchin, “Thinking Critically about and Researching Algorithms.”

¹⁷⁴ Janssen and Kuk, *The Challenges and Limits of Big Data Algorithms in Technocratic Governance*.

¹⁷⁵ Canadian Institutes of Health Research (CIHR) and Institute of Gender and Health, “What a Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook.”

¹⁷⁶ Miller, “Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?”

thus this section must introduce some of the dynamics of this type of distribution curve in more detail. This section also presents arguments on how statistical structures are foundational to the strength of conclusions that may be drawn from them, and at the statistical theory behind conflation of variables and various data structures. For many researchers, it has been clear that multiple different variables have been conflated in the borderlands of gender traits and gender markers¹⁷⁷. While this topic was introduced in the previous chapter on histories and backgrounds, it is touched upon again in this section in a discussion of the statistical implications.

Gender markers and gender categories, in terms of data types for statistical analyses, would be considered nominal data, e.g. data that is recorded via named categories, in this case, named categories of gender such as ‘male’, ‘female’, ‘transgender’, ‘non-binary’, ‘androgynous’, or ‘intersex’. Nominal categories are considered relatively weak as a data type as they provide no structural information about the relationship of individual categories to each other¹⁷⁸. Ordinal data types, such as used for letter grades in school, provide some information about the order of categories relative to each other. Some researchers assigned gender a Likert-like, ordinal scale from more masculine to androgynous to more feminine, with some scholars assigning three¹⁷⁹, five¹⁸⁰, and some scholars noting other historical approaches to gender¹⁸¹.

¹⁷⁷ Blackless et al., “How Sexually Dimorphic Are We?”

¹⁷⁸ Babbie, *The Practice of Social Research*.

¹⁷⁹ Hirschfeld, *Berlins Drittes Geschlecht*.

¹⁸⁰ Fausto-Sterling, “The Five Sexes, Revisited.”

¹⁸¹ Sun, “Sex/Gender Systems in Native North America.”

When examining the encoding of gender in medical recordkeeping systems, it becomes clear that gender is being recorded as a nominal data type. If we took a random sample in California and plotted the data, it would produce something like the following breakdown and distribution as a bar graph (Figure 2, below):

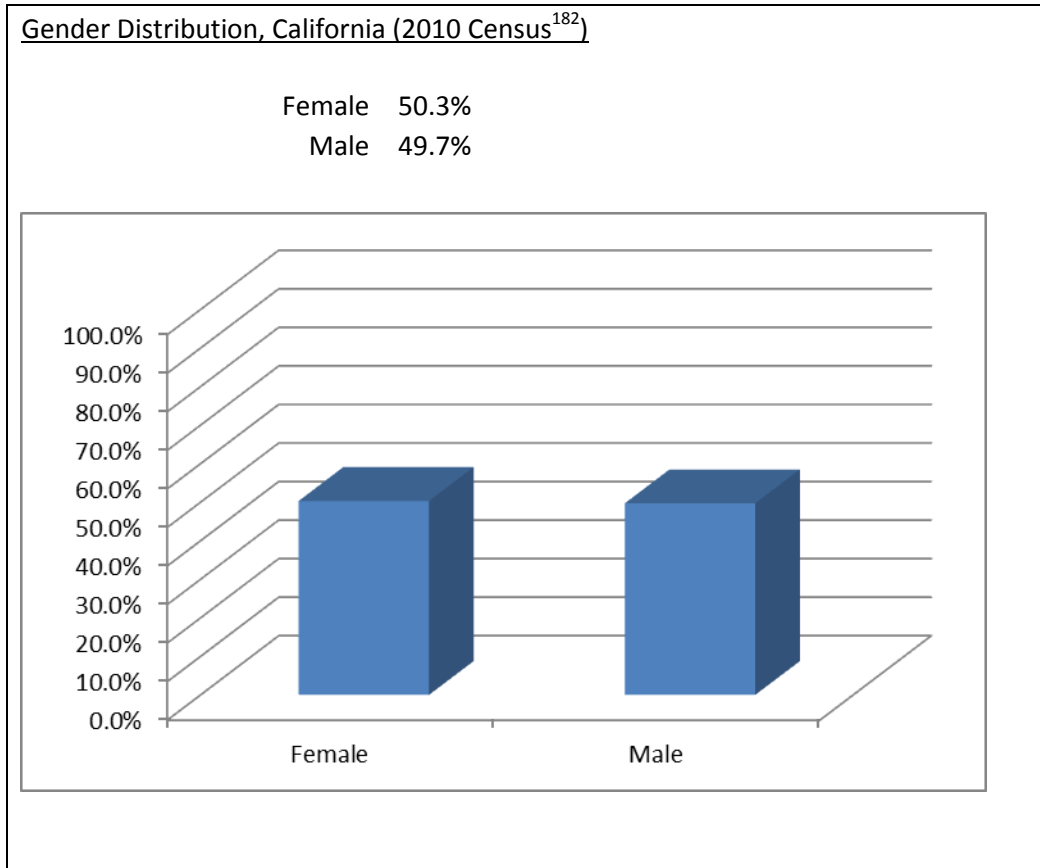


Figure 2: Bar graph showing gender distribution in California, 2010

Nominal data and ordinal data are generally considered by researchers to be the weakest data type, in terms of the data's statistical power¹⁸³. Additionally, they require non-parametric approaches to calculate the statistical analyses. Having 'weak' data means that researchers

¹⁸² "U.S. Census Bureau QuickFacts."

¹⁸³ Scheiner, "Experiments, Observations, and Other Kinds of Evidence."

must either collect more data or accept lower confidence intervals in the resulting statistical analyses. Thus, when researchers are designing data collection practices, they prefer to structure their data using numerical metrics¹⁸⁴, preferably using numerical measures to record the variable or indicator in question.

One of the central epistemic structures behind the power of statistics for numerical analyses is derived from the predictable shape of the ‘normal’ distribution¹⁸⁵. The epistemic power of this distribution stems from observations that probability distributions produce a reproducible and predictable type of distribution curve for probabilities, regardless of the underlying data from which the probabilities are generated. There is a structural assumption to these statistical analyses, namely, that the probability distribution for the observed phenomenon will adhere to the shape of this ‘normal’ distribution around the true mean, and hence is valid to calculate confidence intervals for whether individual data points are likely to be outliers. While it has been a common research problem for variables to be conflated¹⁸⁶, misidentified, or data limitations otherwise mishandled¹⁸⁷, analyses deriving from normal distributions have been widely adopted in analyses¹⁸⁸ and in algorithmic approaches to big data.

¹⁸⁴ Babbie, *The Practice of Social Research*.

¹⁸⁵ Maier and Easton, *The Data Game*.

¹⁸⁶ Rosenberg, *The Logic of Survey Analysis*.

¹⁸⁷ Osterweil, Clarke, and Ellison, “Forecast for Reproducible Data.”

¹⁸⁸ Brown and Jones, “Racial Health Disparities in a Cohort of 5,135 Transgender Veterans.”

For example, below is empirical data showing the distribution of testosterone levels in a study population superimposed with approximate normal distribution curves for the male and female subdivisions of the population:

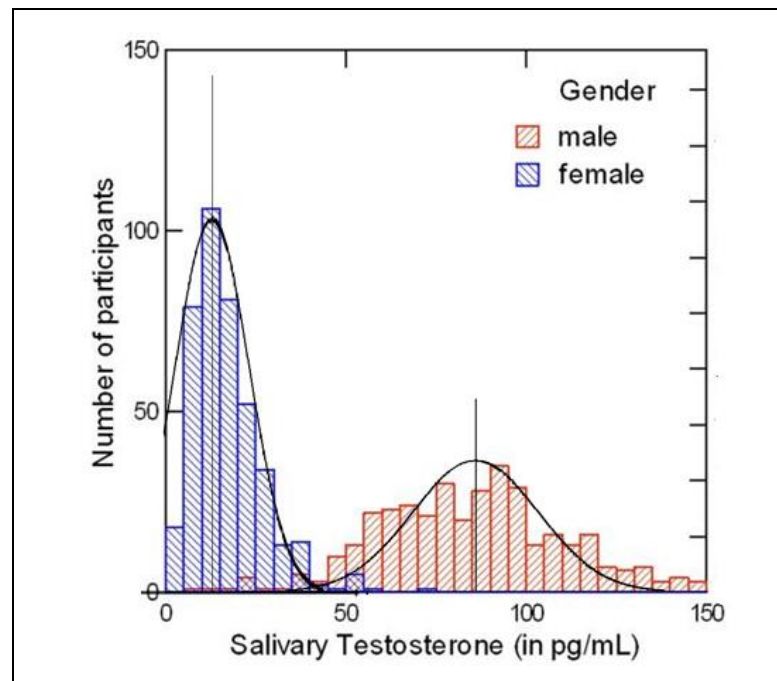


Figure 3: Gendered trait data provided in Stanton¹⁸⁹

When studies have actually measured characteristics associated with assigning gender, e.g. reproductive organs or secondary sex characteristics, such as in the graph above, the resulting data forms an overlapping bimodal distribution around two nodes. There was a small but substantial population of women who had higher levels of salivary testosterone than many of the men in the study, which would make gender assignments based on these measurements more problematic to interpret for these overlapping cases. Some of the characteristics associated with assigning gender are associated with a higher degree of overlap than others.

¹⁸⁹ Stanton, "The Essential Implications of Gender in Human Behavioral Endocrinology Studies."

For example, most brain studies have found a high degree of overlap in the bimodal distributions of gendered brain regions¹⁹⁰. Measures of characteristics associated with determining gender have not formed an exclusive binary in observed natural populations. Forcing a bimodal distribution into an exclusive binary of M vs F erases the area of overlap, shoehorning the genders of gender variant respondents into a grey area of representational mis-expression.

Another important aspect of the discourse around bimodal distributions of gender characteristics in populations has been the recognition that the degree of overlap between 'male' and 'female' binary designations often exceeds the degree of difference between the two. In other words, the intra-gender variation of measured gender features is greater than inter-gender variation. For example, even if males are, on average, taller than females, the observed variation of height between two males (intra-group) can still be greater than the variation in height between males and females (inter-group). The primary recordkeeping problem observed in using binary categorical markers to represent gender results from the invisibility and discounting of overlapping edge cases between the two genders that result regardless of whether one is basing the measurements on chromosomal, reproductive, or hormonal markers.

Publications from researchers with backgrounds in statistically-intensive domains tend to demonstrate forms of tacit knowledge¹⁹¹ and professional instincts around the

¹⁹⁰ Joel et al., "Sex beyond the Genitalia."

¹⁹¹ Star, "Invisible Work and Silenced Dialogues in Knowledge Representation."

representational differences between a binary category and a bimodal distribution¹⁹² and the ways these structures may affect the resulting data¹⁹³ and invisibility of certain populations. hence the widespread and long-standing¹⁹⁴ arguments by researchers and community members alike for improved data collection¹⁹⁵ structures around gender and gender identity. While statistical analyses of gender and gender related health conditions would benefit in terms of accuracy from numerical representations of gender¹⁹⁶, there is a lack of consensus around functional numerical measures for gender, probably resulting from the conflation of variables and from the assumption that inconsistencies between variables will never occur. Furthermore, arguments about scaling systems to better serve long tail¹⁹⁷ population dynamics can also be applied to populations in the long tail of gender variance in the population.

Demography/Survey Theory

When representing gender metrics from a population demographics perspective, the representation of gender as an aggregation of characteristics, roles and behaviors has been recognized by LGBT focused discourses¹⁹⁸ and mirrors approaches in social science survey

¹⁹² Fausto-Sterling, "Sexing the Body: How Biologists Construct Human Sexuality."

¹⁹³ Blackless et al., "How Sexually Dimorphic Are We?"

¹⁹⁴ Denny, "Sex Certainly Did Change!"

¹⁹⁵ Bockting, "Biological Reductionism Meets Gender Diversity in Human Sexuality."

¹⁹⁶ Miller, "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?"

¹⁹⁷ Anderson, "The Long Tail."

¹⁹⁸ Stryker, "(De) Subjugated Knowledges: An Introduction to Transgender Studies."

methods of other demographic characteristics such as race¹⁹⁹. Population biologists²⁰⁰ and demographers²⁰¹ generally consider gender markers to represent an aggregate formation of naturally occurring biological and social characteristics that follow statistical patterns of population distribution. Across these characteristics, statistical data documenting these characteristics are represented using distributions rather than a binary gender category system²⁰². Data analysts typically differentiate data, in statistical analyses, based on different data types, which each have statistical approaches optimized for the limitations presented by the data type, e.g. nominal versus ordinal versus numeric data²⁰³, parametric versus non-parametric statistics²⁰⁴, and so on.

As the previous historical background section and the above examples indicate, gender has been commonly assumed to be much simpler than the population-based evidence and data indicate. A handful of countries outside the US²⁰⁵ have been in the process of adding a third legal gender option (in addition to the binary of male/female). In early 2017, legislation was introduced in California to allow for a third gender marker on state-issued IDs and government

¹⁹⁹ Rosenberg, *The Logic of Survey Analysis*.

²⁰⁰ Fausto-Sterling, "Sexing the Body: How Biologists Construct Human Sexuality."

²⁰¹ Meier and Labuski, "The Demographics of the Transgender Population."

²⁰² Blackless et al., "How Sexually Dimorphic Are We?"

²⁰³ Babbie, *The Practice of Social Research*.

²⁰⁴ Vickers, "Parametric versus Non-Parametric Statistics in the Analysis of Randomized Trials with Non-Normally Distributed Data."

²⁰⁵ Staff and agencies, "Australian Passports to Have Third Gender Option."

records, but medical recordkeeping practices with long histories of encoding gender as a binary have acted so far as inertial weight to changing practices.

Recent statistical estimates indicate gender variance for infants at birth (i.e. infants that have ambiguous or atypical genitalia) at 1 in 1000 births²⁰⁶ and is likely closer to 1.7% of the general population²⁰⁷. This likely overlaps to some extent with the estimated 0.5% of the general population²⁰⁸ that identifies as transgender or living as a gender other than they were assigned at birth. These statistics form the basis for the estimate that there are 1-2 million of transgender and gender variant persons residing in the United States²⁰⁹. Historically, these two population groups have both overlapped and diverged substantially²¹⁰. Many intersex persons have had surgeries and other kinds of medical interventions as infants that were not disclosed to them²¹¹. Many of them grew up without being informed of their intersex condition, in isolation about their situation and without receiving the kind of support necessary to navigate the medical system. Many of these individuals had to navigate these complex dynamics as a minor within a highly fraught social and medical decision making process²¹². This

²⁰⁶ Rosario, "Quantum Sex: Intersex and the Molecular Deconstruction of Sex."

²⁰⁷ Blackless et al., "How Sexually Dimorphic Are We?"

²⁰⁸ Collin et al., "Prevalence of Transgender Depends on the 'Case' Definition."

²⁰⁹ Steinmetz, "This Is How Many Americans Identify as Transgender."

²¹⁰ Clune-Taylor, "From Intersex to DSD."

²¹¹ Rosario, "Quantum Sex: Intersex and the Molecular Deconstruction of Sex."

²¹² Greatheart, *Transforming Practice*.

history has had an alienating effect on the relationship between many intersex populations, their social spheres, and their medical providers²¹³.

Because of these histories of shame²¹⁴, non-disclosure²¹⁵, and genital surgeries²¹⁶, many intersex persons did not learn of their condition²¹⁷ until much later in life²¹⁸. However, it should also be noted that intersex populations and populations of persons with disorders of sexual development may better be regarded as a highly heterogeneous collective of persons with miscellaneous gender and developmental conditions unified only by the friction generated by their embodied experiences of gender variance. There is no unifying bond of gender identity, gender dysphoria or sexual orientation, as these conditions co-occur with the full spectrum of genders and sexualities. Many persons with intersex conditions shared stories where they exhibited no childhood gender dysphoria and discovered their atypical gender constellations during routine chromosomal²¹⁹ or other gender screenings²²⁰.

Not only does a binary gender marker system fail to record information on transgender or gender variant persons, it excludes recording the variance, removing variance from the

²¹³ Dreger and Herndon, "PROGRESS AND POLITICS IN THE INTERSEX RIGHTS MOVEMENT."

²¹⁴ Morland, "Intersex and After."

²¹⁵ *BBC World News - Interview about an Intersex Childhood Shattered by Ignorance.*

²¹⁶ *Growing up Intersex Part 1.*

²¹⁷ Beck, "My Life as an Intersexual."

²¹⁸ Morland, "What Can Queer Theory Do for Intersex?"

²¹⁹ Cooky and Dworkin, "Policing the Boundaries of Sex."

²²⁰ Sykes, "Transsexual and Transgender Policies in Sport."

enunciative modalities²²¹ of the data itself. In other words, by excluding gender variance from the recordkeeping structures of gender markers, it places gender variance outside the perspective of the record, outside the frame of analysis of the data and outside of the system of medical evidence. Population-based surveys assessing the current state of access to medical care for and transgender, gender variant and intersex bodies presents a sobering picture of exclusion²²², discrimination²²³, and abuse²²⁴ at the hands of medical providers, medical staff, medical policy²²⁵, and the general public²²⁶. These analyses point towards a system of marginalization aggregating multiple forms and venues of disadvantage along with other marginalizing social factors such as race²²⁷, educational background²²⁸, class²²⁹, ability to pass²³⁰, age, and disability²³¹. Moreover, the slippage and tensions in assigning gender bears a number of similarities to the slippage and tensions in the development of assigning categories of race²³². These cycles of invisibility and dis-inclusion mirror the problems within health care

²²¹ Foucault, "The Formation of Enunciative Modalities."

²²² Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey."

²²³ Cruz, "Assessing Access to Care for Transgender and Gender Nonconforming People."

²²⁴ Bradford et al., "Experiences of Transgender-Related Discrimination and Implications for Health."

²²⁵ Barry et al., "Bare Desire to Harm."

²²⁶ Temple-O'Conner, Wehr, and NIH LGBT Research Coordinating Committee, "Response to the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals."

²²⁷ Gehi and Arkles, "Unraveling Injustice," December 1, 2007.

²²⁸ Bilimoria and Stewart, "Don't Ask, Don't Tell."

²²⁹ Olson and Ward, "Ghettos and Diaspora in Classification."

²³⁰ Johnson and Ghavami, "At the Crossroads of Conspicuous and Concealable."

²³¹ Barry, "Disabilityqueer."

²³² Omi and Winant, *Racial Formation in the United States*.

provider training²³³ and research²³⁴ circles. The tensions that develop as a result of lack of data are discussed later in this chapter under ‘Representational Data Voids’.

Scholarly Communication

The field of scholarly publishing has been involved in discussions of the publishing, dissemination and circulation of scientific and scholarly research for generations. While the functions of scholarly publishing have changed little in recent years, the advent of online publishing platforms, open access policies and digital publications has changed the interactional dynamics within scholarly publication²³⁵. These processes resemble the epistemic knowledge production practices described previously in social studies of science²³⁶, including observations of complex iterative streams of data production²³⁷, the collection of evidence²³⁸, information seeking behaviors²³⁹, the assembly of datasets, the assembly of observations²⁴⁰, the analysis of results²⁴¹ and the distribution of findings.

²³³ Obedin-Maliver et al., “Lesbian, Gay, Bisexual, and Transgender–Related Content in Undergraduate Medical Education.”

²³⁴ Zimmerman, “Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research.”

²³⁵ Borgman, *From Gutenberg to the Global Information Infrastructure*.

²³⁶ Knorr Cetina, *Epistemic Cultures*.

²³⁷ Hilgartner and Brandt-Rauf, “Data Access, Ownership and Control: Toward Empirical Studies of Access Practices.”

²³⁸ Anderson, “Some Challenges and Issues in Managing, and Preserving Access to, Long-Lived Collections of Digital Scientific and Technical Data.”

²³⁹ Forsythe, “Using Ethnography to Investigate Life Scientists’ Information Needs.”

²⁴⁰ Sanjek, *Fieldnotes*.

²⁴¹ Collins, “The Meaning of Data: Open and Closed Evidential Cultures in the Search for Gravitational Waves.”

Because knowledge production practices depend on data originating from health data practices and medical recordkeeping, downstream structural dependencies are of central concern to designing and maintaining health information and medical recordkeeping systems. Representational problems in the foundational record and data structures can thus result in representational issues in the downstream narratives²⁴² that participate in the formation of medical practices²⁴³ and public health interventions²⁴⁴. In this way, gender markers can be viewed as boundary objects²⁴⁵ between legal, medical, social and personal constructions of gender. This exposes the tensions in the question of who is responsible for producing and updating these information structures in health recordkeeping systems²⁴⁶.

3.3 FUNCTIONAL EXCLUSIONS AND REPRESENTATIONAL DATA VOIDS

This research refers to the situation of functional exclusion in the data as a data void, a blind spot in the data structures that reproduces itself across contexts and levels of abstraction. In this case it derives from a structural inability to represent gender as anything other than a fixed binary category. This perspective derives in part from scholarly discourses around situated knowledges and ways of knowing²⁴⁷. Without moving the data from the lossy categorical/nominal data structures present in the current health data structures, we lack the

²⁴² Conron et al., "Sex and Gender in the US Health Surveillance System."

²⁴³ Miller, "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?"

²⁴⁴ Winter et al., "Transgender People."

²⁴⁵ Star and Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects."

²⁴⁶ Star, "The Politics of Formal Representations: Wizards, Gurus, and Organizational Complexity."

²⁴⁷ Bellacasa, "Nothing Comes Without Its World."

granularity to move evidence based medicine of gender related health issues forward statistically.

Because public health data and medical recordkeeping are foundational to designing medical practices and public health interventions, these data voids in the foundational structures can result in data voids at every level of granularity and abstraction, resulting in a void of information and practices about health effects and interventions for LGBTIQ populations. Because of the epistemic dependencies on the original data and records, the data void is reproduced at every level of abstraction within the health knowledge systems and medical knowledge production. This section attempts to summarize the literature and research that has documented these structural dynamics of records and data.

This section summarizes the dynamics of records and data production into a generalized overview grouped by the scale of the basic functions of the production, from the micro minutia of designing individual data elements to the macro functions of designing health care policy or the metanalysis and aggregative functions of fitting datasets into the scholarly production of evidence based medical practices and public health interventions. This process of understanding the interactions of multiple complex socio-technical systems can be critical to the analysis of the production of data structures in evidence-based recordkeeping systems²⁴⁸. Understanding the contributions of the above domains of knowledge production and data practices does not necessarily give the reader a good sense of how they fit together into cycles and ecologies of data production, which is why they are discussed in more detail in this section.

²⁴⁸ Star, "The Structure of Ill-Structured Solutions."

As demonstrated by other scholars analyzing recordkeeping systems²⁴⁹, splitting the examination of different levels of abstraction allows the analysis to trace the aggregate systemic effects of individual recordkeeping practices and data element structures. It also reiterates the importance of questioning whose voices are being recorded²⁵⁰ and to question what kinds of social relationships are being reproduced within the recordkeeping structures²⁵¹. Dividing the examination of record and data structures along different levels of micro/macro granularity allows for the formation of a narrative tracing the dependencies from the micro-focused individual data elements into the macro-focused health systems. The levels of abstraction presented here are: 1) Constituting measurements and metrics; 2) Constituting records and data; 3) Constituting evidence based medical studies and public health datasets; and 4) Constituting health care systems and health care policy.

Constituting measurements and metrics

Various well developed standards, medical practices and measurement paradigms operate in tandem to constitute individual elements within the records and data. Abstractly speaking, these metrics play a role in the constitution of records themselves. There are numerous regimes of evidence and standardized metrics that form dependencies for interpreting health and medical records. In some cases, these metrics even extend into formalized data standards, such as ones for electronically transmitting laboratory test results of

²⁴⁹ Caswell, *Archiving the Unspeakable*.

²⁵⁰ Flinn, Stevens, and Shepherd, "Whose Memories, Whose Archives? Independent Community Archives, Autonomy and the Mainstream."

²⁵¹ Duff and Harris, "Stories and Names."

patient specimens²⁵². In short, there are a variety of medical instruments, protocols and standards that contribute to the formation of health records and health data. Thus a structural failure of the system to represent a single data element can result in structural representational problems at every level of granularity/abstraction.

Within medical recordkeeping systems, there may be hundreds of overlapping data structures operating in tandem at the same time within any given EMR system. For example, blood pressure is a standard metric that is collected across a variety of health records. The metric of ‘blood pressure’ is constituted via a number of standards and protocols that define the units of measurement in addition to the processes of measurement, e.g. what scale is used, how the pressure is ‘read’, what types of measuring instruments are used and what position the patient’s body should be in during a measurement. These aspects are foundational to evaluating any given a blood pressure measurement. Moreover, these practices themselves are not typically included within the health record or health data. For example, a health data structure might specify that body temperature should be recorded in Fahrenheit, or a medical record data structure might specify the average result levels for healthy males associated with a specific sample type (e.g. blood) and sample test (e.g. hematocrit). There is a foundational structuring of information into a representation that is both essential to the process of creating the representation of evidence while always remaining necessarily incomplete²⁵³. Moreover, many of these structures operate in multi-faceted recordkeeping contexts. For example, gender markers in medical recordkeeping systems must interoperate with insurance billing

²⁵² “HL7 Standards Product Brief - HL7 Version 3 Standard: Data Types - Abstract Specification, Release 2,” 7.

²⁵³ Derrida, *Archive Fever*.

records, patient treatment records, lab tests, prescription drugs, and other government records. Recordkeeping regimes around gender markers thus act as complex boundary objects²⁵⁴ both between and within institutions.

The constitution of different types of data and measurements is a major component of health data and medical records. One type of representational problem commonly encountered in medical records derives from the lack of functionality in a binary category system to represent normal statistical variance, which this project refers to as ‘category failure’. Category failure results when the categories cannot functionally represent the topographies present in the data. In research design it would be considered a problem of conflated or unidentified variables, an error in structuring the data which would yield a dataset with problematic blind spots around these unidentified or conflated variables. These problematic aspects of conflation and lack of affordances are mentioned by numerous scholars in varied recordkeeping contexts²⁵⁵, from medical records²⁵⁶ to government records²⁵⁷ and legal arguments²⁵⁸. The treatment of edge cases is critical for transgender and gender variant populations to be able to navigate access to healthcare and identity documents. These populations are at the epicenter of tensions around gender markers and recordkeeping. The

²⁵⁴ Star, “The Structure of Ill-Structured Solutions.”

²⁵⁵ Deutsch et al., “Collection of Gender Identity Data Using Electronic Medical Records.”

²⁵⁶ Currah and Moore, “‘We Won’t Know Who You Are’: Contesting Sex Designations in New York City Birth Certificates.”

²⁵⁷ Shrage, “Does the Government Need to Know Your Sex?”

²⁵⁸ Spade, “Resisting Medicine, Re/Modeling Gender.”

problematic conflation of variables is even more damaging²⁵⁹ for populations that exist as edge cases²⁶⁰ and for whom the system functionally excludes or for whom it makes no accommodations²⁶¹.

Constituting records and data

At the closest view of data structures, examining the administrative minutia of data production yields a close reading of the structures of individual data elements and their representational affordances. Examining the flows of data at the organization level yields a view of the bottlenecks and tunnel vision of the recordkeeping systems. Stepping back to examine complex system and network effects in public health datasets and evidence based medicine yields an algorithmic perspective on the macro level effects related to micro level data structures. The type and quality of digital representation of evidence yields varying strengths and limitations that affect the functionality of data, making it necessary for any given research project to understand how these strengths and deficits affect the representation of the evidence of the phenomenon²⁶².

In current medical recordkeeping systems, certain diseases can only be treated with the correct gender markers for the recordkeeping regime. If someone is marked 'male' in the system, they cannot receive treatment for organs that have been designated as 'female'. So if a

²⁵⁹ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives."

²⁶⁰ Ohle, "Constructing the Trannie."

²⁶¹ Gehi and Arkles, "Unraveling Injustice," December 1, 2007.

²⁶² Amann and Knorr Cetina, "The Fixation of (Visual) Evidence."

person is born with atypical genitalia (which is more common than most people realize – about 1 in 1000 births), they will have problems accessing care for any part of their physiology that does not match the binary. These complex dependencies result in a system where a simple structural problem in the foundational data element can cause a domino effect throughout the recordkeeping system.

Gender variance is one such foundational element that can result in representational exclusions cascading through the recordkeeping system. These systems lack the affordances to ‘see’ gender variance outside the binary, and as such, each instance of organ/gender mismatch is automatically rejected by the system as fraudulent each and every time it comes up in the treatment process. Some systems have begun to allow some variance represented within disease codes describing transgenderism and the disorders of sex differentiation (formerly called intersex conditions), but these processes are still often considered novel and not yet widely implemented. By forcing all gender variant persons into information structures that represent them as non-variant, gender variant bodies become invisible, uncountable and unfindable for everyone in health systems reliant on the data. Because gender variance information has not been functionally recorded within these binary structured recordkeeping systems²⁶³, gender variance has been functionally uncountable within the records²⁶⁴.

Constituting evidence based medical studies and public health datasets

²⁶³ Spade, “Resisting Medicine, Re/Modeling Gender.”

²⁶⁴ Reisner et al., “‘Counting’ Transgender and Gender-Nonconforming Adults in Health Research.”

The first textbook on transgender surgery and medicine introduced the reader to the topic by explaining that “gender variance is the most misunderstood area of human behavior.”²⁶⁵ The author continued, “sensationalized by the media and misconceived even by mental health professionals, individuals who are uncomfortable with their gender and seek to modify their bodies to attain a level of comfort are often unable to find medical allies.” In addition to epistemic knowledge production practices of evidence based medicine, medical and public health contexts also include the provision of health care²⁶⁶ to the general population²⁶⁷ under the Hippocratic oath to ‘do no harm’²⁶⁸.

The sentiment about the inability to find medical allies summarized an unspoken truth about the difficulties presented by navigating health care. The author is speaking to the volume of evidence that indicates that the lack of access to a medical ally is, in practice, equivalent to being unable to access health care at all. This is due to the central role of health care professionals as gatekeepers and coordinators of health care for the patient, whether in primary care, hospital care or specialty care environments. Given the centrality of health care professionals in managing care, the social complexity of recordkeeping practices representing gender for transgender and gender variant individuals is non-trivial.

Examining recordkeeping practices in medical and health contexts yields observations of complex dependencies between the data collection processes and the later statistical analyses,

²⁶⁵ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*, 1.

²⁶⁶ Bockting, “Transforming the Paradigm of Transgender Health.”

²⁶⁷ “Editorial: New Guidelines on Transgender Health.”

²⁶⁸ Bryant and Schilt, “Transgender People in the U.S. Military: Summary and Analysis of the 2008 Transgender American Veterans Association Survey.”

the former feeding evidence into the latter. Health data may contribute directly to the development of medical practices via case studies, patient surveys and other retrospective studies of patient records²⁶⁹. As such, if certain information is disincluded from the medical recordkeeping process, this disinclusion propagates throughout the records as a lack of information, as an information void which will be discussed in more depth under the heading 'data voids'.

The lack of data propagates via its informational dependencies, e.g. if records lack affordances for the formation of treatment paradigms, for identifying affected patients, and for evaluating medical interventions²⁷⁰, then the lack of data can be considered a data void in the recordkeeping systems resulting from these information dependencies. While this problem of sounds abstractly theoretical, the theoretical effects of disinclusion from data collection matches with the current state of evidence for medical care for LGBTIQ populations, particularly the paucity of data around the treatment of transgender, intersex and gender variant populations²⁷¹.

Because gender variant bodies are invisible to the recordkeeping systems, their disinclusion creates a data void around evidence for gender variance in the current system of evidence based medicine²⁷². In other words, in order to identify transgender or gender variant

²⁶⁹ Brown and Jones, "Racial Health Disparities in a Cohort of 5,135 Transgender Veterans."

²⁷⁰ Institute of Medicine, "The Health of Lesbian, Gay, Bisexual, and Transgender People."

²⁷¹ Johnson, Mimiaga, and Bradford, "Health Care Issues among Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Populations in the United States."

²⁷² Deutsch et al., "Electronic Medical Records and the Transgender Patient."

patients within a medical recordkeeping system , one cannot use the gender marker field.

Researchers have resorted to use other ancillary information in order to identify these patients from their records, such as formal medical condition diagnoses²⁷³ (e.g. gender dysphoria, transgenderism, etc), having undergone gender related surgery²⁷⁴ , or having been prescribed hormones. This lack of ability to readily identify patients directly from their patient records has also presented some unexpected protections as well. This inability to readily identify gender variant patients has been used by some providers historically as a weak institutional mechanism by which to protect patients from being identified by hostile individuals and policies²⁷⁵.

The lack of data and evidence upon which to base trans health care and public policy itself participates in the perpetuation of a form of structural violence:

Structural violence is violence exerted systematically—that is, indirectly— by everyone who belongs to a certain social order: hence the discomfort these ideas provoke in a moral economy still geared to pinning praise or blame on individual actors. In short, the concept of structural violence is intended to inform the study of the social machinery of oppression²⁷⁶.

This framework of structural violence has been applied to the legal adoption of the medicalization of gender under the term ‘administrative violence²⁷⁷’.

Constituting health care systems and health care policy

²⁷³ Kauth et al., “Access to Care for Transgender Veterans in the Veterans Health Administration.”

²⁷⁴ Ettner, Monstrey, and Coleman, *Principles of Transgender Medicine and Surgery*.

²⁷⁵ Kauth et al., “Access to Care for Transgender Veterans in the Veterans Health Administration.”

²⁷⁶ Farmer, “An Anthropology of Structural Violence.”

²⁷⁷ Spade, *Normal Life*.

Structural data problems have been extensively discussed and researched in social and biological research practices²⁷⁸, but in recent years, the academic literatures and media accounts have demonstrated increased documentation of epistemic and sociotechnical mismatches²⁷⁹ between data structures²⁸⁰, funding structures²⁸¹ and actual population dynamics²⁸². Moreover, researchers estimating the population of transgender and gender variant persons have used different measures of gender, giving estimates of the population that vary by several orders of magnitude²⁸³, from early estimates of 0.0005% to more recent²⁸⁴ estimates of 0.1-1%, (depending on how one defines gender, gender variance and transgender).

One of the central concerns motivating recommendations for LGBTIQ related health data collection has been the widespread invisibility of the population within the pre-existing data and recordkeeping practices²⁸⁵. Moreover, the invisibility has been multi-fold. The information structures lack the ability to represent gender variance. The healthcare practitioners lack the training to interact with gender variant populations. The literature lacks data on health outcomes for these populations and related health conditions. Current estimates place the broadly combined incidence of (lifetime) same sex attraction and gender

²⁷⁸ Rosenberg, *The Logic of Survey Analysis*.

²⁷⁹ Star, "Invisible Work and Silenced Dialogues in Knowledge Representation."

²⁸⁰ Ansara, "Making the Count: Addressing Data Integrity Gaps in Australian Standards for Collecting Sex and Gender Information."

²⁸¹ Zimmerman, "Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research."

²⁸² Scout, "Déjà Vu."

²⁸³ Collin et al., "Prevalence of Transgender Depends on the 'Case' Definition."

²⁸⁴ Horton, "The Incidence and Prevalence of SRS among US Residents."

²⁸⁵ American Psychological Association and Rennie, "Response to RFI NOT-OD-13-076."

variance as implicating 5-10% of the general population, but in 2013 only 0.1% of National Institute of Health (NIH) research grant funding focused on LGBTIQ research²⁸⁶; the majority of which was awarded to research focused on HIV.

During a widely reviewed discussion of these results and other national health data collection practices, the collection of data on sexual orientation and gender identity (SOGI) was widely recognized as a major blind spot in medical recordkeeping and health data structures²⁸⁷, leading the NIH to lead an 2013 engagement project requesting recommendations for constructing health data and medical recordkeeping structures. After widely soliciting comment from researchers, policy analysts, health providers and the public²⁸⁸, recommendations for the collection of sexual orientation and gender identity data collection were presented via formalized ‘Meaningful Use Guidelines’ issued for medical recordkeeping systems and public health data.²⁸⁹

3.4 CONCLUDING THOUGHTS: ON THE RECORDS

Trans and gender variant bodies present information features which are orthogonal to the representational structures for encoding gender in health data and medical records. In order to be recorded, trans and gender variant populations must entrust the representation of gender to a recordkeeping system that functionally excludes them. In many descriptions of

²⁸⁶ Zimmerman, “Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research.”

²⁸⁷ American Psychological Association and Rennie, “Response to RFI NOT-OD-13-076.”

²⁸⁸ NIH, “NOT-OD-13-076: Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations.”

²⁸⁹ Cahill et al., “Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines.”

negative experiences with being denied access to health care, trans people were also held personally responsible for the frictions and failures of the administrative systems. Rather than holding the system accountable for its failures, marginalized populations were blamed for the friction arising from the system's inability to parse gender variant bodies. This suggests an intimate relationship between stigma, violence, discrimination and the information voids in the records.

CITED REFERENCES (LITERATURE REVIEW)

- Agre, Phil. "Living Data." *Wired*, 1994. <http://www.wired.com/wired/archive/2.11/agre.if.html>.
- Agre, Philip E. "From High Tech to Human Tech: Empowerment, Measurement, and Social Studies of Computing." *Computer Supported Cooperative Work* 3, no. 2 (1995): 167–95. <https://doi.org/10.1007/BF00773446>.
- Ah-King, Malin, and Sören Nylin. "Sex in an Evolutionary Perspective: Just Another Reaction Norm." *Evolutionary Biology* 37, no. 4 (December 1, 2010): 234–46. <https://doi.org/10.1007/s11692-010-9101-8>.
- Amann, K., and Karin D. Knorr Cetina. "The Fixation of (Visual) Evidence." *Human Studies* 11, no. 2/3 (April 1, 1988): 133–69.
- American Psychological Association. "Guidelines for Psychological Practice with Transgender and Gender Nonconforming People." *American Psychologist* 70, no. 9 (2015): 832–64. <https://doi.org/10.1037/a0039906>.
- American Psychological Association, and Leo Rennie. "Response to Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations." Response to RFI NOT-OD-13-076. Washington, DC: American Psychological Association, 2013. <http://www.apa.org/about/gr/pi/news/2013/NIH-LGBTI-RFI-response.pdf>.
- Anderson, Chris. "The Long Tail." *Wired*, October 2004.
- Anderson, R. J. "Representations and Requirements: The Value of Ethnography in System Design." *Human-Computer Interaction* 9, no. 3 (1994): 151–182.
- Anderson, W. L. "Some Challenges and Issues in Managing, and Preserving Access to, Long-Lived Collections of Digital Scientific and Technical Data." *Data Science Journal* 3 (2004): 191–201.
- Ansara, Y. G. "Making the Count: Addressing Data Integrity Gaps in Australian Standards for Collecting Sex and Gender Information." Newtown, Australia: National LGBTI Health Alliance, 2016. <http://www.lgbtihealth.org.au>.
- Babbie, Earl. *The Practice of Social Research*. 11 th ed. Belmont CA: Thomson Wadsworth, 2008.
- Baker, Kellan. "Gathering Sexual Orientation and Gender Identity Data in Health IT." Center for American Progress, February 2012.

- <https://myhs.ucdmc.ucdavis.edu/documents/41620/0/Gathering+Sexual+Orientation+and+Gender+Identity+Data+in+Health+IT.pdf/27ab7713-51b3-419a-9d4c-efd852895a32>.
- Barry, Kevin M. "Disabilityqueer: Federal Disability Rights Protection for Transgender People." *Yale Human Rights and Development Law Journal*, 2014.
http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2084351.
- Barry, Kevin M., Brian Farrell, Jennifer L. Levi, and Neelima Vanguri. "Bare Desire to Harm: Transgender People and the Equal Protection Clause, A." *BCL Rev.* 57 (2016): 507.
- Bauer, Greta R., Jessica Braimoh, Ayden I. Scheim, and Christoffer Dharma. "Transgender-Inclusive Measures of Sex/Gender for Population Surveys: Mixed-Methods Evaluation and Recommendations." *PloS One* 12, no. 5 (2017): e0178043.
<https://doi.org/10.1371/journal.pone.0178043>.
- Bauer, Greta R, Rebecca Hammond, Robb Travers, Matthias Kaay, Karin M Hohenadel, and Michelle Boyce. "'I Don't Think This Is Theoretical; This Is Our Lives': How Erasure Impacts Health Care for Transgender People." *The Journal of the Association of Nurses in AIDS Care: JANAC* 20, no. 5 (October 2009): 348–61.
<https://doi.org/10.1016/j.jana.2009.07.004>.
- BBC World News - Interview about an Intersex Childhood Shattered by Ignorance*, 2013.
http://www.youtube.com/watch?v=p8id0IzR0Io&feature=youtube_gdata_player.
- Beauchamp, Toby. "Artful Concealment and Strategic Visibility: Transgender Bodies and US State Surveillance After 9/11." *Surveillance & Society* 6, no. 4 (2009).
- . "The Substance of Borders Transgender Politics, Mobility, and US State Regulation of Testosterone." *GLQ: A Journal of Lesbian and Gay Studies* 19, no. 1 (January 1, 2013): 57–78. <https://doi.org/10.1215/10642684-1729545>.
- Beck, Max. "My Life as an Intersexual." *NOVA* (blog), October 30, 2001.
<http://www.pbs.org/wgbh/nova/body/intersexual-life.html>.
- Beemyn, Genny. "A Presence in the Past: A Transgender Historiography." *Journal of Women's History* 25, no. 4 (2013): 113–21. <https://doi.org/10.1353/jowh.2013.0062>.
- Bellacasa, María Puig de la. "'Nothing Comes Without Its World': Thinking with Care." *The Sociological Review* 60, no. 2 (May 1, 2012): 197–216. <https://doi.org/10.1111/j.1467-954X.2012.02070.x>.
- Bettcher, Talia Mae. "Evil Deceivers and Make-Believers: On Transphobic Violence and the Politics of Illusion." *Hypatia* 22, no. 3 (2007): 43–65.
- . "Trans Identities and First Person Authority." In *You've Changed: Sex Reassignment and Personal Identity*, 98–120. Oxford University Press, 2009.

- Billimoria, Diana, and Abigail J. Stewart. "'Don't Ask, Don't Tell': The Academic Climate for Lesbian, Gay, Bisexual, and Transgender Faculty in Science and Engineering." *NWSA Journal* 21, no. 2 (2009): 85–103.
- Blackless, Melanie, Anthony Charuvastra, Amanda Derryck, Anne Fausto-Sterling, Karl Lauzanne, and Ellen Lee. "How Sexually Dimorphic Are We? Review and Synthesis." *American Journal of Human Biology* 12, no. 2 (2000): 151–166.
- Bockting, Walter O. "Biological Reductionism Meets Gender Diversity in Human Sexuality." *The Journal of Sex Research* 42, no. 3 (August 1, 2005): 267–70.
- . "Transforming the Paradigm of Transgender Health: A Field in Transition." *Sexual and Relationship Therapy* 24, no. 2 (May 2009): 103–7.
<https://doi.org/10.1080/14681990903037660>.
- Borgman, Christine L. *From Gutenberg to the Global Information Infrastructure: Access to Information in the Networked World*. The MIT Press, 2003.
- Bowker, G. C. *Memory Practices in the Sciences*. Cambridge: MIT Press, 2005.
- Bowker, G. C., and S. L. Star. "How Things (Actor-Net) Work: Classification, Magic and the Ubiquity of Standards." *Philosophia* 25, no. 3–4 (1996): 195–220.
- Bowker, G., and S. Star. "Building Information Infrastructures for Social Worlds—The Role of Classifications and Standards." *Community Computing and Support Systems*, 1998, 231–248.
- boyd, danah, and Kate Crawford. "Critical Questions for Big Data." *Information, Communication & Society*, 2012, 1–18. <https://doi.org/10.1080/1369118X.2012.678878>.
- Bradford, Judith, Sari L. Reisner, Julie A. Honnold, and Jessica Xavier. "Experiences of Transgender-Related Discrimination and Implications for Health: Results from the Virginia Transgender Health Initiative Study." *American Journal of Public Health* 103, no. 10 (2013): 1820–1829.
- Briet, S. *What Is Documentation?* Translated by Ronald E. Day and L. Martinet. Scarecrow Press, 2006.
- Brown, George R., and Kenneth T. Jones. "Racial Health Disparities in a Cohort of 5,135 Transgender Veterans." *Journal of Racial and Ethnic Health Disparities* 1, no. 4 (December 2014): 257–66. <https://doi.org/10.1007/s40615-014-0032-4>.
- Bryant, Karl, and Kristen Schilt. "Transgender People in the U.S. Military: Summary and Analysis of the 2008 Transgender American Veterans Association Survey." Santa Barbara, California: The Palm Center, 2008. <http://www.tavausa.org/survey-result/>.

- Buckland, M., and T B Hahn. "Introduction: History of Documentation and Information Science." *Journal of the American Society for Information Science* 48, no. 4 (April 1997): 285–88.
- Burrell, Jenna. "How the Machine 'Thinks': Understanding Opacity in Machine Learning Algorithms." *Big Data & Society* 3, no. 1 (2016): 2053951715622512.
- Cahill, Sean R., Kellan Baker, Madeline B. Deutsch, Joanne Keatley, and Harvey J. Makadon. "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health." *LGBT Health* 3, no. 2 (December 24, 2015): 100–102. <https://doi.org/10.1089/lgbt.2015.0136>.
- Califia, Pat. *Sex Changes: The Politics of Transgenderism*. Cleis Press, 1997.
- Califia, Patrick. "Trashing the Clinic and Burning down the Beauty Parlor: Activism Transmutes Pitiably Patients into Fiesty Gender Radicals." In *Sex Changes: Transgender Politics*. Cleis Press, 2013.
- Callahan, Edward J., Shea Hazarian, Mark Yarborough, and John Paul Sánchez. "Eliminating LGBTIQ Health Disparities: The Associated Roles of Electronic Health Records and Institutional Culture." *The Hastings Center Report* 44 Suppl 4 (September 2014): S48-52. <https://doi.org/10.1002/hast.371>.
- Canadian Institutes of Health Research (CIHR), and Institute of Gender and Health. "What a Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook." Ottawa, Canada: Canadian Institute of Health Research (CIHR), 2012. <http://www.cihr-irsc.gc.ca/e/8673.html>.
- Carlson, S., and B. Anderson. "What Are Data? The Many Kinds of Data and Their Implications for Data Re-Use." *Journal of Computer-Mediated Communication* 12, no. 2 (2007): 635–51.
- Cartwright, Donna, Kara Desiderio, Jamison Green, Maceo Persson, and Jason Tescher. "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy." San Francisco, California: Transgender Law Center, 2012. <http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.
- Caswell, Michelle. *Archiving the Unspeakable*. University of Wisconsin Press, 2014.
- Chalabi, Mona. "Why We Don't Know The Size Of The Transgender Population." *FiveThirtyEight Life* (blog), July 29, 2014. <http://fivethirtyeight.com/features/why-we-dont-know-the-size-of-the-transgender-population/>.
- Clements-Nolle, Kristen, Mitchell Katz, and Rani Marx. "The Transgender Community Health Project." San Francisco, California: SF Dept of Public Health, 1999. <http://hivinsite.ucsf.edu/InSite?page=cftg-02-02>.

- Clune-Taylor, Catherine. "From Intersex to DSD: The Disciplining of Sex Development." *PhaenEx* 5, no. 2 (2010): 152–178.
- Collin, Lindsay, Sari L. Reisner, Vin Tangpricha, and Michael Goodman. "Prevalence of Transgender Depends on the 'Case' Definition: A Systematic Review." *The Journal of Sexual Medicine* 13, no. 4 (April 1, 2016): 613–26. <https://doi.org/10.1016/j.jsxm.2016.02.001>.
- Collins, H. M. "The Meaning of Data: Open and Closed Evidential Cultures in the Search for Gravitational Waves." *American Journal of Sociology* 104, no. 2 (1998): 293–338.
- Conron, Kerith J., Stewart J. Landers, Sari L. Reisner, and Randall L. Sell. "Sex and Gender in the US Health Surveillance System: A Call to Action." *American Journal of Public Health* 104, no. 6 (June 2014): 970–76. <https://doi.org/10.2105/AJPH.2013.301831>.
- Cooky, Cheryl, and Shari L. Dworkin. "Policing the Boundaries of Sex: A Critical Examination of Gender Verification and the Caster Semenya Controversy." *The Journal of Sex Research* 50, no. 2 (February 1, 2013): 103–11.
- Cruz, Taylor M. "Assessing Access to Care for Transgender and Gender Nonconforming People: A Consideration of Diversity in Combating Discrimination." *Social Science & Medicine* 110 (June 2014): 65–73. <https://doi.org/10.1016/j.socscimed.2014.03.032>.
- Currah, Paisley. "Gender Pluralisms under the Transgender Umbrella." In *Transgender Rights*, 3–31, 2006. http://www.academia.edu/download/30752239/Currah_Gender_Pluralisms0001.pdf.
- Currah, Paisley, and Lisa Jean Moore. "'We Won't Know Who You Are': Contesting Sex Designations in New York City Birth Certificates." *Hypatia* 24, no. 3 (August 1, 2009): 113–35. <https://doi.org/10.1111/j.1527-2001.2009.01048.x>.
- Davidson, Megan. "Seeking Refuge under the Umbrella: Inclusion, Exclusion, and Organizing within the Category Transgender." *Sexuality Research & Social Policy* 4, no. 4 (December 2007): 60–80.
- Denny, Dallas. "Sex Certainly Did Change!" *The Journal of Sex Research* 40, no. 3 (August 1, 2003): 316–17.
- . "Transgender: Some Historical, Cross-Cultural, and Contemporary Models and Methods of Coping and Treatment." *Gender Blending*, 1997, 33–47.
- Derrida, Jacques. *Archive Fever: A Freudian Impression*. University of Chicago Press, 1996.
- . "Structure, Sign and Play in the Discourse of the Human Sciences." In *Writing and Difference*, 278–339. University of Chicago Press, 1978.

- Deutsch, Madeline B. "Making It Count: Improving Estimates of the Size of Transgender and Gender Nonconforming Populations." *LGBT Health* 3, no. 3 (June 2016): 181–85. <https://doi.org/10.1089/lgbt.2016.0013>.
- Deutsch, Madeline B, Jamison Green, JoAnne Keatley, Gal Mayer, Jennifer Hastings, and Alexandra M Hall. "Electronic Medical Records and the Transgender Patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group." *Journal of the American Medical Informatics Association : JAMIA* 20, no. 4 (July 2013): 700–703. <https://doi.org/10.1136/amiajnl-2012-001472>.
- Deutsch, Madeline B., JoAnne Keatley, Jae Sevelius, and Starley B. Shade. "Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-User Practices." *Journal of the Association of Nurses in AIDS Care* 25, no. 6 (November 2014): 657–63. <https://doi.org/10.1016/j.jana.2014.04.001>.
- Dozier, Raine. "Beards, Breasts, and Bodies Doing Sex in a Gendered World." *Gender & Society* 19, no. 3 (2005): 297–316.
- Dreger, A. D., and A. M. Herndon. "Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action." *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 2 (January 1, 2009): 199–224. <https://doi.org/10.1215/10642684-2008-134>.
- Drescher, Jack. "Queer Diagnoses: Parallels and Contrasts in the History of Homosexuality, Gender Variance, and the Diagnostic and Statistical Manual." *Archives of Sexual Behavior* 39, no. 2 (2010): 427–60. <https://doi.org/10.1007/s10508-009-9531-5>.
- Duff, Wendy M., and Verne Harris. "Stories and Names: Archival Description as Narrating Records and Constructing Meanings." *Archival Science* 2, no. 3–4 (2002): 263–285.
- Duguid, Paul. "'The Art of Knowing': Social and Tacit Dimensions of Knowledge and the Limits of the Community of Practice." *The Information Society* 21, no. 2 (2005): 109–18.
- Dykes, Daryll C, and Augustus A White. "Getting to Equal: Strategies to Understand and Eliminate General and Orthopaedic Healthcare Disparities." *Clinical Orthopaedics and Related Research* 467, no. 10 (October 2009): 2598–2605. <https://doi.org/10.1007/s11999-009-0993-5>.
- "Editorial: New Guidelines on Transgender Health." *The Lancet* 382, no. 9903 (November 2013): 1460. [https://doi.org/10.1016/S0140-6736\(13\)62277-1](https://doi.org/10.1016/S0140-6736(13)62277-1).
- Edwards, Paul N. "The Army and the Microworld: Computers and the Politics of Gender Identity." *Signs* 16, no. 1 (1990): 102–127.
- Ettner, Randi, Stan Monstrey, and Eli Coleman. *Principles of Transgender Medicine and Surgery*. Routledge, 2016.

- Ettner, Randi, Stan Monstrey, and A. Evan Eyler. *Principles of Transgender Medicine and Surgery*. New York: Haworth Press, 2007.
- Fallik, D. "For Big Data, Big Questions Remain." *Health Affairs* 33, no. 7 (July 1, 2014): 1111–14. <https://doi.org/10.1377/hlthaff.2014.0522>.
- Farmer, Paul. "An Anthropology of Structural Violence." *Current Anthropology* 45, no. 3 (June 1, 2004): 305–25. <https://doi.org/10.1086/ca.2004.45.issue-3>.
- Fassinger, Ruth E., and Julie R. Arseneau. "'I'd Rather Get Wet Than Be Under That Umbrella': Differentiating the Experiences and Identities of Lesbian, Gay, Bisexual, and Transgender People." 2007. <http://psycnet.apa.org/psycinfo/2006-11835-001>.
- Fausto-Sterling, Anne. "Sexing the Body: How Biologists Construct Human Sexuality." *International Journal of Transgenderism* 4, no. 3 (2000).
- . "The Five Sexes, Revisited." *The Sciences* 40, no. 4 (2000): 18–23.
- Flinn, Andrew, Mary Stevens, and Elizabeth Shepherd. "Whose Memories, Whose Archives? Independent Community Archives, Autonomy and the Mainstream." *Archival Science* 9, no. 1–2 (October 2009): 71–86. <https://doi.org/10.1007/s10502-009-9105-2>.
- Forsythe, D. E. "'It's Just a Matter of Common Sense': Ethnography as Invisible Work." *Computer Supported Cooperative Work (CSCW)* 8, no. 1 (1999): 127–145.
- Forsythe, D E. "Using Ethnography to Investigate Life Scientists' Information Needs." *Bulletin of the Medical Library Association* 86, no. 3 (July 1998): 402–9.
- Foucault, M. "The Formation of Enunciative Modalities." In *The Archaeology of Knowledge*. Harper & Row, 1972.
- Friedlander, Amy. "The Triple Helix: Cyberinfrastructure, Scholarly Communication, and Trust." *Journal of Electronic Publishing* 11, no. 1 (Winter 2008). <http://dx.doi.org/10.3998/3336451.0011.109>.
- Friendly, Micheal, and Daniel Denis. "Milestones in the History of Thematic Cartography, Statistical Graphics, and Data Visualization." Accessed April 7, 2010. <http://datavis.ca/milestones/>.
- Fry, Jane. "Conclusion: On the Records." In *Being Different: The Autobiography of Jane Fry.*, edited by Robert Bogdan, 213–33. New York: Wiley, 1974.
- Frye, Phyllis Randolph. "International Bill of Gender Rights vs. the Cider House Rules: Transgenders Struggle with the Courts over What Clothing They Are Allowed to Wear on the Job, Which Restroom They Are Allowed to Use on the Job, Their Right to Marry, and the Very Definition of Their Sex, The." *Wm. & Mary J. Women & L.* 7 (2000): 133.

- Furner, Jonathan. "What Is Documentation?: English Translation of the Classic French Text." *Libraries & the Cultural Record* 43, no. 1 (February 2008): 107–9. <https://doi.org/BookReview>.
- Furner, Jonathan, Marcia J. Bates, Michael K. Buckland, and Anne J Gilliland-Swetland. "Conceptions of Information as Evidence." *Proceedings of the American Society for Information Science and Technology* 39, no. 1 (November 1, 2002): 497–98. <https://doi.org/10.1002/meet.1450390181>.
- Gan, Jessi. "'Still at the Back of the Bus': Silvia Rivera's Struggle." *Centro Journal* 19, no. 1 (2007): 124–39.
- Gay and Lesbian Historical Society, and Elliot Blackstone. "MTF Transgender Activism in the Tenderloin and Beyond, 1966–1975." *GLQ: A Journal of Lesbian and Gay Studies* 4, no. 2 (1998): 349–372.
- Gehi, Pooja S., and Gabriel Arkles. "Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People." *Sexuality Research & Social Policy* 4, no. 4 (December 1, 2007): 7–35. <https://doi.org/10.1525/srsp.2007.4.4.7>.
- . "Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People." *Sexuality Research & Social Policy* 4, no. 4 (December 1, 2007): 7–35. <https://doi.org/10.1525/srsp.2007.4.4.7>.
- Gilliland-Swetland, Anne J. *Enduring Paradigm, New Opportunities: The Value of the Archival Perspective in the Digital Environment*. Council on Library and Information Resources, 2000.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster, 1963.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling. "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey." Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011. http://www.thetaskforce.org/static_html/downloads/reports/reports/ntds_full.pdf.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jody L Herman, Jack Harrison, and Mara Keisling. "National Transgender Discrimination Survey Report on Health and Health Care." National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- Greatheart, Marcus. *Transforming Practice: Life Stories of Transgender Men That Change How Health Providers Work*. Ethica Press, 2013.

- Green, Jamison. "Transgender: Why Should We Care?" *The Lancet* 388, no. 10042 (July 23, 2016): 334–35. [https://doi.org/10.1016/S0140-6736\(16\)30840-6](https://doi.org/10.1016/S0140-6736(16)30840-6).
- Gregory, Judith. "Sorcerer's Apprentice: Creating the Electronic Health Record, Re-Inventing Medical Records and Patient Care." PhD, University of California, San Diego, 2000. http://love.com.au/PublicationsTLminisite/jgregory/phd_mstrx.pdf.
- Gressgard, Randi. "When Trans Translates into Tolerance-or Was It Monstrous? Transsexual and Transgender Identity in Liberal Humanist Discourse." *Sexualities* 13, no. 5 (2010): 539–561.
- Groth, Paul, Simon Miles, and Steve Munroe. "Principles of High Quality Documentation for Provenance: A Philosophical Discussion." In *Provenance and Annotation of Data*, 278–286. Springer, 2006. http://link.springer.com/10.1007%2F11890850_28.
- Growing up Intersex Part 1*, 2013. https://www.youtube.com/watch?v=I9a1rXOpluc&feature=youtube_gdata_player.
- Hale, C. J. "Consuming the Living, Dis (Re) Membering the Dead in the Butch/FTM Borderlands." *GLQ: A Journal of Lesbian and Gay Studies* 4, no. 2 (1998): 311.
- Hartzell, E., M. S. Frazer, K. Wertz, and Masen Davis. "The State of Transgender California: Results from the 2008 California Transgender Economic Health Survey." San Francisco, California: Transgender Law Center, 2009. http://transgenderlawcenter.org/pdf/StateTransCA_report_2009Print.pdf.
- "Healthy People 2020 Transgender Health Fact Sheet," November 2010. <http://www.lgbttobacco.org/files/TransgenderHealthFact.pdf>.
- Herman, Jody L., Bianca DM Wilson, and Tara Becker. "Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey." Health Policy Brief. University of California, Los Angeles: UCLA Center for Health Policy Research - UCLA Williams Institute, October 2017.
- Hilgartner, Stephen, and Sherry I Brandt-Rauf. "Data Access, Ownership and Control: Toward Empirical Studies of Access Practices." *Knowledge* 15 (1994): 355–72.
- Hirschfeld, Magnus. *Berlins Drittes Geschlecht*. Berlin: rosa Winkel, 1991.
- "HL7 Standards Product Brief - HL7 Version 3 Standard: Data Types - Abstract Specification, Release 2." Accessed July 5, 2016. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=264.
- Horton, Mary Ann. "The Incidence and Prevalence of SRS among US Residents." *International Journal of Transgenderism*, 2008.

- Institute of Medicine. "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." Accessed May 28, 2016.
<http://www.nationalacademies.org/hmd/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>.
- Jacobson, Matthew Frye. *Whiteness of a Different Color: European Immigrants and the Alchemy of Race*. Cambridge, MA: Harvard University Press, 1998.
- Janssen, Marijn, and George Kuk. *The Challenges and Limits of Big Data Algorithms in Technocratic Governance*. Elsevier, 2016.
- Joel, Daphna, Zohar Berman, Ido Tavor, Nadav Wexler, Olga Gaber, Yaniv Stein, Nisan Shefi, et al. "Sex beyond the Genitalia: The Human Brain Mosaic." *Proceedings of the National Academy of Sciences* 112, no. 50 (December 15, 2015): 15468–73.
<https://doi.org/10.1073/pnas.1509654112>.
- Johnson, Carey V, Matthew J Mimiaga, and Judith Bradford. "Health Care Issues among Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Populations in the United States: Introduction." *Journal of Homosexuality* 54, no. 3 (2008): 213–24.
- Johnson, Kerri L., and Negin Ghavami. "At the Crossroads of Conspicuous and Concealable: What Race Categories Communicate about Sexual Orientation." *PLoS ONE* 6, no. 3 (March 31, 2011): e18025. <https://doi.org/10.1371/journal.pone.0018025>.
- Kauth, Michael R., Jillian C. Shipherd, Jan Lindsay, John R. Blosnich, George R. Brown, and Kenneth T. Jones. "Access to Care for Transgender Veterans in the Veterans Health Administration: 2006–2013." *American Journal of Public Health* 104, no. S4 (2014): S532–S534.
- Kent, William. *Data and Reality : Basic Assumptions in Data Processing Reconsidered*. Amsterdam; New York: North-Holland Pub. Co., 1978.
- Kitchin, Rob. "Thinking Critically about and Researching Algorithms." *Information, Communication & Society* 20, no. 1 (January 2, 2017): 14–29.
<https://doi.org/10.1080/1369118X.2016.1154087>.
- Kitts, Robert Li. "Barriers to Optimal Care between Physicians and Lesbian, Gay, Bisexual, Transgender, and Questioning Adolescent Patients." *Journal of Homosexuality* 57, no. 6 (2010): 730–747.
- Knorr Cetina, Karin D. *Epistemic Cultures: How the Sciences Make Knowledge*. Harvard University Press, 2009.
- Koenig, Jonathan L. "Distributive Consequences of the Medical Model." *Harv. CR-CLL Rev.* 46 (2011): 619.

- Kosenko, Kami, Lance Rintamaki, Stephanie Raney, and Kathleen Maness. "Transgender Patient Perceptions of Stigma in Health Care Contexts." *Medical Care* 51, no. 9 (September 1, 2013): 819–22.
- . "Transgender Patient Perceptions of Stigma in Health Care Contexts." *Medical Care* 51, no. 9 (September 1, 2013): 819–22.
- Kristeva, Julia. "The System and the Speaking Subject." In *The Kristeva Reader*, edited by Toril Moi. Columbia University Press, 1986.
- Lakoff, George. *Women, Fire and Dangerous Things—What Categories Reveal about the Mind*. Chicago: University of Chicago Press, 1987.
- LeBreton, Marianne. "The Erasure of Sex and Gender Minorities in the Healthcare System," 2013. <https://papyrus.bib.umontreal.ca/xmlui/handle/1866/9811>.
- Leigh, Suzanne. "Young People Exploring Nonbinary Gender Roles." *SFGate*. February 12, 2014, Online edition. <http://www.sfgate.com/health/article/Young-people-exploring-nonbinary-gender-roles-5225994.php#src=fb>.
- Lofland, John, David A Snow, Leon Anderson, and Lyn H Lofland. *Analyzing Social Settings a Guide to Qualitative Observation and Analysis*. Belmont: Wadsworth, 2006.
- Maier, Mark, and Todd. Easton. *The Data Game : Controversies in Social Science Statistics*. Armonk, N.Y.: M.E. Sharpe, 1999.
- Makadon, Harvey J. "Ending LGBT Invisibility in Health Care: The First Step in Ensuring Equitable Care." *Cleveland Clinic Journal of Medicine* 78, no. 4 (2011): 220–224.
- Mays, Vickie M., Ninez A. Ponce, Donna L. Washington, and Susan D. Cochran. "Classification of Race and Ethnicity: Implications for Public Health." *Annual Review of Public Health* 24 (2003): 83–110. <https://doi.org/10.1146/annurev.publhealth.24.100901.140927>.
- Mazur, Diane H. "Arbitrary and Capricious: Six Inconsistencies Distinguishing Military Medical Policies for Transgender and Non-Transgender Personnel." Palm Center, October 2014.
- McKemmish, Sue. "Traces: Document, Record, Archive, Archives." In *Archives: Recordkeeping in Society*, edited by Sue McKemmish, M. Piggot, B. Reed, and F. Upward, 1–20. Wagga Wagga, Australia: Centre for Information Studies, Charles Sturt University, 2005.
- Meier, Stacey Colton, and Christine M. Labuski. "The Demographics of the Transgender Population." In *International Handbook on the Demography of Sexuality*, 289–327. International Handbooks of Population. Springer, Dordrecht, 2013. https://doi.org/10.1007/978-94-007-5512-3_16.

- Meyerowitz, Joanne. "Sex Change and the Popular Press: Historical Notes on Transsexuality in the United States, 1930–1955." *GLQ: A Journal of Lesbian and Gay Studies* 4, no. 2 (1998): 159–187.
- Miller, Virginia M. "Why Are Sex and Gender Important to Basic Physiology and Translational and Individualized Medicine?" *American Journal of Physiology - Heart and Circulatory Physiology* 306, no. 6 (March 15, 2014): H781–88. <https://doi.org/10.1152/ajpheart.00994.2013>.
- Mogul, Joey L., Andrea J. Ritchie, and Kay Whitlock. *Queer (In)Justice: The Criminalization of LGBT People in the United States*. Beacon Press, 2011.
- Morland, I. "What Can Queer Theory Do for Intersex?" *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 2 (January 1, 2009): 285–312. <https://doi.org/10.1215/10642684-2008-139>.
- Morland, Iain. "Intersex and After." *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 2 (2009): 191–197.
- Namaste, Viviane. *Invisible Lives: The Erasure of Transsexual and Transgendered People*. University of Chicago Press, 2000.
- National Academy of Sciences. *Ensuring the Integrity, Accessibility, and Stewardship of Research Data in the Digital Age*. National Academies Press, 2009. http://www.nap.edu/catalog.php?record_id=12615.
- National Research Council (U.S.). *A Question of Balance: Private Rights and the Public Interest in Scientific and Technical Databases*. Washington, DC: National Academy Press, 1999.
- National Science Board. "Long-Lived Digital Data Collections: Enabling Research and Education in the 21st Century." Arlington VA: National Science Foundation, 2005. Open WorldCat (Web). <http://www.nsf.gov/pubs/2005/nsb0540/nsb0540.pdf>.
- NIH. "NOT-OD-13-076: Request for Information (RFI): Inviting Comments and Suggestions on the Health and Health Research Needs, Specific Health Issues and Concerns for Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) Populations." Request for Information. Washington, DC: National Institutes for Health, June 27, 2013. <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-13-076.html>.
- Nissenbaum, Helen. "How Computer Systems Embody Values." *Computer*, 2001.
- Obedin-Maliver, Juno, Elizabeth S. Goldsmith, Leslie Stewart, William White, Eric Tran, Stephanie Brenman, Maggie Wells, David M. Fetterman, Gabriel Garcia, and Mitchell R. Lunn. "Lesbian, Gay, Bisexual, and Transgender–Related Content in Undergraduate Medical Education." *JAMA: The Journal of the American Medical Association* 306, no. 9 (2011): 971–977. <https://doi.org/10.1001/jama.2011.1255>.

- Ohle, John M. "Constructing the Trannie: Transgender People and the Law." *Journal of Gender, Race & Justice* 8 (2005 2004): 237.
- Olson, Hope A. "Assumptions of Naming in Information Storage and Retrieval: A Deconstruction." In *Information as a Global Commodity: Communication, Processing and Use—21st Annual Conference of the Canadian Association for Information Science, Canadian Association for Information Science, Antigonish, NS*, 110–119, 1993. http://www.cais-acsi.ca/proceedings/1993/Olson_1993.pdf.
- Olson, Hope A., and Dennis B. Ward. "Ghettoes and Diaspora in Classification: Communicating across the Limits." In *Communication and Information in Context: Society, Technology, and the Professions. Proceedings of the 25th Annual Conference/Association Canadienne Des Sciences de l'information: Travaux Du 25e Congrès Annuel*, 1997. http://cais-acsi.ca/proceedings/1997/Olson_1997.pdf.
- Omi, Michael, and Howard Winant. *Racial Formation in the United States: From the 1960s to the 1990s*. Psychology Press, 1994.
- Osterweil, Leon J., Lori A. Clarke, and Aaron M. Ellison. "Forecast for Reproducible Data: Partly Cloudy." *Science* 325, no. 5948 (September 25, 2009): 1622-b. https://doi.org/10.1126/science.325_1622b.
- Peterson, Lee M. "Workplace Harassment against Transgender Individuals: Sex Discrimination, Status Discrimination, or Both." *Suffolk UL Rev.* 36 (2002): 227.
- Prewitt, Kenneth. *What Is "Your" Race?: The Census and Our Flawed Efforts to Classify Americans*. Princeton University Press, 2013.
- Ravishankar, Mathura. "The Story About Robert Eads |." *Journal of Global Health Online* (January 18, 2013). <http://www.ghjournal.org/jgh-online/the-story-about-robert-eads/>.
- Reisner, S. L., K. J. Conron, Scout, K. Baker, J. L. Herman, E. Lombardi, E. A. Greytak, A. M. Gill, and A. K. Matthews. "'Counting' Transgender and Gender-Nonconforming Adults in Health Research: Recommendations from the Gender Identity in US Surveillance Group." *TSQ: Transgender Studies Quarterly* 2, no. 1 (January 1, 2015): 34–57. <https://doi.org/10.1215/23289252-2848877>.
- Renear, Allen H., Simone Sacchi, and Karen M. Wickett. "Definitions of Dataset in the Scientific and Technical Literature." *Proceedings of the American Society for Information Science and Technology* 47, no. 1 (November 2010): 1–4. <https://doi.org/10.1002/meet.14504701240>.
- Ribes, David, and Geoffrey C. Bowker. "Between Meaning and Machine: Learning to Represent the Knowledge of Communities." *Information and Organization* 19, no. 4 (October 2009): 199–217. <https://doi.org/10.1016/j.infoandorg.2009.04.001>.

- Roberts, Tiffany K., and Corinne R. Fantz. "Barriers to Quality Health Care for the Transgender Population." *Clinical Biochemistry, Men's Health and Laboratory Medicine*, 47, no. 10 (July 1, 2014): 983–87. <https://doi.org/10.1016/j.clinbiochem.2014.02.009>.
- Rosario, V. A. "Quantum Sex: Intersex and the Molecular Deconstruction of Sex." *GLQ: A Journal of Lesbian and Gay Studies* 15, no. 2 (January 1, 2009): 267–84. <https://doi.org/10.1215/10642684-2008-138>.
- Rosenberg, M. *The Logic of Survey Analysis*. Basic Books New York, 1968.
- Safran, Charles, Meryl Bloomrosen, W. Edward Hammond, Steven Labkoff, Suzanne Markel-Fox, Paul C. Tang, and Don E. Detmer. "Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper." *Journal of the American Medical Informatics Association* 14, no. 1 (January 1, 2007): 1–9. <https://doi.org/10.1197/jamia.M2273>.
- Sanjek, Roger. *Fieldnotes: The Makings of Anthropology*. Cornell University Press, 1990.
- Sausa, L. A., J. Sevelius, J. Keatley, J. R. Iñiguez, and M. Reyes. "Policy Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services." University of California, San Francisco: Center of Excellence for Transgender HIV Prevention, 2009. <http://transhealth.ucsf.edu/pdf/data-recommendation.pdf>.
- Scheiner, Samuel M. "Experiments, Observations, and Other Kinds of Evidence." In *The Nature of Scientific Evidence: Statistical, Philosophical, and Empirical Considerations*, edited by Mark L Taper and Subhash R Lele, 51–66. Chicago: University of Chicago Press, 2004.
- Scout. "Déjà Vu: National Surveys Leave Trans People Behind." *Huffington Post* (blog), June 13, 2013. http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html.
- Serano, Julia M. "The Case Against Autogynephilia." *International Journal of Transgenderism* 12, no. 3 (October 12, 2010): 176–87. <https://doi.org/10.1080/15532739.2010.514223>.
- Shankar, K. "Order from Chaos: The Poetics and Pragmatics of Scientific Recordkeeping." *Journal of the American Society for Information Science and Technology* 58, no. 10 (2007): 1457–1466.
- Shankar, Kalpana. "Recordkeeping in the Production of Scientific Knowledge: An Ethnographic Study." *Archival Science* 4, no. 3–4 (February 2006): 367–82. <https://doi.org/10.1007/s10502-005-2600-1>.
- Shannon, C. E. "A Mathematical Theory of Communication." *Bell System Technical Journal* 27 (October 1948): 379–423, 623–56.

- Shrage, Laurie. "Does the Government Need to Know Your Sex?" *Journal of Political Philosophy* 20, no. 2 (2012): 225–247. <https://doi.org/10.1111/j.1467-9760.2010.00379.x>.
- Sloop, J. M. "Disciplining the Transgendered: Brandon Teena, Public Representation, and Normativity." *Western Journal of Communication* 64, no. 2 (2000): 165–189.
- Spade, Dean. *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law*. South End Press Cambridge, MA, 2011.
- . "Resisting Medicine, Re/Modeling Gender." *Berkeley Women's Law Journal* 18 (2003): 15.
- Staff, and agencies. "Australian Passports to Have Third Gender Option." *The Guardian*, September 15, 2011, sec. World news. <http://www.theguardian.com/world/2011/sep/15/australian-passports-third-gender-option>.
- Stanton, Steven J. "The Essential Implications of Gender in Human Behavioral Endocrinology Studies." *Frontiers in Behavioral Neuroscience* 5 (2011): 9. <https://doi.org/10.3389/fnbeh.2011.00009>.
- Star, Susan Leigh, ed. *Ecologies of Knowledge: Work and Politics in Science and Technology*. Albany: State University of New York Press, 1995.
- . "Invisible Work and Silenced Dialogues in Knowledge Representation." *Women, Work and Computerization*, 1991, 81–92.
- . "The Politics of Formal Representations: Wizards, Gurus, and Organizational Complexity." In *Ecologies of Knowledge: Work and Politics in Science and Technology*, 88. Albany: State University of New York Press, 1995.
- . "The Structure of Ill-Structured Solutions: Boundary Objects and Heterogeneous Distributed Problem Solving." *Distributed Artificial Intelligence* 2 (1989): 37–54.
- Star, Susan Leigh, and Geoffrey C Bowker. *Sorting Things Out: Classification and Its Consequences*. Cambridge, Mass.: MIT Press, 1999.
- Star, Susan Leigh, Geoffrey C. Bowker, and Laura J. Neumann. "Transparency beyond the Individual Level of Scale: Convergence between Information Artifacts and Communities of Practice." In *Digital Library Use: Social Practice in Design and Evaluation*, edited by Nancy Van House and Ann Peterson Bishop. Digital Libraries and Electronic Publishing; Cambridge, Mass.: MIT Press, 2003.
- Star, Susan Leigh, and James R. Griesemer. "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology,

- 1907-39." *Social Studies of Science* 19, no. 3 (1989): 387–420.
<https://doi.org/10.1177/030631289019003001>.
- Steinmetz, Katy. "This Is How Many Americans Identify as Transgender." *Time*, June 30, 2016.
<http://time.com/4389936/transgender-americans-statistic-how-many/>.
- Stryker, Susan. "(De) Subjugated Knowledges: An Introduction to Transgender Studies." In *The Transgender Studies Reader*, edited by Susan Stryker and Stephen Whittle. New York: Routledge, 2006.
- . *Transgender History*. Berkeley CA: Seal Press, 2008.
- . "Transgender History, Homonormativity, and Disciplinarity." *Radical History Review* 2008, no. 100 (January 1, 2008): 145–57. <https://doi.org/10.1215/01636545-2007-026>.
- Suchman, Lucy A. "Making Work Visible." *Communications of the ACM* 38 (September 1995): 56–ff. <https://doi.org/10.1145/223248.223263>.
- Sun, Midnight. "Sex/Gender Systems in Native North America." *Living the Spirit*, 1988, 32–47.
- Sussman, Rebecca, Felix Vargas, Aydin Kennedy, Shom Dasgupta, and Jim Mangia. "Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles." Los Angeles, California: St. John's Well Child and Family Center, 2015. <http://www.wellchild.org/sjwcfcfinalthpwhitepaper.pdf>.
- Sykes, Heather. "Transsexual and Transgender Policies in Sport." *Women in Sport and Physical Activity Journal* 15, no. 1 (2006): 3–13.
- Taborsky, Edwina. "Codal Regimes." In *Architectonics of Semiosis*, 91–115. New York: St. Martin's Press, 1998.
- Taylor, C. R. "Consumer Privacy and the Market for Customer Information." *RAND Journal of Economics* 35, no. 4 (2004): 631–650.
- Temple-O'Conner, Meredith, Elizabeth Wehr, and NIH LGBT Research Coordinating Committee. "Response to the Institute of Medicine (IOM) Report on the Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals." Accessed March 8, 2014.
http://report.nih.gov/UploadDocs/LGBT%20Health%20Report_FINAL_2013-01-03-508%20compliant.pdf.
- "This Tiny Clinic Is Fighting for Trans Patients Illegally Denied Medical Care." *TakePart* (blog). Accessed April 15, 2016. <http://www.takepart.com/feature/2015/09/18/transgender-health-care>.
- Trace, Ciaran B. "What Is Recorded Is Never Simply 'What Happened': Record Keeping in Modern Organizational Culture." *Archival Science* 2, no. 1 (2002): 137–159.

- Traweek, Sharon. "Bodies of Evidence: Law and Order, Sexy Machines, and the Erotics of Fieldwork among Physicists." In *Choreographing History*, edited by Susan Foster, 211–228. Bloomington, Ind.: Indiana University Press, 1995.
<http://www.sscnet.ucla.edu/history/traweek/evidence.pdf>.
- "U.S. Census Bureau QuickFacts: California." Accessed August 29, 2018.
<https://www.census.gov/quickfacts/ca>.
- Vickers, Andrew J. "Parametric versus Non-Parametric Statistics in the Analysis of Randomized Trials with Non-Normally Distributed Data." *BMC Medical Research Methodology* 5 (November 3, 2005): 35. <https://doi.org/10.1186/1471-2288-5-35>.
- Warner, J. "Semiotics, Information Science, Documents and Computers." *Journal of Documentation* 46, no. 1 (1990): 16–32.
- "What We Don't Know: The Unaddressed Health Concerns of the Transgendered." *Trans Health*, September 10, 2001. <http://www.trans-health.com/2001/unaddressed-health-concerns-transgendered/>.
- "Why We Don't Know The Size Of The Transgender Population." *FiveThirtyEight* (blog). Accessed May 5, 2015. <http://fivethirtyeight.com/features/why-we-dont-know-the-size-of-the-transgender-population/>.
- Winter, Sam, Milton Diamond, Jamison Green, Dan Karasic, Terry Reed, Stephen Whittle, and Kevan Wylie. "Transgender People: Health at the Margins of Society." *The Lancet* 388, no. 10042 (July 23, 2016): 390–400. [https://doi.org/10.1016/S0140-6736\(16\)00683-8](https://doi.org/10.1016/S0140-6736(16)00683-8).
- Yakel, Elizabeth. "Recordkeeping in Radiology : The Relationships between Activities and Records in Radiological Processes." PhD, University of Michigan, 1997.
- Zimmerman, Alex. "Study Shows Just 0.1 Percent of NIH Funding Went to LGBT Research." *Pittsburgh City Paper*. December 12, 2013, Online edition, sec. Blogh.
<http://www.pghcitypaper.com/Blogh/archives/2013/12/12/study-shows-just-01-percent-of-nih-funding-went-to-lgbt-research>.

CHAPTER 4: METHODS

4.1 Introduction to Methods	141
Frame of Analysis	142
4.2 Situational Analyses	144
Coding & Transcription	146
Research Stance & Significance of Methods	149
4.3 Data Collection	150
Protecting Confidentiality of Research Participants.....	152
Data Collection Process	154
Sample Questions:	155
4.4 Selecting Study Sites	156
Site 1: California Health Interview Survey (CHIS), Los Angeles	158
Site 2: Lyon Martin Clinic, San Francisco	159
Site 3: Gender Health Center, Sacramento	159
Cited References (Methods)	161

4.1 INTRODUCTION TO METHODS

This research project draws on mixed methods, including document analysis, ethnography, participant observation, and historical analysis to produce a close reading of three case studies. The study brings these mixed methods together under a framework developed by Adele Clarke and known as Situated Analysis¹. A student of Anselm Strauss, Clarke based this type of analysis on Grounded Theory, but adapted the method for challenges presented by the post-modern turn of inquiry that engages with the positionality of the researcher. The analysis draws together multiple data sources to produce a rich descriptive analysis of each case, examining the research object from a number of different discourses and intellectual traditions. The analysis relies on "framing systematic and flexible means of research design that facilitate multisite research, including discursive, textual, visual and archival historical materials and documents, as well as ethnographic (interview and observational) transcripts and field notes to more fully take into account the sea of discourses in which we are continually awash in the postmodern era²."

These analyses derive from grounded theory and accordingly they rely on an iterative approach of close reading, description, summarization, and analysis of the materials in order to develop conceptual themes, maps of social arenas, maps of situational relations, and maps of discourse. Because thematic coding is a common methodological approach within grounded theory, and because these themes structured the discursive maps, I have included the thematic

¹ A. Clarke, *Situational Analysis: Grounded Theory after the Postmodern Turn* (Thousand Oaks, Calif.: SAGE Publications, Inc, 2005).

² Adele E. Clarke, "Situational Analyses," *Symbolic Interaction* 26, no. 4 (2003): 553–76.

coding analysis alongside the situational analysis even though the situational analysis does not explicitly call for a description of the coding analysis.

Frame of Analysis

The primary frame of analysis for this research project places a specific non-human socio-technical element, namely records of gender, at the center of the inquiry. This chapter presents both the thematic (discursive) and situational analyses. It presents a summary of how the conceptual analyses were developed and how the situation was mapped for analysis. In many cases quotes from published sources were preferentially selected (instead of interview transcripts) because the quality of information contained therein was higher. The ethnographic interviews reflect spoken (rather than written) English conventions and there are inherent challenges in representing innocuous inconsistencies related to verbal forms of communication.

This data analysis relies on the iterative research practices of grounded theory and situational analysis, but the inquiry itself focuses on classification and its consequences rather than individual persons or organizations. This type of inversion of perspective, or ground-figure inversion, has contributed to a number of studies looking at infrastructure as it pertains to information systems and is used in this analysis and is helpful for examining these materials. Performing this type of ground-figure inversion places records and recordkeeping at the center of inquiry, but a number of researchers have engaged with records and recordkeeping practices, both in health care and in the sciences. Science studies have conducted observations

of data practices³ and concluded that records play a central role in knowledge production, referred to below as ‘inscriptions’:

Ethnographic work has shown that the use of "inscription devices" is a central feature of laboratory practice. Initially, researchers use primary inscription devices, such as x-ray film, to record information. Later, scientists produce second-, third-, and n'-order inscriptions (inscriptions about inscriptions) as, for example, they convert markings on x-ray films into numbers, and the numbers into tables, graphs, models, and pictures that are eventually incorporated into scientific papers. Laboratories process materials in a similar manner, extracting purified samples from pieces of tissue and subjecting them to further manipulation. The production of inscriptions and the manipulation of samples are both hierarchical operations that produce a series of products; the process of data production tends to move from raw materials, at the upstream end, to increasingly refined materials and inscriptions downstream.

The translations and conversions that occur as scientific work proceeds, generally speaking, change not only the information content and material form of the data, but also the purposes for which they can be used. But even more fundamentally, the fact that data streams are composed of chains of products suggests the advantages of conceiving of data streams as continuous phenomena, a move that shifts the level of analysis from the individual end-product to the stream as a whole. This shift leads to broader questions. One no longer asks simply whether access to a particular end-product is provided; one asks which portions of the entire data stream are disseminated, to whom, by what means, and when⁴.

Interestingly, the above researchers conceptualized records as a stream of data production with complex interactions around production and access. Other researchers have focused on questions of information infrastructure. However, infrastructure tends to be invisible, making it difficult to observe until the point of breakdown⁵. This type of approach to infrastructural

³ Stephen Hilgartner and Sherry I Brandt-Rauf, "Data Access, Ownership and Control: Toward Empirical Studies of Access Practices," *Knowledge* 15 (1994): 355–72.

⁴ Hilgartner and Brandt-Rauf, 361–62.

⁵ G. Bowker and S. Star, "Building Information Infrastructures for Social Worlds—The Role of Classifications and Standards," *Community Computing and Support Systems*, 1998, 231–248.

inversion was employed by Bowker and Star⁶ to engage in researching the practical politics of classifying and standardizing:

There are two aspects of these politics: arriving at categories and standards, and, in the process, deciding what will be visible within the system (and of course what will thus then be invisible). The negotiated nature of standards and classifications follows from indeterminacy and multiplicity that whatever appears as universal or, indeed, standard, is the result of negotiations or conflict. How do these negotiations take place? Who determines the final outcome in preparing a formal classification? Visibility issues arise as one decides where to make the cuts in the system, for example, down to what level of detail one specifies a description of work, of an illness, of a setting. Because there are always advantages and disadvantages to being visible, this becomes crucial in the workability of the schema.⁷

In some ways, the above comments about visibility echo the concerns about invisibility and erasure of trans and gender variant bodies in healthcare contexts. Looking at how gender is encoded in medical records is particularly interesting using this approach to infrastructural inversion because looking at gender allows one to see the edges between where the category system functions and where it breaks down.

4.2 SITUATIONAL ANALYSES

As noted above, the study uses mixed methods to produce a close reading of recordkeeping practices at three different research sites. The analysis brings together multiple data sources to produce a rich descriptive analysis of each site, examining the research object from a number of different discourses and intellectual traditions. Like many grounded theory-

⁶ Geoffrey C. Bowker et al., "Toward Information Infrastructure Studies: Ways of Knowing in a Networked Environment," in *International Handbook of Internet Research*, ed. Jeremy Hunsinger, Lisbeth Klastrup, and Matthew Allen (Springer Netherlands, 2010), 97–117, <http://www.springerlink.com/content/h58653g788645w56/abstract/>.

⁷ G. C. Bowker and S. L. Star, "How Things (Actor-Net) Work: Classification, Magic and the Ubiquity of Standards," *Philosophia* 25, no. 3–4 (1996): 195–220.

type analytical frames, determining the number of participants needed involves attaining saturation with the inquiry. In other words, the researcher will continue to collect data and interview participants until they are no longer observing novel features in the evidence. Because the approach is exploratory, it does not claim to be representative of the populations involved, but rather to be extensive in descriptive terms. The research is rich in description and analysis, but does not claim external generalizability. These situational analyses are composed of:

- 1. Situational maps that lay out the major human, nonhuman, discursive, and other elements in the research situation of concern and provoke analyses of relations among them.*
- 2. social worlds/arenas maps that lay out the collective actors, key nonhuman elements, and the arena(s) of commitment within which they are engaged in ongoing negotiations, or meso-level interpretations of the situation;*
- 3. positional maps that lay out the major positions taken, and not taken, in the data vis-a-vis particular discursive axes of variation and difference, concern, and controversy surrounding complicated issues in the situation⁸.*

The research relies on a grounded theory type of iterative approach involving reading, summarizing, and describing the materials. Because situational analysis and grounded theory were developed from a social science paradigm that places the individual and the social organization at the center of focus, there was some slippage in inverting the analyses to focus on the collective processes contributing to the establishment and evolution of these classification and recordkeeping practices. To address this slippage, the analyses collected a large amount of data and engaged in qualitative coding to establish the themes and discursive

⁸ Clarke.

constructions used in the situational analyses. However, one should also be aware that these two approaches stem from slightly different epistemic traditions.

Coding & Transcription

In order to develop the analytical topographies described above, I developed coding practices to identify major topical themes in the research materials and data. The themes were identified via a process based in grounded theory whereby each piece of research data (e.g. publication, interview, webpage, form, video, presentation, etc) was marked up with keywords representing major themes discussed within the document. After all of the documents had keywords added, I went back through the collection of materials and consolidated the keywords into codes and code groups. All of the source materials and data were stored and coded using bibliographic research software, Zotero⁹.

The codes were developed iteratively both as the materials were processed, assembled and as the materials were being analyzed. A total of 1820 documents contributed to the development of themes and coding. 945 of these documents were considered 'research data', such as interview recordings, transcripts, white papers, journal articles, newspaper articles and emails. The remaining 875 documents contributed to the literature review and historical background. Given that many of the research participants had published formally on the topics discussed in this research, it seemed necessary to develop themes in such a way as to give joint perspective across both the published literature and the research data.

⁹ Center for History and New Media, "Zotero Documentation," April 7, 2011, <http://www.zotero.org/support/>.

In order to illustrate the coding, I have included quotes from various formal and informal literatures to serve as examples of usage. In a few instances, I have paraphrased the comments from oral sources, both for purposes of clarity and to protect confidentiality. I recognize that assigning codes reflect complex interpretive acts requiring additional description in order to understand whether the materials are adequately represented.

It should be noted that while the thematic analysis appears to be a term-based synthesis of themes, in actuality it is a synthesis of central functional concepts rather than terms. As such, the themes weave together experiences across different embodied intersections of gender and the language used to describe them. Many of the themes draw on foundational theory drawn from background readings and the literature review. In these instances, I try to be clear as to where the concept is being drawn from and how it is intended to function. By placing research materials into groups based on conceptual themes, new parallels and relationships between the concepts came into view. It is also important to understand that the numerical data about the number of instances of a concept represents the number of research documents that include the concept.

Although this research project focuses primarily on data and record structures, the complex socially interrelated dynamics between marginalization, information management, and stigma was inescapable in the research materials. As I was coding, I began to see groups of issues that were interacting to contribute to the dynamics of social interactions in healthcare contexts. During the process of coding, I concluded that it was unrealistic to examine the details of recording gender in health records without unpacking some of the complex dynamics

of stigma and marginalization operating within these recordkeeping practices. As a result, the thematic coding process resulted in a multifaceted picture of the interactions of gender designation, social normativity, stigma and healthcare recordkeeping.

This research relies on both formal and informal sources of information utilizing both written and oral forms of communication. It should be noted that the conventions of spoken English are substantially different from written English. As such, the audio recordings are considered to be the original verbal material and the transcripts are a written translation of the content. It should be noted that there is a slight amount of subjectivity within the process of translation because it relies on the researcher's understanding of what the participant was intending to communicate verbally. When changes were made, it was solely to improve clarity and readability, as voice intonation and inflection are lost during the transcription process. In these cases, the literal meaning is privileged over idiomatic expression because this research does not engage in linguistic analysis. For this reason, any researchers interested in re-using this data to examine idiomatic expressions should engage with the original audio recordings rather than the transcripts. In the small number of recordings where participants have asked to be anonymized, the audio will not be archived and the written version has been designated as the original copy.

Because this research is being reported via written English, some of the interview transcripts citations herein have been modified to conform to written English. These modifications include, but are not limited to, adding punctuation, splitting long sentences, and removing non-essential verbally idiomatic usages of 'like', 'so', 'kind of', 'um', and 'really'. It

also includes anonymizing individuals who did not want to be identified, i.e. removing names, assigning aliases, etc. 'Like' is used heavily as an idiomatic expression in some California linguistic communities, sometimes referred to as speaking like a 'Valley Girl'. For example, if participant A said, 'Um, like, how do we, like, do this?', it would be cited herein as saying 'Um, how do we do this?' because the 'like' is being used idiomatically for verbal emphasis rather than for literal meaning. In this example, the 'um' would be left in because it communicates uncertainty in the posing of the question. In most other cases, 'um' is used as to communicate a pause while the speaker is formulating speech. For example, 'um, in 1997, um, I would have been, uh, 27 years old' would be transcribed as 'in 1997, I would have been 27 years old.' The majority of instances of 'um' and 'uh' have been removed.

Research Stance & Significance of Methods

After more than a decade of immersion in this topic, the materials in this dissertation do not seem particularly novel or original from my perspective. However, I could find no publications that specifically examine the health recordkeeping practices for trans and gender variant populations. I could find no instances of researchers bringing the disparate intellectual traditions of information theory to analyze the recordkeeping practices in relation to the intersectionality of the populations. Situational analysis was chosen as the analytic framework for this research because of the manner in which it facilitates rich qualitative analysis across heterogeneous research materials while still allowing for inquiry into intersectionality and the post-modern tensions of subjectivity.

In addition to data collection efforts, I attended a number of conferences, visited the sites in person regularly, made observations at the sites, collected information on the networks of people interacting in the community, observed and documented the online footprint of the research sites, and recruited participants at different career stages, gender transition stages, life stages, and level of experience with health care systems. Conferences were especially helpful in bringing together stakeholders from all over California, although there was a noticeable difference in which communities participated between northern and southern California locations. Conferences in S. California had more robust participation from southern California stakeholders while conferences in N. California had more robust participation from N. California stakeholders. I have presumed that this is due to the large geographic size of the state combined with the high cost of lodging for many conference venues.

4.3 DATA COLLECTION

While the primary focus of the research was on the data elements used to record gender and gender variance, there was a broad collection of materials and practices implicated in and around these records. During this project I endeavored to speak to a wide variety of participants and stakeholders, from providers to managers, from patients to parents, from isolated individuals to central figures of the trans health movement. I aspired to achieve both breadth and depth to the data collection efforts by speaking to participants from a wide variety of backgrounds and experiences.

It should be noted that in addition to the three research sites introduced below, I also collected contextual materials around the sites, speaking to individuals within the organizations

but also speaking to individuals with experience within the sphere of the site but who were not necessarily affiliated with the organizations directly. For example, I spoke with healthcare providers and administrators who worked in the same region as the site, but who were not affiliated with any of the sites directly. For example, because one of the sites was located in San Francisco, I collected additional information about data practices and services provided by other nearby clinics and hospitals to assess the regional and community contexts of the environment for community clinics in the San Francisco Bay Area. For this reason, there are very large numbers of documents and publications covered within the context of the research materials, with more than 1800 items cataloged in the Zotero database.

The analysis also calls for materials documenting the stakeholders of the community. Stakeholders for trans healthcare issues cut across almost every social group, class, culture, educational and economic background, making it less of an individual community and more of an intersection between many different and disparate communities with a shared need for recordkeeping practices that support effective health services and evidence based health care. Again, this necessitated a broader approach to collecting research materials. In some cases, certain parts of the data may, on the surface, appear thin, as most health care providers cannot spend more than a few minutes chatting with researchers before they have to get back to their patients. In order to vet and understand these short interactions, in addition to the dozens of formal interviews, I also engaged in dozens of informal interactions at conferences and in hallways, explaining the research and asking for feedback.

Because of deep tensions around health care data privacy, I did not want to be collecting primary data on patient-provider interactions or engage in observing direct patient-provider interactions. It would have introduced difficult tensions into the research and would not have provided novel observations for the results. There is an increasingly large amount of quantitative data being produced about lgbt patient-provider interactions in addition to many hundreds of smaller sample qualitative studies already available. Instead of duplicating observations that are relatively well documented in the published literature, this dissertation research relies on the existing studies and discourse to construct and evaluate patient-provider interactions, while focusing the dissertation research data collection on the representation of gender in information systems via traces of the interactions of providers with the information system, the traces of patients interactions with the information system, and the traces of system designers/managers interacting with the information system. By examining documents and ethnographic interviews from the perspective of traces of interactions, I engage with an archival perspective in the situational analysis.

Protecting Confidentiality of Research Participants

In assessing the appropriate research approach for trans and gender variant populations, multiple perspectives were considered. Given the lack of documentation and the tendency to mischaracterize the population as malicious, it seemed important for this research project to be enabled to release documentation of community groups and individuals who contributed substantively to providing informed and respectful health care access for this population. Forcing a default system of anonymizing the organizations would erase the link

between the contributions of these groups and the benefits to their respective communities. It would dissociate the organizations from the discourse around their contributions. As such, it seemed more reasonable to allow the participants to decide whether and how they would be identified.

Traditionally, many social science researchers anonymize sites and persons to allow the researcher to engage with difficult questions and interactions that coincide with the focus of the research without bringing negative repercussions to the persons and organizations. The anonymization enables the researcher to focus on complex, problematic and/or contested trends in the evidence without subjecting research participants (or populations) to negative repercussions and/or negative publicity. In contrast, many oral historians have the opposite approach, viewing their research practices as a method to formally document the lives and experiences of individuals or groups who have contributed to various historical moments. Both traditions typically engage in a process of informed consent that has mechanisms which allow participants to speak confidentially and/or anonymously.

While contributing to the documentation of these organizations was recognized as a priority for these populations, the need to anonymize and/or maintain confidentiality of individual participants remained. Instead of anonymizing participants categorically, the research project was structured so as to allow the participants to decide themselves whether they would be identified, how they would be referred to, and whether they wanted to be individually identified. Each of the sites has a relatively large organizational footprint such that we were confident that it would be possible to effectively obfuscate the identity of a single

individual within the organization. Research participants were allowed to choose whether they wanted to be identified or anonymized. Each site has a relatively large body of professionals supporting and contributing to the organization, large enough to obfuscate the origin of any individual's testimony. For those participants who chose to remain anonymous, identifiable elements of their contributions have been altered to protect their identity. All participants consented to being included in the study. Participants were given the choice of whether they wanted to be identified and whether they wanted the interview materials to be archived at the end of the research project. The project had IRB supervision of the research methods and approaches under an oral history model of research. Where possible, members of the respective organizations have proofed the text for oversights and mischaracterizations.

Data Collection Process

Data collection for this research project centered around identifying and documenting the information structures of the records being used to represent gender and gender identity. Radiating out from these information structures are data sources documenting human interactions within and under the shadow of the gender constructs governing the recordkeeping system at each site. As such, I collected ethnographic data from a wide variety of patients, providers, managers, policy authors and system designers, which yielded a wide variety of data types, including: ethnographic interviews, patient intake forms, websites, training materials, conference presentations, government reports, NGO reports, journal articles, email correspondence, data standards, screenshots, video recordings, informal

publications, internal documents, legislative bills, health care policies, standards of care, blog posts and newspaper articles.

However, this type of conceptual mapping of collective points of view presents a focal plane of analysis that functions to construct a coherent point of view both metaphorically and in terms of logical consistency. As with many forms of representational work, this conceptual mapping of themes results in tensions at the margins where the metaphor breaks down and the edge effects become substantial. This tension, ironically, is also the focus of the study, looking at the margins where systems of representations of gender break down and the edge effects become substantial. Where possible, I try to be clear both about the centrality of the concept and the limitations stemming from epistemic margins and edge effects.

Like many grounded theory-based research frameworks, data collection was continued until saturation was achieved with the inquiry. Saturation is a principle whereby the researcher should continue to collect data and interrogate research materials until the researcher is no longer collecting novel features in the data. Because the research approach is exploratory, it does not claim to be statistically representative of the populations involved, but rather to be rigorously explicative in descriptive terms.

Sample Questions:

The interviews do not represent structured data collection, but did have questions developed to serve as prompts for the ethnographic interviews (see below). These open ended questions were customized for each participant depending on their professional background and the case study they were contributing to. Each open ended interview lasted approximately

1-2 hours at a private location of the participant's choosing and focused on aspects of medical and health records, their structures and their histories.

Topic Area:	Sample Questions:
Background	Could you talk about how you came to work at [this organization] and your role in the organization?
Name Fields	Does this recordkeeping system accommodate a preferred or nickname in addition to the legal name? Do the providers use an alternate record keeping system to track preferred names or nicknames? If so, how are the names recorded? What are the mechanisms for adopting a name change?
Standards	Are you familiar with the preferred data structures suggested by the Center for Excellence in Transgender Care based out of UC San Francisco? Has anyone at your institution discussed adopting them?
Data Structures	What categories or fields are used to encode gender and gender identity in your record keeping system? Have those fields changed over the years? How were the changes implemented?
Research	Are you familiar with the NIH call for input on LGBTIQ health research issues? Has your institution contributed to that request?
Education	Does your organization work with students and/or providers to train them in LGBTIQ healthcare? How is that organized? How many?

Figure 4: Sample Participant Interview Questions

4.4 SELECTING STUDY SITES

The sites for these case studies were selected specifically because they represent examples of organizations that had invested substantially in developing a positive relationship

with their trans and gender variant populations. Each of the three sites have been investing in complex, time-consuming, multi-year projects to improve the provision of healthcare for trans and gender variant populations. To completely anonymize the organizations (and their efforts) would cripple my ability as a researcher to contribute to the historical records produced about these organizations. It would be a disservice to these organizations to anonymize their efforts, as these organizations have produced little to no public documentation around their accomplishments. These organizations are not well documented outside of their immediate community, making documentation projects such as this a major contribution to the historical record.

These case studies present the opportunity to study sites of information voids that intersect with the invisibility of transgender and gender variant populations in medical information systems. The case studies look at medical information systems in terms of their structures and design, speaking with people who work with the records or are involved with their design. The research relies on close readings of the information structures (database fields, blank patient intake forms, publicly available healthcare information datasets, categories used, etc) without reliance on individually identifiable medical records. The research also relies on historical and contextual information about the institutions and projects that created the information systems and structures.

This project explores three major research sites: the California Health Interview Survey (1), a small community clinic in San Francisco with a large trans and gender variant population (2), and a transgender health project in Sacramento run as a student clinic of the UC Davis

Medical School and allied UCD Health System (3). The first research site is an example of a large public health survey, giving the opportunity to examine how gender-related information is structured within the survey. Examining the public health survey engages with questions about how these information structures can render a population in/visible within a large statistical survey. The other two research sites are situated in clinical environments interacting with patient recordkeeping systems and healthcare providers. All three research sites were chosen because they are situated at a complex intersection where the rubber hits the road for gender markers in health care data. Each research site illustrates both successes and failures of categories for representing trans and gender variant populations from a public health perspective. The three research sites range in analytical focus from the broad social granularity of public health survey datasets to the level of the individual with the reading of blank patient intake forms.

Site 1: California Health Interview Survey (CHIS), Los Angeles

CHIS was chosen for several reasons. First, CHIS was chosen because it is a robust, population-based, public health dataset that has been widely used by researchers and is also used for allocating funding for state and federal health care initiatives¹⁰. At the time this research project was initiated, CHIS was not recording any information about gender variance or gender identity. CHIS was chosen because the survey administrators had a history of making

¹⁰ CHIS, "California Health Interview Survey | Home Page," UCLA Center for Health Policy Research, 2014, <http://healthpolicy.ucla.edu/chis/Pages/default.aspx>; Ninez A. Ponce et al., "The California Health Interview Survey 2001: Translation of a Major Survey for California's Multiethnic Population.," *Public Health Reports* 119 (August 2004): 388–95.

changes to demographic category structures to improve the quality of health data for individual populations¹¹.

Site 2: Lyon Martin Clinic, San Francisco

Lyon Martin is a relatively small community clinic in San Francisco located on Market Street, serving a few thousand patients every year. It was founded in 1979 by community-minded women working at UCSF and SF General Hospital. Their goal at the time was to provide women's health services to lesbian and bi women in a community environment. The clinic has grown and transitioned between generations of providers and community members, but its mission has remained one of a community-based clinic focused on improving healthcare access for women and trans persons¹². At the time this research project was initiated, approximately one third of the patient population stemmed from trans and gender variant populations and the clinic had extensive investment in recordkeeping processes to support these populations.

Site 3: Gender Health Center, Sacramento

The Gender Health Center in Sacramento provides access to services for trans and gender variant persons. It opened in 2010¹³ and has been providing medical and mental health services for a few hundred patients every year. The medical services are set up as a student run clinic of the UC Davis Medical School utilizing a cloud based electronic medical records system.

¹¹ Ponce et al., "The California Health Interview Survey 2001: Translation of a Major Survey for California's Multiethnic Population."

¹² Donna Cartwright et al., "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy" (San Francisco, California: Transgender Law Center, 2012), <http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.

¹³ "Gender Health Center," accessed June 2, 2016, <http://www.thegenderhealthcenter.org/>.

The clinic is affiliated with the UC Davis Health System, a very large health system that relies on EPIC. The institutional context of this clinic is particularly interesting, as it actually presents two kinds of approaches to recordkeeping practices. The clinic itself has one set of recordkeeping practices and electronic health recordkeeping system that operates independently of the hospital system records and practices¹⁴. Both have been working to improve barriers to care¹⁵, but this site is particularly interesting because it offers both the perspective of a semi-autonomous student-run clinic and the perspective of a large hospital system with a teaching hospital at its core.

¹⁴ Edward J. Callahan et al., "Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience," *Academic Medicine* 90, no. 2 (February 2015): 154–60, <https://doi.org/10.1097/ACM.0000000000000467>.

¹⁵ Sean Cahill et al., "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers," *PLoS ONE* 9, no. 9 (September 8, 2014): e107104, <https://doi.org/10.1371/journal.pone.0107104>.

CITED REFERENCES (METHODS)

- Bowker, G. C, and S. L Star. "How Things (Actor-Net) Work: Classification, Magic and the Ubiquity of Standards." *Philosophia* 25, no. 3–4 (1996): 195–220.
- Bowker, G., and S. Star. "Building Information Infrastructures for Social Worlds—The Role of Classifications and Standards." *Community Computing and Support Systems*, 1998, 231–248.
- Bowker, Geoffrey C., Karen Baker, Florence Millerand, and David Ribes. "Toward Information Infrastructure Studies: Ways of Knowing in a Networked Environment." In *International Handbook of Internet Research*, edited by Jeremy Hunsinger, Lisbeth Klastrup, and Matthew Allen, 97–117. Springer Netherlands, 2010.
<http://www.springerlink.com/content/h58653g788645w56/abstract/>.
- Cahill, Sean, Robbie Singal, Chris Grasso, Dana King, Kenneth Mayer, Kellan Baker, and Harvey Makadon. "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." *PLoS ONE* 9, no. 9 (September 8, 2014): e107104.
<https://doi.org/10.1371/journal.pone.0107104>.
- Callahan, Edward J., Nicole Sitkin, Hendry Ton, W. Suzanne Eidson-Ton, Julie Weckstein, and Darin Latimore. "Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience." *Academic Medicine* 90, no. 2 (February 2015): 154–60. <https://doi.org/10.1097/ACM.0000000000000467>.
- Cartwright, Donna, Kara Desiderio, Jamison Green, Maceo Persson, and Jason Tescher. "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy." San Francisco, California: Transgender Law Center, 2012.
<http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.
- Center for History and New Media. "Zotero Documentation," April 7, 2011.
<http://www.zotero.org/support/>.
- CHIS. "California Health Interview Survey | Home Page." UCLA Center for Health Policy Research, 2014. <http://healthpolicy.ucla.edu/chis/Pages/default.aspx>.
- Clarke, A. *Situational Analysis: Grounded Theory after the Postmodern Turn*. Thousand Oaks, Calif.: SAGE Publications, Inc, 2005.
- Clarke, Adele E. "Situational Analyses." *Symbolic Interaction* 26, no. 4 (2003): 553–76.
- "Gender Health Center." Accessed June 2, 2016. <http://www.thegenderhealthcenter.org/>.

Hilgartner, Stephen, and Sherry I Brandt-Rauf. "Data Access, Ownership and Control: Toward Empirical Studies of Access Practices." *Knowledge* 15 (1994): 355–72.

Ponce, Ninez A., Shana Alex Lavarreda, Wei Yen, E. Richard Brown, Charles DiSogra, and Delight E. Satter. "The California Health Interview Survey 2001: Translation of a Major Survey for California's Multiethnic Population." *Public Health Reports* 119 (August 2004): 388–95.

CHAPTER 5: DESCRIPTIONS OF RESEARCH DATA

5.1 Overview of the Data Collection Processes	164
Research Materials and Data Sources.....	165
5.2 Summary of Results	171
Table: Gender Identity Data Elements	174
Table: Data Elements for Pronouns.....	175
Table: Sex-Assigned at Birth Data Elements.....	176
Table: Legal Gender Data Elements	177
Table: Organ Registry Data Elements	178
Table: Hormone Status Data Elements	179
5.3 About the Research Sites	180
California Health Interview Survey, UCLA	180
Gender Health Center (GHC), Sacramento.....	184
Lyon Martin Community Clinic, San Francisco	188
About the Records.....	190
Community Support	195
Financial Backstory.....	198
Cited References (Data Descriptions).....	203

5.1 OVERVIEW OF THE DATA COLLECTION PROCESSES

The projects relied on the grounded theory based approach of Situational Analysis to bring these different perspectives into a frame of analysis with the research. Many different kinds of data were collected for this research project, from informal hallway discussions to formal interviews, from conference presentations to formal research publications. Unlike more traditional ethnographic research that focuses on the ethnographic interview as the primary source of information, this research incorporates many types of interactions and records. This approach is somewhat unusual for its approach to incorporating many different kinds of research objects into the analysis, including both interviews and records structures, informal conversations and formal publications in dialogue with each other to attempt to constitute the key aspects of the research topic into a holistic analysis of both documents and ethnographic observation.

In several cases, research participants agreed to be identified and shared anecdotes that were already included in formal publications. Most of the participants were discussing their contributions and motivations to their field of medicine. As such, many of them were more interested in being cited formally than being anonymized. Unless there were substantial differences between the two versions, this work includes quotes from their formal publications for reasons of scholarly attribution and professional courtesy. In other words, this research takes the approach that the formally published versions of the anecdote are more thoroughly error checked and have been approved by the author for dissemination.

Situational analysis differ from more ethnographic oriented analysis as it considers the analysis of records and information structures to be of equal importance with other data types such as formal interviews and formal publications. Research data was collected following a grounded theory approach that focuses on data saturation, which refers to the pragmatic approach to collect data at each site until there are no 'new' data, e.g. new observations yield no new information for the data collection effort. In some cases, I had to limit the research data collection by pragmatic concerns about centrality of relevance rather than saturation. Some aspects have not been pursued to the point of data saturation because they were seen as ancillary topics to the primary research questions. For example, the research looks at the role of specific records standards that affect the performance of the systems in regards to representing gender and gender identities, but it does not pursue the development histories of these standards. Or similarly, legal briefs about gender markers have been included, but not exhaustively, as these legal discussions included many aspects not immediately relevant to the research topic. Additionally, some health care information infrastructures and health care policies were changing relatively quickly over the study period, such that some aspects of the recordkeeping practice were changing so rapidly during the primary data collection period (2013-2017) that saturation was not feasible.

Research Materials and Data Sources

Data collection for this research project centered around identifying and documenting the information structures of the records being used to represent gender and gender identity. Radiating out from these information structures are data sources documenting human

interactions within and under the shadow of the gender constructs governing the recordkeeping system at each site. As such, I collected ethnographic data from a wide variety of patients, providers, managers, policy authors and system designers, which yielded a wide variety of data types, including: ethnographic interviews, patient intake forms, websites, training materials, conference presentations, government reports, NGO reports, journal articles, email correspondence, data standards, screenshots, video recordings, informal publications, internal documents, legislative bills, health care policies, standards of care, blog posts and newspaper articles. Appendix II includes an explanation of each of the various data types mentioned above and in the tables below. The following tables (Figure 5 and Figure 6, below) show a summary of the data sources, types and locality in the research data collected.

TYPES OF DATA SOURCE	Los Angeles (local region)	San Francisco Bay Area (local region)	Sacramento (local region)	California (entire region)	United States (entire region)	Canada (entire region)	<i>Total # of data sources</i>
audio recording	14	1	3	1	13		18
community report	5	2		13	17		33
conference poster					30		30
data standards	1			1	12		13
email correspondence	20	3	5	3			41
ethnographic interview	17	3	3	2	15		24
formal publication	7	11	3	21	260		305
governmental report	2	1		3	16		21
informal publication		1	10	4	3		23
internal document			4	3	2		8
legislative bill				8	1		9
lgbt provider index	10	2	1	2		1	22
newspaper or blog article	7	7	1	6			48
patient intake form		12	2	3	12		33
presentation	4	3		9	8	1	21
health protocol or standard of care	3	24	2	21	32	1	84
health surveys / questionnaires	4	2		38	26	1	70
video recording	4	1		9	26		37
web site	27	36	10	37	59	4	147
Geographic Totals	90	89	39	149	516	10	905

Figure 5: Summary of research data source types and their geographical breadth

Please note that the source materials and documents of the research data are heterogeneous. Most documents had only one data type, but a substantial number represented more than one data type. For example, a conference poster focusing on data standards would be associated with two data types: conference posters and data standards. Individual source materials may overlap in their data type associations. As such, the individual

columns do not 'add up' to the totals, but rather reflect the totals from the data directly. The goal of these tables is to present a legible overview to the reader of the types and quantities of data that went into the qualitative analysis. Please note that these tables do not represent a quantitative analysis of the data, but rather a summary of the sources. The sources were collected and managed using a Zotero reference management database. The data type nomenclature was developed using a grounded-theory heuristic approach after the data had been collected, the development of which is described in the analysis. The purpose of the nomenclature was to provide an overview of the types of materials collected.

TYPE OF DATA SOURCE	CHIS	Williams Institute	US Trans Survey	Gender Health Center	UCDMC	Lyon Martin	TransLine	Totals:
audio recording		3		1	1	1		18
community report		1	1			2		33
conference poster								30
data standards		1			3			13
email correspondence	5			1	1	2		41
ethnographic interview	2			1	1	1		24
formal publication	8	8			1			305
governmental report								21
informal publication	2			19	2	2	25	23
internal document				8	3			8
legislative bill								9
lgbt provider index					1	1		22
newspaper or blog article		2	2			5		48
patient intake form				1	1	8		33
presentation	3	4						21
health protocol or standard of care					1	2		84
health surveys / questionnaires	36	8	4					70
video recording								37
web site	12	4	4	9	3	24	2	147
Site Totals	68	22	7	45	16	54	27	905

Figure 6: Summary of research data source types across research sites

The goal of organizing sources by geographical application was to situate the topic in the local policy and social environment. It should be noted that this type of designation is not the same as the location of the publisher or the location of data collection. Materials were situated geographically by summarizing their ‘sphere of influence’, looking at the geography of the potential audience and whether the materials are applicable as a local, statewide, national, or international issue. For example, a report estimating the size of the transgender population in Los Angeles was characterized as being associated with the Los Angeles area. It is not

considered applicable statewide, as the materials only document individuals in Los Angeles. Similarly, a report summarizing the health insurance policies of the county of San Francisco was characterized as being associated with the SF Bay area, as it only documents the policy environment of San Francisco. Contrastingly, a report published by the California Health Interview Survey (CHIS) in Los Angeles (at UCLA) would be characterized as being associated with the entire state of California. The survey operates at the statewide level, both in terms of its data collection and in terms of its audience. Similarly, most of the academic literature was written for national and international audiences, and were characterized as having their audience and sphere of influence associated with the broadest levels of geography, e.g. the United States, Canada, Europe, etc.

5.2 SUMMARY OF RESULTS

While the research focused primarily on data elements used to record gender and gender variance, it also engaged in a broad collection of documentation around the materials and practices implicated in these records. The goal of the methodological approach was to take an ethnographic approach to the social construction of gender as it intersects with information theories of classification and medical recordkeeping. The dissertation project begins by problematizing how little data on trans and gender variant populations has traditionally been kept. It then moves on to challenge the assumptions about the benefits of keeping records on trans and gender variant populations and to analyze the risks presented by these recordkeeping practices that are born predominantly by the trans and gender variant populations. This section presents the foundational elements of the research, namely the data elements used to record gender at the research sites and related contexts. Within the patient intake forms, data element recommendations and survey methodology practices, the project found six data elements stemming from gender, namely gender identity (1), pronoun preferences (2), sex assigned at birth (3), legal gender (4), organ registry (5) and hormone status (6).

These terms grew organically from the research data collected: Gender identity relates to one's internal sense of gender and is considered by many researchers to be foundational to certain personality functions such as the sense of self¹. 'Sex assigned at birth' refers to the sex designation given to the person by a medical professional just after birth. It is part of the person's vital record that is administratively managed by the state, the exact policy and

¹ David Valentine, "'I Went to Bed with My Own Kind Once': The Erasure of Desire in the Name of Identity," *Language & Communication* 23, no. 2 (2003): 123–138.

practices of which vary from state to state². Pronoun preferences have become relatively well understood in recent years, but the critical informational aspect of pronouns is that they contain an assertion about the person's social gender, gender roles, and domains of gender performance. Legal gender refers to the gender on file for the person for legal purposes. Unfortunately, because identity documents are initiated and managed across a host of governmental agencies, the policies for updating these records vary somewhat between agencies, many trans and gender variant persons are in the position of not being able to update all of their records. This leaves them in the position of having incongruous gender records between different forms of identity documents.

The 'organ registry' is a relatively recent addition to medical practices and involves making a registry of relevant organs that may need to be tracked for ongoing health care purposes, such as ovaries, prostates, breast tissue, surgical artifacts, or congenitally atypical organs. It applies to a larger context of medical recordkeeping, as the general population may also have had surgeries, birth defects, or damage to specific organs that may require more in depth recordkeeping practices. The hormonal status refers to whether the person has the hormone profile typically associated with male bodies (testosterone predominant), female bodies (estrogen/progesterone dominant), or something in between. Since these hormones are responsible for regulating many physiological processes, the hormone status is critical for

² Stephen Chong and Meredith Wallis, "ID Please! A Guide to Changing California & Federal Identity Documents to Match Your Gender Identity" (San Francisco, California: Transgender Law Center, 2014), http://transgenderlawcenter.org/wp-content/uploads/2012/05/ID_Please_FINAL_7.25.14.pdf.

the interpretation³ of many laboratory results⁴ and for interpreting statistical models of disease processes⁵.

Below are six tables of results that show the details of the data elements across all three research sites as well as those from their scoping studies. As mentioned above, the research practices for this project rely on looking both at the sites, but also at their local contexts. As such, several sources reflecting the data practices from similar organizations in nearby areas were included to give a richer context to the research.

³ Tiffany K. Roberts et al., "Interpreting Laboratory Results in Transgender Patients on Hormone Therapy," *The American Journal of Medicine* 127, no. 2 (February 2014): 159–62, <https://doi.org/10.1016/j.amjmed.2013.10.009>.

⁴ "Primary Care Protocol for Transgender Patient Care: Baseline Laboratory Tests," accessed April 15, 2016, <http://www.transhealth.ucsf.edu/trans?page=protocol-baseline-tests>.

⁵ Tiffany K. Roberts and Corinne R. Fantz, "Barriers to Quality Health Care for the Transgender Population," *Clinical Biochemistry, Men's Health and Laboratory Medicine*, 47, no. 10 (July 1, 2014): 983–87, <https://doi.org/10.1016/j.clinbiochem.2014.02.009>.

Table: Gender Identity Data Elements

Site:	Form Name	Gender Identity Questions and/or Data Elements
<u>Lyon Martin</u> (Community Clinic)	Transgender supplemental patient intake form (2007)	1) man; 2) transgender; 3) FTM; 4) genderqueer; 5) woman; 6) transsexual; 7) MTF; 8) intersex; 9) other: __[free text field]__;
	General patient intake form (2016?)	1) Woman; 2) Man; 3) Trans (MTF); 4) Trans (FTM); 5) Genderqueer; 6) Other: ____; 7) Decline;
<u>Gender Health Center</u> (student-run community clinic)	General patient intake form (2016)	[Select all that apply] 1) Female; 2) Genderqueer 3) Trans Man/FTM 4) Trans Woman/MTF; 5) Queer; 6) Intersex; 7) Androgynous; 8) Agender; 9) Male; 10) Two-Spirit; 11) Unsure; 12) Non-binary; 13) My gender identity: __[free text field]__;
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	1) Female; 2) Male; 3) Intersex; 4) Trans FtM; 5) Trans MtF; 6) Queer; 7) Questioning/Unsure; 8) Other; 9) Decline to state; 10) comments: __[free text field]__
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	[Select all that apply] 1) Male; 2) Female; 3) Transgender Male/Transman/FTM; 4) Transgender Female/Transwoman/MTF; 5) Genderqueer; 6) Additional category (please specify): __[free text field]__; 7) Decline to answer;
	health data recommendation (2016)	1) Male; 2) Female; 3) Transgender Man/Transman; 4) Transgender Woman/Transwoman; 5) Genderqueer/ Gender Nonconforming ; 6) Additional identity (please fill in the blank): __[free text field]__; 7) Decline to state;
<u>California Health Interview Survey</u>	public health survey (2013)	[data element not collected]
	pilot test (2014)	1) Male; 2) Female; 3) Transgender; or 4) Do not identify as M, F, or T;
	public health survey (2015)	1) Male; 2) Female; 3) Transgender; or 4) Do not identify as M, F, or T;
<u>US Transgender Survey 2015</u>	survey materials	1) "Do you think of yourself as transgender?" Y/N 2) Do you identify as more than one gender or as no gender (such as genderqueer or non-binary)? Y/N
<u>Geniuss Group</u>	Two-step (2014)	1) Male; 2) Female; 3) Transgender; or 4) Do not identify as M, F, or T;
<u>Massachusetts BRFS</u>	One-step (2013)	(Check all that apply) 1) Male 2) Female 3) Trans male/Trans man 5) Trans female/Trans woman 6) Genderqueer/Gender non-conforming 7) Different identity (please state): __[free text field]__
<u>WPATH</u>	Recommendations (2013)	1) Male; 2) Female; 3) Transgender Man/Transman; 4) Transgender Woman/Transwoman; 5) Genderqueer/ Gender Nonconforming ; 6) Additional identity (please fill in the blank): __[free text field]__; 7) Decline to state;

Figure 7: Summary of Gender Identity Data Elements

Table: Data Elements for Pronouns

Site ↓ :	Form Name	Pronoun Preference
<u>Lyon Martin</u> (Community Clinic)	Supplemental intake form (2007)	<i>[data element collected on separate form]</i>
	General intake form (2016?)	1) She/her; 2) He/his 3) They/them/their; 4) Zie/hir; 5) Other: _____;
<u>Gender Health Center</u> (student-run community clinic)	General intake form (2016)	[free text field]
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	<i>[data element collected on separate form]</i>
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	[free text field]
	health data recommendation (2016)	1) She/her; 2) He/his 3) They/them; 4) Ze/Zir; 5) Xe/Xem; 6) Ze/Hir; 7) Per/Per;
<u>California Health Interview Survey</u>	public health survey (2013)	<i>[data element not collected]</i>
	pilot test (2014)	<i>[data element not collected]</i>
	public health survey (2015)	<i>[data element not collected]</i>
<u>US Transgender Survey 2015</u>	Survey materials	<i>[data element not collected]</i>
Geniuss Group	Two-step (2014)	<i>[data element not collected]</i>
Massachusetts BRFS	One-step (2013)	<i>[data element not collected]</i>
WPATH	Health data recommendation (2013)	1) Masculine pronouns 2) Feminine pronouns 3) Neutral pronouns 4) No pronouns 5) Something else (please specify): ___[text field]___

Figure 8: Summary of Data Elements for Pronouns

Table: Sex-Assigned at Birth Data Elements

Site ↓ :	Form Name	Sex Assigned at Birth
<u>Lyon Martin</u> (Community Clinic)	Supplemental intake form (2007)	[At what age did you first feel your gender identity did not match your physical body?]
	General intake form (2016?)	1) Female; 2) Male; 3) Intersex; 4) Other: _____; 5) Decline;
<u>Gender Health Center</u> (student-run community clinic)	General intake form (2016)	1) Female; 2) Male; 3) Intersex; 4) Decline;
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	1) Female; 2) Male; 3) Intersex; 4) Other; 5) Declined to state; 6) comments: __[free text field]__;
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	1) Male; 2) Female; 3) Decline to answer;
	health data recommendation (2016)	1) Male; 2) Female; 3) Decline to answer;
<u>California Health Interview Survey</u>	public health survey (2013)	<i>[data element not collected]</i>
	pilot test (2014)	<i>[data element not collected]</i>
	pilot test (2014)	1) Male; 2) Female;
	public health survey (2015)	1) Male; 2) Female;
<u>US Transgender Survey 2015</u>	Survey materials	1) "Do you currently live full time in a gender that is different from what you were assigned at birth?" Y/N 2) "How old were you when you started to live full time in a gender that is different from the one you were assigned at birth?"
Geniuss Group	Two-step (2014)	1) Male; 2) Female;
Massachusetts BRFS	One-step (2013)	<i>[data element not collected]</i>
WPATH	One-step health data recommendation (2013)	<i>[data element not collected]</i>

Figure 9: Summary of Data Elements for Sex Assigned at Birth

Table: Legal Gender Data Elements

Site ↓ :	Form Name	Legal Gender
<u>Lyon Martin</u> (Community Clinic)	Supplemental intake form (2007)	[Have you changed your gender on your IDs? y/n]
	General intake form (2016?)	1) Female; 2) Male;
<u>Gender Health Center</u> (student-run community clinic)	General intake form (2016)	[Have you changed your gender on identity documents? y/n]
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	1) Female; 2) Male;
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	<i>[data element not collected]</i>
	health data recommendation (2016)	[recommended but not instantiated with categories]
<u>California Health Interview Survey</u>	public health survey (2013)	<i>[data element not collected]</i>
	pilot test (2014)	<i>[data element not collected]</i>
	pilot test (2014)	<i>[data element not collected]</i>
	public health survey (2015)	<i>[data element not collected]</i>
<u>US Transgender Survey 2015</u>	Survey materials	<i>[data element not collected]</i>
Geniuss Group	Two-step (2014)	<i>[data element not collected]</i>
Massachusetts BRFS	One-step (2013)	<i>[data element not collected]</i>
WPATH	One-step health data recommendation (2013)	<i>[data element not collected]</i>

Figure 10: Summary of Data Elements for Legal Gender

Table: Organ Registry Data Elements

Site ↓ :	Form Name	Organ Registry
<u>Lyon Martin</u> (Community Clinic)	Supplemental intake form (2007)	Have you had any 'sex-reassignment-surgery'? [y/n]
	General intake form (2016?)	<i>[data element collected on separate form]</i>
<u>Gender Health Center</u> (student-run community clinic)	General intake form (2016)	[Surgeries] 1) none; 2) Chest Reconstruction (top surgery); 3) Silicon Injections; 4) Tonsillectomy; 5) Breast Augmentation (Implants); 6) Vaginoplasty; 7) Gallbladder removed; 8) Orchiectomy (testes removal); 9) Phalloplasty 10) Hernia repair 11) Hysterectomy (uterus removal); 12) Metoidioplasty; 13) Appendectomy; 14) Oophorectomy (ovary removal)
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	[on their wishlist]
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	<i>[data element not collected]</i>
	health data recommendation (2016)	[recommended but not instantiated with categories]
<u>California Health Interview Survey</u>	public health survey (2013)	<i>[data element not collected in public health surveys]</i>
	pilot test (2014)	<i>[data element not collected in public health surveys]</i>
	pilot test (2014)	<i>[data element not collected in public health surveys]</i>
	public health survey (2015)	<i>[data element not collected in public health surveys]</i>
<u>US Transgender Survey 2015</u>	Survey materials	<i>[data element not collected in public health surveys]</i>
Geniuss Group	Two-step (2014)	<i>[data element not collected in public health surveys]</i>
Massachusetts BRFS	One-step (2013)	<i>[data element not collected in public health surveys]</i>
WPATH	One-step health data recommendation (2013)	<i>[data element not collected in public health surveys]</i>

Figure 11: Summary of Organ Registry Data Elements

Table: Hormone Status Data Elements

Site ↓ :	Form Name	Hormone Status
<u>Lyon Martin</u> (Community Clinic)	Supplemental intake form (2007)	What hormone treatments have you been on, when, and for how long? [Name, Dose, When did you start it? How long did you take it for?]
	General intake form (2016?)	<i>[data element collected on separate form]</i>
<u>Gender Health Center</u> (student-run community clinic)	General intake form (2016)	Have you ever used transitioning hormones in the past? No/Yes If Yes, 1) what hormones, 2) How Long? 3) Did you have any complications?
<u>UCDMC</u> (regional hospital system)	Supplemental intake form (2016)	[on their wishlist]
<u>UCSF Center of Excellence in Trans Medicine</u>	health data recommendation (2014)	<i>[data element not collected]</i>
	health data recommendation (2016)	<i>[data element not collected]</i>
<u>California Health Interview Survey</u>	public health survey (2013)	<i>[data element not collected in public health surveys]</i>
	pilot test (2014)	<i>[data element not collected in public health surveys]</i>
	pilot test (2014)	<i>[data element not collected in public health surveys]</i>
	public health survey (2015)	<i>[data element not collected in public health surveys]</i>
<u>US Transgender Survey 2015</u>	Survey materials	<i>[data element not collected in public health surveys]</i>
Geniuss Group	Two-step (2014)	<i>[data element not collected in public health surveys]</i>
Massachusetts BRFSS	One-step (2013)	<i>[data element not collected in public health surveys]</i>
WPATH	One-step health data recommendation (2013)	<i>[data element not collected in public health surveys]</i>

Figure 12: Summary of Data Elements for Hormone Status

5.3 ABOUT THE RESEARCH SITES

This dissertation focuses on three different research sites in California, one in San Francisco, one in Los Angeles, and one in Sacramento. All of the sites engage with the research questions around how gender is constructed as a category, specifically looking the information structures that represent sex and gender in the site's data and recordkeeping systems. One of the sites revolves around the data collected during a large population-based quantitative health interview survey. One of the sites is a small to mid-size community health clinic. One of the sites is a student-run community health clinic nested within the layered bureaucracy of a large university teaching hospital. Each has a different scale of health care provision, different stakeholders, management structures, communities, and type of health care records being constructed. The research takes an archival approach to the records, looking at the gender structures built into the recordkeeping systems at the sites in question. The ethnographic element of this research is constituted by the pursuit of bringing these information structures into discourse with the patients, providers, managers, data authors and system designers.

California Health Interview Survey, UCLA

The California Health Interview Survey (CHIS) is a population-based, statistically representational health care survey for the state of California. CHIS first started collecting data in 2001 with approximately 55'000 respondents and has grown to approximately 80'000 in recent years⁶. CHIS surveys a random sample of Californians (via landline and cell phone) to attain data that is statistically representative of the state's residents at the county level. It is

⁶ CHIS, "CHIS: A Leading Source of Population-Based Lesbian, Gay, Bisexual and Transgender Health Data" (University of California, Los Angeles: UCLA Center for Health Policy Research, 2016), http://healthpolicy.ucla.edu/impact/Documents/CHIS_LGBT_2016.pdf.

used by state and federal agencies to allocate resources, assess health care status, health care needs and health care access for populations across the state. It is also widely used by researchers, policy analysts, media and others in their analyses of the health care issues in California⁷.

California's diversity presents some challenges for conducting telephone surveys, as the survey methodology must bridge multi-lingual and multi-cultural populations⁸. In order to sample more effectively, the survey was translated into multiple languages and field tested repeatedly. This was done in order to be confident that the survey was structured to be able to successfully capture high quality data across all of the sampled populations. CHIS was one of the first large population-based surveys to formally work with multi-lingual versions of their survey. While they could not accommodate all of the languages and demographic groups, they were able to target their efforts to capture data from 3 poorly represented communities⁹. They focused on adding methods that would capture high quality data for substantial populations that were poorly represented in other datasets. When this study was initiated in 2013, CHIS was not collecting data on gender identity or gender variance. However, because of CHIS' history of attempting to capture data on poorly represented populations, it seemed likely that

⁷ Ninez A. Ponce et al., "The Effects Of Unequal Access To Health Insurance For Same-Sex Couples In California," *Health Affairs* 29, no. 8 (August 1, 2010): 1539–48, <https://doi.org/10.1377/hlthaff.2009.0583>.

⁸ Ninez A. Ponce et al., "The California Health Interview Survey 2001: Translation of a Major Survey for California's Multiethnic Population.," *Public Health Reports* 119 (August 2004): 388–95.

⁹ Ponce et al.

CHIS would likely address gender identity in the coming years. CHIS added questions on same sex partnerships in 2011 and began working on how to ask gender identity questions in 2014¹⁰.

In the early 2010s, there were a number of calls to better include sexual orientation and gender identity questions in public health data. During this time, many researchers began to favor a ‘two step method¹¹’, which refers to asking about gender in two steps with one question about current gender identity and another asking about natal sex designation aka sex at birth aka sex on original birth certificate. Researchers at the Williams institute convened a multi-institution research group in order to evaluate how gender identity is monitored in US public health surveys and similar population based surveillance systems¹². Several researchers from the Williams Institute at UCLA worked in collaboration with CHIS to develop recommendations for gender identity questions for inclusion in CHIS using the ‘two-step’ method described above¹³.

In 2014 CHIS began testing its own questions to assess gender and gender identity. This included pilot testing of questions on gender identity for the survey¹⁴. CHIS tested four versions of gender-identity questions. At this time, many organizations were evaluating whether to

¹⁰ David Grant et al., “Putting the ‘T’ in LGBT: A Pilot Test of Questions to Identify Transgender People in the California Health Interview Survey,” *AAPOR Proceedings Issue*, 2015, <http://ww2.amstat.org/sections/SRMS/Proceedings/y2015/files/234234.pdf>.

¹¹ Madeline B. Deutsch et al., “Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-User Practices,” *Journal of the Association of Nurses in AIDS Care* 25, no. 6 (November 2014): 657–63, <https://doi.org/10.1016/j.jana.2014.04.001>.

¹² GenIUSS Group, “Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys” (Los Angeles: Williams Institute, 2014), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.

¹³ Grant et al., “Putting the ‘T’ in LGBT.”

¹⁴ Grant et al.

inquire about gender identity using one versus two questions, referred to as ‘one step’ versus ‘two step’ questions. Their pilot project tested both ‘one step’ and ‘two step’ versions of gender identity questions. The ‘one step’ questions included a definition of the term ‘transgender’ and asked whether the participant identified as transgender. The ‘two step’ questions ask first about sex recorded at birth (on the original birth certificate), and then asks the person to describe their current gender identity using the terms ‘male’, ‘female’ or ‘transgender’(see Figure 13, below).¹⁵

	Sex at birth	Gender identity
One-step ver. 1	n/a	Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?
One-step ver. 2	n/a	Sex is what a person is born. Gender is how a person feels. When a person’s sex and gender do not match, they might think of themselves as transgender. Are you transgender?
Two-step ver. 1	What sex were you assigned at birth, on your original birth certificate?	Do you currently describe yourself as male, female, or transgender?
Two-step ver. 2	What sex were you assigned at birth, on your original birth certificate?	Do you currently describe yourself as male, female, transgender, are you not sure yet, or do you not know what this question means?

Figure 13: Questions tested in CHIS pilot study (2014)¹⁶

Fall 2017 saw the first release of CHIS data (2015-16) that included gender identity questions. For the first time ever, Californians had a representative sample of public health issues that included a metric for gender and gender identity. Pilot studies (from the east coast) have indicated that disclosure is still a major issue, even with the improvements of the two-step

¹⁵ Grant et al.

¹⁶ Grant et al.

method. Participants in a similar pilot study on the east coast indicated that they had concerns about disclosing information about the sex listed on their original birth certificate:

Several transgender respondents raised concerns about being asked their sex assigned at birth. One wrote, "Though I understand the importance of knowing birth sex when dealing with trans medical issues, it's still a very sensitive question that most [transgender people] would probably not want to answer." While 87% of transgender men agreed that they would answer the birth sex question, only 65% of transgender women agreed. Some 7% of transgender men and 16% of transgender women indicated that they would not answer the sex assigned at birth question.¹⁷

Not surprisingly, the first release of CHIS data indicated that trans women were likely refusing to answer about their birth sex at a higher rate than other respondents, especially for Chicano/a populations, Latino/a populations and populations constituted by people of color¹⁸.

Gender Health Center (GHC), Sacramento

The Gender Health Center in Sacramento provides access to various health services for trans and gender variant persons. It was conceived of and initial work conducted to set up the organization in 2008-09 by LGBT community member, healthcare advocate and mental health professional Danelle Saldana¹⁹. When Danelle passed away unexpectedly in 2009, other community members stepped in and continued the project in her honor. The center opened in 2010 and has dual sets of programs to support both medical care and mental health services.

¹⁷ Robbie Singal and Harvey Makadon, "Asking Patients Questions about Sexual Orientation and Gender Identity in Clinical Settings: A Study in Four Health Centers," White Paper (Boston, MA: Fenway Institute, December 2013), http://thefenwayinstitute.org/wp-content/uploads/COM228_SOGI_CHARN_WhitePaper.pdf.

¹⁸ Jody L. Herman, Bianca DM Wilson, and Tara Becker, "Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey," Health Policy Brief (University of California, Los Angeles: UCLA Center for Health Policy Research - UCLA Williams Institute, October 2017).

¹⁹ "Gender Health Center," accessed June 2, 2016, <http://www.thegenderhealthcenter.org/>.

As of March 2016, the GHC had 780 patients in their roster and providers were seeing 10-15 new patients each month.

The center has been serving to bring together services from a variety of organizations into a community hub. One important service available via the Gender Health Center has been a free/no cost hormone clinic run by volunteer UC Davis medical students:

We're under the UC Davis student-run clinics. So they are a free clinic program that UC Davis runs. Essentially we leverage that relationship with UC Davis and the Gender Health Center - so we have the center and we have the community and they have the resources like the labs and the med[ical] students. So we collaborate in that way.²⁰

However, the student-run clinics at the UC Davis Medical School are somewhat unique compared to community clinics, teaching hospitals, or traditional HMO care. The clinic itself is an extension of the learning environment:

The students are first and second year medical students, so the answer to your question is 'no, they are not well educated when they first come in'. Sometimes they are in the second week of their medical school experience, so they are learning the very basics. They are learning how to engage with the patient, how to gather information, some bedside manner, all of that which comes with interacting with a patient for the first time. They are learning how to speak to somebody who identifies as transgender or queer or gender non-conforming and how to have that competency. What they learn the least is all of the medical stuff. All of that stuff will come as they go through school, and so we don't worry about their charting or diagnosing. We've been more engaged in how they talk to our community²¹.

Both Lyon Martin and the Gender Health Center invested in long-term institutional structures around teaching, education, and building capacity for competencies in trans health care, but

²⁰ Alejandro Contreras, 20160627_Contreras.MP3, interview by L. Wynholds, June 27, 2016.

²¹ Contreras.

the GHC was the only site that worked directly with medical students to address shortfalls in the curriculum:

Sometimes we get 3rd and 4th year students that are well into their medical school practice. And sometimes we actually get some residents as well. So it's really nice when we have a [garbled] scoop of providers coming from very early in their education until almost finishing up their residency. So we can see that GHC has a big impact systemically around educating a good portion of our young new providers in trans and queer health.

In some ways the learning environment de-centralizes the relationship of the provider as 'all-knowing' with the understanding that the provider is still developing their skills:

It's an interesting experience for our patients, letting them know that it is a learning environment. We have to inform our patients that mistakes may happen. And often these are new allies who may need practice. We hope that our patients can have a little lee-way with any kind of mistakes that our medical students make. Our doctors [supervising faculty] who are doing this work are super well trained. We haven't had a lot of bad experiences here, other than long wait times.

The medical services are under the umbrella of the UC Davis Medical School and utilize a cloud based electronic medical records system, Practice Fusion²². However, the Gender Health Center has been working with a number of institutions to offer internships and related educational opportunities:

LAW: [You're the second person I've talked to who has come to work at the GHC via a student internship.]

AC: That is basically our model. We partner with 6 or 7 different universities. Our main program here is our mental health program. So we get MFT interns, MSW interns and BSW interns from different programs and schools

LAW: [Sac State? UC Davis?]

²² "About the Largest Cloud-Based EHR," Practice Fusion, accessed June 27, 2016, <http://www.practicefusion.com/about-practice-fusion/>.

AC: Yeah, Sac State, UC Davis, Alliant University, USF [University of San Francisco], Walden University...there's quite a few I can't think of off the top of my head. But they all provide us with students at either the Bachelors or Masters level trying to get into therapy or some sort of social work position here. At any one time we have about 40 interns here at the center doing different things like direct therapy, advocacy work, case management work, helping with the clinic or other things. It's a really great model to have.²³

The GHC's clinic operates independently, but is organizationally affiliated with UC Davis's hospitals, a very large health system that utilizes a different electronic health record system, EPIC²⁴. Both sides of the organization have worked with this research project, providing intake forms, research papers, and internal documents about their recordkeeping practices.

Patient Intake Form

Current Name: _____ **Date of Birth:** ____/____/____ **Pronouns:** _____

Legal Name (name on your IDs): _____ **Place of Birth (city, state, country):** _____

If you are under 18 years old, what is/are the name(s) of your legal guardian(s): _____

Home Address: _____ **City/State:** _____ **Zip:** _____

Figure 14: Sample text from Gender Health Center's Intake Forms

²³ Contreras, 20160627_Contreras.MP3.

²⁴ Edward J. Callahan et al., "Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center's Experience," *Academic Medicine* 90, no. 2 (February 2015): 154–60, <https://doi.org/10.1097/ACM.0000000000000467>.

Transgender Health History

At what age did you first first feel your gender identity did not match your physical body? _____

Have you felt depressed or suicidal because your gender identity does not match your body?
 No _____ Yes _____

Are the following people supportive of your transition/gender expression?

Employer/School	No _____	Yes _____	Family of Origin	No _____	Yes _____
Friends	No _____	Yes _____	Significant other	No _____	Yes _____

Are you "out" at work/school? No _____ Yes _____

What are your fears if any about coming out or identifying as transgender?

Have you changed you gender on your identity documents? No _____ Yes _____

Have you ever discussed your gender identity with a healthcare provider? No _____ Yes _____

If Yes, what happened? _____

If No, why not? _____

Have you ever used transitioning hormones in the past? No _____ Yes _____

If Yes, 1) what hormones, 2) How Long? 3) Did you have any complications?
 1) _____

Figure 15: Gender Health Center Intake Form, Transgender Health History, Supplemental Form

Lyon Martin Community Clinic, San Francisco

Lyon Martin is a relatively small community clinic in San Francisco located on Market Street. It was founded in 1979 by community-minded women working at UCSF and SF General Hospital. Their goal at the time was to provide women’s health services to lesbian and bi women in a community environment. The clinic has grown and transitioned between generations of providers and community members, but its mission has remained one of a community-based clinic focused on improving healthcare access for women and trans persons.

The clinic has been located on the second floor of a well-worn office building on Market (near Valencia) since the early 1980's²⁵. The location on Market Street is near the SF Gay and Lesbian Center and it is readily accessible from the Mission district, the Castro district, SOMA and the Tenderloin. Like many community clinics, the organization has operated on a limited budget run by dedicated staff. Their focus has been on making healthcare accessible to historically underserved populations. In addition to routine healthcare, the clinic also provides women's health services, mental health services, healthcare advocacy, assistance to patients signing up for insurance via California's healthcare marketplace, hormone monitoring and prescriptions, and referrals for more specific healthcare services in the greater San Francisco Bay Area. In addition, the clinic currently offers clinical rotations for providers to gain competency in queer and trans health. During the late 2000's, Lyon Martin also hosted Americorp service volunteers working within a program of bay area community healthcorps²⁶. Between the volunteer programs, internships, clinical rotations, and direct employment, Lyon Martin has trained hundreds of providers in LBTIQ health over the last two decades, making their contribution to medical education as substantial as their contribution to patient care for LGBTIQ communities.

The clinic employs about a dozen providers, a handful of office staff, (plus a variable crew of volunteers and interns) providing primary and community specific healthcare services to a few thousand patients. Approximately a third of their patient population identify as transgender and/or gender variant. In 2010 their operating budget was \$2.2 million per year.

²⁵ Lyon Martin moved to a new location late 2017/early 2018, approximately 5 blocks away.

²⁶ "Americorps/Community HealthCorps," SFCCC, accessed March 9, 2017, <https://www.sfccc.org/amicorpsvista/>.

While \$2.2 million may seem like a large budget, but with approximately 3000 patients, it translates to less than \$1000 per patient per year. On an average day, the office is immersed with a colorful variety of patients, office staff and providers. Similarly to many community clinics, clinic staff contribute to a variety of responsibilities, from insurance billing to implementing electronic medical records software.

About the Records

This case study examines the medical record structures used and examines the record structures in terms of affordances for and representation of gender and gender variance. Figures 16-18 show patient forms that collect gender based information. Lyon Martin was chosen as a site, in part, because the level of detail on the forms was indicative of a system of recordkeeping practices with well-developed approaches to collecting gender related health care information. The information collected includes separate information fields for gender identity, sex at birth, preferred pronouns and legal gender (for insurance billing).

Lyon-Martin Health Services Information Update Form Date: 2/28/2014

Legal Name: _____

Preferred Name: _____

Address: _____

Phone Number: _____

May we leave you a message at this phone number? Yes No

What is your gender identity? Female GenderQueer
 Male Decline
 Trans(MTF) Other: _____
 Trans (FTM)

What is your pronoun preference? She/Her Zie/Hir
 He/His Other: _____
 They/Them/ Their

What is your housing status? (Check all that apply)
 Alone On the street
 With roommates In a shelter
 With partner/spouse In a transitional program
 With family Is this a temporary situation?

What type of insurance/coverage do you have? (Check all that apply)
 Medi-Cal FPACT
 Medi-Care CDP
 Healthy San Francisco Private/Commercial: _____
 None Other: _____

How many people are in your household, including yourself?
**Household members include those persons living in the same home who are related by birth, marriage, registered domestic partnership, or adoption.

What is your household's monthly income?
Due to Federal Regulations, we must ask all patients their household size and income, regardless of health insurance status. If you are interested in applying for our Sliding Scale Program, please request an application from the Front Desk as providing this information here does not constitute an application.

We treat everyone regardless of ability to pay.

Figure 16: Lyon Martin patient update form, February 2014

Figure 16 shows a photo of the standard paper patient information update form given to all Lyon Martin patients semi-annually circa 2014. The 8.5" by 5.5" update form included the following information fields:

Legal Name: [free text, 1 line long]

Preferred Name: [free text, 1 line long]

Gender Identity: [7 check-box options including 'other' with optional free text]

Pronoun Preference: [5 check-box options including 'other' with optional free text]

Figure 17 contains an excerpt of suggested best practices for data collection from faculty at the UCSF Center of Excellence in Transgender Health. The center's staff recommended the following information fields:

Gender Identity: [7 check-box options including 'other' with optional free text and 'check all that apply']

Sex Assigned at Birth: [3 check box options]

Figure 18 and Figure 19 contain excerpts from the 2016 version of the Lyon Martin 'patient update form'. The 'update form' included the following information fields:

Gender Identity: [7 check-box options including 'other' with optional free text]

Sex Assigned at Birth: [5 check-box options including 'other' with optional free text]

Sexual Orientation: [8 check-box options including 'other' with optional free text]

Pronoun Preference: [5 check-box options including 'other' with optional free text]

Preferred Name: [free text field, single line]

Legal Name: [free text field, single line]

Legal Gender: [free text field, single line]

Figure 20 contains an excerpt of the trans-specific intake form for Lyon Martin patients, dated 2007 and posted their website in 2016. The form includes the following information fields for gender identity:

Gender Identity: [9 check-box options including 'other' with optional free text]

Identifying a transgender patient is easiest if intake forms have a place for transgender patients to safely and confidentially identify themselves to the physician and office staff, and the staff is trained to handle the information respectfully.

The ideal patient intake form has both a "gender question" and an "assigned-sex-at-birth question" such as those shown below, and an optional "preferred pronoun" question. Asking both a gender and a sex question instead of just one (either sex or gender), and offering many choices, allows for specific disclosure of a person's history and also validates their current gender identity. Many trans people do not currently identify as transgender or transsexual for a variety of reasons. Some believe it is part of their past and not a present identification, others may not identify with "trans" terms due to cultural beliefs, social networks, or linguistic norms in various geographic areas.

1. What is your current gender identity? (Check and/or circle ALL that apply)

? Male

? Female

? Transgender Male/Transman/FTM

? Transgender Female/Transwoman/MTF

? Genderqueer

? Additional category (please specify): _____

? Decline to answer

2. What sex were you assigned at birth? (Check one)

? Male

? Female

? Decline to answer

3. What pronouns do you prefer? _____

Figure 17: UCSF Center of Excellence in Transgender Health's recommendation for data collection²⁷, 2011

²⁷ Madeline B. Deutsch and David Buchholz, "Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data," *Journal of General Internal Medicine* 30, no. 6 (June 2015): 843–47, <https://doi.org/10.1007/s11606-014-3148-7>.

My gender identity is: <input type="checkbox"/> Woman <input type="checkbox"/> Man <input type="checkbox"/> Trans (MTF) <input type="checkbox"/> Trans (FTM) <input type="checkbox"/> Genderqueer <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My sex assigned at birth is: <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Intersex <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My marital status is: <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Registered Domestic Partner <input type="checkbox"/> Widowed <input type="checkbox"/> Unmarried Partner <input type="checkbox"/> Legally Separated <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline
My sexual orientation is: <input type="checkbox"/> Lesbian <input type="checkbox"/> Gay <input type="checkbox"/> Queer <input type="checkbox"/> Bisexual	<input type="checkbox"/> Heterosexual <input type="checkbox"/> Celibate <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline	My pronoun preference is: <input type="checkbox"/> She/her <input type="checkbox"/> He/his <input type="checkbox"/> They/Them/Their <input type="checkbox"/> Zie/Hir <input type="checkbox"/> Other: _____
I live (please check all that apply): <input type="checkbox"/> In a house or apartment or SRO or hotel <input type="checkbox"/> In an RV or vehicle <input type="checkbox"/> On the street	<input type="checkbox"/> In a shelter <input type="checkbox"/> In a transitional or treatment program <input type="checkbox"/> My situation is temporary and/or unstable	I am Hispanic/Latin@: Yes No My race is: <input type="checkbox"/> Native American and/or Alaskan Native <input type="checkbox"/> Hispanic or Latin@ <input type="checkbox"/> Black/African American <input type="checkbox"/> Caucasian or White <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Asian <input type="checkbox"/> Other Pacific Islander <input type="checkbox"/> More than one race <input type="checkbox"/> Other: _____ <input type="checkbox"/> Decline
I am a veteran: Yes No	I am a seasonal agricultural worker: Yes No	

Figure 18: Lyon Martin patient demographic intake form (Feb 2016), excerpt of page 2

For billing purposes, if you have insurance, what gender do they have on record for you? Female Male

Legal Name as it appears on your insurance card: _____

We must collect ALL patients' income information in order to stay in compliance with Federal Regulation, as Lyon-Martin is a Federally Funded Community Health Clinic. (Even if you have insurance).

Figure 19: Lyon Martin patient demographic intake form (Feb 2016) excerpt of page 1

Date: _____ new trans patients

Name _____ Birthdate _____ Chart No. _____

Transgender History/Intake: This form should be done in addition to the regular intake form. It tells us more about you as a transgender person and how we can help you. Lyon-Martin uses a *Harm Reduction* method to help transpeople. We want to keep you safe and healthy. We know that not everyone needs to or can follow the WPATH (formerly HBGDA) Standards of Care. We will **NEVER** penalize you or deny you care based on what you tell us on this form. If you feel uncomfortable answering a question, leave it blank.

<p>How do you identify (check all that apply):</p> <p> <input type="checkbox"/> man <input type="checkbox"/> transgender <input type="checkbox"/> FTM <input type="checkbox"/> genderqueer <input type="checkbox"/> woman <input type="checkbox"/> transsexual <input type="checkbox"/> MTF <input type="checkbox"/> intersex <input type="checkbox"/> other: _____ </p> <p>At what age did you first feel your gender identity did not match your physical body? ____</p> <p>Have you ever felt depressed or suicidal because your gender identity does not match your body? <input type="checkbox"/> yes <input type="checkbox"/> no</p> <p>Who is in your support system? Who do you talk to about your problems (e.g. feeling sad or angry)?</p> <p> <input type="checkbox"/> Significant other <input type="checkbox"/> Family of origin <input type="checkbox"/> Support group <input type="checkbox"/> Friends <input type="checkbox"/> Therapist <input type="checkbox"/> Other: _____ </p> <p>Are the following people supportive of your transition/gender expression?</p> <p> Employer/School <input type="checkbox"/> no <input type="checkbox"/> yes Family of origin <input type="checkbox"/> no <input type="checkbox"/> yes Significant other <input type="checkbox"/> no <input type="checkbox"/> yes Friends <input type="checkbox"/> no <input type="checkbox"/> yes </p> <p>Are you out at work/school?</p> <p> <input type="checkbox"/> No one knows <input type="checkbox"/> Some people know <input type="checkbox"/> Everyone knows If not, would you be safe if you chose to come out? <input type="checkbox"/> no <input type="checkbox"/> yes </p>	<p style="text-align: center;"><i>for office use only</i></p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
--	---

Figure 20: Excerpt from Lyon Martin Trans Intake Form (acquired Feb 2016, form dated 2007)

Community Support

The clinic is highly regarded in both the LGBT and medical communities for making healthcare caring, particularly around LBT health topics that are poorly covered in the literature and formal medical education ²⁸. Lyon Martin’s patient-centric approach often resulted in recordkeeping and other office organizational practices becoming secondary to providing care and facilitating their health care services. This has both served to strengthen the community

²⁸ Jeff Krehely, “How to Close the LGBT Health Disparities Gap” (Center for American Progress, December 21, 2009), <http://www.americanprogress.org/issues/lgbt/report/2009/12/21/7048/how-to-close-the-lgbt-health-disparities-gap/>; Harvey J. Makadon, “Ending LGBT Invisibility in Health Care: The First Step in Ensuring Equitable Care,” *Cleveland Clinic Journal of Medicine* 78, no. 4 (2011): 220–224.

ties and community support of the organization, but also led to the collapse of the fiscal management of the clinic in 2011. More importantly, the whole-hearted dedication to patient care also gave the clinic the widespread community support needed to survive the financial crises in 2011.

Lyon Martin has invested in leveraging its strengths and expertise for the larger healthcare communities. In addition to providing direct healthcare services, the clinic serves as a major hub of hands-on training around healthcare needs of trans and gender variant individuals. With thousands of patients, providers at Lyon Martin have very large patient loads (patients per provider). On the one hand, a large patient load is difficult for most providers to sustain and the clinic has seen a fair amount of turn-over in providers over the last decade. On the other hand, the turn-over creates circulation of individuals into a community network of providers who have trained and worked with a large population of trans and gender variant patients. Many of these providers move on, but they take their training and community values into their subsequent positions, resulting in a constant contribution to the community of providers. Given the near total lack of formal education in LGBT medicine in US medical schools²⁹, clinical rotations and volunteer positions at Lyon Martin provide a much needed opportunity for medical providers to gain experience with LGBT medicine and transgender specific healthcare needs. The clinic has participated in piloting expertise networks and telemedicine projects for transgender healthcare.

²⁹ Juno Obedin-Maliver et al., "Lesbian, Gay, Bisexual, and Transgender-Related Content in Undergraduate Medical Education," *JAMA: The Journal of the American Medical Association* 306, no. 9 (2011): 971–977, <https://doi.org/10.1001/jama.2011.1255>.

Over the last decade, hundreds of healthcare providers, AmeriCorp interns, community volunteers and medical students have gained hands-on experience working in a patient centric and harm-reduction based clinical environment. Many of these training opportunities were organized by San Francisco's Community Clinic Consortium (SFCCC) via AmeriCorp and AmeriCorp VISTA programs. Over the years a rich network of experienced providers and alums has developed around the clinic, the members of which have been increasing the capacity of health systems to provide for trans and gender variant individuals³⁰.

Patient reviews and patient comments (from Yelp and other similar sources) give the picture of a busy community clinic that works hard to serve their community against the backdrop of an increasingly complex and opaque healthcare and insurance system. However, patient comments also demonstrate how difficult it can be to negotiate patient care for non-routine or chronic conditions. It is an environment where determining what kind of help will be most effective in a primary care environment is enormously complex, fraught with infrastructural contingencies, and is often undervalued as a skill in the medical profession. The clinic has functioned as a hub of health related activities for a number of women's and trans communities in SF and the greater Bay Area³¹. The walls have flyers advertising community services and health projects such as binder exchanges and body positive yoga. The interior was repainted and lightly remodeled in 2011.

³⁰ Donna Cartwright et al., "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy" (San Francisco, California: Transgender Law Center, 2012), <http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.

³¹ artkade, "Lyon-Martin Health Services- A Project Snapshot," *Rebuilding Together SF* (blog), December 4, 2012, <http://www.rebuildingtogethersf.org/lyon-martin-health-services-a-project-snapshot/>; "Trans Health & Identity Document Pop-Up Clinic | Lyon-Martin Health Services," accessed March 9, 2017, <http://lyon-martin.org/freeclinic/>; "Transgender Telehealth | Lyon-Martin Health Services," accessed April 23, 2014, <https://lyon-martin.org/transgender-telehealth/>.

Financial Backstory

In January 2011 the clinic board (non-profit board) announced that the clinic would be forced to close its doors by the end of the month. The non-profit governing board had realized that that the clinic lacked the capital to operate beyond the end of the month. The executive director had left the organization and the board lacked effective approaches to fiscal oversight leading to administrative stagnation of the organization's financial processes. Patient care was not being affected, but the organization lacked basic funds for payroll and operations. The situation was so dire that the board saw no other option than to close the clinic. The financial situation was bleak: the clinic faced a debt burden of over \$1 million, largely related to multi-year backlogs of patient billing processes and funding agency reimbursement processes. The loosely orchestrated mayhem common to community organizations overwhelmed the administration when the board discovered the full extent of the debt and billing problems.

After news of closing the clinic was leaked to the community, volunteers from across the San Francisco Bay Area stepped up to rescue the clinic from its own mismanagement. The revelation sent shockwaves through the communities of the San Francisco Bay Area³². No one wanted to see the expertise in patient care and training disbanded³³. However, the situation was critical: the clinic was under water with no operating capital and approximately \$1 million in debt. Many of the members of the non-profit board were burnt out from administrative problems with backlogs in patient billing and reimbursement processes. Relatively quickly,

³² Rebecca Bowe, "Saving Lyon-Martin," *SF Bay Guardian*, February 1, 2011, Online edition, <http://www.sfbg.com/2011/02/01/saving-lyon-martin>.

³³ Marj Plumb, "An Open Letter to the Lyon-Martin Health Services Community | Save Lyon-Martin Health Services," *Save Lyon-Martin!* (blog), July 26, 2011, <http://www.savelyonmartin.org/?p=138>.

news of the clinic's problems went out on social media, news, and community email lists. Over the course of the crisis, the clinic had developed a core group of dedicated health care activists tending the clinic's infrastructure, both in terms of providers and healthcare advocates, but also of volunteers and community members.

Once the word starting getting out that Lyon Martin was facing closure, community members came forward to help salvage the beleaguered organization³⁴. Hundreds of people came forward to help, donating time, donating money, organizing fundraisers, donating consultations of fiscal assessments/plans, providing budget oversight, and providing professional management consultations. In 3 months, \$350'000 had been raised and donated by community members³⁵. The previous non-profit board members resigned and community members stepped in to assess the problem. This rapid influx of donations and support convinced the owners of the debt to give Lyon Martin more time to reorganize their administrative processes.

Over the course of 2011, approximately \$600'000 had been donated and clinic staffing re-organized to maintain services for current patients. By 2012 new patients were again being accepted. It is indicative of the organizational cultural that Lyon Martin providers were more concerned with the loss of provision of care for their patients during a time when their own payroll was precariously underfunded³⁶. The long standing commitment of Lyon Martin and

³⁴ Victoria Colliver, "Lyon-Martin Health Services in S.F. Faces Closure," *SFGate*, January 26, 2011, Online edition, <http://www.sfgate.com/health/article/Lyon-Martin-Health-Services-in-S-F-faces-closure-2531098.php#src=fb>.

³⁵ Plumb, "An Open Letter to the Lyon-Martin Health Services Community | Save Lyon-Martin Health Services."

³⁶ Seth Hemmelgarn, "Lyon-Martin on Life Support," *Bay Area Reporter*, January 27, 2011, Online edition, <http://ebar.com/news/article.php?sec=news&article=5414>.

their health care providers to culturally competent provision of care and training had developed a broad and deep base of support in the San Francisco Bay Area and beyond. The outpouring of support was visceral, widespread, and generous. The support touched many communities and generations of both patients and providers. The situation was unprecedented in the attention and care that was given to the organization by the community.

Community members continued to work on creating sustainable funding models for the organization. During the period of financial reorganization, hiring was frozen and several positions were held empty. Staff worked to cover empty positions and maintain basic services for patients. Throughout the fiscal collapse and transition, various contributors came forward from the public and private sectors to provide consulting, oversight, visioning, and problem-solving for the organization's finances. The goal was to deal with the organization's debt and create a financially stable organization. In 2011, in addition to the fiscal problems, Lyon Martin was in the process of transitioning from paper to electronic medical records. At the time, clinic staff members were occupied with transitions around the ACA and its policy changes. In 2013-14 the NIH and related agencies were convening information gathering practices (RFIs) for population data gathering of sexual orientation and gender identity (SOGI).

About News Opinion Arts Obituaries BARTab Search Classifieds

Latest Blogs | UC Berkeley student accused of attack, anti-gay remarks - Feb 27, 2014

Lyon-Martin on life support NEWS

by Seth Hemmelgarn Published 01/27/2011
s.hemmelgarn@ebar.com



Lyon-Martin Health Services, the San Francisco-based clinic that provides health care to women and transgender people regardless of their ability to pay, needs to raise \$250,000 within the next month or it will close, according to board treasurer Peter Balon.

The news caught city health officials and community members by surprise. The clinic is named after pioneering lesbians Phyllis Lyon and her wife, the late Del Martin.

The board had planned to close the clinic today (Thursday, January 27), but after word of the board's decision leaked early in the week, many community members, including staff, expressed concern about what would happen to patients. The clinic has expected to see 2,500 patients this year. The budget for 2010 was about \$2.2 million.

Balon, who said Lyon-Martin also has up to \$1 million in debt, said that it appears the clinic will close "unless we can fundraise or get assistance from the city, everything else remaining equal."

Asked if the board had thought it could just close the clinic today and be done with it, Balon said, "Yeah, we did, actually. We just didn't know about all the rules."

As of Wednesday morning, key staff were trying to craft a plan to ensure patients could continue to somehow receive care.

Dr. Nick Gorton, a volunteer doctor at Lyon-Martin Health Services, stands at the entrance to the clinic Tuesday morning. Photo: Rick Gerharter

ARTICLE TOOLS

-  Print this Page
-  Send to a Friend
-  Share on Facebook
-  Share on Twitter
-  Share on MySafari

Figure 21: Bay Area Reporter news story on Lyon Martin, January 2011

Over the course of 2014-5, Lyon Martin evaluated the decision to reorganize the administration of the clinic. After a number of consultations, announcements and public community meetings, Lyon Martin board members disbanded their non-profit organization and merged into the HealthRight360 non-profit clinic group³⁷. It allowed them to step away from the remaining unpaid debt via the disbanding of the formal organization. It allowed them to integrate the

³⁷ Dawn Harbatkin and Marj Plumb to L. Wynholds, "Special Announcement about Lyon-Martin!," May 15, 2014.

clinic's administration within an organization that was already managing several community clinics in the city of San Francisco. This consolidation provided a better operational scale for Lyon Martin under a parent organization. Lyon Martin is a relatively small operation. It benefitted from moving the clinic to a parent organization which oversees multiple clinics. The assistance in fiscal and administrative duties offered an improved efficiency of scale via centralization with HealthRight360.

CITED REFERENCES (DATA DESCRIPTIONS)

- “About the Largest Cloud-Based EHR.” Practice Fusion. Accessed June 27, 2016.
<http://www.practicefusion.com/about-practice-fusion/>.
- “Americorps/Community HealthCorps.” SFCCC. Accessed March 9, 2017.
<https://www.sfccc.org/amicorpsvista/>.
- artkade. “Lyon-Martin Health Services- A Project Snapshot.” *Rebuilding Together SF* (blog), December 4, 2012. <http://www.rebuildingtogethersf.org/lyon-martin-health-services-a-project-snapshot/>.
- Bowe, Rebecca. “Saving Lyon-Martin.” *SF Bay Guardian*. February 1, 2011, Online edition.
<http://www.sfbg.com/2011/02/01/saving-lyon-martin>.
- Callahan, Edward J., Nicole Sitkin, Hendry Ton, W. Suzanne Eidson-Ton, Julie Weckstein, and Darin Latimore. “Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record: One Academic Health Center’s Experience.” *Academic Medicine* 90, no. 2 (February 2015): 154–60. <https://doi.org/10.1097/ACM.0000000000000467>.
- Cartwright, Donna, Kara Desiderio, Jamison Green, Maceo Persson, and Jason Tescher. “Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy.” San Francisco, California: Transgender Law Center, 2012.
<http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.
- CHIS. “CHIS: A Leading Source of Population-Based Lesbian, Gay, Bisexual and Transgender Health Data.” University of California, Los Angeles: UCLA Center for Health Policy Research, 2016. http://healthpolicy.ucla.edu/impact/Documents/CHIS_LGBT_2016.pdf.
- Chong, Stephen, and Meredith Wallis. “ID Please! A Guide to Changing California & Federal Identity Documents to Match Your Gender Identity.” San Francisco, California: Transgender Law Center, 2014. http://transgenderlawcenter.org/wp-content/uploads/2012/05/ID_Please_FINAL_7.25.14.pdf.
- Colliver, Victoria. “Lyon-Martin Health Services in S.F. Faces Closure.” *SFGate*. January 26, 2011, Online edition. <http://www.sfgate.com/health/article/Lyon-Martin-Health-Services-in-S-F-faces-closure-2531098.php#src=fb>.
- Contreras, Alejandro. 20160627_Contreras.MP3. Interview by L. Wynholds, June 27, 2016.
- Deutsch, Madeline B., and David Buchholz. “Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data.” *Journal of General Internal Medicine* 30, no. 6 (June 2015): 843–47.
<https://doi.org/10.1007/s11606-014-3148-7>.

Deutsch, Madeline B., JoAnne Keatley, Jae Sevelius, and Starley B. Shade. "Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-User Practices." *Journal of the Association of Nurses in AIDS Care* 25, no. 6 (November 2014): 657–63. <https://doi.org/10.1016/j.jana.2014.04.001>.

"Gender Health Center." Accessed June 2, 2016. <http://www.thegenderhealthcenter.org/>.

GenIUSS Group. "Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys." Los Angeles: Williams Institute, 2014. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.

Grant, David, Matt Jans, Royce Park, Ninez Ponce, Jane Kil, Gary Gates, Bianca DM Wilson, and Jody L. Herman. "Putting the 'T' in LGBT: A Pilot Test of Questions to Identify Transgender People in the California Health Interview Survey." *AAPOR Proceedings Issue*, 2015. <http://ww2.amstat.org/sections/SRMS/Proceedings/y2015/files/234234.pdf>.

Harbatkin, Dawn, and Marj Plumb. Letter to L. Wynholds. "Special Announcement about Lyon-Martin!," May 15, 2014.

Hemmelgarn, Seth. "Lyon-Martin on Life Support." *Bay Area Reporter*. January 27, 2011, Online edition. <http://ebar.com/news/article.php?sec=news&article=5414>.

Herman, Jody L., Bianca DM Wilson, and Tara Becker. "Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey." Health Policy Brief. University of California, Los Angeles: UCLA Center for Health Policy Research - UCLA Williams Institute, October 2017.

Krehely, Jeff. "How to Close the LGBT Health Disparities Gap." Center for American Progress, December 21, 2009. <http://www.americanprogress.org/issues/lgbt/report/2009/12/21/7048/how-to-close-the-lgbt-health-disparities-gap/>.

Makadon, Harvey J. "Ending LGBT Invisibility in Health Care: The First Step in Ensuring Equitable Care." *Cleveland Clinic Journal of Medicine* 78, no. 4 (2011): 220–224.

Obedin-Maliver, Juno, Elizabeth S. Goldsmith, Leslie Stewart, William White, Eric Tran, Stephanie Brenman, Maggie Wells, David M. Fetterman, Gabriel Garcia, and Mitchell R. Lunn. "Lesbian, Gay, Bisexual, and Transgender-Related Content in Undergraduate Medical Education." *JAMA: The Journal of the American Medical Association* 306, no. 9 (2011): 971–977. <https://doi.org/10.1001/jama.2011.1255>.

Plumb, Marj. "An Open Letter to the Lyon-Martin Health Services Community | Save Lyon-Martin Health Services." *Save Lyon-Martin!* (blog), July 26, 2011. <http://www.savelyonmartin.org/?p=138>.

- Ponce, Ninez A., Susan D. Cochran, Jennifer C. Pizer, and Vickie M. Mays. "The Effects Of Unequal Access To Health Insurance For Same-Sex Couples In California." *Health Affairs* 29, no. 8 (August 1, 2010): 1539–48. <https://doi.org/10.1377/hlthaff.2009.0583>.
- Ponce, Ninez A., Shana Alex Lavarreda, Wei Yen, E. Richard Brown, Charles DiSogra, and Delight E. Satter. "The California Health Interview Survey 2001: Translation of a Major Survey for California's Multiethnic Population." *Public Health Reports* 119 (August 2004): 388–95.
- "Primary Care Protocol for Transgender Patient Care: Baseline Laboratory Tests." Accessed April 15, 2016. <http://www.transhealth.ucsf.edu/trans?page=protocol-baseline-tests>.
- Roberts, Tiffany K., and Corinne R. Fantz. "Barriers to Quality Health Care for the Transgender Population." *Clinical Biochemistry, Men's Health and Laboratory Medicine*, 47, no. 10 (July 1, 2014): 983–87. <https://doi.org/10.1016/j.clinbiochem.2014.02.009>.
- Roberts, Tiffany K., Colleen S. Kraft, Deborah French, Wuyang Ji, Alan H. B. Wu, Vin Tangpricha, and Corinne R. Fantz. "Interpreting Laboratory Results in Transgender Patients on Hormone Therapy." *The American Journal of Medicine* 127, no. 2 (February 2014): 159–62. <https://doi.org/10.1016/j.amjmed.2013.10.009>.
- Singal, Robbie, and Harvey Makadon. "Asking Patients Questions about Sexual Orientation and Gender Identity in Clinical Settings: A Study in Four Health Centers." White Paper. Boston, MA: Fenway Institute, December 2013. http://thefenwayinstitute.org/wp-content/uploads/COM228_SOGI_CHARN_WhitePaper.pdf.
- "Trans Health & Identity Document Pop-Up Clinic | Lyon-Martin Health Services." Accessed March 9, 2017. <http://lyon-martin.org/freeclinic/>.
- "Transgender Telehealth | Lyon-Martin Health Services." Accessed April 23, 2014. <https://lyon-martin.org/transgender-telehealth/>.
- Valentine, David. "'I Went to Bed with My Own Kind Once': The Erasure of Desire in the Name of Identity." *Language & Communication* 23, no. 2 (2003): 123–138.

CHAPTER 6: ANALYSIS

6.1 Engaging in the Analysis.....	205
6.2 Overview of Situational Analysis.....	206
Individual Human Agents/Elements/Actors	208
Health Care Stakeholders	209
Health Care Providers & Administrators	210
Medical and Public Health Research	210
Information Technology.....	211
Invisible Human Agents/Elements/Actors.....	212
Non-Human Elements.....	212
Collective Human Elements/Actors	215
Spatial and Temporal Elements	217
Discursive Constructions of Individual/Collective Actors	218
Discursive Constructions of Non-Human Actors	219
6.3 Analysis of Major Issues & Debates	220
Overview of Themes	223
Theme: Dynamics of Social Interactions.....	224
Theme: Gender as Exclusionary Social Formation.....	229
Theme: Institutionalized Disparities	237
Theme: Stigma	241
Theme: Structural Violence	243
Theme: Erasure and Invisibility.....	245
Theme: Passing and Legibility.....	248
Theme: Authenticity & Authority of Personhood.....	251
Theme: Counting Transgender Bodies.....	254
Theme: Medicalization of Gender	257
Theme: Barriers to Care	261
Theme: Education	264
Cited References (Analysis).....	270

6.1 ENGAGING IN THE ANALYSIS

The data analyses for this project were constructed with the goal of summarizing the major human, non-human, discursive and other elements operating within the research sites and the relationships between those different elements. The data collection focused on records and data collection practices, examining forms of documentation used for encoding gender in medical and health records, such as patient medical records, insurance documents, birth certificates or other governmental records. These records instantiate legal gender on driver's licenses, medical gender in patient records, and are used in a complex network of medical and non-medical arenas. The situational maps were generated using not only the research data, but also the thematic analysis, the literature review, the historical background, and feedback from participants.

One of the central aspects to situational analysis is the articulation of many different elements of the situation, from individuals to collective organizations, from key events to discursive constructions. The first two subsections of the situational analysis section focus on the human elements of the situation, which provide on a general overview of the participants in these social interactions and institutional disparities. The other sections cover major issues and debates, sociocultural elements, symbolic elements, political elements and economic elements. These elements include discourses around the tensions between safety, disclosure, erasure, invisibility, stigma, violence, education, medicalization of gender, barriers to care, discounting gender variance, authenticity, agency and system design.

6.2 OVERVIEW OF SITUATIONAL ANALYSIS

INDIVIDUAL HUMAN ELEMENTS/ACTORS

- I. Health Care Stakeholders
Patients, parents, spouses, family, community health advocates, LGBT allies, politicians, legislative advocates;
- II. Healthcare providers
Surgeons, doctors, nurses, medical assistants, receptionists, lab technicians, hospital/clinic staff;
- III. Information technology
Software programmers, computer scientists, computer engineers, software designers, network managers, user interaction designers, database managers, records managers;
- IV. Medical research
Surgeons, teaching faculty, medical researchers, medical educators, pharma, data analysts;
- V. Healthcare administration
Healthcare administrators, billing supervisors, health insurance policy purchasers, employers, government regulators, insurance administrators;
- VI. Universities
Students, staff, faculty, researchers, educators, administrators, regents;
- VII. Public Policy and Legislative Analysis
policy analysts, legislative analysts, public policy advocates, legislative lobbies, political analysts, political advocates, governmental record managers;

INVISIBLE HUMAN ELEMENTS/ACTORS

- I. 'Stealth' trans and gender variant persons who hide their status from health records and providers
- II. Persons with atypical genders who would benefit from improved recordkeeping but who have not been included in current gender variant population surveys

NON-HUMAN ELEMENTS

- III. Records
medical records, legal name/gender records, identity documents, vital records, birth certificates, informed consent forms;
- IV. Information Systems
computers, networks, EMR systems (EPIC, Practice Fusion, etc.), enterprise database systems, cloud-based services, laboratory testing data and data exchange systems,
- V. Health care policy & practice
treatment standards, treatment protocols, standards of care, treatment paradigms, differential diagnoses, evidence based medicine, DSM, ICD, statistical methods, informed consent, EMR interoperability standards, HIPAA;
- VI. Health data
electronic medical records, longitudinal studies, data collection instruments, health outcomes data, clinical trials, statistical models of bodies, disease & health (e.g. lab reference values);
- VII. Public health monitoring
public health survey data, public health survey data collection instruments, public health data, data collection documents;

COLLECTIVE HUMAN ELEMENTS/ACTORS

- I. Governmental agencies/programs
State of California, NIH, NSF, Medi-Cal, Medicare, Social Security Administration, ACA, County of San Francisco, County of Los Angeles, public health agencies, CDC;
- II. Universities/Research Institutes
medical education, medical schools, policy research institutes, medical device research;
- III. Hospitals/Hospital Systems
- IV. Professional Societies

V. Healthcare & Social Advocacy Groups

Support groups, professional groups, outreach groups, educational groups, information resource sharing, social advocacy groups (LGBT);

KEY EVENTS IN SITUATION

CA AB 1586 (insurance non-discrimination)

CA AB 1121 (vital records gender changes)

US Affordable Care Act (non-discrimination clauses)

DISCURSIVE CONSTRUCTIONS OF INDIVIDUAL/COLLECTIVE ACTORS

Racial & ethnic stereotypes

Gender stereotypes

Stereotypes of patient care

Stereotypes of Western medicine

Stereotypes of socio-economic status

Stereotypes of social deviance

DISCURSIVE CONSTRUCTIONS OF NON-HUMAN ACTORS

I. Concepts of medical care

principles of beneficence, Hippocratic Oath, 'do-no-harm, harm reduction, ethics, informed consent, medically necessary care, experimental medicine;

II. Concepts of gender

medical gender, primary & secondary sex characteristics, hormonal regimens, social gender, gender presentation, pronouns, gender roles, gender performance, gender legibility, passing, gender assignment, legal gender

III. Concepts of disease/health

statistical models, statistical norms, correlation, multi-factor analyses, measurability, longitudinal studies;

IV. Concepts of social systems

intersectionality, stigma, otherness, social marginalization, social categorization, equal access, discrimination

V. Concepts of epistemic knowledge systems

public health, medicine, health outreach, medical training, research data collection methodologies, research data dissemination networks, social sciences, academic disciplines, evidence based medicine,

POLITICAL/ECONOMIC ELEMENTS

Health care policy, health care regulation, medical liability, insurance fraud, legislative policy, health care gatekeeping.

SOCIOCULTURAL/SYMBOLIC ELEMENTS

Symbolisms of belonging, symbolisms of social dis/placement, mythologies of health and disease, mythologies of social relations.

SPATIAL ELEMENTS

Urban vs suburban vs rural, especially around LGBTIQ populations, healthcare and educational access

TEMPORAL ELEMENTS

Histories of race, sex, class, gender and medicine, histories of social exclusion, histories of social violence, histories of pathologizing, relationships between medical fields and public health fields.

MAJOR ISSUES & DEBATES

Safety vs disclosure

Intersectionality

Erasure/Invisibility

Stigma/Blame/Violence

Education

Medicalization of Gender

Barriers to Care/access to care

Passing/Legibility

Dis/Counting Transgender Bodies

Institutionalized Disparities

Authenticity/Authority of Personhood

Individual Human Agents/Elements/Actors

Encoding gender in medical records and public health data takes place at the intersection of a number of social and professional worlds. Because gender markers are considered ‘vital’ statistics in government records, almost every individual in California was assigned one at birth, and every gender was assigned based on specific medical policies and practices, regardless of whether they were problems or complications. Gender markers have a broad recordkeeping application in medical and health fields, but are deeply intertwined in legal designations of gender in identity records. As such, any changes in the practice of applying gender markers could potentially affect millions of health records and identity documents.

Similarly, the California Health Interview Survey was designed to statistically represent the population dynamics of the entire state, collecting on 80’000 responses in the most recent data release¹. These gender markers have a wide footprint in these networks of recordkeeping systems, often being re-used repeatedly across a wide variety of medical systems and public health recordkeeping contexts. The recordkeeping elements used in gender records can thus be said to intersect with individuals across multiple populations, including health care stakeholders, health care providers, IT workers, healthcare researchers, healthcare administrators, legal analysts, community advocates, policy analysts, and legislative lobbies.

¹ CHIS, “CHIS: A Leading Source of Population-Based Lesbian, Gay, Bisexual and Transgender Health Data.”

Health Care Stakeholders

Health care stakeholders for the clinic-based study sites included patients, family members, spouses, community members, community health advocates, LGBTIQ allies, legislative advocates, and politicians. Interestingly, a substantial fraction of clinic staff were engaged in multiply intersecting forms of stakeholderhood, working hard to balance their priorities as healthcare providers, patient advocates and community members. Clinic staff were often tacitly aware of the critical necessity of collaboration between persons with specialized knowledge and expertise in navigating bureaucratic recordkeeping practices within current health care systems. For example, one clinic administrator commented:

Through our advocacy, we have a medical-legal partnership with Legal Services of Northern California. So we have attorneys whenever we do get a denial or rejection of services. [And] they are really well versed in health policy and law. They can say 'you have appeal rights as a consumer'. Then they will partner up with one of our advocates and the patient. And the three of them will collaborate on finding a way to either get an independent medical review or get physician documentation, like a letter, or approval, or anything like that.²

Health care stakeholders for the study sites were distributed across a wide variety of social and demographic groups, albeit with substantial differences in educational background between the two clinical environments and the public health survey. The clinics' stakeholders were primarily focused on healthcare provision while the survey's stakeholders were primarily focused on issues of data quality and related research practices. The community clinics both evolved independently to address multiple intersecting barriers to health care for specific

² Contreras, 20160627_Contreras.MP3.

marginalized populations. Both clinics had a diverse network of stakeholders, including formal affiliations with hospital, HMO, or health care networks.

Health Care Providers & Administrators

In California, gender markers are assigned via recordkeeping regimes that rely on medical expertise in designating gender. This reliance on medical providers yields a complex interactional space between government policy, medical practice, and identity documents. The practice of requiring a medical provider to attest to gender assignment at birth and/or re-assignment at a later date is often referred to as ‘gatekeeping’ within LGBTIQ communities. The ‘gatekeepers’ within these recordkeeping regimes are typically healthcare providers, but these complex regimes of documentation may also require the participation of various other affiliates such as surgeons, doctors, nurses, medical assistants, receptionists, laboratory technicians, mental health specialists, hospital staff, public health administrators, school administrators, employers, insurance billing supervisors, government regulators, insurance administrators, governmental program administrators, and health care administrators.

Medical and Public Health Research

Gender markers in medical recordkeeping also affect the long term data collection processes that produce medical knowledge and medical interventions for transgender and gender variant populations, such as surgeries, hormonal regimens, side effects, and best practices. While each of the research sites had stakeholders engaged in health research, the type of research and stakeholdership varied between sites. One site, the Gender Health Center, was developed and overseen by students and faculty from the teaching hospital and

medical school program at UC Davis. These stakeholders include surgeons, doctors, nurses, medical faculty, medical researchers, medical educators, pharmaceutical researchers and medical students.

The two clinic-based study sites, which have patient care as their primary focus, also have stakeholders who focus on medical research and best practices for transgender and gender variant populations. In contrast with the clinic sites, the public health survey's (CHIS's) primary focus has been providing high quality data for researchers and policy analysts, including legislative analysts, public policy advocates, legislative lobbies, political analysts, political advocates, public health researchers, medical researchers, data wonks, and social science researchers. Within the clinic and public health survey practices observed during this study, two of the sites operated under a nested organizational umbrella of two public universities within the University of California system. Thus, the social sphere of these two sites also includes students, staff, and faculty who have worked to develop the site, practices and recordkeeping thereof.

Information Technology

Over the last thirty years, the majority of medical recordkeeping enterprises have transitioned from paper-based records to digital recordkeeping systems, also known as electronic medical record (EMRs) systems. As such, there are a number of information technology specialists who design, create, and maintain these recordkeeping systems. These specialists include software programmers, computer scientists, computer engineers, software designers, network managers, user interaction designers, database managers, and records

managers. And while the public health surveys examined in this research did not use EMR systems, they did use statistical and research software for their recordkeeping practices and released the data for the survey in a standardized digital format.

Invisible Human Agents/Elements/Actors

The most central invisible human elements in these sites are one of the motivating factors for initiating the study, namely all the transgender and gender variant persons who are unrepresentable or invisible in their medical, public health, and governmental records. There is a substantial fraction of individuals who are transgender, gender variant, intersex or similar who are not counted as such and who would directly benefit from being included in the evidence of evidence based medicine. Some of these individuals are 'stealth' trans and gender variant persons who intentionally and effectively hide their status, often for reasons of personal safety. Some of these individuals are persons who are intersex or have a disorder of sexual development that is associated with a gender that is atypical, in-between, or unexpected based on gender norms. Many LGBTIQ youth are in the unfortunate position of not having the familial, medical or social support necessary to disclose, and a substantial fraction of those unsupported LGBTIQ youth have ended up living hard on the streets in larger cities such as San Francisco.

Non-Human Elements

The non-human elements of the study sites include health and identity records, paper based information systems, electronic based information systems, health care policies, health

care practices, health data and public health surveys. Most of these elements are based on records and recordkeeping. The non-human recordkeeping elements within the context of this research are a central feature of inquiry and include medical records, administrative records, vital records, birth certificates, governmental records and identity documents. They also include health data, which include data from longitudinal research studies, health surveys, data collection instruments, health outcome records, clinical trials, and statistical models of health and disease. For example, many laboratory tests report results along with normal ranges of reference values for the test in question. These normal values are based on statistical evidence of average values for healthy adults. These normal values are typically calculated differently for subsets of various demographic statistical variables such as age, gender, genetic predisposition, race, and ethnicity.

These records also rely on complex information infrastructures including computers, communication networks, electronic medical recordkeeping (EMR) systems, enterprise database systems, cloud-based EMR services, insurance benefit tracking systems and health insurance billing systems. Moreover, these complex information infrastructures span various regimes of paper and electronic records:

When I first started it was a little bit disheveled - we had a lot of paper files. I was leaning towards an all electronic EMR because we currently have a mix of both - having a paper file and having also an electronic file. But in the last few weeks we have been developing procedures - asking how can we best use this EMR to its full capacity and getting rid of all of our hard copy (paper) files. And I've found that it's fairly simple. They've added a lot of opportunities to allow the patient access to their records. So that's great. ... If they have internet access, we can send them documents to fill out or documents to sign electronically.

*We can create our own documents. The EMR itself doesn't have a lot of options around gender or ethnicity or race or anything like that.*³

In addition to clinical records, health surveys may draw on patient records, patient surveys, or general public surveys. These data collection efforts span both the medical aspects of health care and the policy aspects of health care provision.

The California Health Interview Survey, for example, is one of the key public surveys that contributes empirical data to state and federal evaluations of public health policy and health care access. However, in conjunction, these records and data collection elements play a key role in the complex knowledge management systems used in health care.

Health care policy and practice is somewhat difficult to characterize within the framework of situational analysis, as it has components of non-human elements, such as treatment standards, treatment protocols, disease classifications, standards of care, treatment paradigms, differential diagnoses, and other forms of standards that are themselves textual artifacts, but are also the collective endeavor of many generations of medical providers and healthcare administrators. These standards and protocols have been and are continuing to be instantiated into the information infrastructure of EMRs and insurance billing systems.

For example, most insurance systems require a diagnosis code to be associated with each and every medical intervention, prescription or surgery. And since many of these instantiations encode gender as a fixed binary into the information systems, trans and gender

³ Contreras.

variant populations bear a larger burden of the system's inability to process records with artifacts of non-binary gender. The most famous case of this was Robert Eads, who was denied treatment for ovarian cancer at dozens of hospitals and clinics. The primary reason cited was that he looked like a man (and was legally male) and thus could not receive treatment in a specialty clinic for 'female' organs. While Eads family assumed that these denials of care were based on simple transphobia, most health systems would be categorically unable to process procedures for 'female' organs inside of legally 'male' individuals, making the billing processes so complex as to become functionally insurmountable within many health care contexts, regardless of the medical etiology of the condition. Many of these systems were constructed without recourse for effectively resolving such recordkeeping conflicts between 'female' organs and legally 'male' individuals.

Collective Human Elements/Actors

Many aspects of health care operate as collective forms of human activity, from clinics and hospital systems to governmental agencies, from scholarly publishing and peer review to the aggregation of health data. A number of governmental programs also intersect with the study sites, whether indirectly via policy regulation, such as with California Health Insurance regulations in AB 1586⁴, directly via the provision of public insurance programs by state and county authorities, collaterally via public health monitoring or abstractly via the provision of

⁴ Department of Insurance, "Implementation of AB 1586: Insurance Gender Non-Discrimination."

medical education, volunteers and trainees. For example, one participant at the Gender Health Center commented:

*So we're seeing a growth in our Latino and African American communities coming here. [Presumably] because they are either undocumented and have no other way of getting access to care. Or they just don't know [how to access care] and so we are seeing them here. A lot of our patients have Medi-Cal, where most transition-related services are covered. **It's all about finding ways to navigate that system with our patients**⁵. [emphasis added]*

These governmental programs implicated a complex network of state, federal and county resources via shared programs such as Medi-Cal, county-based health coverage such as 'Healthy San Francisco', and the marketplaces for health care under the Affordable Care Act such as 'Covered California'.

All of the research sites have invested considerable effort in forming services designed to be used by marginalized populations, resulting in service rates showing success in serving marginalized populations within a network of community-centered clinics. Given that two of the sites were located within the oversight of public university education and research, the aspects of medical education, medical training, and policy research were substantial. These aspects overlapped with functions of teaching hospitals and hospital systems in the two sites engaged in clinical medical practice. Additionally, professional societies play an important role in the establishment of standards of care and best practices within their domain. The most central professional society encountered in this research has been the World Professional Association for Transgender Health (WPATH), which acts a professional society for specialists

⁵ Contreras, 20160627_Contreras.MP3.

and various care providers. However, other societies have also been important, such as the American Medical Association⁶ (AMA), the Gay and Lesbian Medical Association (GLMA), and the American Psychological Association, as they have engaged in advocacy via formal statements⁷ and standards of the treatment for LGBTIQ populations⁸.

Spatial and Temporal Elements

Many of the spatial and temporal elements are discussed in more detail in the Background and Literature Review sections. Because California has a long and complex history of population migrations, geographical elements were notable in some aspects of interpreting the research data. Some of the larger cities in California, such as San Francisco or Los Angeles, have long histories of LGBTIQ populations organizing community hubs and policy interventions. Beyond these histories, there are substantial differences in the social and educational dynamics between urban and rural populations in California. Some of the major temporal elements observed in this study includes tensions around histories of race, sex, class, gender and medicine, histories of social exclusion, histories of social violence, histories of pathologizing gender variance, and the evolving health care policy environment.

The key events in the situation have been covered in the Background (chapter 2) and Appendix I in depth. Below (Figure 22) is a table summarizing key events for interpretation of

⁶ AMA House of Delegates, "American Medical Association Resolution 122: Removing Financial Barriers to Care for Transgender Patients."

⁷ "GLMA Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients."

⁸ "Just Released: APA Guidelines for Working With Transgender, Gender-Nonconforming People | Trans Health."

the analyses. It is included here because these events created notable structural changes in the health care policy environment, including CA AB 1586 (insurance non-discrimination regulations), CA AB 1121 (vital records gender change procedures), the US Affordable Care Act (non-discrimination clauses), the ADA exclusion clauses, ENDA exclusion debates, and WPATH standards of care around medical necessity.

Institution	Policy/Legislation	date effective
<u>State of California</u>	CA AB 2222	2000
	removed "transsexualism" and "gender identity disorder" from the list of excluded impairments under state disability protections	
	CA AB 1586	2006
	provided health insurance non-discrimination protections for sex and gender	
<u>Federal (US)</u>	CA AB 1121	2014
	simplified vital records gender & name change procedures	
<u>Professional Societies</u>	Affordable Care Act	2014
	included health insurance non-discrimination clauses (section 1557)	
	WPATH Statement	2008
	Medical, surgical, and mental health care services related to gender dysphoria should be considered medically necessary care	

Figure 22: Summary of Major Recent Health Policy Changes in California

Discursive Constructions of Individual/Collective Actors

Within the context of health care, there are multiple overlapping constructions of individual actors, including definitional formations of healthcare providers, transgender bodies, gender variant individuals, gender non-conforming individuals, mentally ill individuals, healthy individuals, socially deviant individuals, medically compliant patients and medically non-compliant patients. These constructions also include stereotype formations, such as racial and ethnic stereotypes, gender presentation stereotypes, and gender role stereotypes. For

example, there is a wide-spread sociocultural myth that trans and gender variant people engage in gender variance to deceive, defraud, or take advantage of others⁹ This type of symbolic denigration of gender variant populations also appears within political and economic elements via health care policy, health care regulation, medical liability, insurance fraud prevention, law enforcement, health care regulation, and health care gatekeeping.

Discursive Constructions of Non-Human Actors

Certain discursive constructions of non-human actors were central to this research, including formalizations of aspects of medical care, concepts of gender, concepts of health, concepts of disease, and formalizations of knowledge production. Conceptual formalizations around medical care included definitions of the principles of beneficence, the Hippocratic Oath, principles of harm reduction, medical ethics, principles of informed consent, definitions of medically necessary care, definitions of experimental medical interventions, and definitions of patient compliance.

Conceptions of gender played a role in a number of formalizations in recordkeeping practice, including medical definitions of gender, medical definitions of primary and secondary sex characteristics, statistical definitions of normal reference values, social definitions of gender, pronoun assignment practices, and legal regimes defining gender. Health data and medical records, by definition as such, involve various formal (statistical) and informal concepts

⁹ Bettcher, "Evil Deceivers and Make-Believers."

of disease and health, including statistical models of normal distributions, statistical means, formalizations of statistical correlations, canonical vis-à-vis innovative measurement practices.

Interestingly, because the complexity of social interactions are a notable feature in trans and gender variant populations, a number of disciplines have developed specialized terms around various types of social complexity and social systems, including both formal and informal terms such as intersectionality, stigma, otherness, social marginalization, social categorization, legal definitions of equal access, or legal definitions of discrimination. These specialized terms also span into formalizations of epistemic knowledge systems, such as in formalizations of evidence based medicine or social science survey methodologies.

6.3 ANALYSIS OF MAJOR ISSUES & DEBATES

The major debates, political, economic and symbolic elements found in the study were aggregated using thematic coding of the research materials introduced in the last chapter. In summary, the thematic coding is based on over 900 documents, which include formal and informal interviews, conference posters, hallway conversations, formal publications, white papers, reports, videos, websites, flyers, and more. Most of the debates and major issues were also articulated in the formal literature, although the specific descriptive language and terms used varied somewhat across populations and scholarly disciplines.

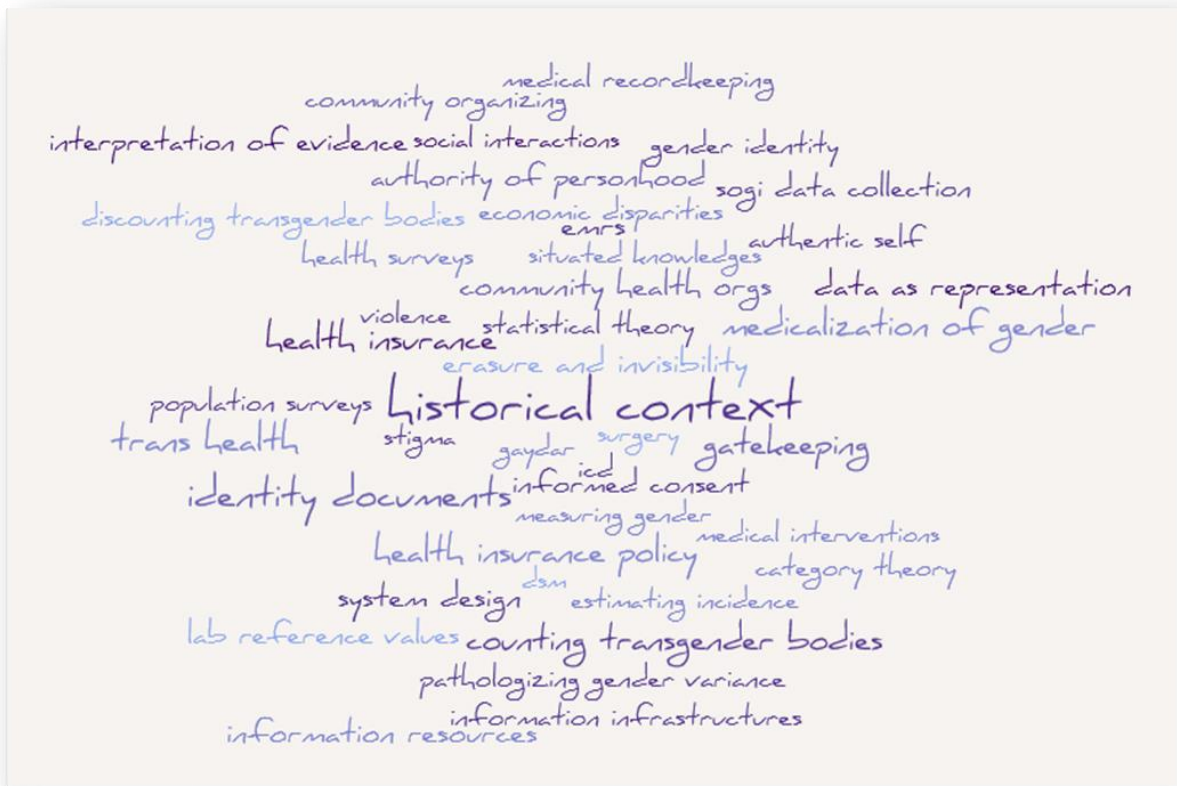


Figure 23: Word cloud showing overview of themes developed during coding process

Transgender populations present obvious frictions for encoding gender variance in the recordkeeping system, but it is not the only population facing data friction via the structural disregard of gender variance in medical recordkeeping systems. Gender markers persist in these networks of recordkeeping systems, often being re-used to populate health, insurance, and medical records. For example, one of the electronic medical recordkeeping systems being tested at Lyon Martin for clinic use was found to have been hardcoded to ingest gender markers from insurance records, which were reused to pre-populate the patient records. But

the design of the system also prevented health care providers from updating gender markers for transgender and gender variant patients while simultaneously requiring them to use the patient's legal gender. Previous paper-based recordkeeping regimes had allowed providers to use preferred gender markers and pronouns for their patients. From a design perspective, the decision to privilege legal gender over current medical gender is misguided in a medical recordkeeping system, as the legal gender invariably derives from an earlier assignment of gender by a healthcare professional. Furthermore, because many transgender and gender variant persons are unable to update all of their identity documents, most trans and gender variant populations exhibit some amount of incongruity between identity records of legal gender and assessments of current medical gender. Many have been prevented from being able to update their gender markers yielding variously mismatched identity documents between agencies, institutions, and policy environments.

Overview of Themes

<u>Theme</u>	<u># documents</u>	<u>Theme</u>	<u># documents</u>
historical context	168	gatekeeping	30
trans health	128	SOGI data collection	25
institutionalized disparities	84	community organizing	23
erasure and invisibility	66	authority of personhood	23
identity documents	57	authenticity (of gender)	18
legal environment	61	population based surveys	35
medicalization of gender	61	informed consent	16
health insurance policy	48	mental health	23
medical interventions	46	patient health advocacy	21
economic disparities	20	gendered lab reference values	15
counting transgender bodies	49	measuring gender	22
education	30	discounting transgender bodies	12
gender identity	42	medical recordkeeping	12
community-based health information resources	35	capacity building	16
pathologizing gender variance	35	DSM	10
dynamics of social interactions	32	estimating incidence	12
stigma	37	race	18
community health organizations	31	incarceration	9
Electronic Medical Records	33	ENDA	6
barriers to care	34	situated knowledge	6
systemic violence	32	passing & legibility	3

Figure 24: Summary of coding terms developed for themes

Theme: Dynamics of Social Interactions

The research materials demonstrated the ubiquity of social marginalization as well as the breadth spanning most spheres of social interaction. Tensions of social marginalization came up during detailed discussions of specific medical record structures as well as during summaries of broad overviews. The embodiment of marginalization is part of the lived experience of the population:

Transgender people face severe discrimination in virtually every aspect of social life--in employment, housing, public accommodations, credit, marriage, parenting and law enforcement, among others. This discrimination is rooted in the same stereotypes that have fueled unequal treatment of women, lesbian, gay, bisexual people and people with disabilities,-i.e. stereotypes about how men and women are "supposed" to behave and about how male and female bodies are "supposed" to appear.¹⁰

However, this marginalization often is discussed in terms of misunderstanding, misconception and misrepresentation:

Gender variance is the most misunderstood area of human behavior. Sensationalized by the media and misconceived even by mental health professionals, individuals who are uncomfortable with their gender and seek to modify their bodies to attain a level of comfort are often unable to find medical allies¹¹.

Many of the interactions described have a common thread of denigration within their experiences of marginalization and stigma, often taking the form of ‘you have no place here’ and ‘you don’t deserve to be treated with human respect and dignity’. One person explained:

¹⁰ Currah and Minter, “Unprincipled Exclusions.”

¹¹ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*.

It is part of social and legal convention in the United States to discriminate against, ridicule, and abuse transgender and gender non-conforming people within foundational institutions such as the family, schools, the workplace and health care settings, every day. Instead of recognizing that the moral failure lies in society's unwillingness to embrace different gender identities and expressions, society blames transgender and gender non-conforming people for bringing the discrimination and violence on themselves.¹²

Experiences with allies and advocacy were deeply transformative for many and there were multiple complex forms of advocacy covered in the research materials, both individually and collectively.

The most prominent form of advocacy was applied to the unmet needs of transgender and gender variant patients for access to basic health care. Interestingly, staff often mentioned the importance of the patient intake and demographic forms in setting up a positive vis-à-vis negative dynamic:

If we say that we want to be a safe place for people to explore their health and create change that they desire, then that starts right from the beginning. And when you talk to any patient in the past who has ever experienced something other than a warm and welcoming environment, it can start right with the forms. That realization was early on for Lyon Martin. I know for me, when I came in, a lot of the forms already adopted that[approach to forms] in a way. They had already been talked about and discussed to make sure that we were [doing a good job]...It's not just about the provider getting the information that they need - it's also about the patient feeling like they are represented among the forms¹³.

A prominent legal organization from San Francisco even put together a how-to guide for community groups advocating around barriers to access to healthcare:

¹² Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey."

¹³ Sekera, 20140502 - Elizabeth Sekera - Interview.

As former organizer Daniel Gould told us, “people were asking questions like, ‘Where do I learn about hormones or sexually transmitted diseases?’ and, ‘How do I find a doctor?’” He concluded that, “It was clear that some people didn’t understand how to explain the physical differences of their transgender bodies to the clinical care workers that they saw. And sometimes people experienced very rude and humiliating treatment when they approached clinics and/or hospitals for basic or emergency care¹⁴.”

As these comments demonstrate, medicine is at an interesting social and epistemic junction, as it is intersecting with both individual level and population level disease models, giving providers both individual level and population level data on the nature of stigma and discrimination. Many providers also spoke about the importance of the social justice and the civil rights movements of the 1960s to their understanding of social marginalization. Values around social justice and equal access strongly motivated many of these healthcare providers to become active advocates for healthcare access for LGBTIQ populations.

Many health care providers reported specific galvanizing moments where they were confronted personally with the stark disparity faced by trans and gender variant patients. One physician stated that they considered untreated gender dysphoria a life-threatening emergency within their clinic. The determination was based on the pragmatic assessment of suicide rates, social violence, and adverse mental health outcomes in the populations they had been working with. Unfortunately, this assessment is overwhelmingly supported by the available quantitative data. The opening paragraph of the preface of a seminal textbook on transgender medicine begins with a reference to an early formative experience by a physician:

¹⁴ Cartwright et al., “Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy.”

In 1992, I saw my first transgender patient, and quickly learned about the health disparities, stigmatization, and minority stress that were pervasive in the transgender population. Not unlike society in general, the health care system was largely indifferent to the needs of people with unique gender identities and presentations¹⁵.

When I spoke with the author of this passage, he explained that he met his first transgender patient by chance, happening to notice that the patient had an uncomplicated bacterial infection that was progressing towards sepsis, which is a life-threatening complication. The author was shocked that another doctor had refused to treat her infection because of her gender presentation. To many health care providers involved with trans and gender variant populations, this kind of denial of care violates their sense of social responsibility in relation to the principles of beneficence of medicine.

Virtually all of the health care providers shared encounters with patients who had been denied access to basic health care because of their gender/gender presentation. Interestingly, many of these key health care providers and patient advocates had had no experience in LGBT communities prior to an initial formative encounter with individuals from marginalized populations. The level of commitment to engaging with problems of social marginalization go above and beyond average health care providers' expectations to provide care to their patients.

Some of the providers who worked in military contexts spoke about the challenges of operating within these institutions with specific policies prohibiting LGBTIQ status disclosure and the provision of care for transgender and gender variant specific conditions. In some cases

¹⁵ Ettner, Monstrey, and Coleman, *Principles of Transgender Medicine and Surgery*.

this included having to obfuscate or omit the nature of the care being provided. Such contexts made it necessary to protect their patients from the harms created by official policies that excluded transgender persons and/or required the provider to report their gender variant status to their supervisor. The large numbers of veterans who participated in the surveys¹⁶ and clinics is a demonstration of the success with which these providers were able to balance the obligations of medical beneficence with internal institutional reporting. The large number of veterans who have disclosed gender identity status in their medical records¹⁷ was notable because until quite recently, transgender persons were not allowed to openly serve in the military and they were not allowed to receive transgender health care via the veteran's health systems. These providers placed their careers and livelihoods at stake to provide basic health care services to transgender patients within military/veteran's health care facilities. In turn, patients entrusted providers with highly sensitive information about their gender identity and transgender status.

The institutionalized disparities that face trans and gender variant patients in healthcare were acutely obvious to all healthcare providers with experience with the population in the research materials. Many founders of the movement for access to healthcare for trans and gender variant persons (such as Harry Benjamin, etc) stated that they decided to work with trans and gender variant patients as a result of encountering the magnitude of disparity facing this patient population. Against the odds, providers have managed to orchestrate care despite

¹⁶ Kauth et al., "Access to Care for Transgender Veterans in the Veterans Health Administration."

¹⁷ Brown and Jones, "Racial Health Disparities in a Cohort of 5,135 Transgender Veterans."

being placed in a double bind by mis-matches in systems of federal policy, health care data, evidence based care, and professional ethics.

In many cases, particularly in the 2000s, providers would often report and/or code their care under non-transgender specific codes. For example, one transman worked with his provider to have his chest surgery coded not as transgender care but as elective breast cancer prevention, as his genetics placed him in a very high risk demographic for breast cancer. Another trans person had them code his counseling as an adjustment disorder rather than a gender identity disorder. Given the high levels of discrimination and social marginalization, providers generally could not ask members of this population to disclose their status when system was failing to protect them. Unfortunately, this type of stealth around encoding health records contributes to the population remaining uncountable, as it leaves virtually no trace in the records of their gender status.

Theme: Gender as Exclusionary Social Formation

At the heart of the challenge of recording gender for transgender and gender variant patients is the challenge that gender variance presents to social expectations of gender norms. Across the recordkeeping practices is a near-ubiquitous black-boxing of physiological and sociological aspects of gender into a normative regime of binary gender that excludes the legitimacy of anything that falls outside the binary. As such, virtually all of the ethnographic documents touch upon the social tensions that relate to the challenge that gender variance presents to the reification of binary gender into a normative regime. Accordingly, one of the first major thematic blocks was titled 'Gender as Social Formation', referring to the formative

topographies between social constructions of binary gender and gender as infrastructural social category.

One prominent transgender activist and legal advocate explained the entanglements of social marginalization into medical and legal arenas:

*As a transgender person, and a lawyer working for trans equality, I must continually negotiate how to use medical evidence responsibly. This negotiation is complicated by my awareness of the contentious and oppressive relationship between the medical establishment and gender transgressive people. In a context in which medical care remains inaccessible to most-and particularly to low-income gender transgressive people, where medical care associated with sex reassignment is still doled out through gender-regulating processes that reinforce oppressive and sexist gender binaries, and where, because of these circumstances and others, many gender transgressive people will choose not to or be unable to access medical care associated with their gender identity, **I must proceed with extreme caution when approaching the interwoven governance mechanisms of legal and medical realms that continue to determine the fates of gender transgressive people.** Similarly, because the reliance on medical evidence and the medical assessment of gender identity is so deeply entrenched, no legal strategist can avoid working within requirements of medical documentation at least sometimes when seeking to expand trans rights.¹⁸ [emphasis added]*

One of the research sites, a smaller community clinic in San Francisco, was chosen for a deeper case study because of its long history in constructing medical recordkeeping practices that functioned in opposition to a normative regime of binary gender. However, even in this case, the normative regime was equally inescapable in the day-to-day functions of the clinic. There are complexly interdependent legal regimes of gender and insurance billing regimes of gender that interact with medical regimes of gender. As the clinic transitioned from highly localized and specialized recordkeeping practices in paper files to a scalable standards-based

¹⁸ Spade, "Resisting Medicine, Re/Modeling Gender."

electronic health records system from a national software vendor, these complex dependencies upon normative systems of binary gender became more inescapable, more difficult to address and less feasible to address.

With the paper records, making a change to the record structure could be as simple as making a photocopy and penciling in new fields. Both patients and providers could write comments and counter-narratives into the margins. With an electronic system, every piece of information must pass through the data structures created by the hands of the vendor and their oversight mechanisms for conforming to standards for the software.

The argument for the widespread nature of the problem of reification of binary gender into a normative regime is supported by the existences of widespread social invisibility/erasure of natural forms of gender variance that do not fall into the binary, both physically and socially. One academic explained:

In the past decades, studies of sex and gender difference, intersexuality, and cross-gender identity strongly suggest that there is no single correct sex classification scheme and that human beings do not have a true sex. People have sex-differentiated physical structures (gonads, chromosomes, genitals, hormones, breasts, brains, body hair, etc.), but these structures do not correlate with two discrete and opposite sexes. Likewise, the body structures to which we ascribe racial meanings (pigment, hair texture, physiognomy, etc.) do not correlate with three or four discrete races.¹⁹

Other scientists have explained it in terms of genetics and chromosomes:

In tracing a path from the chromosomal to the molecular genetics of sex, I point out how this research has shaken off two millennia of Aristotelian sexism to arrive at an interactionist model of genetic sex modifiers

¹⁹ Shrage, "Does the Government Need to Know Your Sex?," 226.

that destabilize a binary model of sex in favor of a polymorphic and multifactorial model, which I call quantum sex.

And even though it has been known within science that gender does not behave as a binary, within medical and legal records, the systems observed here struggled continuously to bring their recordkeeping and billing practices into a framework that could handle exceptions to the assumed gender binary. One trans activist and historian explained:

Sex and gender are quite separate issues, but transsexuals commonly blur the distinction by confusing the performative character of gender with the physical “fact” of sex, referring to their perceptions of their situation as being in the “wrong body.” Although the term transsexual is of recent origin, the phenomenon is not²⁰.

One mental health professional explained, “paradigms and systems of classification dissolve when one interacts with a gender variant child or adult²¹.” Another mental health professional explained:

Just as LGB individuals challenge assumptions of normative heterosexuality and their associated gender roles, so too do transgender individuals challenge conventional notions of sexual orientation and gender categories²².

Many researchers and members of the population tie the invisibility and erasure of gender variance to the expectation of binary gender, which is supported by the widespread lack of mechanisms for collecting data on trans and gender variant populations:

²⁰ Stone, “The Empire Strikes Back,” 152.

²¹ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*, xxiii.

²² Tebbe and Moradi, “Anti-Transgender Prejudice,” 252.

*Health research commonly does not allow for identification of trans participants or address questions relevant to trans communities. It often erroneously presumes that all research participants are cissexual, that their partners or family members are cissexual, and that their sex and gender have been consistent over the lifetime. Thus, trans people who have been research participants have been systematically erased, and by extension, trans experience and subjectivity have been similarly rendered invisible.*²³

Another researcher phrased the problem of invisibility and erasure similarly:

*Health research commonly does not allow for identification of trans participants or address questions relevant to trans communities. It often erroneously presumes that all research participants are cissexual, that their partners or family members are cissexual, and that their sex and gender have been consistent over the lifetime*²⁴.

As mentioned above, the adherence to gender as a binary tends to elicit the epistemic erasure of all individuals who do not fall into the constructed categories, even if the categories include transgender options:

*We screened 645 individuals for eligibility, of whom, 586 (91%) were eligible. Of the eligibles, 523 (89%) completed the interview and HIV test. Eight intersexed individuals were excluded for this analysis because they could not be classified as either MTF [transwomen] or FTM [transmen], resulting in a final sample size of 515.*²⁵

While there has been a great deal of epistemic conflict around the etiology and origins of gender variance, the role of gender as a foundational element for structuring social interactions and locating social hierarchies remains uncontested across the spectrum of discourses present. Because gender plays a foundational role to many social interactions, many of the participants

²³ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives," 352.

²⁴ Bauer et al., 352.

²⁵ Clements-Nolle, Katz, and Marx, "The Transgender Community Health Project."

within trans and gender variant communities commented on the need to address the damage created by reifying social expectations of binary gender into a system of exclusion:

...it is crucial that the transgender continuum foreground the violences of sexual binaries. Identifying inconsistencies in paradigmatic binary sexing; drawing attention to the diversity of lived, gendered experience; and capitalizing on gender performativity are mechanisms for denaturalizing sex. At the same time, they point to the remarkable resiliency of sexual regulation, the ongoing policing of bodies and the very real violence it entails, and the absolute need to address those injustices.²⁶

The idea of addressing the damage created by social expectations of binary gender map well with Goffman's framework of viewing social stigma as the result of a failure to live up to a social expectation of fit²⁷.

The interlocking relationship between gender as a binary and social stigma for gendered expectations was a regular feature of comments about the dynamics of social interactions in health care contexts. Some observers tied the regime of binary gender to social location and social hierarchy placement. One trans community member and prominent academic brought the violence of the system to the fore by examining the social location, social categorization and social placement of the dead by the living. This academic also noted the importance of margins and border zones between categories:

Disputes about contested category placement are one of the arenas in which contemporary categories and their boundaries are articulated. Such articulations, of course, have consequences for the living: they matter for decisions about who is included and who is excluded from contemporary categories, whether in

²⁶ Cole and Cate, "Compulsory Gender and Transgender Existence," 286.

²⁷ Goffman, *Stigma*.

*accordance with or contrary to individuals' desires. More specifically, when a border zone denizen's corpse is claimed by those who are trying to live in the nearly unspeakable spaces created by overlapping margins of distinct categories. Border zone inhabitants infer reasonably that their lack of fixed location within categories is prohibited by the more firmly located, that such absence will be used as ground for subjecting them to multiple indiscriminate erasures, and that their sullen resistant silences and dissenting cries alike will be folded into the discourse of those with more solid categorical and thus social locations.*²⁸

At the same time, many recognized that the challenges in how binary structures of the healthcare records interact with these gendered expectations and structure the initial establishment of patient-provider relationship:

*As transgender people, we often have a difficult time talking with our doctors about our bodies and our gender identities. If our first point of contact with a provider is an intake form that asks us to check F or M, it can create a sense of discomfort from the start. Working with your community clinic to alter forms so that they allow options for patients to self-identify their gender and sexual identities can make transgender people feel more welcome in accessing services at a clinic and can go a long way in making that first appointment a more relaxed, candid and confident experience.*²⁹

The above comment does not mention that the reason for the tension interwoven into the story of medical records for gender variant persons is related to a pervasive history of pathologizing gender variance as a moral and personal failure. One study spoke with trans community members about the kinds of difficulties trans patients have had interacting with providers. The study summarized, "descriptions of mistreatment coalesced around 6 themes:

²⁸ Hale, "Consuming the Living, Dis (Re) Membering the Dead in the Butch/FTM Borderlands," 319.

²⁹ Cartwright et al., "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy,"

gender insensitivity, displays of discomfort, denied services, substandard care, verbal abuse, and forced care."³⁰

This historical tension around of pathologizing gender variance was mentioned during similar discussions of stigma, prejudice and discrimination. One mental health professional explained the problem using terms of basic civil rights:

Continued designation of gender nonconformity as a mental illness allows us, lead by medical and psychological professionals, to unfairly stigmatize individuals who fail to conform to standard gender roles. As a result of that stigma, gender nonconforming individuals are not seen as deserving of the many basic civil liberties afforded any other citizen.³¹

Another echoed:

The fulfillment of basic human needs like having a place to live and feeling safe is often denied them. Given laws in most states, because they have transitioned between gender categories, they may not be allowed to engage common adult life-course tasks such as establishing a career, forming lasting and socially-recognized bonds with romantic partners, and building a family. Enabling these difficulties are antagonistic, pervasive, and powerful social structures that enforce a binary of gender (gender that is either male or female, not both, with no third option), and make normative the notion that the gender label given at birth is the one that must be enacted throughout life³²

Here, one can see both the medical system of labeling gender (e.g. birth certificate) as well as the larger social system in play.

³⁰ Kosenko et al., "Transgender Patient Perceptions of Stigma in Health Care Contexts."

³¹ Gainor, "Including Transgender Issues in Lesbian, Gay and Bisexual Psychology."

³² VanOra and Ouellette, "Beyond Single Identity & Pathology."

Theme: Institutionalized Disparities

The topic of institutionalized disparities very well represented in both the historical and current discussions of administrative practices around trans and gender variant populations. Institutionalized disparities are a central recurrent theme to the research, being mentioned widely and repeatedly in the research data, for at least the last two decades:

Gender non-conforming people have consistently been among the most visible and vulnerable members of gay communities - among the most likely to be beaten, raped, and killed; among the most likely to be criminalized and labeled deviant; among the most likely to end up in psychiatric hospitals and prisons; among the most likely to be denied housing, employment, and medical care; among the most likely to be rejected and harassed as young people, and; among the most likely to be separated from their own children.³³ (Academic/Trans Advocate, 2000)

These institutionalized disparities were observed to be particularly acute when combined with other additive disparities, such as race:

Discrimination was pervasive throughout the entire sample, yet the combination of anti-transgender bias and persistent, structural racism was especially devastating. People of color in general fare worse than white participants across the board, with African American transgender respondents faring worse than all others in many areas examined.³⁴ (US nation-wide survey results, 2011)

³³ Minter, "Do Transsexuals Dream of Gay Rights-Getting Real about Transgender Inclusion in the Gay Rights Movement," 592.

³⁴ Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey," 2.

Follow up surveys to the one above confirmed the dynamic. Every survey of the population done to date has indicated that intersections of race, class and gender carry substantial burdens of social stigma and institutionalized disparities:

While respondents in the USTS sample overall were more than twice as likely as the U.S. population to be living in poverty, people of color, including Latino/a (43%), American Indian (41%), multiracial (40%), and Black (38%) respondents, were up to three times as likely as the U.S. population (14%) to be living in poverty. The unemployment rate among transgender people of color (20%) was four times higher than the U.S. unemployment rate (5%). People of color also experienced greater health disparities. While 1.4% of all respondents were living with HIV— nearly five times the rate in the U.S. population (0.3%)—the rate among Black respondents (6.7%) was substantially higher, and the rate for Black transgender women was a staggering 19%.³⁵

Many advocates have placed this issue of institutionalized disparity into the context of social control and normative categories applied across the entire population:

Control that operates through population-level interventions is particularly significant to trans politics because of the way trans people struggle with gender categorization in the purportedly banal and innocuous daily administration of programs, policies and institutions (e.g. homeless shelters, prisons, jails, foster care, juvenile punishment, public benefits, immigration documentation, health insurance, Social Security, driver licensing, and public bathrooms). An understanding of power that looks at the life chances created by population-level interventions draws our attention to how the categorization of people works as a key method of control. Population-level interventions rely on categorization to sort the population rather than relying on behaviors or traits. What characteristics are used for such categorization and how those categories are defined and applied creates vectors of vulnerability and security.³⁶

³⁵ James et al., “The Report of the 2015 U.S. Transgender Survey (USTS).”

³⁶ Spade, *Normal Life*, 138.

As medical recordkeeping systems have been scaled from local infrastructures in the form of regimes of paper, to large scale infrastructures of electronic medical information systems, the complexity of the interface has changed and increased. Small disparities in how individuals are managed by the data system can have large effects in systems with millions of users. Since many digital recordkeeping systems are increasing in the complexity of scale, it becomes important to have practices in place for the monitoring of disparities. Many of the sources provide information and perspective on systemic disparities framed as a form of feedback on the overall performance of the system. For example:

*What we have learned from 15 months of direct service and close to 500 transgender patients accessing care on a regular basis – is that transgender people face entrenched discrimination and abject denial of care within the health care system.*³⁷ (Los Angeles Area Hospital Outreach Program, 2015)

In terms of trans and gender variant populations, institutionalized disparities (or structural inequalities) is a common topic of discourse for health care professionals, advocates and patients alike. For example, within the clinic and hospital based research sites, the health information systems had no procedural mechanism for automating the structural shortcomings that occurred for processing insurance billing for trans and gender variant populations. In some cases this resulted in every transaction being hand processed on both the health care provider side and on the insurance billing side, often requiring office staff to call the insurance company repeatedly. This resulted in one site having to dedicate a full time staff person to dealing with

³⁷ Sussman et al., "Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles," 2.

erroneous billing rejections. Another site structured its care so as to avoid insurance billing altogether, but was also very limited in the types of care provided. The insurance companies responsible for processing billing claims often had no idea how to override the errors and lacked training on where to forward the issue for resolution. It was also not unusual to have the insurance companies erroneously assert that such care was not covered. These issues were observed at all of the formal and informal sites and while they do seem to be improving, the lack of institutional support for billing and insurance conflicts stemming from conflicts in gender markers remains a pervasive problem. Some health care professionals also commented that these disparities can make the population more difficult to work with:

The providers felt that these difficulties led to a high prevalence of mental health and behavioral issues which made transgender people difficult to deal with as patients. One of the physicians put it this way, 'They've been kicked around so much in their lives because of the territory they've had to traverse that there tend to be a lot of maladaptive behaviors that they've been habituated to. No blame there, but that can make the patients a lot harder to deal with and then they in turn have a hard time integrating into the community. (Primary care physician)³⁸

In this context, it is impressive but not surprising that a wide swath of community in San Francisco came together to re-constitute the administrative structure of the Lyon Martin clinic when their finances imploded in 2011. They had been serving as a critical community health hub, successfully providing care for thousands of patients for more than a decade. Their providers invested extensively in training highly effective health care advocates for their communities. Their under-documented contribution to the network of health care professionals in the SF Bay Area cannot be overstated.

³⁸ Poteat, German, and Kerrigan, "Managing Uncertainty," 26.

Theme: Stigma

As mentioned in the literature review, Goffman's conceptual framework of stigma drew directly from his social observations of marginalized populations in California while a professor at UC Berkeley in the 1960s. Goffman saw tolerance as a narrowly precarious situation, whereby if a stigmatized person allowed themselves to believe that they are more accepted than they really are, then when they attempt to participate socially, they are seen as stepping out of their 'proper' place. Tolerance and acceptance are conditional under his understanding of stigma. Goffman argued that the stigmatized must 'know their proper place' in order to retain acceptance.

Echos of Goffman's formulation of stigma were relatively widespread in the research materials, however, it can be noted that other conceptual understandings of stigma were also in play, such Link and Phelan's understanding of stigma³⁹ appeared widely in the materials:

*Interpersonal stigma functions to reinforce the power and authority of the medical provider during these interactions. Functional theories of stigma posit that we hold stigmatizing attitudes because they serve specific psychological functions. However, these theories ignore how hierarchies of power in social relationships serve to maintain and reinforce inequalities"*⁴⁰.

Goffman emphasized the importance of viewing stigma as role-based relational process rather than a fixed designation of difference, emphasizing the bi-directionality of the process:

³⁹ Link and Phelan, "Conceptualizing Stigma."

⁴⁰ Poteat, German, and Kerrigan, "Managing Uncertainty."

*Stigma involves no so much a set of individuals who can be separated into two piles, the stigmatized and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life. The normal and the stigmatized are not persons but rather perspectives. These are generated in social situations during mixed contacts by virtue of the unrealized norms that are likely to play upon the encounter*⁴¹.

This understanding of stigma lends an interesting framework from which to examine how trans people are treated in healthcare and in LGBT advocacy:

*This study brings to light what is both patently obvious and far too often dismissed from the human rights agenda. Transgender and gender non-conforming people face injustice at every turn: in childhood homes, in school systems that promise to shelter and educate, in harsh and exclusionary workplaces, at the grocery store, the hotel front desk, in doctors' offices and emergency rooms, before judges and at the hands of landlords, police officers, health care workers and other service providers.*⁴²

Another commonly observed facet of stigma involves the social expectation of a gender binary excluding gender variant bodies as if they were delegitimate anomalies that should be held accountable for the friction that results from their exclusion from the binary.

Another significant difference between the formal written discourse in the literature review and the spoken informal discourse of the interviews is the inclusion of the concept of privilege, namely that social privilege as a concept is commonly treated as the other half of social stigma in informal contexts, but the concept of privilege was a more recent addition to

⁴¹ Goffman, *Stigma*.

⁴² Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey."

the print literature. The materials speak about stigma and privilege in terms intrinsically related to systems of social value that form the basis of social hierarchies.

Theme: Structural Violence

The risk of violence that trans and gender variant persons faced in health care contexts was reiterated in virtually every form of data that researchers have collected from these populations. These studies have indicated that being out as transgender presents an elevated risk of violence in medical, social and legal contexts. In these studies, the theme of structural violence was articulated widely, using both qualitative and quantitative social research data collection approaches, even though the domains articulate their concerns using slightly different terms and frameworks. For example, the scholars below introduce the problem for a women's studies/gender studies audience:

it is crucial that the transgender continuum foreground the violences of sexual binaries. Identifying inconsistencies in paradigmatic binary sexing; drawing attention to the diversity of lived, gendered experience; and capitalizing on gender performativity are mechanisms for denaturalizing sex. At the same time, they point to the remarkable resiliency of sexual regulation, the ongoing policing of bodies and the very real violence it entails, and the absolute need to address those injustices.⁴³

Here is a similar sentiment from researchers reporting on the public health data they collected in a national survey of transgender and gender variant populations:

Medical providers and health systems, government agencies, families, businesses and employers, schools and colleges, police departments, jail and prison systems—each of these systems and institutions is failing daily in its obligation to serve transgender and gender non-conforming people, instead subjecting them to

⁴³ Cole and Cate, "Compulsory Gender and Transgender Existence," 286.

*mistreatment ranging from commonplace disrespect to outright violence, abuse and the denial of human dignity. The consequences of these widespread injustices are human and real, ranging from unemployment and homelessness to illness and death.*⁴⁴

Many of the comments place the problem of social violence in relation to sexism, homophobia and transphobia, but researchers are somewhat divided between representing this violence as the result of individuals' prejudice versus representing this violence as the result of embedded organizational practices:

*We therefore argue that interpersonal violence and abuse against transsexual, transgendered and cross-dressing persons (hereafter referred to as anti-transgender violence unless otherwise qualified) represents a form of gender terrorism whose underlying motivation is the maintenance of a social system in which males dominate females through emotional, verbal and physical acts of force, and in which the line between the genders must be rigidly maintained in support of this social schema. Understanding this form of gender-based violence is strongly needed, both to protect its potential victims, and to comprehend the socially constructed gender dynamics that make possible the widespread abuse of women by men.*⁴⁵

Regardless of the conceptualization of violence, the data demonstrated high rates of discrimination and violence perpetrated against transgender and gender variant populations; moreover, the data indicated that these risks worsen with increased visibility:

Unfortunately, our data shows that doctors' knowledge of a patient's transgender status increases the likelihood of discrimination and abuse. Medical professionals' awareness of their

⁴⁴ Grant et al., "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey."

⁴⁵ Witten and Eyler, "Hate Crimes and Violence against the Transgendered."

*patient's transgender status **increased** experiences of discrimination among study participants up to eight percentage points depending on the setting*⁴⁶

Many of the researchers placed this type of violence into a framework of structural violence and its larger systemic impact. One researcher explained:

*Structural violence is violence exerted systematically—that is, indirectly— by everyone who belongs to a certain social order: hence the discomfort these ideas provoke in a moral economy still geared to pinning praise or blame on individual actors. In short, the concept of structural violence is intended to inform the study of the social machinery of oppression*⁴⁷.

One of the central challenges to documenting structural violence for this research has been the challenge of disentangling the complex social interactions involved in the social, medical and legal regimes of gender in current health care contexts.

Theme: Erasure and Invisibility

The conceptually related terms of erasure and invisibility are relatively common topics of discussion and thus form large node within the analysis of the research data. Most of the materials talk about instances of erasure or invisibility in one form or another, but some also discuss the issue using related terms such as 'being out' (disclosing one's status) or 'being stealth' (hiding one's status). Some scholars conducted a study⁴⁸ with trans communities in

⁴⁶ Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care," 6.

⁴⁷ Farmer, "An Anthropology of Structural Violence."

⁴⁸ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives."

Ontario, Canada in an attempt to characterize the erasure and invisibility for trans persons in healthcare:

Erasure appeared in two key domains in the analysis: informational systems and institutional policies and practices. Erasure could be passive or active. Passive erasure included a lack of knowledge of trans issues and the assumption that this information was neither important nor relevant. Active erasure could involve a range of responses from visible discomfort to refusal of services to violent responses that aimed to intimidate or harm. Active and passive erasure within these two domains produced systemic barriers to care and served to reinforce the erasure of individual trans people and, by extension, trans communities... Two key sites of erasure were identified: informational erasure and institutional erasure. How these processes work in a mutually reinforcing manner to erase trans individuals and communities and produce a system in which a trans patient or client is seen as an anomaly is shown. Thus, the impetus often falls on trans individuals to attempt to remedy systematic deficiencies.⁴⁹

Thus, trans people who have been research participants have been systematically erased, and by extension, trans experience and subjectivity have been similarly rendered invisible. Not surprisingly, many trans persons choose to make themselves invisible for their own safety. Many of the materials engaged with the phenomena of ‘going stealth’, ‘passing’ and/or non-disclosure of gender identity:

With such a pervasive cultural emphasis on concealment, it may come as no surprise that the slang used by many trans people to describe non-disclosure of trans status is “going stealth.” Trans people who are living “stealth” are unknown as transgender to almost everyone in their lives – co-workers, employers, teachers, friends – and instead living only as their preferred genders. The term itself invokes a sense of going undercover, of willful secrecy and concealment, perhaps even of conscious deception. Use of this undeniably militarized language also implies a connection to the state, and going stealth does involve a great deal of complicity with state regulation of gender, for example in the changing of legal identity documents such as passports, drivers licenses and immigration paperwork. These are changes that themselves require documentation of particular medical interventions to “irreversibly” change one’s

⁴⁹ Bauer et al., 352.

physical sex characteristics. The state requires compliance with specific legal and medical procedures, and ostensibly offers in return official documentation that enables stealth status.⁵⁰

The issue comes up again and again in the materials. During a discussion of changing gender markers on identity documents, the authors of a how-to-guide explained that the changing practices around digital records might impact one's ability to remain in control of the information:

However you may feel about the political need to be "out" as transgender, it is understandable that some people would like to choose to be in control of how "out" they are. Arguably, people who changed all of their documents as recently as ten years ago had a reasonable expectation that their old identity would be buried after that change. Unfortunately, as our society becomes more and more connected through computers, your ability to remain in control of information about your identity is greatly reduced⁵¹.

However, the theme of erasure and invisibility became particularly concerning when intersecting with the development of evidence based medicine for transgender specific procedures. The lack of data has intersected with the lack of recordkeeping structures to allow insurance companies to classify medical procedures specific to transgender health as experimental or cosmetic for more than 50 years:

"...evidence for the argument that the lack of data provides a platform from which to describe SRS as experimental and cosmetic surgery. It has allowed the denial of care to continue under the explanation that any treatment is experimental because the data is so weak."⁵²

⁵⁰ Beauchamp, "Artful Concealment and Strategic Visibility."

⁵¹ Chong and Wallis, "ID Please! A Guide to Changing California & Federal Identity Documents to Match Your Gender Identity," 5.

⁵² Stroumsa, "The State of Transgender Health Care."

While the Affordable Care Act has changed many of the exclusions affecting transgender medical interventions and the problem of the lack of data and health records was recognized as a major barrier, it will take some time for the data to accumulate and the medical evidence to be on par with what is available in Europe and elsewhere.

Theme: Passing and Legibility

Closely related to issues of erasure and invisibility are issues of passing and personal safety. One researcher explained:

*While there have been many trans organizations in the past 40 years, and living ‘stealth’—remaining closeted about one’s transgender status—is less common than it used to be, it is still rare and difficult for transgender people to choose to risk their lives and livelihoods by being visibly out.*⁵³

This concern about personal information disclosure and mitigation is one of the most central aspects of Goffman’s development of conceptual understandings of stigma. In this context, the terms ‘passing’ and ‘passing privilege’ relate to these tensions around disclosure. Passing refers to being able to ‘pass’ as a member of the intended social category. In Goffman’s work, it surfaced the tension between passing and belonging to social categories, with stigma being the potentially disqualifying element between passing and belonging. In trans and gender variant contexts, passing refers to a person being able to be seen as a member of the category to which they wish to pass. Legibility refers to whether one’s gender can be readily interpreted into existing social categories of gender.

⁵³ Shapiro, “Trans’ Cending Barriers,” 166.

Most of the research materials talk about issues of passing and legibility in relation to how stigma and marginalization function:

Gender stereotypes are a central part of our experience. Conformance with a coherent gender presentation, where clothing and presentation match up with body parts and secondary sex characteristics, can be a significant element of how we define another being as human.' Gender norms are so powerful and pervasive that when someone dares to transgress them openly, destabilizing the presumed synchronicity of sex and gender, that person will almost inevitably face some kind of punishment, with consequences ranging from mere social hostility to discrimination in employment and housing to outright violence.⁵⁴

Within the social pressures to conform to the binary are other social expectations for passing and gender legibility:

Central to this standardized definition of trans identity, however, is the expectation that trans people will, through the process of transition, eliminate all references to their birth gender and essentially disappear into a normatively gendered world, as if they had never been transgender to begin with. ...To be classified as normatively gendered is also to adhere to norms of racial and economic privilege. Under this logic, marginalized gender identities can approximate the norm in part through clinging to ideals of whiteness and class status. Concealing gender deviance is about much more than simply erasing transgender status. It also necessitates altering one's gender presentation to conform to white, middle class, able-bodied, heterosexual understandings of normative gendering.⁵⁵

These tensions in healthcare are most acute for the members of the trans and gender variant populations who are unable to conform to white, middle-class, able-bodied, heterosexual understandings of normative gendering. The quantitative data collected on trans populations (discussed in the literature review) indicate that trans women of color have

⁵⁴ Turner, "Sex Stereotyping per Se."

⁵⁵ Beauchamp, "Artful Concealment and Strategic Visibility," 357.

substantial barriers to access care, are the most difficult populations to survey with statistical methods, have among the worst health outcomes, have some of the highest rates of violent victimization, homelessness, poverty and are often some of the most overlooked socially. The discussions about the precarity of passing and how it results in a paralyzing social bind have been going on for decades in California:

The contrast between gender presentation (appearance) and sexed body (reality), when intersected with possibilities of either being or not being visibly trans, yields a dangerous double bind... To understand this bind, we need only examine the rhetoric of deception and disclosure that informed the murder of Gwen Araujo [a trans teenager from near San Jose]. While she was considered a deceiver for failing to disclose her “true status,” one can only imagine the reaction that she would have received had she simply announced herself as trans. For in coming out, she would have no doubt been interpreted as “really a boy, who dressed up like a girl.” Hence the option: disclose “who one is” and come out as a pretender or masquerader, or refuse to disclose (be a deceiver) and run the risk of forced disclosure, the effect of which is exposure as a liar.⁵⁶

The assumption of intentional deception ascribed to transgender and gender variant persons by the uninitiated is not a new trope. It also mirrors Goffman’s observations of personal information management⁵⁷, whereby persons must negotiate the disclosure of their inability to conform to social norms and expectations. Comments about deception often come up in conjunction with normative comments about authenticity, about whether someone could be considered a ‘real’ man or a ‘real’ woman.

⁵⁶ Bettcher, “Evil Deceivers and Make-Believers.”

⁵⁷ Goffman, *Stigma*.

Theme: Authenticity & Authority of Personhood

As mentioned above, there is a common cultural trope that associates trans and gender variant behavior with deception and falsehood, including taking what these people say about their experiences of gender:

The stereotype that transsexuals purposefully misrepresent themselves also feeds into the common presumption that what transsexuals say about their own gender identities and experiences need not be taken seriously⁵⁸.

Throughout, the disparity between how people are represented and how they represent themselves, is a haunting reminder of erasure and institutionalized structural violence. This problem was particularly acute when the LGBT rights movements began in the 1960s, but continues to show up in discourse and political issues even now. One particularly clear example between the person and their medical record can be seen here; both are taken from ‘The Autobiography of Jane Fry’⁵⁹:

“I know what I am. I like it...I am the only one responsible for what I do, and as long as I don’t harm another human being mentally or physically, I’m being a good person.”

--Jane Fry

“Mr. Fry displayed a psychotic profile evidenced by strong expressions of unconventional values, intense lack of self-acceptance, and a great need for more affection and support... He displays overt sexual inversion, is non-conforming and feels hurt if one doesn’t pay attention to him.”

⁵⁸ Serano, “The Case Against Autogynephilia.”

⁵⁹ Fry, “Conclusion: On the Records.”

--Jane Fry's medical record

According to Jane, most of her problems are not internal, but rather are imposed by others... her problems do not stem from the fact that she want to be a woman, but from the reactions others have to that desire... Her problems are compounded by having to deal with a system of authority and power which systemically prevents her from becoming what she knows she is. ... Her reluctance to accept their [psychiatrists'] interpretation...is devalued as being a manifestation of her inability to accept the 'cause' of her problems and is considered further evidence of her illness⁶⁰.

--Jane Fry's mental health advocate

The tension around authenticity and authority of personhood in medical contexts largely revolved around the question of whether a provider was following a Standards of Care model (such as WPATH), which requires letters of support from various mental health professionals, versus a model of informed consent. The tensions around authenticity and authority of personhood resulted in a medico-legal drama in the 1960s that formed the models for accessing care today:

The real crux of the medicolegal drama was whether a transsexual's consent was valid. If the desire for surgery is a delusion, an obsession, or a symptom of complex psychopathology, then an informed consent lacks legal validity, therefore, the issue hinged on the etiology of gender dysphoria. Was it a 'real' condition or a psychiatric disorder?... Proponents of the surgery, anticipating legal challenges, established protocols that mandated rigorous assessment of surgical candidates⁶¹.

Within the model of informed consent, patients are evaluated for their ability to give informed consent and allowed to consent to treatment. Within the Standards of Care model, patients

⁶⁰ Fry, 213–16.

⁶¹ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*, 2.

must be evaluated by a mental health professional for a period up to a year before they are allowed to consent to treatment. The history and development of these models was discussed in more detail in the Background section. The requirement for a mental health professional to establish mental health is anomalous compared to other health care interventions. It places a higher level of scrutiny on the authenticity of the person's gender and on their authority to engage in informed consent.

Across the research materials and sites, community members and health care providers invested large amounts of effort to mitigate the complexity of these two treatment paradigms for patients. One prominent academic and activist explained:

However, the abilities, autonomy, and full moral status of gender variant people are undermined in many ways by many institutions, policies, and juridical entities, which interact with one another and with the SOC [Standards of Care] in a variety of complex ways. The simple fact that the social risks of medical interventions are so great demonstrates this adequately.

Ironically, the very social risks which tell in favor of the SOC's mental health evaluation requirement are supported by it, for by implying that gender variant prospective patients have less than full autonomy, and thus less than full moral status, this belief enables mistreatment of gender variant people.⁶²

Even if it were to be demonstrated that adult gender variant prospective patients are, as a category, significantly incapable of making autonomous decisions in their own best interests, proponents of the SOC's mental health evaluation requirement would still need to argue

⁶² Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients."

*convincingly that the principles of non-maleficence and beneficence override the principle of respect for autonomy in this area of medical policy-making.*⁶³

Theme: Counting Transgender Bodies

As mentioned above, trans and gender variant populations are often excluded from data collection categories at every level. For many years, the only medical studies of trans persons came from European medical systems:

*Currently, only a few prospective, large scale studies regarding transgender health care exist. The best available evidence comes from a Dutch retrospective chart review involving 816 MTF and 293 FTM transsexual patients*⁶⁴

In examining medical evidence for treatment, there were numerous comments about counting vis-à-vis discounting transgender bodies, from the localized perspective of an individual study:

*Using targeted and snowball sampling techniques, we were able to sample a large number of transgendered persons who typically are not eligible for studies or are excluded from analyses because their gender does not fit the male/female dichotomy.*⁶⁵

To the national public health data surveillance systems:

LGBT health disparities, housing challenges, access to care problems, hate-crimes -- all the flotsam and jetsam of discrimination is effectively invisible if national surveys don't count us. Even though many smaller or regional surveys have shown beyond a doubt these problems exist ...Those data just don't carry the same authority as federal data in grant applications, policy

⁶³ Hale.

⁶⁴ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*, 37.

⁶⁵ Clements-Nolle, Katz, and Marx, "The Transgender Community Health Project."

decisions, and resource allocation. That is why I am one of hundreds of people at the national level who just keep beating this drum for data collection...

Exactly two years ago we were extremely pleased to celebrate... that LGBT data collection was going to be added to the most frequently referenced federal health survey, the National Health Interview Survey. Data wonks everywhere jumped up cheering (pocket protectors flapping in the wind).

*While those data are on track to come out, unfortunately our data holiday will only include LGB but not T data. Ironically, this is despite the fact that some of the loudest voices in this advocacy are, like me, openly trans. I'll cheer for all the LGB people I love, **but it will be an empty data holiday for me**⁶⁶.*

The policy analysts at the Williams Institute (UCLA) and elsewhere were particularly attentive to these data collection issues:

US population-level surveys do not utilize standardized questions to collect information about sex and gender. Most surveys measure sex with a self-reported demographic question (male or female). Some surveys rely on telephone interviewers to assess perceived sex or gender based on the vocal tone of respondents. The lack of standardized measures of both sex and gender impacts the empirical rigor of research on sex and gender differences in US population health by obfuscating differences between natal sex (biological) and gender (social) pathways.⁶⁷

Many comments and publications also note the centrality of the Healthy People 2020 report and its comments about the lack of data collection on the national level:

Accurate epidemiology is key to the documentation and elimination of health disparities. Continuing the traditional practice of conflating sex and gender, and viewing them not only as static, but also limited to the traditional binary choices, effectively erases transgender people and their health needs and concerns

⁶⁶ Scout, "Déjà Vu."

⁶⁷ Reisner et al., "'Counting' Transgender and Gender-Nonconforming Adults in Health Research."

*from public health surveillance. A salient example is the inclusion of transgender women in the MSM risk category by the CDC in HIV/AIDS surveillance.*⁶⁸

The HIV epidemic in some populations has been one such point where the lack of records has long been apparent to medical professionals and community members alike:

*Although it is true that certain key people have understood the terrible consequences of HIV within transsexual communities since at least the late 1980s, it is also true that there was very little scientific data to support such a claim. Epidemiological categories, organized around distinct ‘risk groups’ (for example, men who have sex with men, intravenous drug users, people from a county where HIV is endemic), had no place for transsexual women or transsexual men. Unrecorded in official statistics, the extent of the epidemic among transsexual women remained hidden.*⁶⁹

And once data become available, it was clear that the epidemic among trans women has had the highest infection rates in the country. The relationship between data collection and public health concerns was mentioned by many:

*We can only estimate the full extent of LGBT disparities due to a consistent lack of data collection on sexual orientation and gender identity. No federal health survey includes a question on sexual orientation or gender identity, and only a few states ask respondents their sexual orientation or gender identity, severely limiting researchers’ ability to fully understand the LGBT population’s needs and hindering the development of public policies and programs that seek to improve the LGBT population’s health and well-being.*⁷⁰

As mentioned in the background and literature review section, many states have started collecting gender identity information in their public health surveys, but the addition of these

⁶⁸ “Healthy People 2020 Transgender Health Fact Sheet.”

⁶⁹ Namaste, “Undoing Theory.”

⁷⁰ Krehely, “How to Close the LGBT Health Disparities Gap.”

data collection practices have yet to accumulate much data with the first datasets being published in 2017.

Many of the comments had thoughts about larger system design issues as they intersected with concerns about data structures. Below, the author brings to the forefront the importance of understanding gender data structures as they fit into large, complex administrative regimes and administrative systems:

It moves us away from an uncritical call to 'be counted' by the administrative mechanisms of violent systems and instead allows us to strategize our interventions on these systems with an understanding of their operations and their tendencies to add new categories of legibility as methods of expanding their control. This is particularly meaningful given that quests for recognition and inclusion tend to forgo such politics in favor of being incorporated into harmful systems and institutions.⁷¹

Theme: Medicalization of Gender

There are many aspects to the medicalization of gender, from identity documents to medical interventions (e.g. surgeries and other procedures) that came up in the research materials, but the central aspect to the theme is the placement of medical professionals in the position of arbitrating legal gender (mentioned above). In California, the change of gender process for the vital records office requires a form/letter from a physician attesting that the gender change is medically supervised and permanent. However, the process is not standardized and the requirements vary from state to state. The federal policies were made

⁷¹ Spade, *Normal Life*, 154.

more coherent in the last 5 years, but it remains unclear as to whether those changes will persist in the current political climate.

The complex relationship between medical gender and legal gender is something that comes up again and again across the materials. From the moment of birth to the moment of death, legal gender interacts with social and medical gender in complex ways. For example, most EMRs do not fully support the use of a preferred name field, which precipitates unique workarounds for clinics serving trans and gender variant patients:

With our EMR, it will say 'first name, last name', and then there's a section for a preferred name or nickname. And we've learned that, unfortunately, the preferred name often doesn't show up as the name on the patient's chart. And that's not what we want to see, right? So we often do it the other way around. We put the name of choice in the regular field and then any kind of other legal name (or name that has to be documented), we put that in the preferred name section. We honor our patients preferred identities and names. [the EMR] doesn't have any other options other than male or female for sex assigned at birth, so what we'll do is, because we only prescribe either testosterone or estrogen, we figured out a way to say that if we prescribe you testosterone, we are going to identify you as male on here. And if you are being prescribed estrogen, we are going to describe you as female on here. And that's only for medications. And if we want to gather different information around identities, we gather that on a different document⁷².

These comments demonstrated the commitment of the organization to providing competent care for trans and gender variant communities, but they also showed how these systems are being adapted and reconfigured to accommodate populations that do not 'fit' the paradigms embodied within the structures of the recordkeeping software. In this instance, the GHC is using hormone status to designate gender. While a little unusual, using hormone status to

⁷² Contreras, 20160627_Contreras.MP3.

represent gender offers one major advantage: hormone status provides a better (statistical) basis to evaluate bloodwork, laboratory tests, and disease risk compared to legal or social gender. When there is a mismatch between gender markers and hormone status, the reference values are incorrect, which often results in misinterpretations of bloodwork, laboratory tests, and disease risk by providers.

One substantial change observed over the course of this research was the advent of a ‘two-step’ method for asking about gender via two questions. The first question inquires about current gender and second one asks about sex assigned at birth. This format allows for persons who fully identify with their chosen gender within the binary (e.g. person A has transitioned from being assigned male at birth and currently identifies as a woman) to be able to disclose their past association with a different gender marker at birth. However, what has remained unclear is whether trans and gender variant persons who withhold or obfuscate their status would be any more likely to disclose via the ‘two-step’ method. Preliminary studies indicate that they would not answer the birth gender question if they do not wish to disclose their status, but these studies have not disclosed the non-response rates for the two individual questions. Earlier studies (circa 2000) indicated that only about 55% of transgender people disclosed their gender transition and/or gender identity to their healthcare provider⁷³.

Another major aspect to the medicalization of gender is the process of enabling gender healthcare practices to pass through the normal billing and policy systems. Many people have

⁷³ Ettner, Monstrey, and Eyley, *Principles of Transgender Medicine and Surgery*, 33.

commented on the lack of the healthcare system to be able to deal with exceptions to the gender rules hardcoded into their processes:

Once the carrier labels the patient as transgender or transsexual, many types of coverage may be routinely denied, where they would be covered for patients who are not identified as transgender or transsexual. Physicians or their support staff members may need to interact with insurance claims processors on behalf of their transgender or transsexual patients to insist that medically necessary treatments are covered.⁷⁴

In 2014, Lyon Martin had a full-time employee dedicated solely to dealing with these billing and insurance issues, as the insurance companies did not have the processes in place to be able to deal with transgender procedures and billing exceptions, despite a state policy environment that has essentially banned such categorical exclusions since the mid-2000s (see also the Background section). The transgender health outreach project in South Los Angeles had similar comments about billing and insurance issues:

While building the sensitivity and cultural competence took care and time – in retrospect, it was a walk in the park compared to the health plan denials (particularly for Medi-Cal patients), and abject violation of federal and state law, which our patients have experienced time and time again in attempting to access the health care to which they are entitled. This systematic denial of service is outlined throughout the white paper to follow, and specifically in the final section. Despite a mandate for transgender services outlined in the Affordable Care Act, an “All Plan Letter” issued to all Medi-Cal managed care health plans in 2013 by the California Department of Health Care Services and a Supreme Court “Writ of Mandate” on this topic issued in 2001 – our

⁷⁴ “Primary Care Protocol for Transgender Patient Care: Primary Care Protocol for Transgender Patient Care.”

*transgender patients are consistently and uniformly denied access to basic trans healthcare services*⁷⁵.

Similarly, the lack of education and awareness comes up again and again, with different facets:

*Beyond insurance coverage, access to care is limited by the dearth of physicians who focus on, or are comfortable with, providing care for transgender people. A stark example is the paucity of surgeons performing genital reconstructive surgery: As of 2012, only 6 identified surgeons in the United States performed genital reconstructive surgery, thus limiting options for people seeking this surgery.*⁷⁶

Theme: Barriers to Care

Many of the problems that trans and gender variant populations have with accessing health care are grouped under the term ‘barriers to care’, both in the literature and in informal dialog. Many comments referenced different types of barriers to healthcare:

*LGBT people and people living with HIV are too often denied the care they need because of their sexual orientation, gender identity and/or HIV status. Almost 8 percent of LGB respondents reported that they had been denied needed health care outright. Over a quarter of all transgender and gender-nonconforming respondents (almost 27 percent) reported being denied care and 19 percent of respondents living with HIV also reported being denied care.*⁷⁷

⁷⁵ Sussman et al., “Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles,” 2–3.

⁷⁶ Stroumsa, “The State of Transgender Health Care.”

⁷⁷ “When Health Care Isn’t Caring.”

Denials of care are one particularly worrisome aspect of barriers to care, as most denials of care run counter to decades of healthcare policy and provider ethics. They often act as an indicator of overall stigma and social exclusion within the culture of the organization:

Respondents also encountered high levels of mistreatment when seeking health care. In the year prior to completing the survey, one-third (33%) of those who saw a health care provider had at least one negative experience related to being transgender, such as being verbally harassed or refused treatment because of their gender identity. Additionally, nearly one-quarter (23%) of respondents reported that they did not seek the health care they needed in the year prior to completing the survey due to fear of being mistreated as a transgender person, and 33% did not go to a health care provider when needed because they could not afford it.⁷⁸

The problem of barriers to care was discussed extensively and understood implicitly by virtually all of the providers working in the field of transgender medicine, although many providers were oriented to the individual level rather than the aggregate collective processes that occur within recordkeeping systems:

Nearly 21 percent of transgender and gender-nonconforming respondents reported being subjected to harsh or abusive language from a health care professional, and almost 8 percent reported experiencing physically rough or abusive treatment from a health care professional. Over 20 percent of transgender and gender-nonconforming respondents reported being blamed for their own health conditions.

In almost every category measured in this survey, transgender and gender-nonconforming respondents reported experiencing the highest rates of discrimination and barriers to care. Transgender and gender-nonconforming respondents reported facing barriers and discrimination as much as two to three times more frequently than lesbian, gay or bisexual respondents.

⁷⁸ James et al., "The Report of the 2015 U.S. Transgender Survey (USTS)," 3.

In nearly every category, a higher proportion of respondents who are people of color and/or low-income reported experiencing discriminatory and substandard care. For example, close to 33 percent of low-income transgender and gender-nonconforming respondents reported being refused care because of their gender identity and almost a quarter of low-income respondents living with HIV reported being denied care.

Respondents reported a high degree of anticipation and belief that they would face discriminatory care and such concerns were a barrier to seeking care. Overall, 9 percent of LGB respondents are concerned about being refused medical services when they need them, and 20 percent of respondents living with HIV and over half of transgender and gender-nonconforming respondents share this same concern.⁷⁹

Reading through these higher level synopses of barriers to care makes clear the system level nature of barriers to care for trans and gender variant populations.

Many of the providers working with records management noted the artifacts of systemic marginalization and/or institutionalized violence:

*We were supposed to go live with our EHR [electronic health record system] last year, in July. We chose a vendor. We told them ‘this is our patient population, thirty-some-odd percent of our patients identify as trans, genderqueer or gender variant’. We cannot have the system not work for us. And they told us, ‘we can definitely do that’. But then once we actually went live with the EPM portion (the billing and scheduling portion)... We ran into issues after the fact: It actually genderizes...It puts blue male symbols and pink female symbols next to a name based on the gender markers from the insurance [e.g. legal gender and not medical gender]. ... So we have to create workarounds within the scheduling system even just to make it work for us....which there is an element of **‘[this is so] typical’ right? [sigh] That it is always the case around queer community in general, having to make it safe for us⁸⁰**. [emphasis added]*

⁷⁹ “When Health Care Isn’t Caring.”

⁸⁰ Sekera, 20140502 - Elizabeth Sekera - Interview.

These barriers to care also played a role in the architecture of services of clinics that are successfully serving trans and gender variant populations:

We're getting a lot of our patients into care elsewhere - Our advocacy program is geared to help our patients find ways to use their current healthcare to get access to hormones or to whatever surgeries they might be interested in or anything like that. Our advocates work one-on-one to make phone calls to insurance companies. Or we will often collect provider information from other community members that are having good experiences with providers - making soft referrals - which is essentially getting folks out of this kind of stop-gap service that we have (it's a free service) and into a primary care setting where they can access a multitude of other services if they so wish.⁸¹

In the comments about barriers to care, one can see tensions around access and marginalization that operate in large networks of aggregate interactions across healthcare providers, time, bodies and institutions.

Theme: Education

Education was another major arena where erasure and invisibility was discussed extensively, especially in relation to discussions of 'barriers to care' and the 'medicalization of gender':

Due to the social and institutional stigma against transgender people, their care is excluded from medical training. Therefore, providers approach medical encounters with transgender patients with ambivalence and uncertainty. Transgender people anticipate that providers will not know how to meet their needs. This uncertainty and ambivalence in the medical encounter upsets the normal balance of power in provider/patient relationships⁸².

⁸¹ Contreras, 20160627_Contreras.MP3.

⁸² Poteat, German, and Kerrigan, "Managing Uncertainty."

Most trans populations and population surveys mention the challenge of having to teach their providers how to ‘do’ transgender medicine, so much so that the last two national surveys have surveyed to find out the rate at which trans people are having to teach their providers how to manage their health:

When respondents saw medical providers, including doctors, they often encountered ignorance about basic tenets of transgender health... Fully 50% of study respondents reported having to teach providers about some aspect of their health needs....Over one-quarter of respondents (28%) reported verbal harassment in a doctor’s office, emergency room, or other medical setting and 2% of the respondents reported being physically attacked in a doctor’s office⁸³.

The comments from physicians were equally challenging:

All but one of the medical providers expressed feeling either ambivalent about or unprepared for transgender patients. The endocrinologists who were interviewed felt medically prepared to manage hormones yet expressed ambivalence about the psycho-social issues raised by their transgender patients. Several providers (both primary care and endocrinologists) struggled with the concept of transgender altogether and expressed ambivalence about the necessity for gender confirming therapies, even though they prescribed them.

‘I find the whole area difficult. Nobody really understands it. I don’t. I’m accepting of it because I see it, and I believe it, but obviously we don’t understand it . . . So part of me wants to sort of say like, “Can’t you just dress as a woman,” or “Can’t you just be a tomboy and not have to get involved with hormones and stuff?” – Endocrinologist’

Providers who felt uncertain about the appropriateness of transgender care described strategies to manage this ambivalence. Most providers sought a specific narrative of lifelong discomfort with natal sex as confirmation that patients met criteria for gender affirming therapies and many required a letter from a

⁸³ Grant et al., “National Transgender Discrimination Survey Report on Health and Health Care,” 6.

*mental health provider confirming a diagnosis of Gender Identity Disorder. All of the primary care providers reported feeling unprepared for their first medical encounter with a transgender patient.*⁸⁴

The lack of training of medical professionals in dealing with issues of gender variance has long been recognized as a major issue for LGBT populations, exacerbating problems of exclusion and mistreatment in medical contexts:

*Informational erasure encompasses both a lack of knowledge regarding trans people and trans issues and the assumption that such knowledge does not exist even when it may. It is manifest in research studies, curricula, and textbooks and in the information learned by or readily accessible to health care providers and policy makers*⁸⁵.

The lack of coverage of trans populations and gender variance in medical education means that these populations have not been included in the cycles of scholarly research that yield publications of data and produce the evidence to build evidence based medical practice:

*Long-term prospective studies for most transgender-specific health issues are lacking, thus resulting in variable preventive care recommendations based primarily on expert opinions*⁸⁶.

Unfortunately, these intersections of precarity, invisibility, and stigma result in interactions that are shattering for the patients in this context:

I am transgender (female to male), and have been trying desperately to get into some sort of gender therapy for hormones and surgery. Unfortunately, most of the folks who I have dealt with in the medical community ... have no background, or do not want anything to do with my journey. [The psych evaluation] was nothing but pure hell. That group is very much anti-trans. ... I have never been so offended, or

⁸⁴ Poteat, German, and Kerrigan, "Managing Uncertainty."

⁸⁵ Bauer et al., "I Don't Think This Is Theoretical; This Is Our Lives," 352.

⁸⁶ Ettner, Monstrey, and Eyler, *Principles of Transgender Medicine and Surgery*, 34.

*insulted in my entire life. It was by far the worst experience in all 41 years of my life. I did not know that I could have gotten up and walked out of that because I would have. **I am the second only female to male transgender individual that they have ever evaluated before.** ... Like I said, it was very traumatizing. I would strongly not recommend anyone who is anything but heterosexual to go to Johns Hopkins. **I feel like I was mentally raped.** I am writing you with tears running down my cheek because of just how horrible it was. I even filed a complaint with the State of MD against them, but was told that they have insufficient evidence to warrant an investigation. **I was just a lab rat for the residents.** That is all.⁸⁷*
[emphasis added]

With the above comments taken into context with the whole situation, it is not surprising that a substantial fraction of the population categorically avoids medical care and identity disclosure:

Lack of health care insurance, experiences of discrimination in the health care setting, lack of access to medical personnel competent in transsexual medicine, and (for some) discomfort with the body can lead the transgendered patient to avoid medical care altogether⁸⁸.

It is then also unsurprising that there are so many stories of trans people dying for lack of appropriate health care. Fortunately, over the period of 2000-2018, these stories have become less frequent, but no less harrowing⁸⁹. For example, currently there is a public health crisis around dangerous street injections of silicone to increase the appearance of curves. It has remained a deadly risk for trans women⁹⁰ and cis-women alike for about a decade now.

Many healthcare providers have been operating in direct engagement with these problems of education and medical expertise with transgender health issues. All of the

⁸⁷ <http://www.tsroadmap.com/info/johns-hopkins.html>

⁸⁸ Ettner, Monstrey, and Eyley, *Principles of Transgender Medicine and Surgery*, 34.

⁸⁹ Ravishankar, "The Story About Robert Eads |."

⁹⁰ Edgar, "Silicone Injections Are Deadlier Than Ever."

research sites were aware and engaged increasing quality of care for trans patients. Lyon Martin has been testing various lightweight administrative structures in order to bring providers together across different provider networks to share expertise and ask questions about trans medicine:

...the Transgender Law Center and Lyon Martin Health Services, an LGBT community clinic in San Francisco, created Project HEALTH (Harnessing Education, Advocacy and Leadership in Transgender Health), a collaboration that works to improve access to transgender health care throughout the state of California. Project HEALTH was designed as a provider-community partnership to provide technical expertise to clinics and other medical providers in order to increase capacity to provide care to the transgender community⁹¹.

One of these projects that Lyon Martin has been involved with has been 'Transline':

Providers submit questions and we answer so they are able to provide care to their patients. They have a professional outlet for questions that they may consider silly, or questions that they would normally actually ask patients. That's what we've found in the past, that when they don't know, they ask the patient, when really they need a professional contact in order to not objectify or tokenize their patients.

And it's been really amazing. Some folks who now have the support of the trans line have started their own trans clinics and they are becoming known in their community. There are a few I can think of, one in MI, one in Ohio, um, and I want to say it's in Nebraska. Someone recently who was talking to the medical director. She was saying 'Since I've been using the trans line, I feel so much more confident in my care (and I know that I have the backup), so I'm fine

taking on whomever or whatever. ‘ I never realized how much of a need there was of competent care⁹².

The medical and administrative staff at Lyon Martin had invested substantially in patient-centered care, but were also remarkably focused on issues of education and capacity building for such a small community clinic. This capacity building included building expertise networks such as the ‘Transline’, hosting Americorp volunteers and offering formal clinical rotations for training providers.

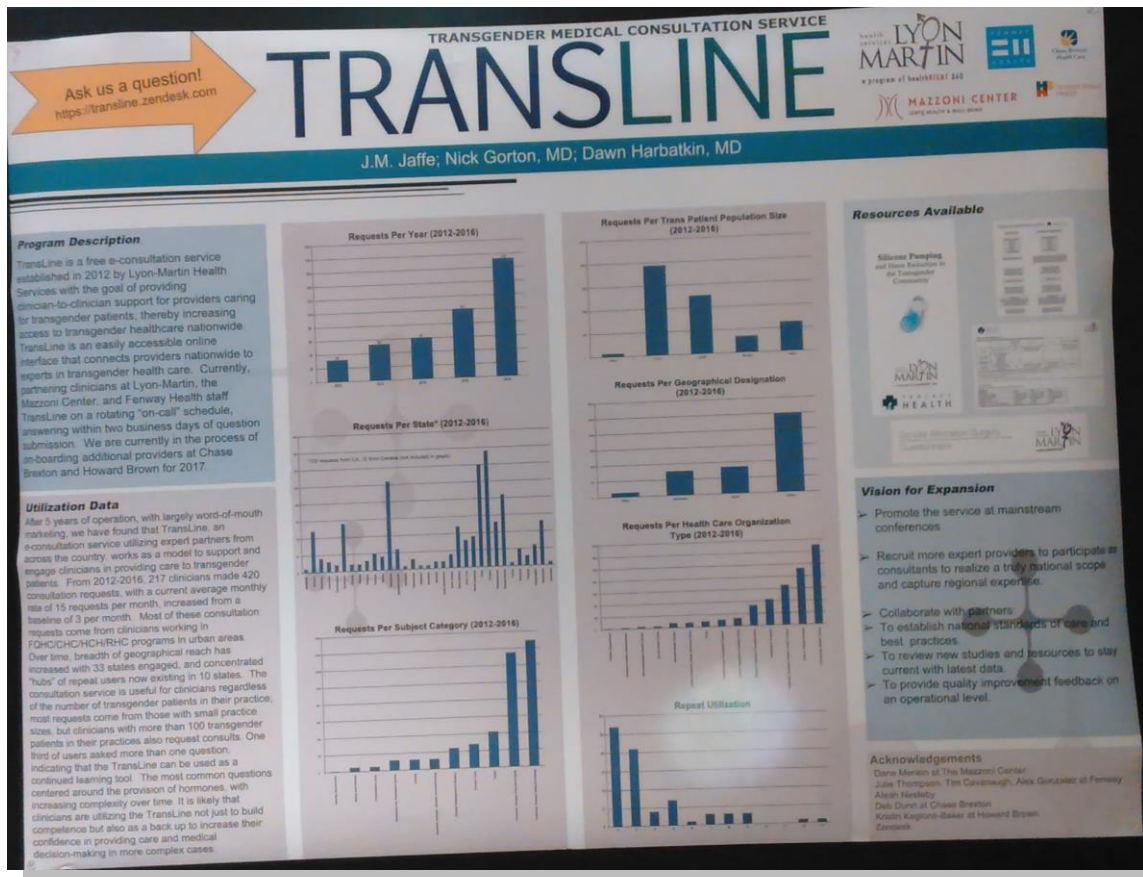


Figure 25: Image of TransLine Poster from WPATH/USPATH conference at UCLA (2017)

⁹² Sekera, 20140502 - Elizabeth Sekera - Interview.

CITED REFERENCES (ANALYSIS)

- AMA House of Delegates. "American Medical Association Resolution 122: Removing Financial Barriers to Care for Transgender Patients." American Medical Association (AMA), April 18, 2008. <http://www.uclgbtia.org/AMA-TransInsuranceResolution.pdf>.
- Bauer, Greta R, Rebecca Hammond, Robb Travers, Matthias Kaay, Karin M Hohenadel, and Michelle Boyce. "‘I Don’t Think This Is Theoretical; This Is Our Lives’: How Erasure Impacts Health Care for Transgender People." *The Journal of the Association of Nurses in AIDS Care: JANAC* 20, no. 5 (October 2009): 348–61. <https://doi.org/10.1016/j.jana.2009.07.004>.
- Beauchamp, Toby. "Artful Concealment and Strategic Visibility: Transgender Bodies and US State Surveillance After 9/11." *Surveillance & Society* 6, no. 4 (2009).
- Bettcher, Talia Mae. "Evil Deceivers and Make-Believers: On Transphobic Violence and the Politics of Illusion." *Hypatia* 22, no. 3 (2007): 43–65.
- Brown, George R., and Kenneth T. Jones. "Racial Health Disparities in a Cohort of 5,135 Transgender Veterans." *Journal of Racial and Ethnic Health Disparities* 1, no. 4 (December 2014): 257–66. <https://doi.org/10.1007/s40615-014-0032-4>.
- Cartwright, Donna, Kara Desiderio, Jamison Green, Maceo Persson, and Jason Tescher. "Organizing for Transgender Health Care: A Guide for Community Clinic Organizing and Advocacy." San Francisco, California: Transgender Law Center, 2012. <http://www.thecentersd.org/pdf/health-advocacy/organizing-for-transgender.pdf>.
- CHIS. "CHIS: A Leading Source of Population-Based Lesbian, Gay, Bisexual and Transgender Health Data." University of California, Los Angeles: UCLA Center for Health Policy Research, 2016. http://healthpolicy.ucla.edu/impact/Documents/CHIS_LGBT_2016.pdf.
- Chong, Stephen, and Meredith Wallis. "ID Please! A Guide to Changing California & Federal Identity Documents to Match Your Gender Identity." San Francisco, California: Transgender Law Center, 2014. http://transgenderlawcenter.org/wp-content/uploads/2012/05/ID_Please_FINAL_7.25.14.pdf.
- Clements-Nolle, Kristen, Mitchell Katz, and Rani Marx. "The Transgender Community Health Project." San Francisco, California: SF Dept of Public Health, 1999. <http://hivinsite.ucsf.edu/InSite?page=cftg-02-02>.
- Cole, Cheryl L., and Shannon LC Cate. "Compulsory Gender and Transgender Existence: Adrienne Rich’s Queer Possibility." *WSQ: Women’s Studies Quarterly* 36, no. 3–4 (2008): 279–87. <https://doi.org/10.1353/wsqr.0.0088>.

- Contreras, Alejandro. 20160627_Contreras.MP3. Interview by L. Wynholds, June 27, 2016.
- Currah, Paisley, and Shannon Minter. "Unprincipled Exclusions: The Struggle to Achieve Judicial and Legislative Equality for Transgender People." *Wm. & Mary J. Women & L.* 7 (2000): 37.
- Department of Insurance. "Implementation of AB 1586: Insurance Gender Non-Discrimination." Bulletin. State of California, January 3, 2007. http://www.insurance.ca.gov/0250-insurers/0300-insurers/0200-bulletins/bulletin-notices-commiss-opinion/upload/bulletin_2007_2.doc.
- Edgar, Jolene. "Silicone Injections Are Deadlier Than Ever." *Harper's BAZAAR*, January 30, 2018. <https://www.harpersbazaar.com/beauty/health/a14478122/silicone-injection-danger/>.
- Ettner, Randi, Stan Monstrey, and Eli Coleman. *Principles of Transgender Medicine and Surgery*. Routledge, 2016.
- Ettner, Randi, Stan Monstrey, and A. Evan Eyler. *Principles of Transgender Medicine and Surgery*. New York: Haworth Press, 2007.
- Farmer, Paul. "An Anthropology of Structural Violence." *Current Anthropology* 45, no. 3 (June 1, 2004): 305–25. <https://doi.org/10.1086/ca.2004.45.issue-3>.
- Fry, Jane. "Conclusion: On the Records." In *Being Different: The Autobiography of Jane Fry.*, edited by Robert Bogdan, 213–33. New York: Wiley, 1974.
- Gainor, Kathy A. "Including Transgender Issues in Lesbian, Gay and Bisexual Psychology." *Education, Research, and Practice in Lesbian, Gay, Bisexual, and Transgendered Psychology: A Resource Manual* 5 (2000): 131–160.
- "GLMA Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients." Gay and Lesbian Medical Association (GLMA). Accessed June 27, 2014. http://www.glma.org/_data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster, 1963.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling. "Injustice at Every Turn: A Report of the National Transgender Discrimination Survey." Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011. http://www.thetaskforce.org/static_html/downloads/reports/reports/ntds_full.pdf.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jody L Herman, Jack Harrison, and Mara Keisling. "National Transgender Discrimination Survey Report on Health and Health Care."

- National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- Hale, C. J. "Consuming the Living, Dis (Re) Membering the Dead in the Butch/FTM Borderlands." *GLQ: A Journal of Lesbian and Gay Studies* 4, no. 2 (1998): 311.
- . "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients." *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505. <https://doi.org/10.1353/pbm.2007.0047>.
- "Healthy People 2020 Transgender Health Fact Sheet," November 2010. <http://www.lgbttobacco.org/files/TransgenderHealthFact.pdf>.
- James, Sandy E., Jody L. Herman, Sue Rankin, Mara Keisling, Lisa A Mottet, and Ma'ayan Anafi. "The Report of the 2015 U.S. Transgender Survey (USTS)." Washington, DC: National Center for Transgender Equality, 2016. <http://www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF>.
- "Just Released: APA Guidelines for Working With Transgender, Gender-Nonconforming People | Trans Health," 2015. <http://www.trans-health.com/2015/apa-guidelines-transgender-gender-nonconforming/>.
- Kauth, Michael R., Jillian C. Shipherd, Jan Lindsay, John R. Blosnich, George R. Brown, and Kenneth T. Jones. "Access to Care for Transgender Veterans in the Veterans Health Administration: 2006–2013." *American Journal of Public Health* 104, no. S4 (2014): S532–S534.
- Kosenko, Kami, Lance Rintamaki, Stephanie Raney, and Kathleen Maness. "Transgender Patient Perceptions of Stigma in Health Care Contexts." *Medical Care* 51, no. 9 (September 1, 2013): 819–22.
- Krehely, Jeff. "How to Close the LGBT Health Disparities Gap." Center for American Progress, December 21, 2009. <http://www.americanprogress.org/issues/lgbt/report/2009/12/21/7048/how-to-close-the-lgbt-health-disparities-gap/>.
- Link, Bruce G., and Jo C. Phelan. "Conceptualizing Stigma." *Annual Review of Sociology*, 2001, 363–385.
- Minter, Shannon. "Do Transsexuals Dream of Gay Rights-Getting Real about Transgender Inclusion in the Gay Rights Movement." *NYL Sch. J. Hum. Rts.* 17 (2000): 589.
- Namaste, Viviane. "Undoing Theory: The 'Transgender Question' and the Epistemic Violence of Anglo-American Feminist Theory." *Hypatia* 24, no. 3 (July 1, 2009): 11–32.

- Poteat, Tonia, Danielle German, and Deanna Kerrigan. "Managing Uncertainty: A Grounded Theory of Stigma in Transgender Health Care Encounters." *Social Science & Medicine* 84 (May 2013): 22–29. <https://doi.org/10.1016/j.socscimed.2013.02.019>.
- "Primary Care Protocol for Transgender Patient Care: Primary Care Protocol for Transgender Patient Care," 2011. <http://transhealth.ucsf.edu/trans?page=protocol-00-00>.
- Ravishankar, Mathura. "The Story About Robert Eads |." *Journal of Global Health Online* (January 18, 2013). <http://www.ghjournal.org/jgh-online/the-story-about-robert-eads/>.
- Reisner, S. L., K. J. Conron, Scout, K. Baker, J. L. Herman, E. Lombardi, E. A. Greytak, A. M. Gill, and A. K. Matthews. "'Counting' Transgender and Gender-Nonconforming Adults in Health Research: Recommendations from the Gender Identity in US Surveillance Group." *TSQ: Transgender Studies Quarterly* 2, no. 1 (January 1, 2015): 34–57. <https://doi.org/10.1215/23289252-2848877>.
- Scout. "Déjà Vu: National Surveys Leave Trans People Behind." *Huffington Post* (blog), June 13, 2013. http://www.huffingtonpost.com/scout-phd/national-health-interview-survey-transgender_b_3428446.html.
- Sekera, Elizabeth. 20140502 - Elizabeth Sekera - Interview. Interview by L. Wynholds. 3gpp audio file, May 2, 2014.
- Serano, Julia M. "The Case Against Autogynephilia." *International Journal of Transgenderism* 12, no. 3 (October 12, 2010): 176–87. <https://doi.org/10.1080/15532739.2010.514223>.
- Shapiro, Eve. "'Trans'cending Barriers: Transgender Organizing on the Internet." *Journal of Gay & Lesbian Social Services* 16, no. 3–4 (2003): 165–179.
- Shrage, Laurie. "Does the Government Need to Know Your Sex?" *Journal of Political Philosophy* 20, no. 2 (2012): 225–247. <https://doi.org/10.1111/j.1467-9760.2010.00379.x>.
- Spade, Dean. *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law*. South End Press Cambridge, MA, 2011.
- . "Resisting Medicine, Re/Modeling Gender." *Berkeley Women's Law Journal* 18 (2003): 15.
- Stone, Sandy. "The Empire Strikes Back: A Posttranssexual Manifesto." *Camera Obscura: Feminism, Culture, and Media Studies* 10, no. 2 29 (1992): 150.
- Stroumsa, Daphna. "The State of Transgender Health Care: Policy, Law, and Medical Frameworks." *American Journal of Public Health* 104, no. 3 (2014): e31–e38.
- Sussman, Rebecca, Felix Vargas, Aydin Kennedy, Shom Dasgupta, and Jim Mangia. "Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in

- South Los Angeles." Los Angeles, California: St. John's Well Child and Family Center, 2015. <http://www.wellchild.org/sjwcfcfinalthpwhitepaper.pdf>.
- Tebbe, Esther N., and Bonnie Moradi. "Anti-Transgender Prejudice: A Structural Equation Model of Associated Constructs." *Journal of Counseling Psychology* 59, no. 2 (April 2012): 251–61. <http://dx.doi.org/10.1037/a0026990>.
- Turner, Ilona M. "Sex Stereotyping per Se: Transgender Employees and Title VII." *California Law Review* 95, no. 2 (April 1, 2007): 561–96. <https://doi.org/10.2307/20439102>.
- VanOra, Jason, and Suzanne C. Ouellette. "Beyond Single Identity & Pathology: Revealing Coherent Multiple Selves and Transformative Activism in the Narratives of Two Transgender Women." *International Review of Qualitative Research* 2, no. 1 (May 1, 2009): 89–115.
- "When Health Care Isn't Caring." New York: Lambda Legal, 2010. http://data.lambdalegal.org/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.
- Witten, Tarynn M., and A. Evan Eyler. "Hate Crimes and Violence against the Transgendered." *Peace Review* 11, no. 3 (1999): 461–468. <https://doi.org/10.1080/10402659908426291>.

CHAPTER 7: DISCUSSION

7.1 Framing the Data Analysis 276

 The Making of Records 278

 The Making of Archives..... 279

 The Making of Narratives..... 280

 On Turning Narratives into Policy 281

7.2 Recommendations for Best Practices 282

Cited References (Discussion)..... 285

7.1 FRAMING THE DATA ANALYSIS

Caswell's groupings¹ of 'the making of records', 'the making of archives' 'the making of narratives' and 'the making of commodities' construct an excellent framework for discussing the data and results of this project in terms of the coproduction of health records, records in aggregate, data as evidence, the gray area of commodities, and the narrative based erasure of trans bodies. This framework, when examined in the context of health data, brings into focus questions of distilling records into evidence, evidence into narratives, and narratives into policy. This approach allows for more complex discussions, as there are deep tensions around who speaks for trans and gender variant populations in the US. Some of these tensions are related to problematic histories where the legitimacy of trans voices were treated dismissively.

The guiding questions for this research project have followed four main avenues of questioning, which also happen to correspond to the levels of abstraction discussed above, e.g making records, making archives, making narratives, and turning narratives into policy. The main avenues of questions in this research project have been:

- 1) How is gender and gender variance represented in electronic medical records and public health datasets?
- 2) Is the size of the trans population knowable? How do trans populations manage to remain uncounted in the massive volume of health data currently available for evidence based medicine? What does it mean for large health information datasets to contain

¹ Michelle Caswell, *Archiving the Unspeakable* (University of Wisconsin Press, 2014).

populations that are made invisible by the category construction? What does it mean for these datasets when they fail to represent marginalized populations?

- 3) What role to metadata structures, categorization and data structures play in the invisibility of trans populations in California's health care systems? How did substantial numbers of trans bodies come to be invisible under existing gender and diagnostic categories? How do these information and metadata structures relate to the provision of trans healthcare services and/or the lack thereof?
- 4) How do these information disparities affect the recordkeeping activities and abilities of institutions? Is it possible to observe secondary and tertiary effects of these information disparities?

Dividing the examination of record and data structures along different levels of micro/macro granularity allows for the formation of a narrative tracing the dependencies from the micro-focused individual data elements into the macro-focused health systems. The levels of abstraction presented here, from micro to macro, are:

- 1) Constituting measurements and metrics – e.g. the making of records
- 2) Constituting records and data – e.g. the making of archives
- 3) Constituting evidence based medical studies and public health datasets – e.g. the making of narratives
- 4) Constituting health care systems and health care policy – e.g. turning narratives into policy

The archival frameworks around granularity are particularly relevant to the discussion of the results of this study, as it has also become clear to most healthcare professionals and LGBTIQ scholars that anecdotal data is inadequate for observing systemic effects of social marginalization.

The Making of Records

The research materials indicated that there are six (6) major functional (information) recordkeeping elements conflated under the current system of binary gender markers. The first element revolves around one's internal sense of gender, also commonly referred to as 'gender identity' (1). The second element revolves around the gender one engages in socially (2) including aspects such as pronouns, gender performance, and gender roles. The third gender variable element revolves around the functional gender for medical care (3). Typically this is related to one's hormonal status/hormone regimen and impacts other health metrics substantially, as is the case for reference values for blood tests². The fourth data element relates to one's phenotypic gender at birth, also known as the sex assigned at birth (4). The final data element is the designation of gender for legal purposes (5), which includes billing and insurance processing purposes. Due to the vagaries of the legal system, not all trans and gender variant persons are able to update their legal gender for all of their identity documents and there are commonly incongruities between medical gender, sex at birth and legal gender.

The research showed evidence of a complex relationship between the lack of health care access for trans/gender variant people and the historical barriers in medical and health

² Tiffany K. Roberts et al., "Interpreting Laboratory Results in Transgender Patients on Hormone Therapy," *The American Journal of Medicine* 127, no. 2 (February 2014): 159–62, <https://doi.org/10.1016/j.amjmed.2013.10.009>.

data structures to recording gender variance. Rather than a direct barrier, it appeared as an additive sum of everyday frictions and failures of the socio-technical recordkeeping systems in interacting with trans and gender variant populations. The lack of inclusion in the representational affordances of the recordkeeping system illustrates another danger of marginalization, namely that of being reduced to individual/anecdotal data that cannot readily be aggregated into trends and health effects. These recordkeeping barriers resulted in being excluded for more than 50 years from modern, aggregate datasets that form the basis for current practices around evidence based healthcare.

The Making of Archives

The size of the trans and gender variant populations have been becoming increasingly knowable as improved data collection structures have been implemented. However, the dynamics of social marginalization make the disclosure of gender identity information fraught with risks. In addition to the issues of social stigma, the categorical data structures have substantial implications for scaling up electronic medical records for algorithmic based analysis of health conditions. Rigorous multivariate analysis of bimodal distributions requires numerical metrics of phenomena, rather than the nominal structure of categories present in a gender binary. The mathematics of numerical scales is simply more powerful than the mathematics of categories, and the world of big data is foundationally built on statistical models of data and data distributions.

The information structures are implicated in the ways in which the population has remained invisible and virtually undetectable in the existing data. While all of the study sites

had similar infrastructural frictions in serving trans and gender variant populations, some sites were exceptional in their proactive model of care and stewardship in managing the problems caused by such friction. Several of the hospital systems invested in changing their data collection practices to be able to record gender variance. The structural differences presented by scale were also notable – i.e. large hospital systems had to approach the problem with a different toolbox from the smaller community clinics, despite having highly similar overall goals. The research leaves open the question as to what aspects of the administrative and healthcare systems have allowed such extensive investment in the marginalization of this population via the denial of access to modern healthcare. However, given the inertial effects of a long history of marginalization, some of these information disparities will likely continue to persist for decades into the future.

The Making of Narratives

Modern health care requires evidence based analyses that are downstream of high quality datasets aggregated from records of health interventions and treatment outcomes. In this knowledge production modality, the lack of representation of gender variance within the original data definitions has resulted in several interrelated problems, namely lack of ability to discern this population within the datasets, the lack of inclusion in the aggregate health outcomes, lack of statistical power in the analysis and the erasure of this population in the evidence overall. Gender records stand at the headwaters of this data stream, as it one of the primary demographic variables for public health data and medical records alike. Gender and

age are used in virtually all medical records to create data structures that form the basis of statistical analysis such as reference values and metrics of disease.

Many social science researchers have concluded that stigma functions to delegitimize marginalized populations, to belittle their input, and to reduce their social status to less than human. The social erasure and invisibility of the population gives the illusion of tranquility, but one does not have to dig very deep to uncover reservoirs of deep anger at the social histories of marginalization that have enabled such treatment. Unfortunately, these frustrations fuel the tendency to dismiss the perspective of any outsider to the LGBT communities in question. Neither necessarily acknowledges that both perspectives have inherent weaknesses of subjective positionality, blind spots, and information disparities. This analytical approach has relied on the multiplicity of perspectives to expose the blind spots and tunnel visions of these subjectivities. Each perspective spans a locus of fluid and evolving rituals of interaction that are poorly approximated in the fixity of printed text.

On Turning Narratives into Policy

The information disparities in the functionality of the records in their ability to record gender variance suggests that we need to be more concerned with the edge effects of populations who are poorly represented within data structures, especially as these data structures are scaled up to include the general population writ large. The evidence corroborates the observation that less information collected in studies and records leads to less data driven medical treatments, and the more likely that providers will rely on biased and mistaken assumptions for questions of how to provide medical services their trans patients.

In addition to developing metrics for measuring gender variance, most population based evidence suggests that there are still many reasons for patients to withhold gender identity information from bureaucratic healthcare systems with histories of exclusion or violence. This suggests that recordkeeping practices cannot be changed without addressing basic safety and data security issues for trans and gender variant populations. However, the lack of ability to identify gender variant patients directly from their records has also been used to protect the identities of their transgender and gender variant patients from being singled out by hostile individuals and institutional policies. Patients will not share this information without better security protections for recording highly sensitive information such as gender identity or surgical histories.

The evidence indicates the widespread need for measures that protect patients from violence, stigma, harassment, substandard care and denials of medically necessary care. Future studies could include testing the effectiveness of interventions, such as requiring staff education before they are given access to sensitive information, or by implementing technical mechanisms by which staff must confirm support of the tenets of beneficence for these patients and treat patient information with higher standards of confidentiality. The evidence also indicates the need for clear mechanisms to deal with related problems when they arise.

7.2 RECOMMENDATIONS FOR BEST PRACTICES

This research project observed that there are a minimum of six elements conflated under current practices around assigning gender markers in medical records. The major data elements and related name fields discussed above are presented in the table below (Figure 26)

in the context of data structure recommendations. The privacy and security problems posed by records that structure health care interactions of socially marginalized populations remain the largest area of concern stemming from this research. The concern that trans and gender variant populations regularly risk social violence in order to access basic healthcare remains one of the most significant challenges for recordkeeping practices for this population, as the practice of medicine is broadly obligated to mitigate well-known risks that have been shown to place the patient in harm's way. The research materials demonstrated the importance of active educational interventions that healthcare providers and patients both have been investing in to address problems of systemic violence, marginalization, and barriers to care. The materials also demonstrate how extensively medical and public health provider communities value and invest in culturally competent care for marginalized populations.

Data Element	Data Structure Recommendation	Verification? Identity Dependencies?	Concerns/Explanation
Legal Name and any legal aliases	Must be able to accommodate records of multiple legal names or legal aliases, preferably with the ability to record details of the identity documents used to verify legal names. Name changes are very common, e.g. with marriage, divorce, adoption, immigration, etc.	Name(s) listed on identity documents	Legal name should be restricted to identity verification purposes, e.g. registration, billing and insurance functions. The risk of identity theft is too great to make this information universally available within the recordkeeping system.
Preferred Name	Patient should be able to designate their preferred name or nickname. The records should support the preferred name being used as the primary name listed in records supporting interactions with medical providers.	Name used by social acquaintances, name used to introduce oneself in public	Full legal name should be considered protected personally identifiable information within the EMR. Public facing name fields should be drawn from the preferred name field, if given.
Legal Sex	Because the procedures for updating gender markers vary from state to state and institution to institution, patients may have multiple documents with different genders listed on each document	gender listed on identity documents,	The recordkeeping system must be able to track legal identities of patients, including the gender listed for each identity document, e.g. social security records versus driver's license records.
Sex Assigned at Birth	Because birth certificates can be amended and/or sealed in some states, the recordkeeping system needs to be able to record references to both the original and the amended birth certificate information	birth certificate and/or vital records office	
Hormone Status	Must support records of temporal change with multiple types of hormone statuses (e.g. estrogen dominant with pre-pubescent levels, estrogen dominant with post-menopausal levels, testosterone dominant with post-pubescent levels, etc). Must also support flagging atypical hormone configurations such as those occurring in certain intersex conditions (e.g. CAH)	Hormone status is needed for correct medical interpretation of certain disease screenings, symptoms, and laboratory reference values.	Mismatches between hormone status and gender marker can potentially lead to serious misinterpretations of lab results, bloodwork, and other basic medical tests.
Preferred Pronoun	language around pronouns has been changing – if using semi-standardized options, consider including 'other' as a field option, e.g. male pronouns, female pronouns, non-binary pronouns, other: _____[fill in the blank]_____	social gender	Using the wrong pronoun in social interactions is alienating to the patient and disruptive to establishing the rapport necessary to conduct a medical encounter.
Organ Registry	Patient histories, medical imaging, surgical histories	Many gender-related medical procedures are dependent on organ configurations rather than legal gender, e.g. mammograms for breast tissue, prostate exams for prostates, etc.	An organ registry is critical to efficiently track surgical histories and manage atypical anatomical features for all populations. It is critical both for the provision of routine care and for the provision of emergency interventions.

Figure 26: Summary of Recommendations for Data Elements

CITED REFERENCES (DISCUSSION)

Barry, Kevin M., Brian Farrell, Jennifer L. Levi, and Neelima Vanguri. "Bare Desire to Harm: Transgender People and the Equal Protection Clause, A." *BCL Rev.* 57 (2016): 507.

Caswell, Michelle. *Archiving the Unspeakable*. University of Wisconsin Press, 2014.

Roberts, Tiffany K., Colleen S. Kraft, Deborah French, Wuyang Ji, Alan H. B. Wu, Vin Tangpricha, and Corinne R. Fantz. "Interpreting Laboratory Results in Transgender Patients on Hormone Therapy." *The American Journal of Medicine* 127, no. 2 (February 2014): 159–62. <https://doi.org/10.1016/j.amjmed.2013.10.009>.

CHAPTER 8: CONCLUSION

The research posited a close relationship between the lack of health care access for trans and gender variant populations and the inability of medical and health data structures to capture gender variance. Rather than a direct barrier, it appeared as an additive sum of everyday frictions and failures of the socio-technical recordkeeping systems in interacting with trans and gender variant populations. The burden of these failures seem disproportionately divided onto socially marginalized populations, resulting in an additive intersectionality of barriers to care not only for the LGBTIQ populations, but also for people of color, for people with disabilities, for poor people and for people with mental health issues. At every recordkeeping intersection, gender variant bodies run orthogonal to the information structures and cannot be recorded as such. Seen from the other side of the table, trans and gender variant persons have been socialized into using medical and health recordkeeping systems that have no embedded structures to account for gender variance. Every medical interaction makes them vulnerable to the whim and mercy of strangers, most of which have little to no training in working with LGBT populations.

8.1 Social Aspects

However, while all of the study sites had similar infrastructural frictions in serving trans and gender variant populations, some sites were exceptional in their proactive model of care and stewardship in managing the problems caused by such friction. The structural differences presented by scale were also notable – i.e. large hospital systems had to approach the problem

with a different toolbox from the smaller community clinics despite having similar goals. Both types of organizations were looking towards reducing barriers to care, educating the larger health care professional communities and increasing capacity in the health care system writ large. However, the organizations had substantially different organizational structures, scales of implementation, records systems, and approaches to patient care.

The research materials documented the development of practices around recording gender identity and sexual orientation for both public health and medical recordkeeping purposes at a critical historical moment, when practices were changing substantially. The research materials demonstrated a great deal of variability in approaches and heterogeneity of data structures in clinical practice. However, the research also documented the reduction in variability in public health practices as the disciplines formed a consensus on best practices using a ‘two-step method’ during the time period of the study. The push by public health data analysts, LGBT health advocates, and LGBT policy analysts to improve structural problems in gender recordkeeping structures was impactful and appeared to be instrumental in developing methods for widespread use in US public health surveys.

The analyses of this project encountered a great deal of evidence that the social processes around mitigating the negative social impacts of gendered recordkeeping systems for trans and gender variant patients can be cultivated successfully in small and mid-size clinics by actively managing institutional culture and supporting the educational development of individual staff. However, in larger hospitals and hospital systems, the open-ended sphere of social dynamics, e.g. the aggregate effects of social marginalization, tended to predominate and

require scaled-up institutional interventions, such as regular supervisor trainings, participation in grand rounds and targeted educational interventions with key members of the organization. This project observed a critical role of medical experts and uninitiated strangers voluntarily stepping into roles as allies to mitigate the adverse impacts of social marginalization at every level of healthcare interaction. Healthcare interactions appears to be one of the sheering fronts where meaningful interaction takes place, with healthcare providers and patients forming sites of active resistance to unspoken social inequality and prejudices in their routine practices with vital records and bodily functions.

During the course of this study, several major health data producers invested in changing their data collection practices to be able to record gender variance. However, given the long history of invisibility, notable information disparities have persisted and will persist into the foreseeable future. The information structures are implicated in the ways in which the population has remained invisible and virtually undetectable in the existing data. Discussions of the blind spots of record keeping practices that track gender and/or gender variance over time require a deeper discussion of the histories of medical and policy issues around gender markers.

8.2 Recordkeeping Structures

Unpacking current health recordkeeping systems in the United States yields a Pandora's box of information structures and standards, encountering a dizzying array of policy environments, embodied knowledge, representational systems and formal abstractions at every recordkeeping juncture and level of scale. In summary, in order for gender to be

marked in an information system, there must be a measurement of gender to apply. In the case of health data and medical recordkeeping, up to six different elements are conflated in assigning a gender marker. Forcing multiple complex gender elements to be conflated in the record via an exclusive binary creates representational problems for virtually all of the edge cases. For example, M and F tend to be categorized at birth based on anatomy, but the system fails to account for anyone who cannot immediately be assigned to a category, regardless of the anatomy involved.

8.3 Future Work

The evidence collected around this project suggests that encoding gender as a normative binary creates an assertion of expectation rather than a record of actual population demographics. Thus when recordkeeping systems attempt to quantify gender using oversimplified, multiply conflated variables, the binary categories break down under the natural levels of variance present in the population. Gendered traits do not occur statistically in discrete and concretely binary categories, but rather are distributed around one or more natural averages, as in a bimodal distribution. There is an efficiency of recordkeeping that is afforded by simplifying bimodal distributions into binary categories, but these efficiencies do not serve the recordkeeping needs of the long tail. Any research (or person) that is affected by variance in any of the six conflated elements is thus disadvantaged by recordkeeping practices reliant on binary gender markers. All forms of gender variance are invisible and uncountable when oversimplified binary gender markers are used to record gender for health research and medical recordkeeping purposes.

When scaling recordkeeping practices up for computational recordkeeping practices, numerical data structures are statistically more powerful than binary nominal categories typically used in assigning gender markers. Rather than attempting to bootstrap statistically weak data structures, medical recordkeeping should be investing in developing standardized approaches to measuring gendered traits. These gendered traits are already commonly parameterized to assign social, medical and legal gender, but not captured coherently or consistently in the records. None of the observed electronic medical recordkeeping systems were able to track all six elements effectively, and, surprisingly, none were as efficient in tracking gender information compared to previous paper-based recordkeeping structures. Public health data, compared to medical records, operates around completely different domain practices. The health data surveys focused on the two-step method rather than collecting all six elements, because it was neither appropriate, necessary, nor reliable to capture surgical histories, atypical anatomy or hormone status via a telephone survey. These surveys largely focused on recording changes in social and/or legal gender without much focus on medical gender. However, by identifying these six conflated data elements across both medical and public health contexts allows future researchers to better stratify their data for improved statistical power. This would allow historical datasets to be used in comparison with newly collected data, which in turn creates better evidence to feed into future health policy analyses and evidence based medicine.

8.4 Final Thoughts

Most research has suggested that institutionalized disparities behave additively, meaning that intersections of race, class, sex and gender increase the socio-cultural barriers to medical care to an insurmountable level. Trans and gender variant populations include some of the most economically marginalized groups, most socially marginalized populations, and populations least able to access basic medical care. As such, it is imperative for any information system to carefully consider the procedures in place to iteratively ‘fine tune’ systems as data practices evolve and expose the edge effects of structural inequalities within our data systems. When there is no mechanism by which to ‘fine tune’ the performance of the system to handle unintentional consequences, the additive effect of minor structural disparities can have the power to cripple the functionality of the medical records and health data for generations to come.

APPENDIX: HISTORICAL TIMELINE

1950s

Pop culture representations of LGBT persons in the 1950s were characterized by sensationalized pulp novels where the protagonists were portrayed as deeply flawed and suffering greatly from their transgressive sexuality and/or gender identity. At this time gender variance was considered a moral defect and criminalized. In the 1940s and 1950s, anti-sumptuary and lewd conduct laws prohibited cross-dressing and same sex displays of affection. These laws were used to legitimize harassment and arrests of LGBT populations across California and the US.



In Los Angeles in 1950, LAPD police chief William H. Parker declared them to be criminals guilty of “sex perversion” and made it his department’s top priority ¹. Anti-cross dressing laws required that persons wear at least three items of clothing assigned to their legal sex, e.g. men must wear at least 3 items of men’s clothing and vice versa. These laws were used as grounds to publically detain and strip-search LGBT people (with particular focus on LGBT people of color).

Figure 1: Photo from Los Angeles Daily News Collection, Dept of Special Collections, Young Research Library, University of California, Los Angeles.

At the same time, the first widely publicized/known ‘sex change’ surgeries were performed in Europe on a former GI (Christine Jorgensen) in the early 1950s. She became known internationally as having had a ‘sex change’. Her autobiography was published in 1967. At this time, trans and gender variant persons began approaching providers with requests to access the same kind of hormones and surgery that Christine Jorgensen had received.

¹ Lillian Faderman and Stuart Timmons, *Gay L.A.: A History of Sexual Outlaws, Power Politics, and Lipstick Lesbians* (Basic Books, 2006).

At this time, Harry Benjamin and John Money became known as leading researchers on sex and gender in the US. Harry Benjamin went on to architect a network of health professionals providing trans and gender variant persons with access to medical interventions such as surgery and hormones. This professional organization was initially named in his honor, The Harry Benjamin International Gender Dysphoria Association (HBIGDA), but was later renamed The World Professional Association for Transgender Health (WPATH).

While John Money was considered a leading research on sex/gender in the 1950s and 1960s, his research was called in to question by his former patients. He had been engaged in experimental 'corrective' surgeries on infants with genital abnormalities/damage and had concluded that male infants could be 'reconditioned' to be socially female if done at a very young age until several of his former infant patients spoke out against the practice. These types of surgeries and the marginalization of the patients who spoke up about it alienated many and fueled distrust of patients. Many were concerned about the ethics of experimenting with gender roles unbeknownst to the children who have to live with the consequences. Many felt they were being treated like lab rats.

1960s

The 1960s were colored by the larger social tensions and movements of the period including the civil rights movements, women's liberation movements, gay liberation movements and a social awareness of the problems of social marginalization.

1963 – Stigma: Notes on the Management of Spoiled Identity by Irving Goffman presents observations of social stigma and its management by socially marginalized classes of individuals, including LGBT persons and persons with disabilities. Personal information management and disclosure of LGBT status (or other stigmatized class) is of central importance to the discussion. Many of these observations were conducted in the San Francisco Bay Area while Goffman was a professor at UC Berkeley.

1966 – A doctor in Argentina was convicted of assault for performing SRS surgeries with the argument that the treatment constituted harm to the patient. The modification and/or removal of healthy organs was considered a transgression of the hippocratic tenant, 'do no harm'. Surgeons and physicians fear that similar cases will be brought in US courts.

1966 – The opening of the first gender clinic at Johns Hopkins University ²

John Money worked at this clinic and performed studies where he concluded that children with disorders of sexual development (formerly called intersex and/or hermaphrodites in the literature) could be successfully socialized as either boys or girls if the socialization was conducted from birth. Later, these experimental studies were found to have major ethical problems as several of these children came forward to contest his conclusions.

² Genny Beemyn, "A Presence in the Past: A Transgender Historiography," *Journal of Women's History* 25, no. 4 (2013): 113–21, <https://doi.org/10.1353/jowh.2013.0062>.

1966 – ‘The transexual phenomenon’ by Harry Benjamin published. “Benjamin was one of the first physicians (in the US) to conclude that psychoanalytic approaches to transsexualism were inappropriate because transsexuals did not have a mental disorder”. p. 132 (Gainor 2000, Califia 1997)

1969 – Stonewall riots involving marginalized LGBT people, primarily disenfranchised, transgender and gender variant persons and persons of color. As this historical event became iconic for pride celebrations around the country (in the 1970s), the origins were whitewashed to become more palatable for a white gay and lesbian majority. Transgender and gender variant persons continued to struggle for inclusion within both the burgeoning gay rights movement and society writ large, including major historical figures such as Silvia Rivera, Miss Major, and others.

1970s

1972 – ‘Men with the Pink Triangle’ published (in German) exposing the current erasure of the persecution of gays, homosexuals and gender variant men by Nazis during the Holocaust. In 1980, English speaking activists learn that these groups were labeled as social degenerates and persecuted at rates as high or higher (proportionally speaking) as Jews, Roma, and political prisoners. Additionally, these prisoners were subjected to some of the worst treatments and human rights abuses of any group in the concentration camps. Many of them were not even released from the concentration camps by the Allies, as they were still considered criminals under paragraph 175. (Paragraph 175 was not repealed until 1994)

1973 – Homosexuality was removed from the DSM-II (APA manual of psychiatric diseases). Gender variance (esp. gender role variance for men) continues to be designated a mental illness and the result of psychopathology. The existence of this diagnostic entity is based on the unproven assumption that gender is an exclusive binary with no discontinuities between biological sex, gender role, gender identity, gender presentation and gender performance, despite the fact that all of these terms are socially constructed concepts that have evolved to mean different things at various times. (Gainor p. 134)

1974 – Jane Fry’s autobiography (as written by her therapist) published. In the mid-1970s, a number of autobiographies and biographies of trans people were published. Her story is interesting because it includes commentary from her psychologist, R. Bogdan as well as contrasting comments made by other mental health professionals regarding Jane Fry. The commentary in her medical records demonstrates the stark contrast in epistemological standpoints between gender authenticity and psychopathology.

Bogdan wrote³, “According to Jane, most of her problems are not internal, but rather are imposed by others... her problems do not stem from the fact that she want to be a woman, but from the reactions others have to that desire... Her problems are compounded by having to

³ Jane Fry, “Conclusion: On the Records,” in *Being Different: The Autobiography of Jane Fry.*, ed. Robert Bogdan (New York: Wiley, 1974), 213–33.

deal with a system of authority and power which systemically prevents her from becoming what she knows she is.” (p. 214) The mental health professionals define her as the problem and devalue her definition of the situation by characterizing her behavior as a symptom of mental illness. “Her reluctance to accept their [psychiatrists’] interpretation...is devalued as being a manifestation of her inability to accept the ‘cause’ of her problems and is considered further evidence of her illness.” (p. 216)

These discussions demonstrate the both the productive partnerships as well as the deeply problematic misrepresentations of trans people by mental health professionals in the 1960s and 1970s. Unfortunately, many aspects of these deeply problematic definitions of psychopathology go on to become embedded in the language of the ICD 10 and DSM IV and DSM V.

1979 - "In 1979, Meyer and Reter published a study that purported to show "no objective improvement" in male-to-female transsexuals who had undergone sex reassignment surgery. The effect of this publication was immediate and far-reaching. The Hopkins gender clinic closed in the furor which followed, and other clinics folded in its wake. Of the more than 40 university-affiliated gender programs in the U.S., only three survived." ⁴ Later studies (in Europe) showed surgeries improved outcomes substantially and that post-surgery regrets were had by less than 1% of patients. At issue with the Meyer and Reter studies were the definitions of ‘objective improvement’ and who determined the criteria of improvement.

1979 – Gender clinic at Johns Hopkins shut down by Paul R. McHugh who made (similarly unfounded) claims that homosexual desire is ‘erroneous’ and that sex reassignment surgeries are ‘unsuccessful’ in treating the patients’ underlying psychological disorders. McHugh has continued these claims to this day, despite a substantial amount of quantitative data (primarily from Europe) and qualitative data contradicting these claims.

1979 – Formation of the Harry Benjamin International Gender Dysphoria Association and release of the first edition of their standards of care. The standards of care were created in response to the backlash and contestations of identity described above. The standards were created primarily as a framework of standards that would protect doctors and surgeons from legal challenges for being involved in prescribing hormones and/or performing surgeries. As such, it created gatekeeping roles for doctors and mental health providers that are unlike any other health condition or mental health diagnosis. On the one hand, the standards provide a pathway for trans people to navigate the medical system. On the other, it requires them to prove their sanity before giving them the authority to claim informed consent, something that is not required of any other population. It creates an unspoken standard of considering gender variant persons ‘unreliable unless proven otherwise’ ⁵.

⁴ D. Denny, “A Selective Bibliography of Transsexualism,” *Journal of Gay & Lesbian Mental Health* 6, no. 2 (2002): 35.

⁵ C. J Hale, “Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients,” *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505, <https://doi.org/10.1353/pbm.2007.0047>.

1980s

Backlash against the 1960s: Gender variant patients are told by many in the mental health establishment that the condition is a mental disorder and or a psychological disturbance, that they are psychotic and that sex reassignment surgeries would do nothing to treat their underlying psychological issues. Health care for trans-specific medical procedures became categorically excluded from insurance and governmental practices. It was deemed experimental and the benefit of these surgeries were called into question. The practice of informed consent for surgery was rejected by adversarial psychologists on the basis of the assertion that anyone who would want surgery must be mentally ill, and therefore cannot give informed consent. This same logic was applied to trans women who disagreed with certain psychologists' sexualizing their motivations for transitioning. The women were told that they were suppressing the real truth about themselves and that the psychologists 'knew better' than them. These disputes made many trans people deeply distrustful of medical and mental health professionals.

Trans and gender variant populations responded to the backlash by going underground and developing information networks of transgender friendly providers. Most of them found ways to access care while remaining invisible, passing as cisgender and erasing their pasts. Many of them started going overseas for surgery in nations less hostile to surgical interventions for trans persons. Stories of medical providers refusing to treat trans and gender variant persons remain ubiquitous within trans and gender variant communities from the 1980s throughout the 2000s.

These problems create substantial tensions between gender variant populations and the medical establishment, particularly with the mental health establishment, as illustrated by the McHugh's comments and/or the autogynephilia controversy.

1980 – 'Men with the Pink Triangle' translated and released in English by the Gay Men's Press (UK)

1980 – childhood GID and transsexualism added to DSM-III. Transsexualism remained the main category under DSM-III and was classified as a paraphilia (e.g. a disorder of sexuality). Treatment still presumes to be addressing an underlying form of psychopathology.

1987 – 'The Pink Triangle'⁶ makes the story of the persecution of homosexuals and gender variant persons under the Nazis during WWII widely accessible to North American audiences. The story galvanized a generation of gay rights activists who adopted the symbol of the Pink Triangle as a memorial for those who died for being LGBT and as a reminder of the dangers of prejudice. Many activists from this period hold Reagan and his administration accountable for the lack of responsiveness in the CDC to respond to the AIDS outbreak as a novel communicable disease.

⁶ Richard Plant, *The Pink Triangle: The Nazi War against Homosexuals* (New York: H. Holt, 1986).

HIV and AIDS epidemic results in the deaths of a large fraction of the gay men's and trans women's populations.

late 1980s - Queer theory and feminist theory become a part of the popular cultural discourse within many LGBT communities. Voices of people of color become a part of these discourses, to a larger degree than in the past.

1988 – Transgender population is estimated by academics at 0.01% of the general population based on the number of SRS-procedures completed in the US (but these estimates ignore the growing trend of medical tourism and the large number of surgeries being performed overseas). Other researchers put the estimate at 6% of the general population⁷.

1989 – Jesse Helms includes an amendment to the ADA specifically to have 'transsexualism' and 'gender identity disorder' excluded from the Americans with Disabilities Act. He argued that trans persons were unworthy of protections under the ADA and equated their need for medical interventions (such as surgeries or hormones) with self-harm.

1990s

1990 - Gender Trouble (1990), by Judith Butler presents the feminist argument that gender is performed as well as embodied. The book presents gender as a series of historically situated, socially constructed norms that articulate specific power relations.

1992 – Transgender Liberation by Leslie Feinberg (pamphlet) published, indicating a growing awareness of issues of trans representation within LGBT communities and popular culture.

ICD 10 is released in 1990 and adopted by member states in 1994. ICD 11 is not projected to be released until 2017. As a result of the very long timeframe between ICD versions, medical systems relying on ICD 10 codes (such as the VA) are using twenty and thirty year old terms stemming from DSM-II (1980) and DSM-IV (1994) diagnostic language for describing gender variant populations.

1994 – DSM-IV collapsed transsexualism and childhood GID into GID

1995 - The temporary installation of a giant pink triangle on Twin Peaks becomes a memorialized tradition during SF Pride weekend. The volunteer based foundation that maintains the pink triangle describes it as a visible yet mute reminder of man's inhumanity toward man. The Pink Triangle is a visceral reminder of 'what can happen when hatred and bigotry are allowed to become law'.

mid-1990s - Most UCs form student LGBT centers for organizing social support, advocacy, educational and awareness projects.

⁷ Tarynn M. Witten and A. Evan Eyler, "Hate Crimes and Violence against the Transgendered," *Peace Review* 11, no. 3 (1999): 461–468, <https://doi.org/10.1080/10402659908426291>.

1996 – ‘Don’t ask, don’t tell’ implemented as a policy for managing homosexuality in the US military, intended to be a softening of policy prohibiting gays in the military.

Studies conclude that LGBT students in college face substantial barriers to success (dropout rates, suicide, etc) These studies are used to bolster volunteer efforts to form campus LGBT centers for students. Initially organized and run by students, these LGBT centers are adopted into Student Affairs with professional support staff.

UCSD was the last campus to permanently fund their LGBT center with a director (in 2000).

2000s

2000 – (AB 2142) Bill includes gender identity protections in the State’s employment and housing anti-discrimination statutes.

2003 - Transgender advocacy one of the top concerns identified by student LGBT campus agenda survey (see uclgbtia historical docs p. 20)

2005 – AB1586 declares that insurance companies are not allowed to discriminate against trans persons by categorically excluding medically indicated treatment from plan coverage. Insurance companies realize that they have no way to know how many persons will use the coverage and have no projections as to how much this coverage will cost them. Cost projections vary widely.

2007 – Harry Benjamin International Gender Dysphoria Association renames itself ‘World Professional Association for Transgender Health’ (WPATH)

2008 – CA DMV form DL 329 allows trans persons to update their gender markers on drivers licenses and CA id cards. The form follows the medical model of gender as it requires a physician to sign the form in support of the change.

2009 - UC student health insurance plans begin to offer coverage for trans students. LGBT student advocacy coalitions begin to collect data about how much the coverage costs and what coverage is provided. Costs for the first two years come in much lower than anticipated. Many aspects of care considered medically necessary by WPATH continue to be excluded by UC insurance providers under the argument that they are ‘cosmetic’ in nature.

UC Riverside finds that adding a transgender surgery benefit will not result in any increase in costs to the plan (see 2009-10 pdf)

2009 – Pink triangle installation on Twin Peaks (SF) is set on fire (arson) and vandalized.

2010s

2010 – Largest national survey (to date) of trans persons regarding healthcare access finds epidemic levels of discrimination, harassment and denial of care within healthcare settings (n=1100). The executive summary begins, "Access to health care is a fundamental human right that is regularly denied to transgender and gender non-conforming people."⁸

2011 – ‘Don’t ask, don’t tell’ is repealed as a military policy for LGB service members, but being openly transgender remains a dischargeable offense until June 30 2016.

2011 - A 2011 Veterans Health Administration directive mandates coverage for medically necessary care for transgender veterans. In the 2 years following this directive, the number of trans people having their gender identity recorded in their medical records approximately doubles⁹, making the VA dataset the largest (at that time) in the nation (with 2662 unique persons). However, the dataset is still very likely too small to be representative of the population for statistical purposes.

2011 – Williams Institute study estimates that trans people make up 0.3% of the general population (300 times higher than previous estimates of 0.001%)

Starting in 2013 national (federal health agencies) interests in health data and evidence based medicine came together to attempt to improve the data collection practices surround gender variance in health information systems¹⁰. However, many of these data collection efforts have now been called into question by political changes in the current federal government.

2013 – WPATH issues a recommendation for including gender identity, preferred name, pronoun information in electronic medical records¹¹.

2013 – Bill declares that students are allowed to use gendered facilities in accordance with their gender identity regardless of their legal identity documents (AB 1266)

2013 – DSM changed GID to gender dysphoria and grouped mental health problems related to disorders of sex development into it. While the GID to gender dysphoria change was welcomed by many, the change of transvestic fetishism to a disorder was not welcomed. It was

⁸ Jaime M Grant et al., "National Transgender Discrimination Survey Report on Health and Health Care" (National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010), http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.

⁹ Michael R. Kauth et al., "Access to Care for Transgender Veterans in the Veterans Health Administration: 2006–2013," *American Journal of Public Health* 104, no. S4 (2014): S532–S534.

¹⁰ Emma Green, "The Federal Government Quietly Expands Transgender Rights," *The Atlantic*, May 16, 2016, <http://www.theatlantic.com/politics/archive/2016/05/department-of-health-and-human-services-transgender-rights/482934/>.

¹¹ Madeline B. Deutsch et al., "Electronic Medical Records and the Transgender Patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group," *Journal of the American Medical Informatics Association* 20, no. 4 (2013): 700–703, <https://doi.org/10.1136/amiajnl-2012-001472>.

particularly unwelcome because it includes a subcategory of autogynophilia, a paraphilia that has been deeply contested by trans women and trans communities.

2013 – The CDC’s public health phone survey, the Behavioral Risk Factor Surveillance System (BRFSS) adds questions on gender identity and sexual orientation (SOGI) to an optional module. 19 states collect data using the SOGI module in 2014. 25 states collect data using the SOGI module in 2015.

2013 – Gov Brown authors a letter reiterating that under AB1586, it is illegal to deny insurance coverage of medically indicated health care to trans and gender variant persons

2014 – VA health records survey indicates that their trans incidence is about 0.03% of their general population, which is ten times higher than previous estimates.

2014 – 19 States participate in the BRFSS SOGI data collection module (but not California) – giving an estimate in 2015 that the trans population comprises 0.5% of the general population (more than doubling previous estimates).

2015 – 25 states participate in the (BRFSS) SOGI data collection module (but not California)

2015 – Legal case of ‘Blatt v. Cabela’s Retail, Inc.’ challenges the constitutionality of the exclusion of GID from the ADA under the equal protection clause. In a related brief, the DOJ suggests that gender dysphoria might be protected under the ADA.

2016 – Ban on the open service of transgender persons in the US military reversed.

CITED REFERENCES (APPENDIX I)

- Beemyn, Genny. "A Presence in the Past: A Transgender Historiography." *Journal of Women's History* 25, no. 4 (2013): 113–21. <https://doi.org/10.1353/jowh.2013.0062>.
- Denny, D. "A Selective Bibliography of Transsexualism." *Journal of Gay & Lesbian Mental Health* 6, no. 2 (2002): 35–66.
- Deutsch, Madeline B., Jamison Green, JoAnne Keatley, Gal Mayer, Jennifer Hastings, Alexandra M. Hall, Rebecca Allison, Oliver Blumer, Stephen Brown, and Mary Kay Cody. "Electronic Medical Records and the Transgender Patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group." *Journal of the American Medical Informatics Association* 20, no. 4 (2013): 700–703. <https://doi.org/10.1136/amiajnl-2012-001472>.
- Faderman, Lillian, and Stuart Timmons. *Gay L.A.: A History of Sexual Outlaws, Power Politics, and Lipstick Lesbians*. Basic Books, 2006.
- Fry, Jane. "Conclusion: On the Records." In *Being Different: The Autobiography of Jane Fry.*, edited by Robert Bogdan, 213–33. New York: Wiley, 1974.
- Grant, Jaime M, Lisa A Mottet, Justin Tanis, Jody L Herman, Jack Harrison, and Mara Keisling. "National Transgender Discrimination Survey Report on Health and Health Care." National Center for Transgender Equality and National Gay and Lesbian Task Force, October 2010. http://transequality.org/PDFs/NTDSReportonHealth_final.pdf.
- Green, Emma. "The Federal Government Quietly Expands Transgender Rights." *The Atlantic*, May 16, 2016. <http://www.theatlantic.com/politics/archive/2016/05/department-of-health-and-human-services-transgender-rights/482934/>.
- Hale, C. J. "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients." *Perspectives in Biology and Medicine* 50, no. 4 (2007): 491–505. <https://doi.org/10.1353/pbm.2007.0047>.
- Kauth, Michael R., Jillian C. Shipherd, Jan Lindsay, John R. Blosnich, George R. Brown, and Kenneth T. Jones. "Access to Care for Transgender Veterans in the Veterans Health Administration: 2006–2013." *American Journal of Public Health* 104, no. S4 (2014): S532–S534.
- Plant, Richard. *The Pink Triangle: The Nazi War against Homosexuals*. New York: H. Holt, 1986.
- Witten, Tarynn M., and A. Evan Eyler. "Hate Crimes and Violence against the Transgendered." *Peace Review* 11, no. 3 (1999): 461–468. <https://doi.org/10.1080/10402659908426291>.

APPENDIX II:

EXPLANATION OF SOURCES OF RESEARCH MATERIALS

Audio Recording:

Data type representing materials that are audio recordings (mp3, wav, etc). The most substantive audio recordings in the data are ethnographic interviews, however, there are also a large number of recordings of presentations.

Community Report:

Community organizations often publish local analysis and data collection projects. However, many of these reports are in the 'grey' literature insofar as they are not necessarily indexed or archived in traditional contexts.

Conference Poster:

Many health professionals and community health advocates share information about their projects and efforts at trans health conferences in the Los Angeles and San Francisco Bay areas. The data collection efforts included taking pictures of a conference posters and speaking with the presenters about their projects.

Data Standard:

One of the long-standing points of friction for trans patients has been around the simplistic gender binaries that are hard coded into data standards for health systems. As such, a number of data standards have been proposed and were discussed in conversation with research participants and research sources.

Email Correspondence:

Most of the communication with research participants was via email. In addition, because I have been involved in some of the communities for over a decade, I have received emails that were topically related to the study and were included as research data sources.

Ethnographic Interview:

Data type representing materials related to ethnographic interviews and/or oral history interviews with research participants. These primarily include researcher notes and audio recordings.

Formal Publication:

Data type representing materials published in the formal literature, e.g. journal articles, scientific publications, books, as well as formal reports and white papers.

Governmental Report:

This data type represents publications compiled and released via governmental agencies, including state, federal, county and municipal reports.

Informal Publication:

This data type represents materials that were published in an informal context, e.g. flyers, handouts, information sheets. Many of these would have been classified as 'ephemera' in a traditional archival context.

Internal Document:

Some of the organizations shared internal documents from their information systems and workflows. Some of the internal documents cannot be distributed outside of the organization for intellectual property reasons. While I did get permission to use these documents for the

research, it requires that I speak with them prior to quoting specific blocks of text or images from the materials.

Legislative Bill:

California has had a number of legislative bills related to trans and gender variant persons. This project focuses primarily on the ones that affect health care and health insurance for trans and gender variant persons in California.

LGBTIQ Provider Indexes:

It has long been common knowledge in the LGBT communities that it is nontrivial to find a medical provider who is competent in providing health care for trans and gender variant persons. These documents represent lists of health care providers compiled for various LGBT communities.

Newspaper or Blog Article:

This data type represents materials collected from blogs, newspapers and similar types of media sources.

Patient Intake Forms:

This data type was one of the primary data types for the two sites involved with patient care. The documents are largely intake forms, e.g. blank demographic and medical history forms that are given to patients as a part of their medical record. It should be noted that these forms are blank, meaning that they do not involve patient information. The only actual patient medical records used in this document are my own, and are used for illustrative purposes of the frictions created between the exclusive hardcoded categories of the gender binary within the records.

Presentation:

This data type represents talks and prepared presentations in several formats, including conferences, prepared remarks, and documentary interviews.

Health Protocols and Standards of Care:

Standards of care and protocols of care are another one of the main data types for this project. For a number of historical reasons (mostly around liability), much of trans health care revolves around formalized health care protocols and standards of care. These are essentially standardized models of care for trans and gender variant persons. These protocols include everything from recommendations for collecting gender identity information to procedures for establishing informed consent for specific medical treatments.

Health Surveys and Questionnaires:

There are two main types of data within this data type. The first are materials from the California Health Interview Survey, which is a large, statistical survey of the adult population in California. As such, there is a large amount of survey and questionnaire related documentation from the survey. The second main type of data within this survey comes from other, unrelated surveys related to the project. These documents about surveys and questionnaires include both qualitative and quantitative approaches to surveys and questionnaires. These materials form an important source of information for experiences of trans and gender persons in health care encounters.

Video Recording:

This data type refers to materials that are in a video format, including recordings of conference presentations, group discussions, documentary interviews, and ethnographic interviews.

Websites:

This data type refers to materials that are in a website format. For these materials, offline snapshots were made using Zotero. In some cases, multiple snapshots of the same website were taken to capture changes over time. For example, the Standards of Care manual release by the UCSF Center of Excellence in Transgender Health was initially released via a website. Later, as the second edition was published, it replaced the first edition on the website and was also made available as a pdf.