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Queer Data: Medical Quantification and What Counts About Counting

by

Laura Duncan

DISSERTATION

Submitted in partial satisfaction of the requirements for degree of

DOCTOR OF PHILOSOPHY

in

Medical Anthropology

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

AND

UNIVERSITY OF CALIFORNIA, BERKELEY

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Dedication

To Lark, for whom my love is innumerable.

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Queer Data: Medical Quantification and What Counts About Counting

Laura Duncan

Abstract

Within medicine devoted to LGBTQ+ health, data are everywhere. Large databases teem with numbers waiting for evaluation, buggy online surveys offer rickety drop-down menus filled with identity terms, and clinic bulletin boards host calls for research participants to "stand up and be counted." This dissertation will trace the life of what I will call "queer data" - that is, data documenting queer subjects as well as data that might potentially be understood as "queered" - as it is produced, analyzed, and mobilized. A rich moment for anthropological study emerges when quantification techniques requiring bounded categories are confronted by the foundational fluidity of queerness. This project draws from from anthropological fieldwork within research projects and clinical spaces in the California Bay Area, semi-structured interviews with individuals across the United States, as well as objects and virtual spaces that serve as ethnographic objects. Tracing such queer data through medical settings and discourses provides a unique opportunity to explore questions around the evidence-base of queerness and the ways in which queerness soaks into data processes in transformative ways.

In this dissertation, I describe how this queer data production emerges as a co-constitutive process through which community norms and experiences shape the options for categorization, while at the same time such categories affect how individuals and communities make meaning around their identities, bodies, and desires. I examine how debates around the use of statistics within medical education reanimates counting as a contested space that exposes the political stakes of quantifying queerness and the affective impact of numbers. Data are also a potent force within clinical spaces. Through examinations of clinical intake forms, I describe how efforts to create healthcare spaces that are affirming to queer patients position data as a form of care. How such healthcare data are transformed by bureaucratic reporting requirements is discussed as an example of how queerness both resists and is subsumed by aggregation. The organ inventory is also taken up as an ethnographic object and explored for the ontological claims it makes around what a body is and how it should be cared for. By tracing such queer data, this dissertation explores how quantifying queerness is an act of transformation, but one that is necessarily incomplete. The ever-evolving nature of queerness leaves it in excess of static categories in a way that can productively draw attention to the generative work of quantification.

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Introduction

The research conference is nearing its end and attendees mingle in the building's outdoor courtyard. This conference brought together researchers and community organizers to discuss the future of research on what is described on the programs as "LGBTQ+ Health." Around us the hospital architecture pierces into the sky, all glass and shiny new metal with sharp modernist edges. The conference organizers come outside and raise their voices over the polite chatter, calling out to ask us to form a circle. We all shuffle in to place to stand and wait as we glance at one other in our business casual attire and conference lanyards all decorated with a rainbow name-tag holder. Suddenly the doors to the building burst open to reveal a swirl of long black robes, neon blue eyeshadow, platform boots, and a nun's wimple. A member of the Sisters of Perpetual Indulgence strides into the courtyard. The Sisters of Perpetual Indulgence is an activist organization and performance group of "queer and trans nuns" ("The Sisters of Perpetual Indulgence" n.d.) who participate in protests, fundraising events, and celebrations. They are instantly recognizable by their elaborate nuns habits often dripping with lace, sequins, or flowers and their characteristic face make-up consisting of a white base with shimmering colored accents.

Sister Jonathan is here to bless our research. Moving around the circle, the Sister one-by-one stands in front of each conference attendee and does something with their arm. When my turn arrives, the bejeweled nun gently takes my extended hand and firmly sweeps an index finger across my wrist. Long robes swish away to the next attendee as I looked down at my wrist. I had been anointed. With glitter. A patch of my wrist now shimmers with prismatic, multi-colored sparkles. In this moment, the research projects presented at the conference, posters prepared for *display, and statistical methodologies debated were no longer only defined as community-engaged research, but became community-blessed research. Even as we researchers stood in the shadows of the prestigious medical center funded by billions of dollars in federal money, in that small circle it was the queer nun with a cleanly trimmed beard and inches-long false eyelashes holding a pot of beauty store cosmetic glitter who elevated our work, making sacred the statistics, thematic codes, and survey checkboxes we had spent the conference debating.*

The appearance of the Sister at this research conference is but one of the many ways in which queerness challenged, drew attention to, and was subsumed by scientific quantification processes that I witnessed throughout my research. In this dissertation, I will explore the production and mobilizations of what I call "queer data." For the purpose of this project, I define queer data as quantified information that attempt to document, analyze, or respond to queerness. This paper will explore depictions of queer data traced through a variety of spaces, including conceptual ones built by anthropologists, queer theorists, and other critical thinkers. It will describe how queer data have been mobilized as evidence of categorical difference, analytic figures, and ethnographic sites. It also explores queer as an action, such as when data might be understood as "queered." I describe how moments of queerness inspire changes in research methodologies, documentation techniques, and data analysis protocols. This dissertation asks how data themselves can be thought differently when queerness soaks into statistics, computer code, and demographic forms. This project specifically focuses on health and medical data. Medicine is a space that has been historically and contemporarily particularly interested in quantifying queer experiences, identities, and bodies. The last decade has seen a proliferation of numbers about queerness within medicine. In 2011, the Institute of Medicine called for increased research on the health of lesbian, gay, bisexual, transgender, and queer (LGBTQ) people (Institute of Medicine

(US) Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities 2011). More recently, a large clinical study rallied queer participants stating, “There is strength in numbers” and such data can reduce inequalities. Such calls for data have been responded to with vigor within the medical sciences. During my preliminary research in medical settings dedicated to LGBTQ health, data seemed to be everywhere. Large databases teemed with numbers waiting for evaluation, buggy online surveys offered rickety drop-down menus, and clinic bulletin boards hosted calls for research participants to “stand up and be counted” as a form of political empowerment. This expansion of numbers in research and policy represent common claims that data are a foundational pillar of health and a key to identifying and rectifying disparities, especially in regards to queer communities. While the foundational fluidity of queerness may seem diametrically opposed to the rigid bounding of scientific data, the relationship between queerness and quantification is far more complex than one of binary opposites. The the challenges provided by queerness to quantification processes inspires changes in documentation practices and introduces a productive instability to assumptions about sexuality, gender, and sex embedded in medical discourses. Similarly, research data collection and the scientific usage of identity categories changes how queerness is conceptualized and affects the ways in which gender, sex, and sexuality are presented in order to remain intelligible within institutional, social, and political discourses. Tracing queer data through such medical settings and discourses provides a unique opportunity to explore questions around the evidence-base of queerness, the algorithmic fantasies of research, and the erotics of quantification. The ever-evolving nature of queerness leaves it in excess of static categories in a way that can productively draw attention to the generative work of quantification. Furthermore, queer data are centered not because they are necessarily categorically different from other forms of knowledge, but because of the way such data can expose a fluidity of bodily and identificatory boundaries especially in relation to scientific, and medical logics.

Tracking such data took me many places, both mundane and spectacular, though what often held my view was that which could be considered mundane among the spectacular and the moments of spectacularity within what was considered mundane. For example, within this research in the middle of a fetish event surrounded by partially-clothed revelers strapped into leather garb, I pushed through the crowd laser-focused on a clipboard I had just spotted holding a health survey being proffered to passers-by. I squinted at a computer screen scrolling through medical software programs, examining the digital buttons, text fields, and checkboxes that attempt to document the messy, squishy flesh of the body. I left clinics clutching a copy of their intake form, running my fingers down the expansive list of sexual orientation and gender identity printed on the slightly rumpled paper. Of course, like so many anthropologists doing research during the COVID-19 pandemic, I also pivoted to spending hours on Zoom interviewing researchers, clinicians, and advocates.

Based on that fieldwork, this dissertation asks how queerness is contained within or remains expansive beyond quantification and how this can shed light on the work done by data to solidify contested borders, such as those of gender and sexuality, in the name of categorization. The promises of data are analyzed for how references to representation through categorization open up the potential for certain types of political and social claims while foreclosing others. This project examines queer data production as a co-constitutive process through which community norms and experiences shape the options for categorization, while at the same time the categories that become available affect how individuals and communities make meaning around their identities, bodies, and desires. Quantification of queerness is explored through the tools and techniques used for medical documentation, such as electronic medical records. “Queer data” - that is, both data about queer topics and also data that might potentially be understood as “queered” - are traced for how they are constructed, contested, and mobilized in ways that expose the transformative effects of quantification, inspire fantasies around the power of counting, and make ontological claims about gender and the body. Counting is explored as both a site of conflict and manipulation and an opportunity for affirmation and witness. Tom Boellstorff reminds us of how such contested numbers call for a greater theorization of data.“There is a great need for theorization precisely when emerging configurations of data might seem to make concepts superfluous - to underscore that there is no Archimedean point of pure data outside conceptual worlds. Data always has theoretical engravings that are its condition of making” (Boellstorff 2013, 90). This project heeds this call to open up data as transformative work, not simply documentation or representation.

Theoretical Foundations

This project is situated at the intersection of two bodies of anthropological literature: 1) queer theory and 2) science and technology studies.

Lesbian/gay and queer studies have a rich history in anthropology. From the early explorations of gay and lesbian community (Lewin 1998; Newton 1972; Weston 1991) to place-oriented ethnographies of queer identity (Allen 2011; Bhaskaran 2004; Blackwood 2010; Dave 2012; Engebretsen 2013; Erzen 2006; Kulick 1998; Moore 2011; Murray 2012; Nanda 1990; Ochoa 2014; Parker 1999; Sinnot 2004; Stout 2014; Rofel 2007; Rudolf 2009), this literature deeply informs my project. Transgender studies also continues to open similar discussions in anthropology about not only the diversity of transgender and gender-expansive identities and embodiments, but also the ways in which they are mobilized by gender theory (Butler 2006; Namaste 2000; Plemons 2017; Prosser 1998; Stryker & Whittle 2006). Anthropologists have also used queerness not only as a research site, but as an analytic to interrogate topics such as settler colonialism (Morgensen 2011; Povinelli 2006), sameness and difference, (Boellstroff 2005), and the concept of orientation itself (Ahmed 2006). Queer analyses have been turned back onto the discipline of anthropology itself with articles on the genealogy of lesbian/gay and/or queer anthropology describing how the slippery nature of queerness can expand anthropological epistemology (Boellstroff 2007; Lewin 2016; Salamon 2010; Weiss 2016; Weston 1993). While a solid definition of queerness within anthropology remains evasive, this project echoes this body of theory to mobilize "queer" as a category to describe identities, behaviors, desires, and communities that are not defined by heterosexual or cisgender standards. It also uses the concept of queerness to inspire questions about that process of categorization itself. David Valentine's work explores how the category "transgender" was mobilized by social service providers yet challenged by the experiences of those targeted for care (Valentine 2007). This disseration similarly asks how data projects focused on queer health contend with and construct queerness. Since this project focuses on healthcare settings, it is especially inspired by the anthropological literature that offers queer analyses of medicine. Subjects in this area include oncology and its embedded assumptions about gendered bodies and identities (Jain 2013), how public health interventions solidify sexual identity labels (Cohen 2005), and clinical responses to genitalia deemed ambiguous by medicine (Karkazis 2008). This lineage includes a rich legacy of research on HIV/AIDS (Carillo 2002; Epstein 1996; Farmer 1992; Nguyen 2010; Parker 2001). These authors point to the friction that can occur when medicine attempts to make identities manifest as uniform things while the bodies and experiences of queer people interrupt such knowledge- and discipline-making practices. This work is inspired by such critical explorations about how queerness challenges and absorbs institutional assumptions about desire, bodies, and identity. This dissertation also offers a queer analysis of the body - specifically how data and documentation processes content with bodily materiality. The debates within queer theory and anthropology around the relationship between materiality, political possibilities, and discursive construction are especially robust when it comes to the body. This dissertation will explore how even when the presumption of queerness is present (such as within clinical interventions designed to approve identity affirmation with medicine), medical documentation can be challenged by diverse manifestations of material ambiguity, fluidity, and porosity. Materiality, and especially its gendered categorizations often lies at the center of many of these theoretical conversations within a queer anthropology of medical care. For example, Jay Prosser (Prosser 1998) states that the importance of bodily materiality to transsexual experiences complicates social constructionist views, which are seen as overdetermining the role that discourse plays in embodied genders. Similar questions raised by the work of Eric Plemons (2017) are particularly salient for this project. Plemons, in his ethnography of facial feminization surgery, offers insights into how care practices are disciplined based on socially-situated assumptions about queer bodies, gender, and identity. Like Plemons and Prosser’s work, this project takes the body and its materialization as generative of certain types of knowledge, experience, and intervention that have crucial ramifications for the medical datafication of the body as well as anthropological theory. While such research that explores queer theory within medical care is a widening and deepening field, anthropological theory has yet to look directly at the intersection of data and queerness. Expanding from this literature, my research applies queer analytics to study the work of quantified data and the attendant categorization. I found that data may be considered queer in two senses: 1) the numbers serve as attempts to represent queer experiences and 2) a "queering" of data and research occurring though the premise of quantification itself being confronted by the foundational fluidity and contextual nature of sexuality and gender.

This project is also founded on the anthropological work on quantification, and metrics, much of it emerging from the literature of science and technology studies. Classification is a foundational object of study for anthropology and this project builds on this legacy to focus on a specific form of classification - that of quantification and data production. In *The Order of Things: An Archaeology of the Human Sciences* (Foucault 1994), Michel Foucault opens up the human sciences for epistemological inquiry. Anthropological studies of scientific knowledge production reveal the oftentimes-messy processes of knowledge production and the simultaneous erasure of such work from claims to objective truths (Forsythe 1993; Haraway 1991; Keller 2002; Latour & Woolgar 1979; Martin 1994; Ong 2016; Petryna 2009; Rapp 2000). Specifically, the literature on metrics will be utilized to explore what is unique about quantification and how it becomes such a powerful tool (Adams 2016; Bowker & Star 2000; Epstein 2007; Hacking 1990; Greene 2007; Merry 2016; Murphy 2017; Nelson 2015; Povinelli 2011). Diane Nelson's work reminds us of how counting allows for some political claims while foreclosing others (Nelson 2015). Sally Engle Merry examines the role of metrics within humanitarian work (Merry 216). Vincanne Adams's work, alongside the authors within her edited volume *Metrics: What Counts in Global Health*, crucially engages with metrics and health research as not only as sites and tools of knowledge production, but also spaces where moral claims are leveraged and exposed and ontological questions about what counts as counting are debated (Adams 2016). This work is useed to think not only about what is produced by metrics, but also to examine the techniques of quantification themselves as unique forms of knowledge production and social power.

Anthropological work on paperwork and forms also influence my analysis (Bhangu 2020, Frankfurter 2019, Riles 2000). Queerness already appears in in the legacy of literature on scientific knowledge. Michel Foucault's *The History of Sexuality Vol. 1* offers sexuality as a main axis through which biopower acts to pathologize desire (Foucault 1990). Steven Epstein attends to the intersection of scientific knowledge and lay expertise on HIV/AIDS (Epstein 1998), as well as how attempts to diversity medical research reveal underlying assumptions about the biological causes of health inequalities and how research participation can, and cannot, intervene (Epstein 2007). Recently, Martin F. Manalansan explores how measurement through accounting and audits contends with queer migrant lives (Manalansan 2018). This project is further situated within contemporary anthropological conversations around data (Boellstorff & Maurer 2015; Biruk 2018; Gitelman 2013; Lupton 2013; Ruckenstein & Schüll 2017; Schüll 2016). This literature emphasizes the productive power of data, especially at this moment in history when the accumulation of data is often seen as progress in and of itself.

Choosing Queer

One ever-present question throughout the writing of this disseration was what word I would use to describe my object of study. Specifically, which of the many terms available would I apply to experiences that exist beyond, between, or in contrast to cis- and heteronormative structures? Of course, choosing just one term to use within a project that turns a critical eye on the ways in which such terms are codified is complicated and necessarily incomplete. While I wish that I were able to use a musical note or a flash of light or a liquid wave to represent what I'm trying to describe, much to my chagrin, anthropological projects still mostly end within the two-dimensional world of a computer screen or paper and therefore I'm constrained to using words.

Furthermore, it feels like an unnecessary dodge to avoid making a decision about categorical language when this entire project explores the stakes that come with the choice of naming a gender identity or sexual orientation. Therefore I too will make this choice and open myself to necessary and generative criticism, questioning, or praise. Within this dissertation, I am choosing to use the term "queer." When available, I use whatever terminology my interlocutors use for themselves and will recreate the language I find on forms, surveys, and electronic records as faithfully as possible. Queer has also become the stylistic standard for much of academic writing at least within anthropology. Therefore I am also using this term to identify myself as in conversation with those thinkers who define their work as part of the discipline of queer theory. It also seems appropriate to choose this term becuase queer is the identity term I claim for myself. So while my identity is not and does not have to be your identity or the identity of those you will find within this writing, queer is the term I ground myself in and it felt it important to address that with my language. It feels important to name that this project is one seen through a queer lens (though not the only queer lens, and not necessarily even the most interesting or necessary queer lens). Of course, the responses to the term queer will run the gamut from offended to elated and the voices you will find within this project express all those feelings and more about such language. For a mix of deeply personal, theoretically grounded, and pragmatic reasons, I will use "queer" to refer to communities, individuals, concepts, and experiences that exist outside of heteronormative and cis-centric paradigms.

How to define the term queer is a crucial question that generatively haunts this work. Attempts to answer this question are traced throughout this dissertation as they work define the bounds of identity labels, as well as expose the instability and incompleteness of the very foundations of such identificatory structures. This paper does not attempt to solidify an answer to this question, but responds to it generatively. Queer is traced for how its mobilization moves in "oblique" relation to or "off line" from (Ahmed 2006, 161) normative constructs of identity, relationality, and life course, as well how it gains potency through "violating proper intimacies" (Chen 2012, 11). It is noted as a "site of collective contestation" due to attempts at "affirmative resignification" of the power to harm embedded in the history of the term (Butler 2011, 228). It is used with humility alongside the understanding queer is contextual fluidly and shifts meaning and mobilizations based on time, place, and affective usage. Ironically, the automated speech-to-text transcription service I used to transcribe interviews would not transcribe the word "queer." It was not misheard or replaced with another term; it was simply left out of the transcript entirely. Other identity terms were included in the transcripts, but not queer. When I asked the company technical support contact why the automated transcript left out this word, they told me that their software did not transcribe words that others may find offensive. This moment is just one example of how while the focus of this research is on the ways in which research methodologies are confronted by queerness, such challenges exist within this project as well.

When this dissertation discusses the fluidity of queerness though, it is not solely referring to fluidity as an identity or necessarily requiring queerness to exist as a fluid concept or experience. Instead, it is describing how the contextually-shifting and historically-changing nature of queerness exposes how the foundational fluidity of all identificatory and categorization processes can create friction (or smoothness, as the case may be) when it meets processes of quantification. Identification is a consistently incomplete and unstable process. Therefore, categorization, especially around identity, becomes a slippery process. Such processes not only describe, but also create conceptual structures that can determine what is bestowed intelligibility and entrance into institutional discourses, as well as what is discarded as excessive or irrelevant or even unable to be thought at all. Michel Foucault addresses how classification systems structure methods of thought in *The Order of Things* (Foucault 1994). Geoffrey Bowker and Susan Leigh Star remind "there is more at stake - epistemologically, politically, and ethically - in the day-to-day work of building classification systems and producing and maintaining standards than in abstract argument about representation" (Bowker & Star 1999, 10). Queerness is not unique in its fluidity, solidity, or relation to data processes. That said, the space that queerness holds in contemporary society as explicitly contextual in nature and public in its changing norms, can productively expose the generative work of quantified classification. For example, the fielsites and ethnographic objects studied for this dissertation take sex, or gender, or sexual orientation as objects of study and documentation. These concepts are bounded by the quantitative questions that assume them to be discrete pieces of demographic data, separate from other forms of subjectivity or social classification, such as race, ethnicity, disability, age, income level, or place of residence. Quantification processes require such concepts to become represented as discrete categories from which participants or patients to choose and that can therefore be analyzed as comparative variables in contrast to one another. Such categories remain phyisically separated within the space of surveys and medical software and statistical reports. Generally, these types of data projects do not allow space for methodologies analyses in which these identities may be deeply bound-up with, undone by, and merged within one another (or may not even be able to be considered as separate). Intersectionality offers a challenge to quantification efforts. In *Black on Both Sides: A Racial History of Trans Identity*, author C. Riley Snorton offers a specific example of how to theoretically engage with such frictions by asking, "what pasts have been submerged and discarded to solidify - or, more precisely, indemnify - a set of procedures that would render blackness and trans ness as distinct categories of social valuation?" (Snorton 2017, 7). Data processes have and continue to be part of such a "set of procedures" that work to bound such categories. Such work around intersectionality crucially reminds us that such categorizations exist in a matrix of power through which all can produce, undo, and/or shift one another (Crenshaw 1991). This dissertation analyzes the ways in which queerness becomes constructed through, against, and between other forms of categorization. That said, it also attempts to explicitly hold the contradiction that through my choice of fieldsides and ethnographic objects this dissertation also explicitly and implicitly make claims to what queerness is and isn't. This dissertation works to bring such claims into the light for analysis, not for whether they are true or false, but to examine the conceptual, political, and personal possibilities they open up or shut down. Queer data production offers a particularly fascinating moment to observe how claims to documentation (including this dissertation) create the objects being documented. The distribution of such data further reinforces such bounding, allowing for the ongoing solidification of sex, gender, and sexual orientation as discrete and knowable (even if fluid, contested, or changeable) objects.

Methods and Fieldsites

This dissertation emerges from multi-sited ethnographic fieldwork undertaken between 2017-2021, with the majority occurring in 2019 and 2020. In person observations and interviews mainly took place in the Bay Area, California with some additional research occuring on the East Coast of the United States. Interviews were held with additional participants across the county through Zoom and telephone calls. My interest in focusing my research on the Bay Area is that it is often considered to be a place where cutting-edge medical research takes place and is held up as a model to other queer health projects. In the Bay Area, there is no shortage of researchers, clinicians, and advocates working to document and analyze queer health and local legislation (as discussed in Chapter 4) has recently been passed to support increased collection of sexual orientation and gender identity data. I've chosen to explicitly name the location of much of this research because the relative institutional and political freedom offered to the researchers and clinicians interested in queer health is unique and therefore not generalizable to other parts of the globe. Of course, many researchers I spoke with still described a lack of resources or prestige offered to queer health work, especially that which utilizes community-engaged methodologies. That said, there is an increasing push in the United States to place legislative restrictions on legal rights for transgender people, especially focusing on healthcare for youths (Krishnakumar 2021). The Bay Area therefore stands out in that it offers fewer explicit roadblocks for clinicians, researchers, and advocates who want to offer treatments, perform research, or participate in advocacy related to queer health. Furthermore, the number of research and clinical projects devoted to queer health in the Bay Area are so numerous that it remains possible offer significant de-identification to the projects and people described in this dissertation while still locating them in this specific area. That said, I do not always specify which projects or interviewees are located in the Bay Area and due to the virtual nature of some of this research, many are situated across the country. Due to my position as a medical student, many of these spaces I had previous had access to as a trainee in the Bay Area focusing on queer healthcare. Some of my grounding in this topic comes from those years training in clinics and hospitals where I witnesed (and participated in) the centrality of data in regards to queer health.

For my analysis in Chapter 1, I utilize data from focus groups hosted by a national longitudinal study of LGBTQ+ health that I observed and participated in as a research assistant. These types of focus groups are common for health research projects and a staple of community-engaged research methodologies. These observations were particularly helpful in thinking about the ways in which research design contends with the requirements of quantification and the heterogeneity of queerness. For other observations, I attended health commission meetings (discussed in Chapter 4), participated in research conferences (as described above), and watched webinars about collecting sexual orientation and gender identity data. I also attended community events where queer health research takes place, such as the Folsom Street Fair (as discussed in Chapter 2), and public panels and activist events around queer health such as the ones at the GLBT Museum in San Francisco. A large portion of the research for this project was also undertaken through semi-structured interviews with clinicians, researchers, advocates, and others who produced or utilized queer data. For in-person interviews, I met my interlocutors in the clinics and hospital spaces where they worked or in cafes or other public spaces. Virtual interviews took place over Zoom or the phone and allowed me to speak with individuals at longer distances, though everyone I interviewed for this project currently lived and worked in the United States. A large portion of this research is also focused on objects or virtual spaces, including forms, software, and research materials such as recruitment posters, surveys, and websites. When I observed or interviewed in clinical spaces, I often asked for copies of intake forms or health surveys and requested screenshots of electronic health records templates and forms. I also examined research project websites, looking at their recruitment materials, dissemination methods, and publications. The insights offered by the spaces I observed, the people I talked with, and the objects I collected provide the material grounding for the dissertation.

In all instances, I work to de-identify the institutions, projects, and people I observed and interviewed. The names used within this dissertation for people, porjects, and insitutions are fictional. For those projects that are unique enough that it might prove difficult to change enough details to make them unrecognizable, I had discussions with the participants about how they would like to proceed. All felt comfortable with pseudonyms being used for themselves, the names of the project, and any related insitutions, but wanted to have the research or clinical work described accurately. In a few rare cases, I created composite individuals if I felt pseudonyms or changing identity descriptors was not enough to fully offer anonymity. If not directly relevant to the analysis, the study topics of a few of the reserach projects have been changed to something different, though still representative of the types of subjects being studied. All interviews were recorded and transcribed afterward by an automated transcription service. Some quotes have been lightly edited for clarity and length.

Research during a Pandemic

The COVID-19 pandemic not only changed the research methods avaliable to me, but transformed this project. Many of the plans for observations and interviews for this research were made in late 2019 and early 2020 and were drastically changed by the beginning of the pandemic. Interviews became phone calls. Observations became Zoom meetings. Digital ethnography left me pouring over the Internet effluvia left behind by research studies. The change in research required by the COVID-19 pandemic is a limitation to this research in some ways. It removed the possibility of access to some of the sensory experiences of ethnography. The clinics I had arranged to spend time observing closed to all but essential staff and so I was unable to feel, smell, and move through these observational spaces. That said, the pivot to more virtual and physically distanced research methods allowed for an expansive rethinking of where queer data can be found. I was privileged in that my object of study already lives in virtual spaces and Zoom interviews allowed me to meet interlocutors who worked outside the Bay Area. This pandemic raises questions about how the ethnographic method might be changed when the traditional face-to-face observations become unsafe. Of course, in some field sites and for some ethnographers, in-person observation has always been a risk. This year, some researchers chose 6 feet away and masked for their new methodology and others turned to virtual ethnography. Importantly, some of the research I studed, authors I cite, and clinical spaces I observed, were either born out of, transformed by, or identify as within a historical lineage from the HIV/AIDS pandemic. Thinking critically about how to document queerness in the face of illness and death is not a new exercise. Now, as always, anthropological methodology is being shaped and reshaped by the global community and requires us researchers to consider the ways in which our thinking, writing, bodies, affect, and breath affect others. While some of the research for this dissertation took place before the pandemic, for the latter half of my fieldwork I wasn't able to be in person with my interlocutors. Still, virtual fieldwork allowed me a different view. When one is attempting to ethnographically study how expertise is made, maintained, and how it might be undone, it's tempting to focus on the glamour of professionalism. Shiny offices, white coats, and framed degrees from prestigious institutions are glamorous and attention grabbing. Without a pandemic, many more of my interviews would have taken place in hospitals, private offices, or conference centers and would carry with them their attendant prestige. On the other hand, via Zoom I saw my interviewees in sweatshirts and soft pants, I heard their children yelling or dogs barking in the background (and they heard mine), and I appreciated how meticulously they had arranged their screens so their background consisted of whichever corner of their bedroom looked least like a bedroom. For a project initially interested in questions of professional expertise, scientific knowledge production, and institutional politics, it was an interesting pivot to have many of my virtual interviews occur within the domestic spaces of those I talked to. In short, even when not explicitly discussed, much of this project has the COVID-19 pandemic as its backdrop, which offered a deeply transformative effect on my methods and focus.

Tracking Queer Data: Chapter Outline

Chapter 1 “Drop Down Queers: Research Design and Community-Engaged Research,” focuses on observations and data from focus groups performed by The OUT Study, a national longitudinal study of queer health. These groups were convened in order to solicit community input on the design of research questions that collect sexual orientation and gender identity (SOGI) data. This chapter explores how community-engaged research on queer health tangles researchers and participants in a complex sociality. It uses vignettes from these focus groups to explore how research design processes, even those with community-engaged methodologies, are challenged by the heterogeneous and fluid nature of queerness. I describe how exposure to the language used by researchers - specifically the term “transgender” – introduced participants to new terminology. I explore how these groups represent a trend that pushes researchers to offer more choices of identity options for data collection. This system produces an injunction to choose and while choosing requires one to stake a claim to a specific personal identity, it also reifies the idea that gender, sex, and sexuality are stable objects that are able to be known and quantified. I argue through a Foucauldian lens that that there is actually little conceptual difference in offering 5 or 50 or 5,000 identity choices, as all such quantification requires a specific conceptual bounding (and therefore construction) of gender and sexuality. Lastly, this chapter explores the ambivalence that appears within these focus groups as participants question what it means to be represented on a research survey. Such ambivalence exposes the discordance between the goal of research design to offer representative and affirming identity choices and the discomfort expressed by participants with being asked to solidify their identities when the goal is to turn such categorizations into data.

Chapter 2 “What Counts About Counting: Solidification and Solidarity” begins with fieldwork observations at an erotic fetish event. It focuses on how, in the midst of the smell of well-oiled leather, the sound of cracking whips, and the sight of bare skin, a mundane plastic clipboard appears holding information about a health research survey. This clipboard represents the ways in which research on queer health has long been not only intellectually, but also physically close to the erotic. I explore how this clipboard actually embodies much of the same affective power as the fetishes on display at this event. Research stems from an enticement to pleasure, through the presumed desire for and promise of health (even as the concept of health remains a political and often coercive force). The power of data often stems from a fetishistic reification of numbers as they are imbued with a type of magic to make things happen and reveal truths. These promises of counting are destabilized when I analyze a medical school lecture in which statistics around the relationship between sexuality, disease, and racialized violence are used as teaching tool and spark fervent debate. Building on the anthropological work on metrics and counting, I explore how such statistics become a contested space for debates around how numbers can be violent as they are seen to lock queerness in a relationship with death and violence. These debates expose the political stakes of quantifying queerness. Some argue that such statistics bolster a pathologizing framework that connects queerness to disease and harm and others view them as a way to offer solidarity with and lend power to an acknowledgment queer suffering.

Chapter 3 “Ghosts in the Data: Defining the Aggregate” begins with observations in a

California public health clinic focused on serving the queer patients. This chapter starts with a focus on the ethnographic object of the intake form that lists over 60 identity choices. Clinic staff describes how such data collection is seen as a form of care, on par with medications and other therapeutics. These data emerging from this expansive form is then tracked for how it is transformed by the requirements for federally mandated reports. The analytic frame of haunting is used to describe the ways in which such data become transformed. The process of data aggregation takes this multitude of heterogeneous data points and must funnel them into the fewer categories offered by federal reporting standards. Haunting is used to describe how that which is subsumed into the aggregate or stripped away as irrelevant clings to the resulting data as a ghostly reminder of what has been left behind. Finally, the denominator - as a numerical object and research tool - is studied as a crucial space of contestation and opens up questions about how queerness resists and is subsumed by aggregation. Researchers describe how they decide what counts as part of the denominator when building statistics. The denominator becomes a space in which they deeply feel the instability of queerness as a totalizing category and they are required to make specific personal choices about what numbers claim to represent.

Chapter 4 “Algorithmic Fantasies: Dreaming Disparities” explores the complex relationship between queerness and health disparities that many data projects are founded on. It begins by observing a presentation about an equity initiative that looks to collect sexual orientation and gender identity data from every single patient who passes through a large public health system. The ways in which data collection itself is seen as a necessary intervention into disparities leads to an analysis of what I will call “algorithmic fantasies.” The term fantasy is used not in reference to an untruth or a naive belief, but a fantasy as in daydreaming, pleasure-seeking, and yearning imaginings. This term is used to describe the way certain types of desirous dreaming around research imagines a future in which data will trigger a domino effect toward better health, better policy, and better living. The desire for ever-more data around queerness is then traced through debates around the ethics of research participation, found data, and what happens when data do not reveal disparities.

Chapter 5 “The Carnal Checkbox: Electronic Health Records, Sex, and Organ Inventories” turns it’s attention to the body within queer data. This chapter investigates the use of electronic health records. It begins by describing how the quantitative documentation required by such software contends with queerness. Specifically explores how this software reimagines the category of “sex” as it is fragmented into multiple functions. This resignification of sex can only go so far though, as it runs into economic structures, such as insurance systems, that require data that include binary sex options. Sex assigned at birth becomes replaced by the category of sex assigned by capitalism. The rest of the chapter takes up the organ inventory as an ethnographic object. The organ inventory is a way of documenting what organs a patient posesses. It was originally imagined as an intervention that would increase the ability of the software to document and affirm queerness. This attempt to transform the body into data not only offers a novel entry into theoretical debates around the relationship between gender and materiality, but also makes an ontological claim to what a body is and how it should be cared for.

Chapter 1 - Drop Down Queers: Research Design and Community-Engaged Research

“It’s Time for Us To Be Counted”

I wave at the security guard behind the front desk and wait for the elevator door to Spectrum Health Center to stutter open. The ascent to the 5th floor is always slightly rickety with a long pause at the top. The hallway to the Health Center is painted in block letters with the quote “Your Health Is Political!” and photos from the 1980’s and 90’s depicting Spectrum’s outreach events with smiling participants wearing clinic shirts and hoisting bags of condoms aloft. On the front desk is a small wicker basket full of mini-sized candies, condoms and neon pronoun stickers reading “she/her,” “he/him,” “they/them,” or “ask me my pronouns!” Patients lounge on the three leather sofas in the waiting room as they help themselves to the free food spread out on a folding table. Clinicians and staff members walk back and forth along the long hallway to call patients into a medical exam room in the back or one of the smaller rooms off the hallway that are used for therapy and case management. I am at the clinic today to assist with focus groups for The OUT Study.

The OUT Study is a national longitudinal cohort study of LGBTQ+ health. OUT stands for “Our Unique Terminology.” It consists of one annual general health questionnaire and many sub-studies. In describing a goal for the study, one of the researchers working on it, Dr. Saylor, referenced the Framingham Study, the famous longitudinal study of risk factors for cardiovascular disease. “Part of our inspiration was from frustration that we weren't seeing these data in any other study. So you look at like the National Health Interview Survey or the California Health Interview Survey or the Women's Health Initiative [and] all of these studies, these big cohorts that have spawn thousands and thousands of insights on health and medicine.

And yet LGBTQ plus folks are largely invisible. Not that they're not in those, but they're invisible." The OUT Study therefore recruits only participants who self-identify on their initial screening survey as LGBTQ+. The project is a large undertaking with deep hopes for influencing the future of queer healthcare and research. The study conceptualizes itself not only as a corrective intervention to improve data on queer health, but also as a platform to democratize the research process by including queer people at every level of the study. Questions from this study cover a huge variety of topics - from reproductive health to sunscreen use to depression. Study materials stand out from much of the other research ephemera I studied during this research that tended towards a more stoic aesthetic. Recruitment flyers and social media posts for The OUT Study overflow with bright colors and photos of the queer community smiling proudly with multicolored hair or hugging in the sunshine or dancing at a party. The community-based methodology of these focus groups both critiques common methods of research, in which studies are designed without the input of affected communities, and also situates the The OUT Study as upholding cutting-edge standards for research ethics.

Promotional material for The OUT Study reads as a sort of call-to-arms stating "it is time for us to be counted." Such discourses around the importance of the need for "counting" are repeated frequently within The OUT Study materials. The inclusive pronoun "us" is also notable as it gathers together researchers and participants within one shared community. The researchers - the counters - are implicated in this statement as well. Their time too has come to be counted. Interestingly, while the pronoun "us" is used to identify that both counter and counted as existing under a shared identity, how exactly to describe this "us" is exactly the point of these focus groups. The goal of these groups is to determine which sexual orientation and gender identity terms should be used within health research. One of the goals of The OUT Study is to contribute to best practices for collecting data on sexual orientation and gender identity (referred to as "SOGI") for participants in health research. These groups aimed to create a space for researchers to solicit input from queer community members about how they wanted to be asked SOGI questions. The goal was for researchers to learn from the community, to be educated on identity terminology, community norms, and personal opinions by individuals who hold a diverse variety of gender identities and sexual orientations. In his book *Impure Science: AIDS, Activism, and the Politics of Knowledge* Steven Epstein describes how AIDS research provided a site in which scientists and AIDS activists came together to produce, contest, and debate knowledge production around AIDS. The OUT Study can be seen as part of this lineage in which such collaborations structured AIDS research in such a way that paved a way for such queer-led community-engaged research around queer health. The vast majority of researchers within The OUT Study identify as queer, which wraps them into a complex sociality with study participants. Within these focus groups though, there still remained delineations between participants and researchers, regardless of their shared queerness. The focus groups solicited the personal opinions of the participants and the research absorbed those insights. The participants were encouraged to describe their experiences, while the researchers listened, took notes, and answered questions. Access to the power of expertise and institutional affiliation separate the researchers and participants within this focus group, but the perception of a shared identity remains is crucial to the politics of this project. By using terms like "us" in their materials, The OUT Study continually draws attention to the queerness of the project itself.

The email invite to participants for these focus groups stated, "YOU can help shape the way research and health care is practiced in the future." Debates around the best way to collect SOGI data have long existed in health research spaces. The "best" in best practices becomes an open question as researchers grapple with what aspects of SOGI data collection to prioritize. Is it most important that research participants feel like the research design is affirming of their identity? Does affirmation mean offering the freedom of self-identification through qualitative free-text collection methods? Or is it preferable to have an extensive list of quantitative answer choices that attempts to be as inclusive as possible? Is it important that the data are accurate, which begs the question of what accuracy is and does? Is this research asking about self-identification, behavior, how participants are usually externally labeled, or some combination? Some projects may prioritize data collection methods that allow the results to be easily statistically analyzed. This usually requires quantitative collection methods with a limited number of choices. The trade-offs for each of these options carry heavy stakes for researchers. The researchers I interviewed openly wrestled with this conundrum of research design priorities. Alex, a researcher assistant working with The OUT Study, described the importance of designing SOGI questions thoughtfully. “I think approaching these questions with a little hesitancy or a little - I guess cultural humility is the word that's used - is important because there is a very real risk of traumatizing or at the very least introducing microaggressions to participants in health research if questions are asked poorly… if [the questions] are gendered or relate organs to a gender in an essentialist way [research] can; one, invalidate your participants experience; two, they might write the survey off or lie, and then your results are less accurate and you don't even know it; or three, they might not respond at all.” Another researcher told me, “I really love the phrase nothing about us without us. Just because I think that there's such a history of medical research when they don't involve communities. The end result ends up hurting that community more so than helping them.”

The OUT Study is very focused on the affective impact of research questions. Prior to the focus groups, researchers compiled a collection of ways in which SOGI questions have historically been asked. This included both what OUT Study researchers called the “question stems” such as “What is your sexual orientation?” or “How do you identify your gender identity?”. It also included lists of “answer choices” which were long lists of different terms to represent queer identities. During the focus groups, the various questions stems and answer choices were projected onto a screen and the participants were prompted to share their opinions. The questions varied in terms of wording (“What is your identity…” versus “How do you identify…”), grammar, punctuation, and instructions for answering (“Choose one” versus “Select all that apply”). The answer choices also went through the same process. The group facilitator, Molly, solicited insights on how such questions and answers were received, how participants might change them, and what the best method for asking such questions might be. The discussions that emerged ranged from whether terminology was offensive to if slashes or commas felt like more affirming punctuation. Both an audio recorder in the middle of the table and a research assistant typing the responses into a laptop collected these opinions.

Within the conference room, focus group participants trickle in to the clinic conference room. Some stop at a table where snacks and sodas are laid out, while others wander to pick a chair around the long oval table. This group was recruited from online recruitment calls, community organizations, and within the clinic of the Spectrum Health Center. Participants were assigned to different focus groups based on the gender identity they had indicated on their recruitment survey. A small stack of Visa gift cards sits on the table to be distributed to participants at the end of the group. Dr. Saylor greets participants as they arrive and the facilitator Molly smilingly offers a seat at the table to newcomers. I am in charge of signing *participants in and offering them nametags with instructions to write a pseudonym they would like to use for this group and their pronouns on it in colored permanent marker.*

Once the focus group introduction is over and the discussion about SOGI questions and answers begins, one participant, Mary, pipes up to give her input about how she imagines SOGI data being collected.

"In my head, we're talking about a list that you're, like, checking boxes. My original thought is the more things that you could get down on that list, the better, because you're providing people with more opportunities to identify themselves in some way. Like, from a list that typically has two things listed on it - female and male - to be able to add many terms to that then it's worth putting down on the list so that they can have that box to check."

What it means to "have that box to check" is a deeply foundational question for The OUT Study. These focus groups grapple, implicitly and explicitly, with what can be offered by and what is lost in the institutional recognition provided by being able to check a box that feels accurate to ones identity. The OUT Study is embedded in a contemporary research climate that hopes to fulfill the many promises offered by data-based recognition. The process of research on queer health brings researchers and participants alike face-to-face with how such lofty promises draw individuals to research, but are also challenged by the requirements of data and research design.

Other discussions in the focus group get more granular. A list of different ways to word quantified questions about sexual orientation is projected on the board. One participant responds, "I like 'how' questions better than 'what'." Another seconds this, "I agree with the ones he picked, the A and B ones, because that's cute. That's cute."

Another portion of the focus group examines the identity terminology used for answer choices. Participants are asked to imagine they are taking part in a research study and they're asked to identify their sexual orientation. Which terms would they want to see on the list of answer choices?

Text appears on the projector screen - it is a list of identity terms often used as answer choices within research studies.

A) Straight/heterosexual

B) Gay/Lesbian/Homosexual

C) Bisexual

D) Queer

E) Other

F) Refuse to answer

A debate around the word "queer" emerges.

Molly asks "What about the next one; queer?"

Athena jumps immediately in. "I don't like that word. I don't like that word… it's an old assault to the gay community. It's been around since the beginning of time, and that is the biggest insult word of all time. But I see here, it's like, oh, it's like in Hollywood [and] walking [the] red carpet. But where I'm from, it's the biggest insult ever." Mary disagrees and offers, "For me, queer is a very inclusive word, in that it is a very open and unclear term. Queer leaves you space to say, 'I don't know where I fit on this list. I know I'm probably somewhere on this list, but I don't know where.'" Lee agrees saying, "Queer is the umbrella term now." I sit on a *folding chair in the back of the room typing furiously on a laptop - I've been tasked with attempting to record everything verbatim as a back up in case the audio recording fails. The discussion ricochets around the room as I try to keep up. Some participants appreciate the inclusivity of queerness, others remain put off by it, and still others find it mundanely repetitive. A few minutes of debate pass and the facilitator steps in saying, "All right. Let's move on" and brings up the next topic of discussion.*

Such debates around the reappropriation of the word queer are not unique to this focus group. This focus group is debating not only whetherr the term should be used at all, but also how to define it and whether it can accurately serve as an umbrella for those identities that fall outside of hetero- and cis-normative structures. This debate around the term queer helps to expose one of the foundational challenges of The OUT Study and other attempts to quantify SOGI categories conceptually. The goal of these groups is to produce data that researchers can use to guide how they write questions for SOGI data collection. Within this moment though, there is no agreement as to the affective charge or definitional borders of "queer." Within these focus groups, researchers (myself included) work to record the disagreement, heterogeneity, and instability that exist within attempts to categorize such identities. The audio recording and my computer screen fill with debate, but the group still ended without consensus. The question of what to do with "queer" is left open-ended and remains a moment of instability within a project that is attempting to improve quantitative research that, by design, requires definitional stability for their variables - or at least the appearance thereof. Within the principles of community-engaged research, one guiding value is that community input will influence the ensuing research design. In this moment though, the micro-community of the focus group disagrees. This requires the researchers to explicitly retake some definitional control. It is the reserachers who will ultimately choose if they use the term queer or not and if they do, how they will define it. Queerness is not the only conceptual space that offers such productive destabilization. Many other objects of quantification are subject to similar debates, such as racial and ethnic identities, disease labels, and legal statuses. This focus group makes explicit the messy process of research design and it's required process of defining categories. One researcher within The OUT Study admitted that while initially she was motivated to do this work by the idea that there was one best way to ask SOGI questions and these focus groups would reveal it, her thinking has since evolved. "[I started] this project saying, 'There is a set of questions out there that exists that is the best possible set of questions.' And now [it's] more like, there are questions that are best for right now and what those questions will be will definitely evolve over time. [They] hopefully will suit the needs of the community and how the community evolves over the next several decades, if not more. So I think that even the questions that we had developed and [asked] people about in [the focus groups], those could be wildly different now…And it's just so exciting to realize that there's never going to be like the one perfect set of questions, right? Like it's always going to be an evolving process."

A rapid-fire back-and-forth emerges in the group. The debate is about using slashes (gay/lesbian/homosexual) versus commas (gay, lesbian, homosexual) within answer choices.

"I think I'd probably prefer commas - the slash to me, if you have gay/lesbian it's kind of like it's all merged together, I mean, instead of being two very distinct entities."

"I have a really dissenting opinion here. I like the slashes. Slashes to me are 'and/or'. And commas are very… the comma sounds like this is one of these. To me the slash is pick one or more of these - the slash feels a lot more fluid."

"I just think it's interesting that to some people the slash is very fluid and kind of and/or. To me it's very delineating and that's why I prefer the commas."

"It's funny. I thought they felt very neat and separated with the commas, which is kind of - I'd like that the commas kind of respected that they can be separate identities for some people."

The dissection of research questions within this group becomes so granular as to inspire debate over the tiny slashes and commas within potential answer choices. Even within such seemingly mundane aspects of quantitative questions, strong affective resonances are felt. These debates make it clear that the interaction between research questions and the participants answering them are far from a simple example of direct documentation. While it might not be surprising that the word queer inspires debate around its deep history of discrimination and reclaimation, something that seems as prosaic as commas and slashes also elicit similarly complex responses. Interestingly, even though the focus groups were convened to discuss identity terminology, it becomes clear that questions about how to include queerness within a research study include much more than solely the words used to talk about sex, identity, desire, and behaviors.

Cindy looks up at the screen on which the question "What's your gender identity?" is projected alongside a long list of identity terms. Cindy bluntly states, "I would expect a professional healthcare person to look at me and not ask a stupid question. Like, that's what I would expect. You know? But for a doctor, I expect something other than stupid." Cindy dismisses the request to choose the best answer options and instead identifies the question as something that should be self-evident and unecessary. Cindy continues, "The fact that I feel like a girl, what's it got to do with if I have bronchitis?"

While these focus groups are billed as an opportunity to participate in the research design process, participants also explicitly speak back to the medical and research apparatus. In certain moments, participants such as Cindy even outright undermine the premise of the focus groups (to improve these question and answer options) and destabilize the idea that collecting such data is an important part of how research can affirm queer identities. Even within the space of the focus group, in which the entire premise to improve SOGI questions, Cindy destabilizes the assumption that such questions are necessary at all. The premise of The OUT Study, and many other queer health related projects I explore within this project, is that more information, more data, and more documentation will lead to better care. Cindy bluntly refuses the prospect that answering SOGI questions for researchers and doctors will make her feel more affirmed in her gender, renaming it as "stupid" and irrelevant.

"All of this is new to me"

Molly asks the focus group participants to shout out gender identity terms, not only ones they personally identify with, but also any they have heard in their communities. Participants are tentative at first, but soon the ball is rolling and they are shouting out terms. "Man!" "Intergender!" "FTM!" "Genderqueer!" "Agender!" "Transneutral!" "Woman!" Molly scribbles them onto a paper easel punctuating her writing with encouraging phrases. One participant, Crystal, is closely studying the board as the terms are scrawled on to it. Molly notices her focus and asks if she wanted to share her opinions on any of the terms.

"All of them are real good…Yeah, they're all new to me. All of this is new to me. I've heard of the LGBT, but I've never heard of the gender identity until I [came] here [to the focus group], because where I'm from, you only have one identity that they see. I'm from Louisiana

and Texas. So, they only label you with two, just male or female. So, that's the only thing I'm ever used to. So, when I hear all of these, they're all new to me. So, I listen. That's why I don't say nothing, because I don't know what to say. All these words, I've never heard of before, so I'm learning…It's the new words. It's just the new words. It's the new identity. Because it basically, instead of insulting you or making you feel like you're not - like someone trying to be funny about your sexuality and [you] really know who you are and what you are. Or instead of them trying to be funny, they can use - they have many ways of identifying you without being rude to either their religion or to their self-inner stupidity or to you…Okay, like I said, all this is new. Back home, they just going to call you a shemale, punk, or a cross-dresser. So, all of the transgendered stuff is new to me."

In this moment, Crystal learns that gender identity is a category used by researchers and that it is considered separate from "male or female." She is also introduced to the term transgender and not only that it is an identity term used by these researchers, but also one that they might apply to her experience. In this moment, the focus group creates a loop of co-production. As Crystal learns of these new identity terms, she is asked to communicate how these terms make her feel. Such insight then enters the research process labeled as community knowledge - even though it was through the process of research participation that the definitions of such terms were first made available to Crystal. The research space becomes a multi-way transfer of information. These focus groups were designed so that community terminology could influence how The OUT Study asks SOGI questions, but the research process simultaneously influences such community terminology. While the goal of the focus group is to open up the research design process and allow community members to critique, correct, and offer edits on question stems and answer choices, Crystal's experience underscores the co-constituative nature of such research. It destabilizes an assumption under which much community-engaged research operates; that local knowledge and research data are siloed conceptual spaces. The promise of community-based research is that community and research spaces can influence one another to create a more robust and affirming research experience. Crystal's experience destabilizes the idea that local knowledge is untouched by biomedical conceptualizations. The Patient-Centered Outcomes Researcher Initiative (PCORI) is a funding organization that "requires that patients be engaged in the research we fund, not as subjects but as parters" ("PCORI" n.d.). Focus groups are defined by PCORI as a method of engagement called "stakeholder input" in that it "is primarily unidirectional, where partners share their perspectives or feedback on a particular topic in a singular forum" ("PCORI" n.d.). Crystal's experience represents how the cycles of knowledge production within community-engaged research are often far more complex than simply a "unidirectional" transfer. The OUT Study collects Crystal's opinions on her identity, while at the same time that very act of participant engagement changes the language Crystal has available to describe herself.

Crystal not only learned new language from this focus group, but she also learned that this language is how she could come to be represented in the data from the OUT Study and possibly how other researchers and health professionals might label her in the future. Even within the expansive list of gender identity answer choices offered up for debate within the focus group, "shemale" or "punk" do not appear. Crystal is not given the option to choose the terms she is familiar with, as problematic as she found them, from back home. The terms woman, trans woman, transgender woman, and MTF are all debated by the focus group. While Crystal's response to these new terms is appreciation for the respect, it becomes clear that her local terms are not available to be included in research. There remains a limit for terminology deemed appropriate for this research project, even that which emerges from the local environment of and feels most familiar to the participants.

In *Imagining Transgender: An Ethnography of A Category* anthropologist David Valentine explored how the term "transgender" was embraced and mobilized by social service providers and activists in the late 1990's in New York City. Valentine explores how the people to whom this term was applied by the providers were primarily low-income people of color and were either not familiar with or outright rejected the term, preferring instead to label themselves as "gay" or with other terminology. Within the book, Valentine describes this discordance as representative of how the conceptual separation of gender from sexuality was rapidly gaining acceptance within academia, social services, and healthcare even while many individuals to whom the term was applied did not find it applicable to their lived experiences. In a way, Elizabeth Povinelli also takes up similar questions in *The Cunning of Recognition*. Povinelli argues that a certain form of liberal multiculturalism touts inclusion and diversity as core values while also strictly bounding what practices, identities, and understandings are seen as acceptable to be recognized as authentically cultural. Crystal is invited to share the identity terminology that is familiar (if hurtful) to her, but this language is never considered for the institutional recognition that comes with being included in research surveys. This is not to say that the answer to such conundrums is to include such terms or the researchers were willfully ignoring Crysal's experiences. Instead this moment can demonstrate how the options for identification offered by institutional recognition are already foreclosed in many ways, even within a project that claims to want to critique and expand such options. Community-engaged methodologies attempt to de-emphasize medical institutions as the sole arbiters of truth, but in doing so they run the risk of similarly reifying community knowledge and obscuring the ways in which the concept of "community" is a constructed concept with attendant social and political stakes. Crystal is positioned as a member of the "community" which will be engaged with by the research process, but the conceptual borders of such a community go unnamed. The knowledge gained by the researcher from Crystal's statements emerges from the research process itself, not from the imagined community through which Crystal is envisioned to gain her self-knowledge. While "queer community" is a term that was used frequently throughout the medical and research discourses studied in this fieldwork, the ways in which research methodologies operationalize this term should be critically examined for what they include, leave out, solidify, and dissolve. Cindy refuses the question that might allow her entry into what this imagined doctor might envision the queer community to be. Crystal is interpolated into the community through her acquisition of the term in a research setting, though by dint of her being present at that focus group she has already been labeled as part of said "community" (as opposed to the researchers or facilitators, who may be queer, but were located on the "research" side of the community-engaged research equation). Community becomes an aggregation method that offers an aspirational inclusivity while erasing the implicit and explicit methods by which such a space and concept becomes bounded and set apart from others like "research" or "medicine."

"Oh no, I have to choose"

The projector clicks to the next slide and a long list of gender identity terms fills the entire screen. There are five different lists of answer choices all with a variety of different options. Some are just one word: "man," "woman," "genderqueer." Some are a list of terms presumed to be synonyms, such as: "Trans man/transgender man/FTM". "Holy crap" one participant, Luna, says as they eye the extensive list of identity terms pushing at the boundaries of the *projector screen. Molly asks the participants to take a moment and read the choices. Jonah responds first,*

"I think it's really important to have a sense that there are more things than just male and female represented. But at the same time, it feels really confining to want to, like, fix down [an identity term]. And so, I was wondering - I mean, I guess this is kind of like an open question to the group. What if it was just, like, "male," "female," and then "other" with, like, a write-in, or like if there was just a write-in, which, at the same time, I feel like is kind of violent, because it's like, well, then, "other," and then you'll figure it out. But then, at the same time - for instance, if I was masculine-of-center and I had this very, like, strong understanding of my - you know, I think it would be really startling to see it, like, written down… and then I would think about the entire process by which [the researchers] came to that language, and I would think about the focus group that probably happened, and then I would think about how weird it was that there was this whole apparatus around, you know, figuring out how people identify so that we can make them into data points. You know?"

Jonah identifies a central tension within the project of these focus groups. The OUT Study wants to find methods for asking SOGI questions that will feel affirming and accurate, but still allow for traditional quantitative analysis with a relatively limited number of choices. Jonah doesn't offer a way out of this quandary. Instead, Jonah challenges both options presented. Self-identification feels both freeing and violent. Recognition becomes both affirming and reductive. Jonah questions the affective impact of being defined as "other," even when it is explored as an answer that could provide an open opportunity for self-definition. After these focus groups, The OUT Study published a paper based on data from these focus groups consisting of tools for other researchers writing SOGI questions. They included utilizing a write-in option, a suggestion echoed by many of the focus group participants. The importance of space for qualitative identification is a common theme within discourses aimed at improving the safety of demographics within health research. Allowing participants to write-in their own identity terminology is seen as a method for increasing authenticity, accuracy, and safety. Such self-identification is what Jonah defines as violent though as he describes it as being quite literally "othered" within a research survey. At the same time though, Jonah is left unsettled by the alternative of institutional recognition. The very space in which he shares these ideas becomes suspect as he wonders aloud about how bizarrely reductive it would feel to have his identity appear on a research survey. Institutional recognition does not directly translate into affirmation; it feels similarly "othering" by transforming him into a data point.

Ella pipes up in response to Jonah's comment. "It reminds me of when Facebook changed their gender options. It was actually a little bit overwhelming to see so many options, because then I was like, 'Oh, no. I have to choose the right one.'" Names for identities remain listed on the wall - solid in their typeface, but slightly shimmering with the almost imperceptible movement from the projector screen.

The existence of the blank checkboxes next to identity terms produces a demand for choice to which Ella responds with a disquieted "oh no." It is not the quantity or quality of options that bothers Ella - it is the necessity of choosing at all. Jonah and Ella both puzzle over this conundrum of recognition. To be left out - or in this case, left blank - can be seen as erasure, but to be included requires submitting to a "whole apparatus" embedded within an institutional system. This system produces an injunction to choose and while choosing requires you to stake a claim to a specific personal identity, it also reifies the idea that gender or sexuality is an object that is able to be known at all. In *The History of Sexuality Volume 1: An Introduction*, Michel Foucault tackles this conceptual movement through presenting a historical analysis that focuses on the power of knowledge creation through the multiplication of discourses around sexuality (as well as life, death, health and the body). In opposition to what Foucault describes as traditional representations of a repressive Victorian view of sexuality characterized by silence and stigma, Foucault offers a reading arguing “what is particular to modern societies, in fact, is not that the consigned sex to a shadow existence, but that they dedicated themselves to speaking of it *ad infinitum*, while exploiting it as *the* secret” (Foucault 1990, 35) and an “epoch [that] has initiated sexual heterogeneities” (Foucault 1990, 37). This “discursive explosion” (Foucault 1990, 17) (which could “also administer silences” (Foucault 1990, 12)) was regulated, managed and administered by ever-expanding networks of “experts” (including priests, doctors, psychiatrists, family members, educators, etc.) all engaging with a “will to knowledge” (Foucault 1990, 12). For Foucault, the possibility of speaking about sexuality not only becomes an injunction to confess and a requirement to speak, but also creates the very thing that is spoken about as an object of knowledge.

These focus groups and the related research are but one example of the explosion of efforts to improve and expand data collection around sexual orientation and gender identities. Throughout my research, the discussions, initiatives, and projects around queer data that I witnessed are dominated by questions about choices - how many, which ones, when to ask, etc. Choosing a sexual orientation or gender identity is considered central to the project of creating queer data. Terminology, punctuation choices, and the affective impact of language are frequently debated, but the process of choosing often goes unexamined. Jonah and Ella open up this work of choice when they wonder about their discomfort with the choices offered. How can a project of affirmation, one that solicits their input, cares about the community, and even offers a term that is personally resonant, still feel so unnerving? In this moment, the injunction to confess as described by Foucault echoes in this injunction to choose. This demand within queer research is interestingly not necessarily a putative one, it can be a loving and solicitous one. The organizers within these focus groups listen deeply to the participants and work to integrate their experiences and opinions into the resulting research. Both researchers and participants frequently express their gratitude for the ability to improve research methodologies and have their queer identities documented. Within these research and medical spaces that works to center and affirm queerness, the push for new and better choices for identity terminology produces, solidifies, and then requires a set of objects from which to choose. Not only that, but the object of choice can and must be represented as quantifiable language. Research therefore mirrors this linguistic labeling of sexuality that Foucault describes as exploding within the Victorian era and continuing into our contemporary one. It continues to produce this requirement that to be intelligible (and therefore offer an intelligible subjectivity to those choosing) one must choose and that choosing brings a sexual (or gendered) subject into being. Within the world of queer data, one's gender identity or sexual orientation cannot be represented as a flash of light or a musical note or a tasted flavor and it cannot be unknowable either. Queer research strives to claim the radical potentialities of choice, but remains bounded by the institutional demands that structure research projects and quantification efforts. This conundrum befuddles researchers, just as it did Jonah and Ella.

The OUT Study researchers were clearly motivated by their dissatisfaction with previous methods of asking research questions about sexual and gender identity, but participants offered other vantage points around what it means to quantify identities. While in *How to Do Things*

With Words, J.L. Austin focuses on verbal speech acts (the naming of a ship, the uttering of "I do" in a marriage ceremony, etc), the work of answering a research questions about identity can also be analyzed using Austin's work. Checking a box to denote a certain gender identity in a research study can be productively read as a type of speech act claiming that identity (or at least attaching that identity to any further data collected from that research subject). Austin divides speech acts (while allowing for blurring of their borders) into the locutionary act "which has a *meaning"*, the illocutionary act "which has a certain *force*" and the perlocutionary act "which is *the achieving of* certain *effects*" (Austin 1975, 120). Researchers may assume that resistance to research categorization, especially queer communities, is due to the perlocutionary effects of a list of checkboxes next to a limited number of identity categories. The perlocutionary effect was that it made people *feel* bad, unseen or misunderstood if their identity was not represented. So while researchers organized the focus groups assuming the focus of discussion would be perlocutionary acts, the groups themselves seemed to want to engage more deeply with the illocutionary effects of the speech act that is the research checkbox. The insights offered by participants raised questions around how are they, as subjects, being made and unmade, by their participation in research. Through her discussion of hate speech in *Excitable Speech*, Judith Butler asks "could language injure us if we were not, in some sense, linguistic beings, beings who require language in order to be?" (Butler 1997, 1) and points to the illocutionary power of language to create the subject that could not exist prior to language. Gendered subjectivity is particularly vulnerable to language since, "if gender attributes, however, are not expressive but performative, then these attributes effectively constitute the identity they are said to express or reveal" (Bulter 1999, 180). If gender is performative (in the Austin-ian sense of having illocutionary power) then the research language that is often understood as describing gender might be more productively understood as producing gender itself.

Foucault offers that, “it is through sex - in fact, an imaginary point determined by the deployment of sexuality-that each individual has to pass in order to have access to his own intelligibility” (Foucault 1990, 155). While Foucault engages with questions of how “sex in itself” (Foucault 1990, 152) “was able to function as a unique signifier and as a universal signified” (Foucault 1990, 154) through a separation of sex with sexuality, I’m curious as to how queer research and the requirement of choice participates in this naturalizing and thingification of sexuality and gender identity. Foucault describes how naming sexuality creates a “fictitious unity” (Foucault 1990, 154) that solidifies the production various types of subjectivities within topographies of risk, pleasure, resistance and subjugation. While Foucault addresses both the more obvious explicit naming of sexuality by scientific and religious institutions, an important aspect of this is the more subtle social and affective forces that forge specific and named sexual identities into the very experience of being intelligble as a subject. Many discourses on how to improve SOGI data collection emphasize the importance of providing a more expansive list of identities from which to choose. The requirement of choice - a requirement to be known within and produced through the research study - implies that there is a stable set of objects from which to choose. Jonah and Ella’s unease is not with the available choices though, but with the process of choosing at all. It raises the question: conceptually are 5 choices different from 50? 100? 1000?

These focus groups embody one of the conundrums of collecting data around queerness. The very contextuality and individuality of queer identities makes efforts at community-engaged research so important, but also render them exquisitely slippery targets. The borders required by quantification, not just conceptually, but physically through the survey checkboxes, are challenged by queerness. This is not to say that queer data are more inaccurate or inauthentic than other health metrics. Anthropologists and other researchers who examine health knowledge production have long explored the ways in which quantification creates (as opposed to solely documenting) categories of identity, health, and disease in a wide variety of spaces. Queerness is but one example of this process and one that cannot be teased apart from the ways in which it is produced and mobilized within an intersectional matrix of other identities and social hierarchies. Race as an identity category has been particularly explored as a classification system that is created by and challenges the bounds of quantification processes. Crystal will enter the data as a "transgender woman" and these data will become solidified in academic presentations and clinical publications, leaving the categories of transgender woman dripping in assigned pathology or resiliency or whatever meaning the research is attempting to create about this constructed identity category. The research will imply that there is a community *out there* with authentic knowledge that they collected. It will work to stabilize the category of *transgender woman* or Jonah's *masculine-of-center* through quantitative documentation. Crystal though only gained access to such terminology through participating in the research process. The data did not document a transgender woman - it created her. Queerness thus exposes how quantification practices transform data, while at the same time needing to erase the processes by which the data create the very objects it claims to document. This is not to say that quantification creates falsehoods, or even that the main action is one of narrowing or over-simplification (though that can certainly be the case), but that it may be better understood as a process of *creation* than one of *documentation*.

Cleaning Up The Mess

Long after these focus groups has finished and the data from them pubished, I spoke with Dr. Saylor, one of the researchers working on the study, about her experience. “I would say that people who think, you know, that there is one right way, you know, that that was always a fallacy, but it it's much more transparent. And I think in our research how messy it is. But I kind of think about it, like the way I think about it when I'm not just frustrated - because there are really frustrating moments - is the difference between like fast food and slow food. I think of community-engaged research as like slow food and really delicious, like some truest meal that like really brings in the flavors of different things, really curating. And it's really about the experience. And that, that experience itself is transformative. It's not just about quick calories at the end of the day to fuel a machine that's like disembodied. It's about looking that the whole process of cooking and eating and enjoying is like nourishment of like body, mind, and soul. So that's how we think about it. So in the most enlightened moments, it really feels like that like an incredible feast among community members where you're just like, you know, the, the movie music is playing in the background and it's all like in flow, you know?” Dr Saylor describes the complexity she feels around doing community-engaged research. She sees it as both frustrating, and like a beautiful community meal. It is a method for rethinking not only the time scale of research, but also the attention given to the experience of creating it. Using slow food as a model for research is also done in the essay “Slow Research: Thoughts for a Movement in Global Health” wherein authors Vincanne Adams, Nancy J. Burke, and Ian Whitmarsh call for just such “slow research” (Adams, Burke, and Whitmarsh 2014). It is the experience of slow research that is itself transformative, not only the data that emerge from it. The OUT Study attempted to slow down in order to listen. Though time is not the only metric that Dr. Saylor experienced as different within community-engaged research. She also told me, “I feel like it's more just like, I dunno, it's messy. And I know that people don't like that, but I think it's much more sort of reflective of the richness of human lives and experiences.” Others I interviewed echoed this theme. Another researcher said, “The challenge [of community-engaged research] is that that's messy. And, you know, there are times when I'm like, ‘Why don't I just do database research or something where it's just like ones and zeros?’, you know?”

Metaphors abound to describe the processes by which data become transformed from the moment of documentation to the process of analysis, but many operate around a sense of creating order from disorder, such as; clean/messy and raw/cooked. Crystal Biruk writes in *Cooking Data: Culture & Politics in an African Research World*, “adjectives such as ‘cooked’ versus ‘raw’ and ‘dirty’ versus ‘clean’ figure across multiple scales of data talk in survey research” (Biruk 2018, 3). Messy data are understood to be less useful and more unruly to work with, while clean data are collected and/or processed and/or reported in a way that maintains the border stability of its categories and offer as few confounding variables as possible. Cooked data carry the pejorative assumption that cooked data are overly processed and therefore suspect as having been tampered with or fraudulent. In Biruk’s work, observing the process of health research in Malawi, describes how such binary categorizations of data obscure the way that all data are cooked through collection methods, analyses, and dissemination that require active choices around definitional categorization, algorithmic manipulation, and formulaic presentation. One edited volume is even more explicit as to this idea, with its title of *Raw Data is an Oxymoron* edited by Lisa Gitelman (Gitelman 2013). The use of these metaphors reveals one of the central instabilities of the quantification process. There is a need for data to be seen as truthful documentation that are representative of facts that exist *out there* within the lives, experiences, identities, and biologies of those studied. At the same time, data are required to be sculpted in specific ways in order to be intelligible and digestible to the analyses and statistical processes that create a product able to be disseminated through scientific and medical institutions. These metaphors of raw/cooked and messy/clean reveal the delicate (if impossible) balance demanded if data are to fulfill their promise of serving as truthful representations of reality. Data must be clean, but not cooked. This means that data must undergo the processing of analysis, but that too much manipulation undermines the fidelity of the data. The lack of strict delineation between the categories of clean and cooked belies the inherent ambiguity of the process of data creation through which seemingly contradictory desires emerge. On the one hand, there is a desire for data that are located as close to the object which they are trying to describe as possible, without interfereing manipulation. On the other, data processing is necessary in order to adhere to the statistical representations that make such data useable by the institutions through which they move. While community-engaged research like The OUT Study may be described as especially messy, exploring the processes by which any quantitative research project is designed allows us to better appreciate the ways in which even at its most granular level (down to commas and slashes), the production of data is always an ongoing process of domestication through such work of cleaning and cooking.

Chapter 2 - What Counts About Counting: Solidification and Solidarity

Bondage & The Research Booth

Booths line both sides of Folsom Street stretching for multiple blocks down the center of San Francisco. In one booth, rows and rows of leather collars, harnesses, and leashes gently sway in the breeze as they dangle from metal hooks. At another, a man similarly undulates as he hangs from a metal tripod suspended by the jute bondage ropes criss-crossing his tattooed limbs. This is Folsom Street Fair, an annual street fair dedicated to the celebration of kink, fetish, and bondage, discipline, sadism and masochism (BDSM). It is 3pm and the day has been hot and sunny. I see sweat pooling on the temples of those proudly don their full leather regalia and unique tan lines starting to form for those who show off in only a jockstrap. Above our heads, banners hanging from the lampposts displaying the traditional black and blue stripes of the Leather Pride flag that have been hung by the city government of San Francisco to officially promote the fair. I pass by the drag queens working the entrances by directing people into the fair from the line that spreads multiple blocks down the street and collecting the requested entrance fee donation, which will be donated to a local charity. Bodies crush against each other in front of a stage that hold a DJ playing bass-heavy electronic music behind pedestals holding up glistening go-go dancers. Displays of fetishes and kinks are everywhere through a variety of outfits. From my perch on a curb, I can see elaborate military uniforms, leather vests, shining steel-toed boots, and plenty of nudity. Further down the street more conventional street fair goods, like overpriced hot dogs, popcorn, and foamy beers, are sold.

Even in this setting, which may seem worlds away from the Excel formulas and stoic surveys often associated with health research, I spot a booth out of the corrner of my eye that is *advertising a research study on the sexual health of LGBTQ+ individuals. Informational pamphlets are spread across a table inviting passers-by to learn about hepatitis C or PrEP. On the back wall of the booth, dildos are glued to a wooden board so that they stick out perpendicular to the ground. This handmade "Dildo Ring Toss" invites the curious to stop and test their hand-eye-coordination in a cheeky version of the classic carnival game. For those who do pause to play, a smiling volunteer jumps into action, describing the research study and offering a clipboard for those interested in signing up for more information. The scratched plastic clipboard holding a plain white 8 x 11 inch flimsy printer paper sits mere feet from a stunningly complex metal carriage that glides through the crowd ferrying a woman in leather wielding a whip to spur onwards the two human ponies pulling her forward.*

In the sea of flesh and leather filling Folsom Street all dedicated to the celebration of fetishes, kink, and the erotic, this research is comfortable nestled. As much aesthetic contrast as there is between the mundane plastic clipboard and the gleaming leather whip, the research booth does not feel out of place in this scene. There is a familiarity and comfort with and within the booth. This comfort is partially historical, as the relationship of queer sexuality and health research is a close one with early HIV/AIDS research taking place in explicitly sexual spaces like bathhouses or leather bars. Asking about sexual health may be an intimate experience, but research on queer health has long been not only intellectually close to sexuality, with its questions about behaviors, partners, and identities, but physically close as well. One of the aspects that separates queer health research from many other research fields is this extension into and merging with other queer spaces. In *Impure Science*, Steven Epstein discusses how HIV/AIDS brought activists and researchers into close contact leading to increasing collaboration and conflict, and a rethinking of where expertise can emerge from. The appearance of this research booth at Folsom is part of the legacy this queer history inspired through an increasing porosity of the borders between researcher and research subject, science and community, and quantification and erotics. The study does not need to be at Folsom to do its work because it is not observational and its goal is not to study the erotic experiences occurring around it. Instead it is there as a model of community-engagement and to advertise, recruit, and educate. While other research topics may share this community enmeshment (research on drug use is a particularly apt example), this *queering* of not only the object of research, but also the research process itself creates a potent space for explorations of how queerness and data interact, transform one another, and reveal the pleasure, power, and conflict within the spaces in which the two meet. The Dildo Ring Toss might seem audacious if it was located at a scientific conference or in a research laboratory, but compared to the other booths at Folsom it appears quaint in its winking reference to classic carnival games. That said, an analysis of the appearance of this booth in the middle of a sea of erotic explorations and exhibitions does not need to only be one of contrast and dissonance - the cheery rainbow-colored promotional t-shirts of the research worker versus the squeaky latex catsuits sported by other attendees. The booth and the kink celebrated by the fair both embody a call to pleasure, a fetishistic power, and a recognition of the complex potency of being seen.

The body wrapped taught in bondage ropes hovering above the hot asphalt exudes the erotics of containment. The rapturous expression in his eyes draws an ever-growing crowd to offer witness. The contrasting pressure from the hands of the rigger - gentleness as she slips the ropes around eager limbs and ferocity as she pulls the knots tight - lends the scene a rhythmic cycle of expansion and contraction. The expert knowledge displayed by both top and bottom, of how to submit and how to control, titillates the crowd. Impressed murmurs bubble up every time a new *knot changes the shape of the tied body, levering the arms higher or dropping the torso down low, leaving the body hanging by only a leg.*

While the pamphlets on Hepatitis C in the research booth and the pas de duex with ropes in this exhibition may seem worlds away, their simultaneous presence at this event exposes their mirrored work of seduction, pleasure, and fetishization. The research both is here because it is a community event popular with their desired research subjects, but it should not be overlooked that this booth also has something to say about desire. The more explicitly erotic booths serve as an enticement to the audience, to come closer and witness the pleasure or danger or titillation within. So too does the research booth. Just as the leather toys for sale offer the promise of ecstatic fantasy fulfillment, the institutional pamphlets seduce with the promise of health and of witness. The checkboxes of the survey offer the pleasure of being known by the institution. There are erotics within quantification - the pleasure of containment by checkboxes, just as by ropes. Data dangle the promise not only of knowledge, but also of witness, for participants, for researchers, and for the larger institutions that utilize the resulting numbers. As the focus groups discussed in Chapter 1 explored, there are complex ramifications to having ones identity witnessed by a research form and the experience can inspire both pleasure and discomfort. For a research booth to be located at the Folsom Street Fair is to position it squarely within the same socio-sexual community of that event. The border between the academic medical institution and the participants of the fair becomes blurry as the research booth not only nestles itself between the sale of harnesses and displays of bondage, but offers a cheeky nod to the sexually charged nature of the fair with its dildo ring toss game. While the object of study for the research booth is queer, queerness can also be seen as seeping into the research process itself. Sterile medical professionalism is replaced with sexual innuendo and bawdy humor. This physical and conceptual cozying up to queer erotics does not diminish the power differentials at play though. The large academic medical center sponsoring the study retains the ability to dictate how, when, and why its counting happens and the ways in which the resulting data become analyzed and distributed. Instead of seeing this moment as simply an example of the growing appreciation for community-engagement within research (though it can be that as well), the research project booth and the fetish booths can be seen to echo one another. If at first glance the appearance of a health research project at a fetish event feels out of place, a deeper look can expose how the erotics on display at the fair raise similar questions as the health survey. What does it mean to be seduced by a promise of pleasure - that of sexuality or of health? How does it feel to be seen - by the loving gaze of a voyeristic fetish community or by the exacting science of health quantification? Why do some objects, actions, and experiences carry a fetishistic charge emerging from an almost magic-like belief in their power - whether this be rope or statistics? This chapter will explore these questions by asking; what counts about counting? It will describe how the power of quantification makes things happen within spaces of queer health through the mobilization of numbers as a resource. The counting of queerness will be traced for how it becomes a contested action within medical spaces and a venue for debates around the relationship between queerness, violence, life, and truth. The medical, scientific, and research spaces of queer health teem with such numbers. Far from being simply a method of documentation, the affective responses to data will be used to describe how powerful the desire for numbers is, whether the need is to have them serve as truth tellers, action mobilizers, or objects of political force.

The Seduction of Health

This enticement to medically mediated wellness embodied by the research booth contains the assumption that health is desired and pleasurable. This assumption is widespread through the medical field. Discourses around health promotion often contain the presumption that health is both a culturally universal monolith and a desired outcome and that anything else is pathological. Not only are the diseases or conditions contrasted to health are seen as pathological, but a disinterest in health or seeking pleasure through perceived “unhealthy” behaviors is also pathologized. By viewing the research booth as just as seductive a force as the booth with the bound man, we see how health discourses can be understood as an enticement to pleasure - but a pleasure that is circumscribed by socio-structural assumptions about what counts as a healthy body. The seduction of health is complex as it entices with a pleasure that does not need to necessarily be enjoyable, appreciable, or equitable to remain seductive. Tim Dean’s critical work on barebacking reminds us that the presumed pleasure of health and safety is not universal and there is a stigma that comes with staking a claim for pleasure within risk (Dean 2009). The edited book *Against Health: How Health Became the New Morality* by Jonathan Metzl and Anna Kirkland explores a variety of critical explorations of the ways in which “health” is mobilized as a moral imperative (Metzl & Kirkland 2010). Eli Clare writes within a queer disability studies framework about how the concept of cure can be coercive and punishing (Clare 2017). These writers, among others, work to so thoroughly unpack the moral underpinnings of health because of its presumed connection to pleasure and the popularized discourses that one should desire health and pleasurably revel in it if it’s obtained. Readings of biomedical discourses can often portray the institution as solely putative and acting through a tyranny of health, but these scenes from Folsom Street Fair remind us about how pleasure and desire within health, research, and science can also be potent forces. The way queerness complicates medical research spaces allows for an opening of questions around who defines health, the desirous discourses around seeking it, and how stigma and pleasure are both mobilized as biopolitical stick and carrot.

So while the research booth at Folsom also offers a seduction on par with the erotic performances that litter the same block, zooming into the health survey that the booth is promoting draws attention to the power specifically of counting and numbers. The rest of this chapter will explore how counting is mobilized to access resources and make certain political claims to truth. In order to do such work, counting must be imbued with a forceful power that allows it to be viewed as pure documentation. Within the space of research, numbers are embodied with this type of power and even magic. While the fetishes on display at the Folsom Street Fair may seem more obvious due to their erotic performativity, the numbers littering the research survey and health pamphlets carry an echo of this fetishistic magic. Michael Taussig writes about the fetish and when describing State fetishism he states, "For what the notion of State fetishism directs us to is precisely the existence and reality of the *political power* of this *fiction,* its powerful insubstantiality" (Taussig 1991, 113). While the State, the erotics of a whip, and the numbers on the survey may seem like three disparate objects, this power of insubstantiality echoes throughout. Taussig continues, "What has come to be called science— and this is precisely the formal mechanism of fetishism (as we see it used by Marx and by Freud), whereby the signifier depends upon yet erases its signification" (Taussig 1991, 118). Numbers can feel fetishistic as their power comes from this very ability to erase the processes by which they are imbued with such power. Counting is a transformational process, that requires an obscuring of the ways in which numbers change and are changed by the objects they are said to represent. Raphael Frankfurter specifically describes how numbers can be analyzed as fetish in his anthropological work on biosecurity in Sierra Leone. “The power amassed through the accumulation of numbers on numbers of surveilled patients, with no capacity to act on what these numbers reveal—in Michael Taussig’s words, the “signifier peel[ed] off from [the] signified” (Taussig 1991, 128) and invested with its own magic and significance? Is this not the very definition of a *fetish*?” (Frankfurter 2019, 530).

We are reminded that counting and numbers are socially-contextual and politically charged actions, even as their power emerges from their ability to be mobilizes as ahistorical and apolitical facts. Crystal Biruk writes, “While we tend to think of data as abstract and intangible, these vivid descriptors draw attention to their materiality and life course. Numbers, of course, come from somewhere” (Biruk 2018, 3) in response to her quoting of Claude Lévi-Strauss who writes, “Data and myths are both anonymized artifacts of collective labor and seem to ‘come from nowhere’ (Lévi-Strauss 1969, 18). Throughout my research, numbers emerged as something deeply desired. Researchers crave the ability to definitively state a fact about queerness and health, clinicians utilize the scientific literature to guide their treatment decisions, and by research participants hope to see a label on a survey that would ensure they could be absorbed into an affirming numerical aggregate. Counting was described as a prized methodology. The power provided by counting was not without its instability though. Researchers (as discussed below) regularly referenced their need to produce quantitative data in order to to make things happen, whether that was for funding to appear, publication to be accepted, or policies to be influenced. They simultaneously expressed their complex feelings around the ways in which counting was not as definitive, solid, and incontrovertible a method as it needed to appear in order to sustain the weight of truth-telling it held. As discussed in Chapter 1, the very way research questions are asked already blur categories of quantification and necessitate both a generation and a constriction of options for naming and therefore options for counting that allow certain forms of knowing and refuse others. Chapter 3 will similarly discuss the ways in which the denominator emerges as a particularly slippery object within queer research, demonstrating the complexities of counting.

This Compelling Idea of the Fact

When I interviewed Dr. Lang, she spoke thoughtfully about the role quantitative data plays within queer health. Dr. Lang describes her long history of activism prior to entering medicine; she worked on environmental justice projects and participated in reproductive rights advocacy. She now focuses her research on issues of reproductive health for transgender patients. She has clearly thought about the role of research within political movements before, and often pauses to collect her thoughts before answering a question, as if she has so much to say she requires some time to pare it down before speaking.

When I asked Dr. Lang about the difference between quantitative data and other types of representation, she told me, “I think that one of the opportunities in research actually is that [quantitative data] can be powerfully reductive towards laying bare some experiences. But I think sometimes it's lost. It's this compelling idea of the fact in front of you and that there's an unmistakable fact and it is statistically significant or whatnot. There are certain forms of story, i.e. data, that some people and some systems respond to better than others. And so I think particularly around things like medicine and policy, there is a currency of change that happens and those happen in briefs and in reports. If you can reductively say, you know, gosh there are men who get pregnant. There are men who need abortions. There are men who need birth control. So don't just write a law that talks about women and pregnancy, because here are the data that show men getting pregnant, men needing abortions, men needing contraception, men needing prenatal care, men needing lactation support. That's my hope is that's like an unmistakable thing and that people can't turn away from. Whereas, you know, a narrative, a poem, a story, or visual may not have a seat at the table."

Crucially, contained within Dr. Lang's quote is the nuance that quantitative data is not equated with facts, but with *the idea of the fact.* "It's this compelling idea of the fact in front of you," she says. It is the idea that there is an unmistakable fact that carries power and currency. Dr. Lang describes how when data and the numbers therein are connected to an idea of a fact they can make things happen. They produce responses from systems, hold peoples attention, and they can even change legislative language. A number representing the people who on a survey marked both the box for gender identity in a survey "Male" and the box asking if they used birth control, or had an abortion, or were planning to become pregnant becomes a type of currency - a "currency of change" as Dr. Lang put it. Numbers make things happen. They exist as both objects and actors. Many researchers I interviewed specified that not all data has this power. The numbers making up quantified data carry a specific charge, as Lang references above. Poems, visuals, or stories are referenced as less able to access spaces of power. Vincanne Adams reminds us, "Stories carry a different kind of credibility because they make people feel something quite different from what they feel when they seem compelling numbers…Affective evidence forms a spectral possibility, perpetuating a fantasy of intimacy and social responsibility" (Adams 2016, 48). Though interestingly, later in this chapter we will see how numbers are also defined by the clinician Dr. Jacobs as "affective evidence" and mobilized similarly to the stories Adams describes stories in order to do work. So while quantified data can be mobilized as a resource or an affective narrative, using numbers to represent queer experiences is not without its conflict.

This conflict is not always over which numbers to use, but questions around what the work of quantification is. The debate is not only about what numbers can and cannot contain, but also about how if numbers are an “idea of the fact,” who gets to imagine that idea and how does the insubstantial nature of such an idea become solidified into a fact. The neutrality Dr. Lang describes numbers as being able to convey contains a power though it remains important to foreground how “while it is commonplace to fall back on the truism that numbers are inherently *not neutral* in that they can always *be used* for any political purpose, as many authors have shown, it is another thing to show how the act of data collection becomes always and invariably political as a form of knowledge *because* it claims political neutrality. In fact, it takes a lot of work to make something seem politically ‘neutral’” (Adams 2016, 9). In the rest of this chapter I will explore an example of how quantified data representing queer experiences are mobilized within a healthcare setting and inspire debates over the solidity of numbers, the affective charge of data, and what statistics can or cannot convey.

Challenging Data

“Data is very challenging in the queer community,” Dr. Jacobs told me. “Sometimes data is offensive in a way because people don’t like to hear the truth.”

Dr. Jacobs is a physician and medical educator at the California University School of Medicine. Dishes clatter in the background of our interview as he unloads the dishwasher, a reminder of how the domestic has been bleeding into professional moments as the COVID-19 pandemic stretches on and working from home becomes standard. Within the medical school, Dr. Jacobs oversees the creation and delivery of educational content focused on sexual orientation and gender identity. He speaks energetically, his words flowing quickly with urgency behind them. He is also a surgeon within the affiliated hospital and does not explicitly focus his clinical practice on queer patients, a professional choice that has led some to wonder why he focuses his educational work on this topic. “[A student] said to me, you're a surgeon, why are you doing this work?” Dr Jacobs told me, but as a gay man he feels personally dedicated to the topic. Dr. Jacobs has strong feelings about medical education and easily rattles off the pros and cons of various educational techniques during our conversation. He spends a lot of time thinking deeply about how to get students interested in issues of sexual orientation and gender identity. Dr. Jacobs describes a slide from one of his lectures to medical students;

“I thought about like all of the big things we teach in med school. And then I went and saw how many Americans are afflicted with those things every year. And so I made a slide and I said 4.5% of the population, conservatively, identifies as queer and 10 to 15% of the San Francisco population identifies as queer… so I did the math…this is how many Americans have diabetes. This is how many Americans have colon cancer on an annual basis. And this is how many patients are queer. And I said, so the reason why this is important is because if you think that colon cancer is important, then understanding how to treat [the queer] community fairly and well are important. Nobody's going to argue that those are not important healthcare topics, right? So that was my goal. And some people thought that slide was genius and some people really fucking hated it. So a couple of the students attacked and said that we were medicalizing being queer and we were medicalizing LGBTQ+ people. But an example of when using data went awry because I was trying to get a point across in terms of sheer numbers of people. And what ended up happening was I was accused of medicalizing an identity or an existence, which I was never trying to do.”

A disconnect appears in this moment. Dr. Jacobs feels urgency in these numbers. For him, their starkness drives home the desperate need for these medical students to understand the importance of affirming medical care for queer communities, something that might otherwise be viewed as a “softer” topic then diabetes or colon cancer. The students who critiqued the lecture see these numbers as implying that there is something intrinsic to queerness that draws it close to disease, risk, and death. “The other thing that [students have] historically have gotten mad at is ‘Oh, well, when you talk about PrEP (pre-exposure prophylaxis medication) as a gay thing… that sexualizes gay people, right?’ And I said, I'm not trying to sexualize people, but if you look at the data, the vast, vast, vast, vast, vast majority of people on PrEP in the United States are queer. They're not straight. If you look at the data, the vast, vast, vast majority of people in America who have HIV are not straight. So it's really challenging to say, like, I'm not sexualizing people, but unfortunately - or I don't even think that there needs to be a caveat to it - there's just more queer people on PrEP, then non-queer people, and there are more queer people with HIV then non-queer people. So if you're going to talk about queer health, you have to talk about PrEP and HIV because it affects the community so much…I want to talk about all these things that affect the queer community, but I think some of the students don't like the reality. Does that make sense?”

Such data are viscerally personal for Dr. Jacobs. He describes, “I grew up in, I grew up in the eighties and nineties. So I was just the generation below the generation decimated by HIV. But it was - it was very much a reality for me in my teens and twenties. It was still very much a reality for me. We did not have great drugs. We did not have PrEP. We had nothing like that.” Dr. Jacobs’s evocation of the AIDS epidemic is telling. Activism around HIV/AIDS in the early years of the epidemic was frequently focused on making the disease something that the public was unable to turn away from. The iconic protest dubbed The Ashes Action at which the ashes of people who had died from AIDS were poured on the White House lawn was emblematic of the ways in which the reality of AIDS deaths were used to make powerful political statements. Numbers are one of the ways in which the excess and emergency of the AIDS crises are solidified and attempted to congeal into fact. At another protest of the FDA by ACT UP activists in October 1988, one sign read "One AIDS death every half hour" (*AIDS Protest at Federal Drug Administration Offices in Washington, DC [1]* 1988). This number (one) carries a temporal urgency (every half hour). Seconds tick by adding up to one death. Then another. Then another. A bloody handprint adorns the sign. This number is a piece of the "challenging" data Dr. Jacobs referenced. Such numbers were meant to do just that, challenge, since publicizing such numbers was a purposeful form of activism for ACT UP. These numbers served as a challenge to multiple groups. They derided a president and his administration who refused to utter the word AIDS, shamed a medical establishment moving too slow to save those dying, and siezed the attention of the public, of which many found comfort in assuming that AIDS was a disease they could safely ignore. Not just naming, but *numbering* violence, allows for quantification of a crisis in a way that draws attention to the scale of it. Though quantification can also often be equated with solidification, a move Dr. Jacobs' students were responding to. Numbering queer experiences (of disease, risk, and violence) were seen as in some way to solidify them. Quantifying queerness is a space of critical debates, not only about how queerness is mobilized as a political category, but also about the work of quantification itself. Such work inspires questions about the political stakes of quantification. Should queer data be used draw attention to discriminatory death and disease? Should it be used as a counter-narrative to stigma focusing on resiliency and joy of queer experiences? As discussed above, fetishistic conceptualizations of numbers offer them a power to set the relationships between objects as fact. Queerness, death, and the clock all become statically connected to one another by the numerical representation painted on the ACT UP sign.

While Dr. Jacobs says he sympathizes with the student response, he maintains his belief that data are important even when statistics “may give you something you don’t want to see.” Showing people something they don’t want to see was foundational for much of AIDS activism. Counting down to death transformed the gigantic scale of AIDS related grief, violence, and death down to a daily, domestic time scale - half an hour - that could not be ignored. This protest sign powerfully represented a ticking time bomb that is drawing ever closer to death (a death, such protests argued, that could be prevented by immediate and systemic change within the medical establishment). The sign is quantifying an excess of death - too many, too much, too often - as a call for life as it demands the FDA intervene through providing access to new medications. While Dr. Jacobs’ students may find numbers that connect queerness and disease to be an act of othering and therefore of defining queerness as somehow abnormal, pathological, or less than, this protest sign serves as an example of a moment in which the counting of death offered a powerful call for the affirmation of queer life.

Dr. Jacobs echoes this idea, arguing that such numbers are a conduit for understanding the urgency of violence experienced by the queer community. Dr. Jacobs states, “How do you balance the stark reality of describing the community and describing the disease without painting this picture of gay men being like disgusting promiscuous people, right? So I totally get [the criticism]. But the numbers don't lie.” For Dr. Jacobs such statistics are truth-tellers. They “don’t lie.” There is an echo of a fetishistic imaginary here. The numbers are imbued with a power that engenders a soothing (if challenging) affective feeling and belief that information can enter a quantification process and emerge as numbers that show us an unvarnished truth. When describing his previous work, Dr Jacobs says, “I wrote a chapter in a book about addiction, what was called addiction at the time. And the chapter that I wrote specifically about HIV positive men and addiction, it talked about the numbers and you know, again, the numbers aren't kind, right? It looks like gay men use drugs at a higher rate than their straight counterparts, that they have higher suicide [rates]…the data, the numbers, can definitely look bad.” While these numbers are seen as solid truths, they also carry deep affective weight. It is the numbers themselves that are unkind or that look bad. Counting, in this moment, draws its power from its ability to represent the truth, no matter how bad.

In response to the student feedback, Dr. Jacobs ultimately edited his lecture. “So it's [still] kind of like doom and gloom for the first 40 minutes. And I spend the last 10 minutes talking about like the positive aspects of being gay. So gay people are more philanthropic and gay people are more progressive and gay people are, and this is queer people, sorry, I keep saying gay people, but queer people are more, philanthropic. They're more into social justice…they're more a part of a community. And therefore more likely to like support the civil rights of others. Again this was all data driven, but showed that gay people were happier in their friend circles and they were happier in their relationships that they did maintain with their family. They had more positive relationships than were reported by straight people.” Dr. Jacobs says he wants to leave his students with the reminder that “it's not all horrible being gay, but there's a lot of bad things that affects the queer community that I want you to know so that you can treat them better and help their lives be better…” This response is telling - the “bad” numbers become balanced by “good” in his revised lecture. Disease is contrasted with philanthropy, perversity with progressive politics, and annihilation is softened by celebration. But “data-driven” remains the unquestioned foundation of such claims. While this may placate the students’ discomfort with how “challenging” numbers are seen to pathologize queer lives edit, the solidification caused by data remains. The appearance that both perversion and philanthropy could be scientifically locked onto queer identities is baked into the statistics. Such debates that pit “bad” numbers against “good” may be seen as misapprehending the questioning of the work done by the act of numbering itself. In the essay “The Secret Life of Big Data,” Genevieve Bell asks, “What is the anxiety, the fear, the instability, the place that the world has moved in such a way that the thing that we think will be *comforting*, although we would never use that language, is more data. Why is this so comforting and so seductive, or, why is it that this is the moment in which more data seduces?” When Bell talks of numbers that comfort and seduce, she does not necessarily mean that all numbers are comfortable or seductive. It is not the content of data that soothes, but the context. The solidification that is allowed to take place around the data as they are crystalized into fact offer the confort and seduction of truth. The idea that counting can be counted on to produce facts is what is seductive. Such desire does not require the resulting numbers to be flattering or inspiring, instead comfort emerges from the quantification process itself. The student’s response pushes us in the direction of such an analysis, but it becomes clear that the debate remains bound by the biomedical fetish of numbers that require such quantified solidification to lend legitimacy. Whether affectively bad or good, these numbers are working within a space (the medical school lecture) in which quantification becomes an adhesive as it sticks concepts, objects, and experiences together. Queerness risks becoming statistically cemented to perversity or each numbered death becomes stuck to the inaction of the FDA or a gay identity is shackled to the promise of a more philanthropic life. This debate between Dr. Jacobs and his students emerges as representative of how quantification is often publicly mobilized as a crucible from which objective truth emerges. This generative work of quantification inspires fierce debates around how and when the power of counting should be wielded.

Counting Violence

Dr. Jacobs remembers another debate with his students around how such data power should be utilized. “Another time that [using data] went poorly was [when] I gave a statistic - actually from the AAMC (American Association of Medical Colleges) - about how Black women, Black trans women are most likely to experience sexual assault…What I was trying to impart was that this is probably the most vulnerable population of people in America. So we know that Black women in general are treated like total and complete garbage in the United States and Black trans women are treated just as bad or worse. My whole point in the lecture was this is a very vulnerable segment of the population that you really need to focus on. If you have a patient who's a Black trans woman, you really need to think of all these things…So I was not speaking negatively about Black women or about Black trans women. I was just simply presenting the data and saying, this is a very vulnerable population that we need to focus on and help. And somebody accused me of sexualizing, Black women, oversexualizing Black women, a group of people who have already been sexualized, hyper-sexualized in the media…for that student, she loved the point that I was trying to make, but she had some issues with how I presented it. [She] worked with me to change it, to make it a little more palatable the next time that we presented that information.”

This exchange between Dr. Jacobs and the student questions the relationship between violence and quantification. Is counting violence an act of solidification or solidarity? Do such statistics solidify the perception of an inescapable relationship between violence and Black bodies? Or are they a moment of solidarity, drawing attention to the trauma the future patients of these medical students may have endured? Solidification describes the processes by which the work of quantification is understood as producing unassailable facts. Quantification is often understood as a process of crystalization by which numbers become truth through the squeezing pressure of counting, statistical analysis, and the reporting requirements of charts, tables, and figures. The student's argument is that such solidification implies an inherent or innate connection between Blackness and sexuality that reinforces societal ideas around the excess of sexuality and of trauma contained within Black bodies, especially those of trans experience. For this student, such statistics quantify that excess in a way that represents how Black bodies count only when sexuality - and sexual violence at that - is the focus. Vincanne Adams reminds us that "quantification strategies and the metrics we rely on to *avoid* politics often do not avoid politics at all; they become a form of politics in their own right, augmenting the political stakes and political underpinnings of health projects in a manner that is frequently invisible to those who believe in these exercises in calculation and counting. In this sense the notion that metrics are not (and have never been) political neutral is not only worth repeating, but also exploring further" (Adams 2016, 9). For Dr. Jacobs, such numbers are an attempt at solidarity. The magnitude of these numbers draw much needed attention to the epidemic of racialized sexual assault. These numbers impart a moral imperative for Dr. Jacobs; they are his method of pleading with the future physicians sitting in his lecture hall to not turn away from the scale of such violence.

When this lecture becomes edited in response to student feebdack, it's not the use of statistics that is changed - it's the harshness. He edits the data to make them more "palatable." This is an intervention into the affective load of such data, but not a critical response that takes into account what such data may mean on a structural level. In *Habeas Viscus: Racializing Assemblages, Biopolitics, and Black Feminist Theories of the Human,* Alexander Weheliye discusses the intersections of queerness, Blackness, and violence when describing Hortense Spillers's concept of pornotroping. Weheliye describes this as "the enactment of black suffering for a shocked and titillated audience" (Weheliye 2014, 90). While not explicitly discussing quantification, Weheliye's analysis can be used to think through how the solidification offered by numbers were seen by these students as an example of pornotroping. Pornotroping "reveals spectacularly how racial slavery and its afterlives in the form of the hieroglyphics of the flesh intimately bind blackness to queering" (Weheliye 2014, 97) through the ways racialized violence of the flesh is ungendering, and therefore queering. Weheliye writes that the Black trans experience "serves as one example of how putatively abject modes of being need not be redeployed within hegemonic frameworks but can be operationalized as variable liminal territories or articulated assemblages in movements to abolish the grounds upon which all forms of subjugation are administered" (Weheliye 2014, 82). Quantitative data represent such a hegemonic framework for the students, in that it solidifies a relationship between Blackness and violence that, especially within the space of a medical school, echoes with pathologization. C. Riley Snorton takes up another moment of counting violence in relation to Blackness. "According to an article published on Advocate.com under the headline 'Victim Number 17: Trans Woman of Color Murdered in Missouri,' information regarding Dominquez's death came on the heels of news about 'three African-American trans women [Amber Monroe of Detroit, Michigan; Kandis Capri of Phoenix, Arizona; and Elisha Walker or Smithfield, North Carolina]…reported murdered just in the past few days' The recurrent practice of enumerating the dead in mass and social media seems to conform to the logics of accumulation that structure racial capitalism, in which the quantified abstraction of black and trans wealths reveals the calculated value of black and trans lives through states' grammars of deficit and debt…This mode of accounting, of expressing the arithmetic violence of black and trans death, as it also refers to antilock, antique, and antitrans forms of slow and imminent death, finds additional elaboration in what Dagmawi Woubshet refers to as a 'poetics of compounding loss,'" (Snorton 2017, viii). This ongoing media trend of counting the murders of trans women of color sits at exactly this intersection of debates around solidarity and solidification. Snorton aptly points out how such "enumeration" contains echoes of racial capitalism. The violence itself is "arithmetic" and numbers, far from neutral values, participate in these "poetics of compounding loss."

What would it mean if these statistics presented the numbers of perpetrators of violence against Black trans women? What if the statistic was that a certain percentage of cisgender men have perpetuated violence against Black trans women? Asking such questions allows an unseating of the unidirectionality of data on violence where the arrow points only to the perceived victims and rarely to the actors or forces propelling such violence. What if the number was 10% or 0.5% or 30%? The point being that this number is unavailable and almost unthinkable within the ontology of medical research. Medicine operates through the mobilization of pathologies and the quantification methods that stick violence to certain bodies is a critical tool through which medicine understands its task. Asking if it is possible to quantify trauma, transmisogyny, or racism, reads as almost illegible, not because it can't be done, but because this is not the scale that medicine understands itself as acting on. Number of patients, amount of tumor, percentage cured - medical research lives on the scale of individual cells, personal bodies, or demographic groups, but structures are often absent. This is not to say that reversing the direction of the gaze of data removes the solidification that gives it such power. Counting retains such power, but it is a tricky fit when structural oppression is under the microscope. The discomfort of the students at such solidification echoes anthropological literature that explores racialized data focusing on how techniques of quantification attempt to solidify the borders of identity categories in order to make generalizable claims about bodies and health (Montoya 2011; Nelson 2016; Ong 2016; Roberts 2011; Whitmarsh 2008). In this moment, identity borders are not only solidified, but they are numerically connected to violence and trauma. Counting is often is utilized as a documentary method for violence and trauma, but these moments in the medical school lecture hall reinforce the ways in which numbers can become violence themselves.

Chapter 3 - Ghosts in the Data: Defining the Aggregate

Data as Care

Rae rummages through the empty front desk of the clinic, pulling an intake form out of a folder. "We have our own categories that we think are important to include for both sex assigned at birth and gender identity," he explained. The Park Clinic sits at a busy intersection in a neighborhood filled with industrial buildings. It is a Federally Qualified Health Center that serves mostly low-income patients. The clinic prides itself on being queer-affirming. Rainbow stickers are affixed to the windows, posters advertising various Pride Week events hang on the bulletin board, and the intake form Rae proudly pulls out to show me is impressive in its inclusion of a wide variety of queer identities. The form lists 19 answer choices next to small checkboxes under the question "What is your sexuality?" and 43 options for the question "What is your gender identity?" Terms and checkboxes spill across the page, such as; "Lesbian," "Bisexual," "Dyke," "Asexual," "Skoliosexual," "T4T," "Man," "Trans Feminine," "Stud," "Boi," "Two-Spirit," "Agender," and "Gender Creative." It is by far the most expansive form I have seen during my research.

One of Rae's jobs at the clinic is to manage the sexual orientation and gender identity data collected by this clinic form. He updates the demographic forms and works with their analysis systems to track and report the data. He also trains other clinics on improving or implementing systems for collecting SOGI information. To do this work he keeps his finger on the pulse of queer culture, tracking the constant evolution of language, identity, and community norms. The expansive list of identities on the intake form requires constant upkeep by Rae. "I've just kind of kept an eye on it" he described, "I've kind of just like made recommendations and, you know, obviously if I'm hearing staff or patients request certain things…We had someone who was like, you should have two-spirit on here and we added two-spirit… and just over time, you know, instead of genderqueer, we have non-binary now, you know, and we have asexual now instead of just like queer and lesbian and gay. Yeah. So there's been a lot of evolution over time.” While the rigidness of the checkboxes next to each identity remains, the list is in constant flux as identities are added, removed, or edited.

This process is politically and personally important to Rae. “I’m all about like, you know, having a patient see themself in a form” he tells me. “If there's no way to capture that [identity] information, you're going to misgender everyone. So it's a big deal. And it’s, you know, I always say like getting someone's name and pronoun right is like 75% of trans care. Like, you do that right? You're already on their team, you know. Hormone therapy is easy compared to just like getting that name.” For Rae, such data serve as a form of witness. Clinic paperwork becomes a mirror through which a patient’s identity is reflected back to them -the checking of a box is affirmation promised by the inclusion on “official” medical documents. Furthermore, in Rae’s description, data collection becomes a form of therapeutics, on par with hormone therapy. These data do not only influence or document care; they *are* a form of care. At the Park Clinic, this text-based caregiving is central to what it means to be a queer-affirming clinic. In Rae’s description, to see one’s identity on a form or to have one’s pronoun labeled correctly in your chart is care. To be seen by and recorded within these data processes is a part of healing. So while debates around queerness have long been concerned with the politics of belonging, such as questions of who is and how to be queer, the opportunity for self-making Rae sees in such forms is one of inclusion through institutional recognition. In previous chapters, the power of queer data has been located in how these data can travel after collection and analysis. This travel includes the ability to create facts that can be disseminated and mobilize change. This chapter will explore what happens to this data-care within bureaucratic institutions after the boxes are checked and the identities are recorded..

Queer Aggregation

The Health Resources & Services Administration (HRSA) requires the Park Clinic to submit data on patient demographics using the Uniform Data System (UDS). This reporting is connected to funding allocation. Rae acknowledges that the identities listed on the clinic's expansive intake forms "don't exactly match the UDS categories…because in the UDS report it's like gay and lesbian is like one thing, right? They don't even have a queer option." Rae's description of the facile process by which the clinic's identity documentation is able to shift and mutate in response to cultural norms and changing terminology is in sharp contrast to the reporting requirements for the UDS. The UDS offers far more limited categories for reporting patient demographics. The UDS reporting instructions for 2019 list the following options for documenting patient sexual orientation, gender identity, and sex assigned at birth ("Uniform Data System Reporting Instructions for the 2019 Health Center Data" 2019).

Sexual orientation:

- *Lesbian or Gay*
- *Straight (not lesbian or gay)*
- *Bisexual*
- *Something else*
- *Don't know*
- *Choose not to disclose*

Gender identity:

- *Male*
- *Female*
- *Transgender Male/Female-to-Male*
- *Transgender Female/Male-to-Female*
- *Other*
- *Choose not to disclose*

Sex assigned at birth:

- *Male*
- *Female*

Therefore, in order to prepare the required UDS reports, the Park Clinic must batch the more expansive categories from their intake form and condense them into the UDS options. Rae describes, “We have a system for mapping our categories into that kind of funnel, into what UDS wants. And then the UDS report is, you know, what gets actually sent out…So some patients will for example, a trans woman could say I was assigned male at birth and I'm a woman instead of saying I'm M to F. Cause that's true to their identity. And we don't correct them. It's just whatever you write down, we put in the computer. So when it comes to the actual [UDS] report, if we're just looking at, okay, here's all the people who said that they were a woman. Instead of like M to F, we're going to have a mixture of cis-gender women and trans women. And so part of what I do when I do the SOGI data collection is I actually like pull out the trans women from that woman only category and put them into our trans category. Cause then we have better numbers about the number of trans people we treat. And this is like the actual breakdown of trans feminine spectrum people, trans masculine spectrum people. So, our [quality improvement] person can just like pull this data and like make a report. But I actually did have to go in manually and kind of like clean up the data a little bit." Rae describes how the Park Clinic uses a reporting system that is programmed to "translate" the intake form categories into the more restrictive UDS categories. This software turns queer into gay/lesbian or "woman" when selected alongside "male assigned at birth" into "transgender woman." Interestingly, the UDS reporting instructions, dictate that the answer "Don't know" is to be used to represent "a person who self-reports that they do not know what their sexual orientation is. Also use this category to report patients where the health center does not know the patient's sexual orientation" ("Uniform Data System Reporting Instructions for the 2019 Health Center Data" 2019). Institutional and intrapersonal uncertainty are subsumed into the same category. The very funding that provides the money that pays for the paper on which the Park Clinic prints their extensive intake forms requires an erasure of just that expansion. That is not to say this erasure is a negative or positive move, only the fact that it is necessity for the reporting requirements exposes the complexities that occur when quantitative data are required to hold multiple roles within one setting. Within the Park Clinic, data are being called on to mobilize the power of quantification for different purposes. The data collected by the intake form are asked to serve as welcoming affirmation and healing care, as well as to categorize patients within the clinic system and provide surveillance for funding reports. As these data are mobilized as both loving care and bureaucratic surveillance, these transformations between roles expose the ways in which the very power of recognition and truth afforded to data becomes destabilized. In the process of moving data between these roles, identity labels are added and erased, data points fall out of the analysis, and aggregation requires messy forced affiliations between categories. This exposes the incompleteness and constructed nature of data as they are required to serve so many purposes.

The intake forms are patient facing; they are part of the experience of patients when they seek services from this clinic. These forms are considered a form of care that takes into account the desire for the clinic to be an open and affirming place for all identities. The lengthy identity list works to live up to the ideals of patient-centered care and to create empathetic connections between patients and the clinic. Once the form leaves the patients hands though, it enters quantification processes by which it is transformed. Many researchers and clinicians I spoke to expressed feeling stuck between two competing interests. They wanted to allow for expansive self-identification options and its affective charge as well to access the power that aggregation offers through institutional recognition and requirements. Dr. Tan is a clinician-researcher who focuses her research on health disparities among sexual and gender minorities. When asked about how to balance the desire for larger identity choices with the power that comes from larger aggregation, she explained, “There are a gazillion identities. You have to pick a set that is comprehensive enough, right? And that ‘comprehensive enough,’ I think is hard. You know, what does ‘enough’ mean? And how does that actually work?” Dr Tan exaggeratedly throws up her hands and chuckles. It’s clear that she has thought deeply about this tension, but has yet to come up with a satisfactory solution and is unsure that one may exist at all. Dr Tan goes on to articulate the ways in which the number of identity choices becomes saddled with the responsibility of representation. “I think the tension here is you want to collect data that [uses] more answer choices, even multiple selections, so you have 20 different things that [participants] can check off. [But], you know how many combinations there are of that, right? That's a lot. Which obviously is a real pain as a researcher. But at the same point, you also don't want people to feel alienated by not having their answer choices there. And so that is the continual tension. Having all the answer choices there so that people feel really represented, but then it's a pain in the butt from a researcher side of things to figure out what to do with all the combinations and permutations of checkboxes that have been selected versus having a very short set of answer selections that may alienate the participant, but it's easier for the researcher. So we have to figure out how to do that."

Patient representation is contrasted with research needs. One is described as expansion and the other as contraction. Dr. Tan is caught in this tension wherein more categories means less ability to aggregate, less statistical power, and therefore less legitimacy for these data to be mobilized as facts. Governmental, research, and healthcare institutions are moved by large numbers and they are the spaces which fund, publish, and have the power to transform Dr. Tan's data into policy changes, best practices, or laws. Dr. Tan explains, "I think that numbers and quantitative data is really impactful because it really is what large organizations listen to. So it's what the guideline organizations listen to. It's what the United States preventative services task force listens to. They review trials and these trials have numbers and [they] come up with recommendations. And so I think that numbers are so powerful from a policy change perspective." This tug-of-war is deeply felt by many I spoke with for this project. Aggregation has a power that allows researchers, advocates, and others to speak to positions of power. Aggregation though also necessarily requires a flattening and subsuming of expansive identity options into the specific categories that are intelligible to data reporting systems and institutional processes. Dr. Tan's experiences are echoed by Rae when confronted with the contrast between the sprawling Park Clinic intake form and the requirements of the UDS reporting.

What happens to the power of the political and personal recognition that Rae describes as being offered by these forms if later, within a software program running in the back rooms of the clinic, it necessarily becomes winnowed down to the anemic options of the UDS? What happens to the subject that takes the survey and chooses one (or multiple) from a long list of identities once the data enter the labyrinth of documentation, analysis, and reporting and becomes mutated and transformed in the process? One can analyze this moment as exposing a process of circulatory knowledge production. The data from the intake form enters electronic medical record system of the clinic. The intake data are processed through the system to comply with federal data reporting standards. Researchers, politicians, and administrators can utilize these federal reports to study health, appropriate funding, and ensure quality standards. Eventually, this research can create medical evidence. Evidence-based practice will influence what clinics and clinicians do or don't do with patients. While much writing has been done on the ways in which actors create, manipulate, analyze, mobilize, and move data, data can also be analyzed as actors. Data are moving the people, as much as the people are moving the data. The expansive data from the Park Clinic intake form are sorted into the smaller UDS categories. The UDS reports will then be available for research data analysis. Such research will be published, disseminated, and transformed into clinical recommendations that will end up back at the Park Clinic to change clinical practice as part of their proud dedication to evidence-based care. For example, new evidence-based practice guidelines might emerge around smoking cessation for lesbian patients. A smoker who checks "lesbian" on the intake form may receive such care from the clinician implementing new practice policies. The reporting on this patient creates more data. That said, the data applied to and emerging from this patient may travel with the label of "lesbian," even though it emerged from the intake form of patients who checked any number of identity boxes that were later sorted into the "lesbian" category in order to comply with UDS requirements. In this way, the category of “lesbian smokers” does not emerge organically as pure documentation via the clinic data collection, but is actually created within the data reporting process, detached from the patients who scratched a checkmark next to an identity checkbox on the form.

Ghosts in the Data

It might be easy to see such a transformation as a betrayal and plenty of individuals who are involved in queer data production certainly expressed disappointment and frustration with data reporting requirements to me. This begs the question of what the relationship between subject and data is. If a cisgender woman patient checked “Same Gender Loving” under the “Sexual Orientation” question on the Park Clinic form, what happens when that data point is assigned to the “lesbian” category within the clinic software that translates the data so they conform to UDS standard? Does that data no longer represent the subject? Does the conceptual closeness of the terminology allow for such aggregation? Is it a betrayal? Is it a breakage?

Perhaps a way to conceptualize this relationship is as one of *haunting*. Queer data are haunted. There are ghosts in these data that represent both the choices unchosen and the options swallowed up into other categories. The specters are neither malicious nor violent, but represent a continued resonance from the foundational loss contained within both identification and quantification. Haunting means that what is not chosen or what is subsumed into the aggregate clings to the data as an ever-present reminder of what has been left behind. The relationship between the expansive Park Clinic identity options and the limited UDS options is one of ghostly echoes. The UDS reports, with their large numbers of gay/lesbian, bisexual, and straight data points, are haunted by those identities and experiences it swallowed into its narrowness. A useful analysis might emerge from considering how the data created by re-assigning identity categories into larger aggregates could be seen as haunted by those options that become subsumed. One can use the UDS data to portray statistical facts about one identity or another, but those data will always be haunted by the other options. With the constant movement around the borders and terminology of queer identity, queer data face a specific (not necessarily unique, but possibly more explicit) challenge in that data collected on a category at one time point, or in one space, or from one person, may not share the same definitional borders in another context. Quantification claims to require and represent a stable object and queerness can undermine stable categorization. While such an acknowledgement of how much queer data are manipulated from its "raw" (a binary description discussed in Chapter 1) form could be seen as undermining the power that quantification has been imbued with to solidify fact, it is also a helpful moment of exposure. Haunting steps outside of binary arguments about whether such aggregation is correct or incorrect, affirmation or betrayal, accurate or untruthful. Instead it lets multiple things exist within a space, albeit some in a ghostly form. These ghosts become made invisible by the bureaucratic processing required, but for the clinicians, researchers, and analysts who process the data, that which is subsumed by aggregation remains visible in the original database, in the methods sections of publications, and in their own uncertainty about the stability of data (as discussed later in the analysis of the denominator). The UDS identity labels can be reported as static categories, while at the same time the categories that were swept up into them from the Park Clinic intake form can still exist as echoes within the data offering generative destabilizations at claims to solidification. Crystal Biruk writes, "in their polished form, data reflect the capacity and expertise of all their handlers, even if epistemic rhetoric and metrics for good data tend to obscure the degree of uncertainty absorbed by data in their travels (March and Simon 1958, 165)" (Biruk 2018, 6).

This analysis can be expanded outward to the process of identification as a whole. The subjectivization that comes through identification can be described as a form of haunting as well. Judith Butler writes, “Identification is constantly figured as a desired event or accomplishment, but one which finally is never achieved; identification is the phantasmic staging of the event. In the sense, identifications belong to the imaginary, they are phantasmic efforts of alignment, loyalty, ambiguous and cross-corporeal cohabitation” (Butler, 2011, 105). This quote not only utilizes the ghostly vocabulary of the phantasm, but also offers a theory that takes seriously the echoes left by the identificatory processes of not choosing, of turning away from, and of not fitting in to categorical identities. Butler’s description of identification is made explicit and formulaic within the world of queer data. Many of the anxieties shared with me by researchers who create queer data center on the complex task of creating categorization systems that will never be able to fully encapsulate queer identification and therefore the resulting data will retain this shaky foundation. Creating queer data is an act of transformation, but one that is necessarily incomplete. The ever-evolving nature of queerness leaves it in excess of static categories in a way that can productively draw attention to the generative work of quantification. Butler also emphasizes that within all identification is a mourning of that which we did not choose. Identification is a process of the necessary disavowal of other existences. Talking to people about queer data involves a lot of focus on the answers people choose, such as how to make them better, more accurate, less irrelevant. Butler draws our attention to the just as potent existence of the unchosen. If, as Butler and others argue, there is loss in all identification then we all can’t help but be haunted. Furthermore, while queer data are not necessarily uniquely complicated in how they contains struggles around how to interact with classificatory systems, the slippery nature of queerness does have a power to expose this phantasmic nature of identification. This is not a haunting due to evil-doing or malicious intent; this is a generative haunting that is necessary to identificatory processes. Researchers and clinicians who use data are not unable to see to such ghosts either. Reserachers I interviewed often openly grapple with these phantasams, frustrated with attempts to balance the tension between expansive category lists. This uncertainty will be explored next as researchers work to produce the appearance of stable categories in order to enter them into statistical relationships. Such researchers collect, analyze, and publish data and then spend the future looking over their shoulder, wondering how the solidification of data into public fact will appear in retrospect.

Defining The Denominator

The problem of the denominator was referenced multiple times in my research. Questions were raised about how many gay or trans or queer people existed, which number to use for which statistics was debated, and what these questions might tell us whether and how to trust numbers was discussed. Alex is a public health researcher whose research focuses on mental health among sexual and gender minority adolescents. The research project they work on uses this specific terminology, defining their population of interest as "sexual and gender minorities." This term (often abbreviated as SGM) is one of the more recent ones to gain popularity when referring to individuals who are not cisgender or heterosexual. An increasing number of healthcare institutions now use this term in their names and the titles of projects, conferences, and papers. This includes The Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern University or a continuing medical education course titled "Advancing Excellence in Sexual and Gender Minority Health: A Core Course for the Whole Care Team." This term contains quantification baked into its foundation, as numbers are what define who is covered under the term. Instead of categorizing identities using terminology that attempts to describe desire, behavior, or personal identifications, the SGM label turns to numbers. The SGM label covers those of whom there are the fewer. It is a numerical identity bypassing debates around whether sexual orientation and gender identity are classification systems based on behaviors, internal identification, desires, how one is viewed by society, or a complex combination of these multiple variables. The term "minority" has come under a critical examination within discussions of race and ethnicity. For example, there is an increasing move to no longer use the term racial or ethnic minorities and instead use People of the Global Majority to accurately represent the numbers of Black, Indigenous, and people of color around the world and decenter whiteness. Using SGM though attempts to avoid the troubles that have plagued the "alphabet soup" approach of terms like LGBTQ+ (with the adding or subtracting letters as desired) and dodge the requirement of such terms that there is an attempt at inclusion of every single individual identity. Instead, SGM focuses on amounts. The term is based on and is based on the fact that, as Alex describes, "the LGBT population is - there are less of us. There are more than we thought, but there are less of us in general." While theoretical discourses have often mobilized queerness in order to problematize binaries, the framing of the sexual and gender minority terminology creates a numerical binary: that of majority/minority, more/less, and large/small.

The denominator is a prized variable in public health work. Not only is it necessary for any of the statistical work to be done, but it also allows for a delineation of the borders of the category being focused on. Setting the denominator defines who is included in a given data set. A webinar on how to best collect SOGI data warns participants to "be careful not to lump all LGBT people into every denominator or numerator for every question" and to "provide guidance [to staff] on quality measures (e.g. who should be in a denominator)." Behind the scenes though, defining a queer denominator is a messy process. SGM asks the question "how many" in its process of solidifying the boundaries of identification, but "how many?" is a question that plagues researchers working in queer health. Alex tells me, "We don't know in general how many SGM folk are out there…. It's hard to know a lot of public health markers, a lot of ways we analyze things, because you have to try and imagine your denominator, right? Or you have to try and get like the total population. And we just don't know that. So a lot of work that's done has that as a limitation." This conundrum represents the slippery nature of queer data. When trying to measure percentages, the denominator represents the entirety of the group of people (or diseases, or biological objects) studied, whike the numerator designates the number to whom the issue studied applied (those with a certain diagnosis, or identity, or risk factor, or biological marker). As Alex points out, identifying a queer denominator is an exercise in imagination and estimation. For one, the definition of what it means to be queer, or gay, or transgender, or demisexual is constantly changing over time, through local contexts, and within an individual. Alex describes the statistical struggle that occurs due to the fact that "definitions change, and are developed or rejected or included. The example I think of is the word "gay" and what it meant in the 1940s and what it meant in the 1990s and what it means now. If you ask someone in those three eras, what them identifying as gay in those three eras [meant], I would say [they] are vastly different experiences and people…but if you have a [research] question that asks 'Are you gay?', then all those three people would be included in the same data set. But also is that wrong? You know, it's complicated." Alex sighs and laughs at this definitional tangle. Furthermore, Alex wonders about the work "gay" is doing in this moment. What are questions about sexual orientation truly asking? Alex wonders, "Does it matter if the person identifies as a gay male or not if they are having sex with other men? It depends. It gets very tricky. And so that issue of definition, I don't know what to call it, definition differences? You see that a lot in just social epidemiology in general." Gayness not only shifts temporally, but also begs the question of how sexual orientation is actually defined. Is it self-identification, behavior, desire, or something else? So while these multiple manifestations of gayness complicate any attempt at staking a claim to the meaning of a research denominator, Alex's work is also confounded by attempts to be overly inclusive. "I think there's only one question [on many surveys] and it will ask like: straight/heterosexual, gay/lesbian, and now I think bisexual usually comes up. But sometimes gay, lesbian, bisexual are just grouped into one answer. It's like you're either straight or non-straight. When the surveys are designed that way the analysis is very broad and it suffers…you do lose some analysis ability, because I've had to conclude things like: these three groups, who really don't have the same experiences, might show a higher prevalence of something compared to heterosexual individuals. And so you lose that nuance for the results that you're trying to get."

Secure knowledge seems to always be escaping through the cracks. Trying to get ones hands around queerness as an aggregate or a denominator feels like an impossible numerical task. "Imagine" is not a word that is often found in discussions of statistical methodologies. In using it though, Alex is not referencing wrongdoing or research misconduct, but is instead offering a thoughtful analysis about how queerness exposes the fluidity of research, right down to the units that are often assumed to be solid - the numbers. Alex *imagines* a denominator filled with queer people. What does it mean to try and count a community whose borders are so fluid? Even as the term SGM might be seen as a way to avoid the culturally-, generationally-, and politically-contextual nature of previous sexual orientation and gender identity terms by using numerical identifiers, the numbers prove just as wily. Alex emphasizes that he wishes he could remind researchers "Don't just say LGBT or SGM. Really tighten up your demographics questions."

Alex wishes that researchers could be specific in defining their denominators, but simultaneously acknowledges that the very nature of queerness escapes such definitional specificity. Queerness is not unique in creating a denominator problem; all research must do boundary work to define its scope and focus. Constructing denominators and numberators is not only a definitional question, but an ontological one as well. It points to the issues not only of the borders around the categories we use, but what it means to claim a category exists at all. In *The Gay Archipelago: Sexuality and Nation in Indonesia*, Tom Boellstorff theorizes sameness and difference as it relates to queerness (Boellstorff 2005). His work underscores how deciding not only what is the same and what is different has deep roots and high stakes, but also is an ontological inquiry that can shape what types of questions anthropologists (and scientists, researchers, and clinicians) have available to ask. The denominator problem is ultimately a debate about sameness and difference. It exposes the conundrums around not only who is swallowed into sameness through their positions in the denominator and who is claimed as different when labeled in the numerator, but also who gets to choose and how the power to claim anything through data is assigned, claimed, and mobilized. Defining the denominator requires not only making a claim as to what the research is comparing, but also engaging within ontological frameworks about how to define what is the same and what is different.

Chapter 4 - Algorithmic Fantasies: Dreaming Disparities

Algorithmic Fantasies

The Health Commission Meeting takes place in a room that contains a curious mix of luxury and dilapidation. Antique crystal chandeliers dangle from the ceiling while the audience sits in creaky wooden chairs attached to one another with shared armrests. The commissioners sit behind a long table perched on a stage at the front of the room with a single podium facing them for use by scheduled presenters. While all the commissioner's chairs are full, the room is otherwise sparsely populated. Though the meeting is open to the public it is clear that a hearing on the closure of a local hospital's cardiovascular department and improvements to the health department's electronic health record system are not big draws. I am there to observe a report on a recent initiative within the public health department with the goal of collecting SOGI data from every patient who passes through any of the department's multiple clinics. The presentation begins with a slide providing an overview of the legislative changes that spurred the creation of this initiative. Though many staff within the Department of Public Health had long been advocating for increased focus on health disparities related to gender identity and sexual orientation this legislation added a sense of authoritative urgency to SOGI data collection. This initiative includes not only collecting such data from patients, but also creating spaces for pronouns on wristbands, identification stickers, and within the electronic health system. The presenter walked through the statistics on how much SOGI data had been collected by department. 40% in the primary care department. 55% in the rehabilitation hospital. 20% in the emergency room. The commissioners nod in appreciation and one thanks those involved in this initiative on their hard work.

This initiative is impressive for its magnitude, institutional support, and legislative backing, though its goal is by no means unique. Increasing the collection of SOGI demographic information - and its subsequent transformation into quantitative data - is a frequent quality improvement project in healthcare spaces. One of the most wide-reaching and well-known examples of this is the 2011 Institute of Medicine report titled, “The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding” calling for increased research on the health of LGBT people. They described this need as due to the fact that these communities experience “unique health disparities”(Institute of Medicine (US) Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities 2011) that have long gone understudied. This public health department SOGI data collection initiative is one manifestation of this ongoing movement within medicine.

Josh is a research coordinator within the Primary Care Department of the Department of Public Health and has been involved in this SOGI data collection initiative for multiple years. He explained, “We participated in creating those mandates [for data collection] because we recognize that this community is being underserved…We already know, based on truncated samples, that the disparities that we are observing are huge, particularly for things like access to cultural competent care, access to non-discriminatory care.” For Josh, this initiative is a crucial step towards increased health equity. He continued, “From an empirical place, we struggle with the fact that a lot of the data that we've been able to collect [is] based on convenience sampling… [so there is] question of are we getting representative samples or are we getting sampling bias because we're getting people who want to tell their story or people who are really struggling and those are the voices that we hear?” Queer healthcare research experiences a balance between the known and unknown at this moment in time. Researchers often told me during interviews, we know there are disparities, but we need more data, better data, or different data. In the essay discussed earlier “The Secret Life of Big Data,” Genevieve Bell asks, “What does data want?” and answers; “Data wants more data…Big data wants accumulation of more of itself. If this is true, then the question becomes: what is it about this particular historical moment that makes so compelling the need to return to an empirical point of view? What is going on right now that makes us say we need data, more and more and more of it?” (Bell 2015, 13). This initiative is emblematic of the seduction waged by the promise of more data. How exactly such data will be used is not clarified by the legislative requirements, the presentation to the commissioners, or those involved who I interviewed. Analysis or dissemination was not the impetus at that meeting, collection was. Data became an end unto itself. Bell points to the affective draw of data and the comfort that can emerge from the solidity promised by data. The public health SOGI data collection initiative is but one attempt to soothe the fears and anxieties inspired by the idea of disparities within queer health and healthcare and intervene to provide more equitable care. Data are seen as a crucial tool in that work.

Within the apparatuses that form around queer data, such as the commissioners meeting and the IOM report, disparities are often used to call for more research on queer health. The connection of disparities to data can be understood as an ouroboric cycle; a snake eating its own tail, a continuous loop in which disparities need data, data need disparities and both become simultaneously goal and impetus for each other. The cycle often operates as such; health disparities drive the need for increased research on queer communities. Research is done in order to quantify disparities. Such research is deemed necessary so that data can be used to reduce disparities - those same disparities, which are then used to again legitimatize the need for research. One researcher sighed as she told me that when studying queer health disparities, “sometimes I feel like I'm trying to prove that the water is wet.” The actual mechanism by which data beget a reduction in health disparities isn't fully articulated. It's an opaque box into which documentation, data, and statistical analysis is poured with the assumption that improved clinical practice, better access, and more equitable treatment will somehow emerge. These discourses that conjoin data and disparities and posit data as an intervention represent what I will call *algorithmic fantasies.* This is the concept that data flow smoothly to a desired outcome - that of reducing disparities, increasing affirmation in the research process, and improving healthcare. It encompasses the idea that having the right data will trigger a specific formula leading to the desired effect. The term fantasy is used not in reference to an untruth or a naive belief in the unreal, but a fantasy as in daydreaming, pleasure-seeking, and desirous imaginings. Fantasy reminds us of Bell's description of the ways in which calls for data are also calls for solidification and comfort in response to spaces and moments of destabilization - it is a dream of what might be, titillating in its possibility, and utopian in its imagining. Such fantastical thinking winds throughout queer data projects, though it is not uniquely queer. Vincanne Adams describes that the role of her book *Metrics* is to "make us question the assumption that the use of global health metrics will invariably and inevitable lead us to better health outcomes" (Adams 2016, 225). While there are fantasies that an algorithm will solve as-yet intractable problems, this term algorithmic fantasies also refers to the idea that such a fantasy is itself algorithmic in nature. Such fantasies are algorithmic because they dream in discrete quantified systems, where action occurs in the structure of an "if-this-then-that" formula. This dreaming imagines a future in which data will trigger a domino effect toward better health, better policy, better living, or whatever the goal may be. "There is strength in numbers. With each additional participant, our data becomes stronger to make LGBTQ+ communities healthier" one email recruiting participants to a research study states. As data numbers become larger, stronger, and more robust, so too does the health of queer people. Data become both a representation of and a conduit for health within the algorithmic fantasy.

These fantasies are also algorithmic because such desires for data are almost always referring to quantitative medical data. Quantitative data contain a power frequently referred to by researchers, the power to make unassailable claims or to make people listen - the fetishistic power of counting as discussed in Chapter 2. Josh emphasized, “The only way that we can really know what the true population rates are for these risk profiles is to count people and to make sure that everybody is counted and heard.” Counting is the weapon wielded against risk. Numbers become both impetus and action, as they are counted on to both expose and rectify disparities. When asked what was so powerful about quantitative data, he responded, “I think that one of the opportunities in research actually is that it can be powerfully reductive towards laying bare some experiences…my hope its that that’s like an unmistakable thing and that people can’t turn away from.” Counting is often described like this. Numbers become mobilized as an unarguable fact, more so than other forms of representation, and one that siezes attention in a way that makes things happen. In this quote the reductiveness Josh describes as part of quantification is not a limitation, but a source of power. This is a common way quantitative data are defined; as a stripped-down version of what is being documented. Though through the observations and interviews throughout this dissertation, data processes can at times appear more like a process of productive construction and less like a stripping away. Josh emphasizes, “And the only way, as you know, the only way that we can really know what the true population rates or estimates are for these risk profiles is to count people and to make sure that everybody is counted and heard so we can begin to address those issues.” There is a yearned for singularity in this statement, a fantasy for the algorithm to work as promised. Counting is the *only* way, and only if *everyone* is counted can then the desired future can emerge.

The Ethics of Found Data

"I love data!" Dr. Taylor Armstrong told me with a quiet laugh. Dr. Armstrong is an epidemiological researcher within a large academic public health department. They work with what they call "found data" such as birth certificates or insurance claims. These data already exist as institutional records that Dr. Armstrong mines for what they can tell us about queer people and experiences. I asked Dr. Armstrong why they choose to work with found data instead of designing new prospective research studies, which is common for many of the researchers who focus on questions related to sexual orientation and gender identity. For one thing, Dr. Armstrong sees such data as a corrective to the non-representative sampling methods that have categorized much of past research on queer health. They tell me, "The history of queer research has really been…you go out to queer bars or health clinics and that's how you recruit the people and for your studies. But…that only shows people who are going to bars. So therefore they're going to be drinking more, 'cause they're at bars and they're going to be sick because they're going to the clinic, you know? And so the way you sample is going to drive your results." Social assumptions about queer hedonism or pathology are methodological issues for Dr. Anderson. Engaging with the data produced by the bureaucracy of institutions is a way Dr. Anderson attempts to remove such bias.

Dr. Armstrong also argues that found data are more ethical. "There's also an ethical thing" they explain, "I struggle sometimes when I see a lot of - not you! - but medical students… and they interview trans people…And obviously it's like a learning exercise. I get that. But then the study itself is more for them than for the field. And then it exhausts the participants in that area. You know, there’s only so many [trans people], it's not like, ‘Oh, I'm researching diabetes.’ A student can get a new set of people with diabetes over and over. But I think that using found data until you absolutely need to interview [participants] or in conjunction with [interviews] feels more ethical…There's this huge participant burden on trans folks and sexual minorities.” Even as Dr. Armstrong explicitly works to exempt me (a medical student and researcher) from their critique, they pointedly refer to the system that requires trainees to produce data in order to progress their own careers. This “overburdening,” as Dr. Armstrong later calls it, of transgender communities by researchers adds an interesting twist to the common claims for the ethics of increased community-engaged research. Such methodologies work to embed queer people deeper and deeper into the research process in order to access a percieved localized authenticity of queer experience to influence research design. Instead though, Dr. Armstrong argues for the ethics of simply leaving people alone. Non-participation becomes a gift.

This stands stark contrast to the recruitment materials from The OUT Study that ask, “What mark will you leave?” For The OUT Study, participating in research is a political act of self-determination. It is a method of legacy making through ensuring that medical institutions hear queer voices. For Dr. Armstrong though, that the mark of queerness already exists in institutional data - from the birth certificates with “F” marked in both “Sex of Parent” boxes, or the Medicaid insurance claims with “57335” listed under the “Procedures, Services, or Supplies” table (the code for vaginoplasty). Their work is to find that queerness within the institution and shed light on it instead of calling on queerness to enter institutional spaces. The Park Clinic discussed in Chapter 3 prides itself on its extensive intake form, heavy with identity labels but is then confronted with how such rich data necessarily become winnowed down by the UDS reporting requirements that only list four sexual orientation options. For Dr. Armstrong though, bureaucratic forms that use these seemingly sparse identity options are an opportunity. They admits that such data "only tell a certain amount of the story" and using found data from birth certificates or insurance claim forms means the people being studied never know they are part of research. For Dr. Armstrong though, this can be seen as a strength. Found data research finds queerness among the aggregate, while participatory research looks to add queerness to the aggregate.

Beware the Researcher!

Dr. Armstrong's concerns about the overburdening of research participants are not new. In the August 1973 issue of *Lavender Woman*, a periodical published by the Daughters of Biltis, a lesbian organization founded in 1955, blocky handwritten letters spell out the article headline "Beware the !Researcher¡" by Leigh Kennedy. Kennedy writes, "So, the social outcasts, the perverts, the deviants are a hot and profitable topic! This concerns me. What will be the effects of this sudden interest in lesbians? Will the upcoming popularization and chiqueness *[sic]* of lesbianism become a way of dismissing our real needs, energy and anger, a way for the males and male-oriented females once again to say complacently to an oppressed group: 'you don't have it so bad. Anyway, change takes time. Look at how far you people have come.' And will we be diverted by this? Will we be duped into being nice and patient, believing that good copy and profits for others is a step in the right direction?" (Kennedy 1973, 3)

This echoes not only Dr. Armstrong's wariness with the demands of research participation, but it is particularly telling in that the concern of Kennedy is that research will demonstrate that lesbians "don't have it so bad." This is not a concern about pathologization (though that may additionally exist), but about how research may be mobilized against the communities it studies. Data are suspect for Kennedy in their ability to be infinitely mobilized. Instead, Kennedy says, “I am in favor of lesbians doing the research on lesbians. This is not to say we are paragons of objectivity. Our research may have its flaws. But who knows? It hasn’t happened yet” (Kennedy 1973, 3). Furthermore, Kennedy’s worry that research will undermine the struggles of lesbians is not answered by a desire to have research that finds disparities. Instead it is to have research turn its gaze to study oppression and discrimination. Kennedy writes, “I am more interested in the homophobia or fear of homosexuals. How and why does it start? How and why does it operate? If I do research someday, I want it to be on them and on their problems with us” (Kennedy 1973, 3). Even with this offer that researchers turn their eye towards discrimination and oppression, data are not a savior for Kennedy. “After they've got the data they want, they can do what ever they damn well please with it… ? Oh, they say their methodology is good. They say they are objective. They say they are sincerely interested in letting the public or profession know us better. For what purpose? So they can manipulate us better…I have real doubts about ‘objectivity’, sincerity, or good methodology keeping out biases.” (Kennedy 1973, 3). This article pushes against the algorithmic fantasy that better data, more objective methods, even when coupled with a sincere desire to help or shared community identities, is inherently a path to better health.

The King of Null Findings

What then to do with data when disparities are not found? “I’m kind of a king of null findings though. I have that luck. We dig deep enough [and] there's no differences.” Dr. Mac puts up their hands in a cross between a noncommittal shrug and an exasperated tossing of their arms.

Dr. Mac is an epidemiologist I interviewed who works within a large hospital system focusing on queer health. In a research world both driven by and driven towards disparities, Dr. Mac often finds that their own research comes up with null findings and the queer participants are more similar to those who are not queer. “[We’re] understanding a little bit more about the mechanisms why would we expect to see differences. Why are we actually expecting to see those differences? And you know, [for the health outcomes], we suspect it's stress related to stigma that people are experiencing and that's why there might be differences. So I think when you don't find any differences, it doesn't necessarily mean there are no differences, but in this sample there aren't any. I think, you know, in a lot of these samples there are differences, but when you control for a number of other factors the differences tend to disappear.” I asked Dr. Mac what this might mean for work that takes queer health disparities as a given. “So, you know, what does that mean in terms of like interventions and in clinical findings? I think that's something that we're like still trying to figure out now, like how do you advise clinicians and, and help them understand more about their patient populations?” Dr. Mac’s null findings are not placed here as a counterargument to those who focus on the importance of disparities. Instead, it can serve as an interesting foil to the discourses that see disparities as a forgone conclusion of queerness requiring data to improve and also an unknown mystery requiring data to reveal. Dr. Mac’s null findings expose the ways in which systems that produce and mobilize queer data often implicitly require disparities and disease to emerge from them and when those are not found the algorithmic fantasies of a system that presumes a link between more data and better health is confounded by data that does not demonstrate such inequalities.

Chapter 5 - The Carnal Checkbox: Electronic Health Records, Sex, and Organ Inventories

Chart Review

Opening up the software a field of checkboxes, text fields, and radio buttons bloom across the screen. The background is shimmering white from the pixels slightly vibrating on the old computer screen. At the top left of the screen is a patient name in capital letters and a string of numbers representing their medical identification number. Tabs spread out across the top of the screen with labels like "Results", "Allergies", and "Chart Review." A pop-up window appears blocking out some of the screen and reading "28 y.o. 10/24/1990. Pronouns: they/them/theirs. Gender Identity: Non Binary/Gender Queer. Legal Sex: Male." In the middle of the screen scrolls a long patient note from a recent visit. Under other links, an old x-ray can be opened up, the black and white image opening up over the entire screen. Along the left side of the screen is a list in bold red type; flu shot, Pap smear, PHQ-9 screen, reminders of overdue healthcare maintenance tasks.

Electronic health records (EHRs) have become commonplace in most medical environments within the United States. EHRs are software programs that serve as digital medical charts allowing clinicians and staff to record clinical notes, document medical visits, order medicine and other treatments, track test results, and store patient demographic information. For the clinicians I interviewed and the clinics I studied, EHRs occupy a central position in the provision of care. They serve not only as a digital representation of the patient, but also a conduit through which care is provided. Medications can be ordered through the EHR, requests for lab tests placed, and results received and reviewed. The software can be set up to remind providers to schedule needed healthcare maintenance procedures, tests that must be attached to certain medications or treatments, or show warnings when a laboratory value is abnormal or prescription are at risk of an adverse interaction. EHRs have also become a space in which the documentation of sexual orientation, gender identity, sex, and body parts opens up larger questions about the role of identity within medicine, the borders of categorization, and how bodies become quantified. EHR systems work to create space to document bodies and lives that fall outside or exist beyond the cisgender and heterosexual norms. This is just one of many ways in which medical care is not only attending to queer patients, but that queerness is changing the way medical care and documentation is conceptualized and practiced.

Fragmenting Sex

Sarah works for DataCare, a national electronic health record company. DataCare provides electronic health records for a large number of clinics, hospitals, and healthcare systems. As a project manager Sarah works directly with DataCare customers to oversee their use of her company's EHR whether that be getting them started using an EHR for the first time or transferring them to DataCare's product or providing ongoing troubleshooting and customer service. In the last decade, EHRs have undergone a transformation in the way they record, store, and utilize data about gender identity, sex, and sexual orientation. In Sarah's case, she remembers how in the early 2000's, her company started to have internal discussions about how sex and gender were represented within their software. This was inspired by customer requests that asked for a more standardized system for recording gender identity, sexual orientation, pronouns, legal sex, and names. Sarah tells me, "So a lot sites were kind of jerry-rigging [the EHR], if you will, prior to us having standard development. But we started to kind of see that not only was the trend going this way, but we really weren't set up to support where we saw the industry going and where we saw a gap in care that a lot of our customers were asking us for." Sarah describes how customers would use the "sticky note" function to add a patients name to their chart if it contrasted with the name listed on their insurance documentation. A sticky note in an EHR is a virtual note added to a chart that can be seen by the specific provider, but it is not a formal way of documenting medical data. Such improvisation made space within the digital architecture of the EHR for queerness. In my interviews with people who worked for EHR companies, they described that clinics, hospitals, or larger healthcare systems generally buy an EHR software package that comes with a baseline organizational set-up and then these customers are able to customize the software. Customers can add or change language, include digital forms, and create spaces to document specific types of information they want to gather from patients, such as space for SOGI documentation.

By 2016, the Health Resources & Services Administration (HRSA) changed their reporting requirements for the Uniform Data System (UDS) to require clinics receiving HRSA funding to report sexual orientation and gender identity data for their patients. While the number of categories offered within UDS is small (as discussed in Chapter 3), this change pushed more EHR companies to offer more standardized methods for collecting SOGI data. Sarah tells me "the biggest challenge we ran into is that these fields get used - especially the sex field - it gets used in a whole lot of different places and not every system or administrative entity that might need the information looks at it the same way." DataCare developers realized that the very concept of sex would have to be carefully picked apart to create software that more accurately represented the needs of contemporary healthcare institutions. Ironically, it was the quantified nature of this EHR software is what motivated a rethinking of the assumption that sex is a self-evident, biological, and binary category. Sarah described this process, "[We were] essentially [taking] apart that concept of sex. Having administrative or legal sex as one component, then having sex assigned at birth as another component, and then having gender identity as that third and final component. [These] three things live separately now within the system and can help drive different components or workflows or actions you might take. Also at the same time [the system is] still providing us the ability to send the legal sex to an insurance company that may not recognize anything other than a binary gender identity or sex, but [while also] having the ability to say, what is that person's gender identity so that a caregiver can use the appropriate pronouns." Within this EHR, what used to be classified soley as "sex" becomes fragmented into three different new categories; legal sex, sex assigned at birth, and gender identity. These categories are functional ones - which identity marker that is used depends on where the information is going. Is it for an insurance company for billing? Will the front desk staff use it in order to correctly refer to a patient? Do clinicians look at it in order to determine what form the patient's body may arrive in? Within the world of the EHR, the idea of an implicit, fixed, and binary sex is rethought and replaced with multiple different categories that are contextually mobilized depending on the institutional function required at the time. Judith Butler's words echo especially strongly here when writing about how "culturally intelligible 'sex' ought to be understood as generative political structures rather than naturalized foundations" (Butler 1999, 187). Within the EHR, sex became fragmented into multiple different conceptual categories.

Sarah describe how as DataCare got deeper into editing their software to make spaces for listing gender identity, pronouns, multiple names, legal markers, and insurance documentation they realized just how many forms of knowledge are implicated in the assumption that sex was binary, biological, and a straightforward point of data. "I think that's where we started to kind of realize that this was a whole lot more complicated than we thought it was going to be" Sarah said. “Thinking about like a lab system is a good example of, you know, a lot of labs have normal ranges, but they will be arranged for a male patient or a female patient. And so how do you take that and make sure that you're not giving either an inaccurate or abnormal result. [Taking in to account] where a patient is in their own gender identity and where they are on that transition or if they are in the fact in the process of transitioning. So a lot of those were components and things that we had to work through and make sure that we were not only doing the right thing by the patient, but also continuing to put patient safety at the forefront, [not] throwing incorrect warnings or sending incorrect information that could result in the patient safety issue.” Disassembling the biological presumptions of a purely binary sex system becomes not only a conceptual issue, but also a safety concern within these EHR processes. Queer data require a rethinking of the very concept of normal values. Bringing bodily systems back to a predetermined and standardized normal value is a critical part of medical care that has long been organized by a differentiation between the biology of binary sexes. The ways in which a medical gender transition may change the form and functions of the body needs to have a place in the EHR in order to allow the clinical algorithms to function as intended. Previously, DataCare’s EHR was, quite literally, not built for queerness. Gender transition (or, for that matter, any other bodily process which occurs outside the presumed bounds of a normal male/female biological dichotomy) would risk “throwing incorrect warnings” as Sarah stated and therefore risk patient safety.

Sarah describes this splitting apart of sex within the EHR as a necessary solution to a problem that was both social and technological. Request from customers pushed DataCare to reevaluate how they document sex, but the undercurrent of social changes in thinking about what sex, gender, and sexual orientation were also inspired the changes. Sarah is a white, cisgender, lesbian whose job at DataCare places her solidly in the upper-middle class of the medium-sized Southeastern city where she lives. Within her socio-cultural sphere, the idea of gender has been evolving and her own understanding changing along with it. “For example, [when people] first started talking about gender as a spectrum and how that works, I really just could not understand it. And I feel like that 10 plus years ago now that was where a lot of the country was. You know, going into some of this, I was always, I was concerned as like, ‘Oh gosh, am I about to get into like a philosophical discussion about gender?’ I am not equipped to do that. But the reason why I say that is, I think there was some trepidation about, well, is this going to be the right thing? And that's really not what we've experienced as far as like pushback from these changes. And it's been actually really widespread support. And so I think that's been really cool to see.” Sarah tracks the move from a binary view of gender to one that is more like a spectrum as a trend that not only occurred on a larger national level in the United States, but also as a complex personal journey for her. To disconnect gender from the binary of sex was one of the first domino pieces that lead to the EHR system needing to represent the fact that was formerly understood as “sex” in multiple places. This required the software to attempt to rethink a binary conceptualization of sex that was no longer fully representative of social norms (though many binary norms still persist), nor the ways in which a patients body, self-identity, behaviors, and social history were actually mobilized within medical care. That said, within these EHRs, there is still no spectrum. The checkboxes for insurance sex (sometimes called administrative sex) or legal sex or gender identity are still quantified systems that require solid boundaries within the software. Sex (or what was formerly conceptualized as such) becomes prismatically fragmented into multiple categories.

I attended a webinar aimed at training clinic staff on how to collect and use SOGI data from their patients. From a small window embedded within a slideshow, a data scientist who works with clinics serving queer patients described the importance of collecting what they refer to as "insurance sex." Insurance sex, they go on to describe, is often used as synonymous with "legal sex" and refers to the sex listed on your insurance documentation. Within the United States there is a patchwork availability of the ability to change the sex designation on official documents, such as birth certificates, drivers licenses, and passports. In this webinar and on the other forms and EHRs I have studied for this project, only two options, male and female, are listed as answer choices for legal sex. Sex, in this instance, becomes a category defined by institutional needs. For the purpose of the EHR software, sex is a function. These changes to software expose the economic necessities that shape what is possible within medical knowledge production and data documentation. While within the EHR changing social understandings allow some conceptual categories to become open to resignification (gender identity is allowed expanded options and what constitutes a normal laboratory value is rethought) legal sex remains a solid category. Legal sex is separated out from other identificatory categories and bound into a binary due to the functional requirements of the insurance system. Legal sex is no longer synonymous with sex assigned at birth, the category of legal sex is sex assigned by capitalism. In this moment, resignification within the healthcare system can only go as far as institutional economics allow it. While such changes within healthcare data collection are described as representing a new way of conceptualizing sex, gender, and identity as inspired by queerness, such claims to forward momentum are stymied by the categorization requirements of economic systems. This echoes the conundrum of the Park Clinic when the expansive list of sexualities and gender identities on their intake form must become funneled into the more limited categories required by the UDS reporting system. Queerness has long been described as providing a means for reconceptualizing the borders and labels of categorization systems. When looking at healthcare settings though, we are offered an important reminder about the ways in which institutional participation in economic structures, such as the insurance system, exert profound power on such attempts at resignification. That is not to say that this analysis is claiming that the fluidity of queerness and the solidity of economic structures are necessarily in binary opposition. Instead, exploring how EHRs are designed can offer a view into the ways in which queerness (and its attendant expansion, critique, and blurring of borders) and institutional power (with its requirements of specific ontological boundaries) are co-consitutative forces. This can be observed within the digital space of the EHR. Queerness provided the impetus for a rethinking of the category of sex and an expansion of options for and ways of documenting sexuality while at the same time the insurance system required the retention of at least one binary sex documentation field. Claims of providing a new type of medicine, one not only accepting of, but inspired by queerness, only go so far because a binary and quantifiable understanding of sex is still required to be assigned to each patient by the economic system.

The Carnal Checkbox

Within medical data, the body is everywhere. The continually incomplete task of representing the fleshy corporeal within quantitative software is particularly exposed through clinical care that engages with queerness. One of interventions that many electronic medical records have made to solve this problem of no longer having a static and incontrovertible bodily standard like sex to base clinical decisions on is the "organ inventory." Organ inventories are a section of an EHR that is used to record a list of body parts that a patient has. I observed an organ inventory used in 2020 by a large academic hospital on the East Coast. It sits as a bounded portion of the EHR with light blue lines delineating it from the other sections of the chart. Body parts are listed in black font with light blue highlighting and checkboxes next to them; breasts, cervix, ovaries, uterus, vagina, penis, prostate, testes, clitoris, male chest. Once checked, the EHR will insert the selected list into the patient's chart. Organ inventories were integrated into EHRs in an attempt to improve care by disrupting the assumption that one's legal sex or sex assigned at birth necessarily denotes which body parts are present or absent. One information technology specialist I interviewed at a community clinic described their version of the software. "It's literally a form, right? [It has] checkboxes that the clinician would go through and either check something, to indicate the person has a body part or check something to indicate that the person doesn't have that body part. And that information goes into a discrete data field. So an example of that is like, you know, say somebody has a cervix that would basically be added and subsequently used for billing purposes or reasons why we did or didn't do a procedure. The goal of that really is to get people thinking about it the way that they think about like any review of systems, right? Just like you're going through the process of checking somebody's hearing or their eyes. It should be included in basically that same process there." The goal described here is to integrate such organ inventories such that they are a routine part of clinical practice. It's described "literally" a form, with the hope that the mundanity of other clinical documentation methods will stretch to cover this attempt to document the body itself outside of sex and/or gender and allow it to integrate easily into clinical care. The impetus for creating an organ inventory was the ways in which the category of "sex" collapsed under the weight of attempting to signify too many things (and not just the biology of genitals, hormone levels, and chromosomes, but also the M or F listed on insurance documents or birth certificates, eligibility for health screening procedures, shared personal identities, and exposure to discrimination or trauma). So even as organ inventories are often described as valuable due to the improvements they make to the care of queer patients, this quote emphasizes the hope for the normalization of organ based care for all bodies.

Within an EHR, the organ inventory becomes a particularly important tool for guiding clinical practice. The inventory allows the EHR to automatically remind clinicians about necessary preventative health measures or send the appropriate lab tests. For example, within an EHR without other mechanisms in place, such as an organ inventory, a patient whose legal sex is marked as male will not be included in the algorithm that determines which patients are due for a Pap smear. If this male patient has a cervix though, and it is listed on the organ inventory, the EHR will include his record in the pool of patients who should receive this health maitenance. These types of electronic mechanisms that are able to guide a clinician in providing care are called clinical decision support systems. Examples of the role that clinical decision support systems can play within an EHR include providing alerts of potential medication interactions, reminders of preventative health screening, or automated responses to certain vital signs or lab values (such as triggering orders for more specialized tests when a certain abnormal result is entered). An organ inventory interfaces with such systems to ensure that medical care is specifically tailored to the body of that individual patient. While organ inventories are not solely used for queer patients, they are most often described as being invented in order to provide an intervention that will improve healthcare for transgender, gender-expansive, and other patients whose body parts seen by biomedicine as incongruent with the sex and/or gender listed within the EHR. The destabilization offered by queerness to biological assumptions around sex and gender may have dissolved the former “Sex: Male/Female” checkboxes, but its power is interestingly reconstituted within the standardized practices of organ inventories.

Organs That Have Sex With Organs

One of the goals of the organ inventory is to avoid providing medical care based on any assumptions around gender or sexual identities. One of the challenges the organ inventory is attempting to mitigate is the lack of consistency around the meaning of identity terminology. While this can apply to most if not all identity categories, it is particularly exposed by queerness and queerness is what inspired such an intervention. What it means to be a woman or gay or transgender or have an "M" on your insurance documents are all contextual, shifting, and constructed by the complex matrix of individual and institutional meaning-making. Such labels cannot tell a provider if a prostate exam should be scheduled, but the organ inventory attempts to remedy this, by navigating around the slippery definitions of identity terms and instead utilizing something that medicine sees as stable - the object of the body. Even if the body changes through aging or illness or surgery or medication, the organs are still seen as a stable anchor off of which care decisions can solidly be based. The identity labels of a patient (whether that be sex, gender, or sexual orientation, as well as race, ethnicity, disability, or age) remain in the EHR, but within the organ inventory the care algorithms originate from the existence or absence of organs. This move of the organ inventory echoes the public health intervention that popularized the use of the term "men who have sex with men" as a way of avoiding identity-based concepts such as "gay." Originating in HIV-related work (but now utilized in many disciplines), MSM is a term that attempted to capture those at risk of HIV due to participating in anal intercourse with others who the public health institutions would categorize as "men" (often synonymous with possessing a penis). Tom Boellstorff described the origins of MSM, writing, "From available documentation it seems clear that the category originated in no household or bar, no park or disco, no poem or protest. Instead, "MSM" (like "homosexual") was a scientific and bureaucratic coinage, created to signify behavior without identity, as can be seen in its originary form 'men who have sex with men but do not identify as gay.' It was almost certainly formulated in the United States in the mid-1980s, but just as evidently globalized from the outset (particularly in the United Kingdom, Australia, and other English-dominant countries) via research and then activist networks…Instead, the category appeared in response to a need to analytically describe, for purposes of HIV/AIDS surveillance and behavior change—and thus of social control—men who engaged in anal intercourse with other men but did not identify as gay, as encapsulated in the saying 'it's not who you are, it's what you do'" (Boellstorff 2011, 290-291). The organ inventory similarly emerges as a categorization method applied (though not exclusively) to queerness that originated from medical institutions (though inspired by queer activism). Instead of "it's what you do", the organ inventory claims, "it's what you have." Behavior is the alternative to identity for the MSM label, while in the organ inventory materiality replaces identity. Robert Lorway describes the MSM category in the context of global health projects in postcolonial Namibia as "'MSM' as a 'doing thing' that unsettles the boundaries between subjects and objects" (Lorway 2019, 240). The organ inventory attempts to leave the subject behind entirely to focus on the object. Both the MSM label and the organ inventory serve as attempts to escape the foundational conundrum of not only queer identification, but also all identification. The phrase MSM and the organ inventories are both interventions looking for an escape hatch away from the foundational instability of the process of subjectivization. Organs that are considered ontologically constructed as solid, stable, and material replace the fluid and contextual nature of identification. The subject becomes a collection of pieces (organs) and/or practices (behaviors) that are both solidified as stable objects. What counts as both an organ and as sex are taken as self-evident. These objects are located in the present (currently present/absent) and binary in their mobilization understanding (have sex with men or don't/have an organ or don't). This narrow focus on behaviors and/or organs also interestingly draws focus away from structural causes of health losing the possibility that there is trauma, woundings, and disease that emerges directly from the experience of existing within, claiming, or being placed into stigmatized identify categories. The organ inventory does not capture the violence of living within a cissexist, heteronormative, and racist society. Furthermore there is also resilience, community-care, and generative openings within such identifications that remain undocumented in such an inventory. For example, while the organ inventory may ensure that a patient with a cervix does not miss a Pap smear, it will not do much good if due to discrimination or structural barriers such a patient never makes it into the clinic in the first place.

The organ inventory is not only a documentation method, but also a way of understanding the body, care, and the place of queerness within medical institutions. Such inventories look to disassemble the assumptions about the body contained within the categories of sex and gender. In many ways, this does offer a new and radical way of understanding of the relationship between care, materiality, and gendered or sexed identities. While the organ inventory does provide an important and critical new way to provide care, it remains contained by certain social conceptions. The body is not as resistant to contextual resignification as the organ inventory may hope. Similarly such organ-based care is still confined by a biomedical view that understands health and pathology as existing within discrete organs. Harm and disease are acknowledged, but they must be funneled through the body. The organs become envelopes for holding health and pathology. The organs within an inventory may be given a history (of surgery, hormonal development, presence at birth), but it is a history that remains within a medical and bodily framework - not one of the long temporality of environmental exposure, trauma, or structural violence. The material focus of the inventory allows a dodge of sex essentialism, but, as will be discussed below, the body remains bounded by certain ontological assumptions.

Software for Hard Bodies: Bounding Organs

The organ inventory is a tantalizing ethnographic subject because even as it tries to escape the fluidity of queer identification, the solid ground it attempts to construct out of bodily materiality proves to be just as slippery. For an organ inventory, the corporeal is represented as a checkbox and the squishy materiality of an organ is transformed into a sterile virtual button. Advocates have long fought to center the social determinants of health and allow socio-cultural and political structures to guide treatment decisions. In contrast, the idea that medical care can be stripped down to a series of algorithms that are triggered simply by the existence or absence of a lump of flesh may be disquieting. It is the carnality of medicine is exposed in this moment; a reminder of the deep influence bodily materiality has on the process of treatment and healing. The organ inventory provides a rich opportunity to reconsider the relationship between medicine, the body, and queerness. Anthropological work on queerness and the body is situated within a history of academic debates around the relationship between theories of social construction and bodily materiality. The ways in which medicine conceptualizes and creates knowledge about the gendered, sexed, or sexual body is exposed by the technological changes made within EHR systems. The organ inventory allows for an opening up of questions around the taken-for-granted assumptions around what defines a body and how different conceptualizations of queer bodies engage with questions of gendered bodily materiality.

Feminist theory has long debated the role of the body in relation to gender and/or sex. An organ inventory ingests the political calls to separate gender from the body and in doing so it produces a space in which it is the organs themselves that become the object of care. Interestingly, an organ inventory takes up this task, not by removing focus from the body, but by focusing solely on the body as care becomes dictated by materiality. This move dodges questions of how to apply sex and gender labels to bodily materiality, and instead anchors the body itself as the object that structures care. So while discourses around clinical decision support systems emphasize the high tech use of algorithms to improve patient care, the organ inventory grounds that same technology within the meat of the body. The data points captured in the organ inventory are meaty in their materiality. Such a data collection method moves away from euphemistically gendered terms such as "female-bodied" and instead categorizes the flesh. Identity labels are recorded in the EHR, but physically separated from the organ inventory, creating a categorization system based not on gender or sex, but on flesh.

Within the organ inventory, even as the body becomes digitized and fragmented, the categorization drips with the blood, fluids, scars, and surgeries that have grown, created, or removed organs. Body parts are made binary, but it is not one of a male/female dualism, instead it is a classification system based on the binary of present/absent. Whether they are original or new, grown or sculpted may be documented, but the existence of an organ is what will inspire care algorithms. If we take the promise of the organ inventory seriously, gender effects medical care in terms of the affective relationship between patient and caregiver, but it is the body (and specifically its organs) that are the object of care. Queer and feminist theory have long debated the relationship between sex, gender, and the body. This queer(ed) EHR enters this discussion and points away from an analysis of medical knowledge production around gender and sex that focuses solely on mental experiences or discursive construction of embodiment and instead lands in an exploration of the power of the bodily materiality itself.

Judith Butler addresses such materiality by seeing at as not solely a product, but also a process - that of “materialization” (Butler 2011, 1). She asks, “How precisely are we to understand the ritualized repetition by which such norms produce and stabilize not only the effects of gender but the materiality of sex?” (Butler 2011, x). Within an EHR such materialization is quite explicit. A prostate comes into being and is reified by the institutional recognition the software offers. Checking the box in the organ inventory next to “Prostate” assumes that such an organ is a self-evident object. All of the medical implications of a prostate are then assigned to the patient represented by the chart. It’s normal functioning is attached to this body, as well as the lurking threat of disease specific to that organ: enlargement, inflammation, and cancer. Throught his process, the organ inventory takes organs as materially obvious, solid enough to base medical care on, in contrast to the slippery concepts of gender and/or sex. Through the organ inventory the material existence of certain forms of flesh allow the body to be intelligible to the software algorithms that trigger the appropriate laboratory values, treatments, and/or preventative care. This specific ontological idea of the body - as a container for organs, that are themselves containers for health and disease - is what allows the flesh to enter into the medical data system. Butler describes this type of process of coming-into-being defined as materiality. Furthermore, she respondes to use of her previous work on gender performativity that understands it to be describing a type of gender that can be put on or taken off at will and instead emphasizes that when she uses performativity it is a reference to J.L. Austin’s notion of performative utterances (Austin 1962). For Austin, a performative utterance is a statement that performs an action and does not have truth-value, but instead is judged by whether it is felicitous or infelicitous. Butler describes gendered norms as ones that in their utterance also do work to bring the appropriately gendered condition into being. An organ inventory can be read as a digital utterance that brings the *body* into being in a form that is intelligible to the medical system. Later, in *Bodies That Matter*, Butler turns her theoretical interventions onto bodies, materiality and how gender and sex constitute and are constituted by matter. Writing against readings of her previous work, Butler says, “It is not enough to argue that there is no prediscursive ‘sex’ that acts as the stable point of reference on which, or in relation to which, the cultural construction of gender proceed” (Butler 2011, xi). Instead she asks, “What are the constrains by which bodies are materialized as ‘sexed,’ and how are we to understand the “matter” of sex, and of bodies more generally, as the repeated and violent circumscription of cultural intelligibility?” (Butler 2011, xi). Moving away from analyses that understand social construction as solely a matter of external norms hung on a prediscursive material frame, Butler offers “a return to the notion of matter, not as site or surface, but as a process of materialization that stabilizes over time to produce the effect of boundary, fixity, and surface we call matter” (Butler 2011, 9). Like her previous interventions into gender, here bodily matter is the result of processes that construct what is able to be thought as a body and how this results in a gendered materiality that appears universal, ahistorical, and static. Interestingly, while the organ inventory is deeply implanted in a biomedical system that often relies on such an ahistorical and universal body, this technology requires a very explicit, meticulous, and systematized process of revealing the material history of a body. It asks; were these organs present at birth? Did they develop? Were they created later surgically or chemically? These questions make apparent the complicated and far from static materiality of the body.

Organ inventories are most often discussed in relation to transgender identities (even though people of all identities have organs that are both constructed and removed). Butler’s focus on constitutive performativity and materialization as processes that produce universalizing effects comes under criticism around exactly this subject - that of transgender figures and identities. Critics push back against what is seen as a centering of socio-cultural norms and discursive power over the ways in which materiality can viscerally and politically constrain claims to authenticity. In *Second Skins: The Body Narratives of Transsexuality*, Jay Prosser undertakes a critical exploration of writing on the experience of transsexuality that "foregrounds the bodily matter of gender crossings" and "reveal the materiality of the figure of transition" (Prosser 1998, 4-5). Prosser argues that Butler is representative of the ways in which queer studies have centered transgender identities as theoretical figureheads used to expose the constructed and conditional nature of gender. In Chapter 4 of *Bodies That Matter* titled "Gender is Burning: Questions of Appropriation and Subversion" Butler analyzes Jennie Livingston's documentary of the New York ball scene *Paris is Burning*. This choice of archive is a strange one; in that Butler is writing against a reading of her work that equates gender performativity with play-acting or drag. Yet ball culture is at least partially defined by events that include theatrical performances with the attendant costuming, audience's gaze, and self-aware presentation of aesthetic, even as it is populated by a constellation of identities that are claimed as authentic in various ways. Still, Butler uses ball culture to discuss how "identification is always an ambivalent process" in that "'being a woman' and this 'being a man' are internally unstable affairs" (Butler 2011, 126). While ball culture with its glamor might seem worlds away from the sterile white and blue pixels splashed on the screen of a mundane clinic computer, the organ inventory exposes a similar instability not only of gender, but also of the body itself. Such ambivalence for Butler emerges from the psychoanalytic notion that any sort of representation is an ideal and therefore unable to be fully inhabited. Identification therefore foundationally leads to dissonance between the presumed unity of identity and the ability to "authentically" inhabit given discursive identity categories. This ambivalence is also in reference to Butler's assertion that identification always requires loss - to claim something is to turn away from another. The organ inventory is a software that attempts to account for this chasm (between "male" and "has a uterus") - to create space in the EHR for identity while also documenting the material data that allow a subject to be not only cared for by, but also intelligible to the medical system.

Prosser challenges this use of transgender identities to expose the inherent contradictions in gendered and sexed identifications. Prosser argues that queer and trans studies more broadly must begin to engage with the lived experience of transsexuals, not solely as theoretical examples, but as embodied and material. He focuses on transsexual narratives in the service of reconnecting bodily materiality to the notion of sex. This description could also describe an organ inventory. Though the inventory does not so much as reconnect the body to sex, but dissolves the category of sex and replaces it with a piecemeal body. A focus on materiality is crucial for Prosser because it reminds how "embodiment forms an essential base to subjectivity" (Prosser 1998, 8). Prosser is explicit about the ways in which bodily materiality offers a limit to theory, writing, "Matter may not be commensurable with the cultural construction of identity" (Prosser 1998, 7). Butler's focus on materialization as the process by which matter comes to be and have meaning is resisted by Prosser who sees it as being an analytic too open to resignification, agency, and discursive formation. The materiality of sex, Prosser argues, can be a foundational limit to gendered identification. If queer studies is to utilize transgender experiences as theoretical fodder, such embodiments must draw critical attention back to the body. Interestingly the organ inventory does not conform to this analytic frame. While it draws very specific, digitized, and quantified attention to the body, it allows sex and gender to live in completely separate digital compartments. Sex is, quite literally, separated from materiality. The cervix exists or it does not exist, but from a data perspective it is not connected to whatever sex the body was assigned.

In *Black on Both Sides: A Racial History of Trans Identity*, C. Riley Snorton crucially asks, “What is sex without flesh?” (Snorton 2017, 44). The organ inventory is one attempt to answer that question. If the promise of the organ inventory is taken seriously, it is offering a profound intervention into the relations of sex, gender, queerness, and the body. The body of the organ inventory is a collection of distinct parts - an envelope of envelopes. It not only centers the organs, but the organs are what make things happen. Flesh can become peeled away from gender, sex, and sexual orientation to become the material object of care. Care comes from and is given to the organs. The organ inventory attempts a radical alternative to materiality as necessarily sexed or gendered. Importantly, it is not racialized either. The organ inventory also remains physically separate from other demographic data collection around race, ethnicity, age, disability, or other social categorizations. Through a deft analysis of the history of gynecological violence on the bodies of enslaved persons, Snorton describes how “flesh is, above all else, a thing that produces relations - real and imagined, metaphysical and material” (Snorton 2017, 40) and how “the narratives of American gynecology’s founding clarify how chattel slavery functioned as one cultural apparatus that brought sex and gender into arrangement; the instrument in such an encounter occurred in and as flesh” (Snorton 2017, 52). Even as the organ inventory attempts to remove the body from the data-space of demographics, Snorton reminds us that the ability to separate flesh, sex, and gender is not as self-evident as the virtual borders coded into the EHR software and is an intervention deep ontological implications. So while the organ inventory may be conceptualized as an escape hatch away from the contextually messy definitional slipperiness of identity terms, it recreates another categorization system through the organs. This documentation system remains confined by a biomedical view of the body that views health and pathology as living within discrete organs. Harm, disease, and health must be funneled through the organs to become intelligible within the organ inventory. Organs become an envelope for wellness, disease, health, and pathology.

Within the architecture of the organ inventory, the body is a bounded container holding a collection of distinct parts. Organs become bounded due to the needs of a quantified medical system. This does not imply that this is the only way to conceptualize the body or that the software designers, clinicians, and researchers who use such data do not see the leakage within quantified categories. That said, with the rise of organ-based care offered as a new and progressive solution to an old problem, such inventories are important conceptual spaces to unpack for how they construct the body, medicine, and the place of queerness within both. Organs become “discrete data fields,” as the clinical IT specialist described. Thus the cleanliness of the virtual space of an EHR belies not only the messiness of organs, but the checkboxes create a space in which organs are discrete in their ontological boundedness. These inventories were designed to fix problems not only within the software (how do you order a Pap smear for a patient coded as “Male”?), but also within the conceptual space of medical knowledge (what is sex?). Such inventories are an attempt to respond to not only how the category formerly understood as “sex” cannot predict the make-up of an individual body, but also how bodies can lose, gain, grow, shrink, discard, and create organs and within the medical system such organs require attention, maintenance, investigation, and monitoring. Furthermore, the bounded checkboxes of the organ inventory mirror the ontological boundedness assumed of the organs. Much of the theoretical writing on the body, even in relation to queerness, actually assumes a similar ontology for its material boundaries. What that material means, is read as, and can do is debated, but the fact that the boundaries *exist* is often not. For example, Jay Prosser and Eric Plemons writing on facial feminization surgery, both foreground skin as defining the bounds of the body. Sara Ahmed in *Queer Phenomenology* also describes how "the skin connects as well as contains" (Ahmed 2006, 54) and "spaces are not exterior to bodies; instead, spaces are like a second skin that unfolds in the folds of the body…the social also has a skin, as a border that feels and is shaped by the 'impressions' left by others" (Ahmed 2006, 9). For Ahmed, bodies, space, and objects press upon and shape one another and the skin of the body and the skin of the social are different, yet interacting surfaces. As observed by Mel Chen (Chen 2011, 265), Ahmed retains skin as a moment of ontological separation, such as between the tables and bodies she describes. The body stretches, reaches, and expands through space in relation to objects, but does not seem to absorb, become absorbed by, blend with, or get mixed up in those objects. The organ inventory mirrors such boundedness. The body becomes a container of containers (or organs). Though if we observe the ways in which bodily materiality is mobilized, esepcially within medicine, organs may be categorical names for parts of the body, but their borders are not as materially obvious, static, and rigid as the checkboxes of the inventory imply. Organs merge into surrounding flesh, secrete and absorb materiale, are surgically cut, scraped, removed, grow and dissolve in ways that are in excess of quantitative documentation methods. Within biomedicine as well in conceptual theorizations of bodies, organs and carnal materiality are often anything but contained. Throughout my work in medical spaces, I witnessed and participated as injections pierced the flesh, scalpels carved organs, and medicines were absorbed through organs. This bodily porosity offers not only a challenge to quantification techniques, but also a unique ontological alternative to seeing the body as a bounded envelope containing self-evident, named, and contained organs.

In considering the implications of the organ inventory as an intervention that looks to stabilize itself by using materiality as an anchor that is separated by socially constructed identification, it is helpful to end with an author who similarly takes fleshy materiality seriously as an object of analysis, but allows a different ontology of the body. In "Mama's Baby, Papa's Maybe: An American Grammar Book," Hortense Spillers describes the violence of slavery as being enacted through "the profitable 'atomizing' of the captive body" (Spillers 1987, 43). Fragmenting the body is a mode of dehumanization and trauma for Spillers as it conceptually (and sometimes materially) rips the body into pieces. While the organ inventory may not necessarily represent such violence, it does bring into being a form of the body that attempts to cordon flesh off from the impacts of social concepts like gender or sex. Spillers offers a different analysis that does not require such conceptual separation, while still allowing materiality to hold power. Spillers argues for "a distinction in this case between body and flesh with flesh being the site of "zero degree of social conceptualization that does not escape concealment under the brush of discourse, or the reflex of iconography" (Spillers 1987, 67). So while flesh may dodge the complete overdetermination of social conceptualization, Spillers is clear that it (as a concept and possibly a representation of materiality) still does powerfully generative work within processes of self-identification, social subjugation and generational trauma. The flesh is mobilizable and mobilized, even as Spillers offers analytical insights on how it might escape the symbolism that bodies are caked with. While the organ inventory responds to the challenge of queerness by reifying a pre-discursive material body, Spillers reminds that the body and flesh are not blank slates nor solely social illusions, but objects and spaces that are construted, mobilized, and exude force.

If the promise of the organ inventory is taken seriously, it is offering a profound intervention into the relations of sex, gender, queerness, and the body. It is making significant claims about the ability to bound the body away from other data and other social categorizations, such as gender, sex, and race. The body of the organ inventory becomes a collection of distinct parts - an envelope of envelopes. It not only centers the organs, but the organs are what make things happen. Flesh can become peeled away from gender, sex, and sexual orientation to become the material object of care. Care comes from and is given to the organs. Lawrence Cohen, in his 2011 article "Accusations of Illiteracy and the Medicine of the Organ," similarly tracks how clinic signs in postcolonial India utilized organs as a visual symbol of care and constricted a certain organ-based relationality to care that assumes illiteracy in the patient population. Even though the settings that I study are different from this, organs similarly come to represent a certain structuring of care. The organ inventory attempts a radical alternative to materiality as necessarily sexed or gendered. So while the organ inventory is conceptualized as an escape hatch away from the contextually messy definitional slipperiness of identity terms, it recreates another categorization system through the organs. Within the architecture of the organ inventory, the body is a bounded container holding a collection of distinct parts. Organs become bounded due to the needs of a quantified medical system. This does not imply that this is the only way to conceptualize the body or that the software designers, clinicians, and researchers who use such data do not see the leakage within quantified categories. That said, with the rise of organ-based care offered as a new and progressive solution to an old problem, such inventories are important conceptual spaces to unpack for how they construct the body, medicine, and the place of queerness within both. Organs become "discrete data fields" as the IT specialist told me above. Thus the cleanliness of the virtual space of an EHR belies not only the messiness of organs, but the checkboxes create a space in which organs are discrete in their ontological boundedness. In summary, the organ inventory represents a moment in which queerness soaks into medical data practices, inspiring and requiring challenges and changes to quantification. Such attempts to transform the body into data not only offer a novel entry into theoretical debates around the relationship between queerness and materiality, but also expose the ontological claims made by biomedical documentation as to what a body is and how it should be cared for.

Conclusion

Late one spring afternoon, I spoke with Madeline, the organizer who invited the Sisters of Perpetual Indulgence to perform the research blessing described in the introduction to this dissertation. When I asked her why she chose to organize this blessing, she said, "LGBTQ+, what does that mean? We've got like some common experiences, we've got some common interests but we also have these histories of fighting each other of opposing each other, invisiblizing each other, of deplatforming each other. And we have really divergent interests depending on lots of different factors. But what we all have in common is some level of experience of what I would call trauma. We have familial rejection; we have social experiences of early stigma. We've got all kinds of experiences of discrimination in workplaces or other kinds of public spaces. And so and there's a wide variety of trauma, but we've all got it. And that trauma is based in in large part, in being kicked out, and not being a part of and being othered, being sort of pushed to the margins. And so for me, it was really important to, to really think about belonging, what does it mean to welcome people in? What does it mean to create? Because we, the researchers, that's what we're doing…It was risky, it was different. It was strange, like in a lot of ways in terms of what you would expect in a conference setting that would be in an academic institution. And so I knew that it would be that it would work for some people and won't work for other people."

This risky, different, and strange experience, as described by Madeline, encapsulates many of the themes explored by this project on queer data. How did a nun in leather boots end up in this hospital courtyard? What does it mean that glitter is the substance offered for approval for a scientific project? Why do data need a queer benediction? The leather boots represent the ways in which queerness becomes not only an object of study, but a force to queer research methodologies as well. The glitter reminds us of ways in which community expertise becomes centered in complex ways that both influence research and allow data to shape the meanings of queerness. The benediction reads as an apology, for the ways in which research is felt to have failed queer communities, people, and bodies. This blessing remains representative of the seeming conundrums represented by queer data as the campy glamour of a queer nun traipses through the shiny prestige of a medical research center. In describing the work of queer research, Madeline emphasizes belonging, exposing how the queer data tracked throughout this project holds multiple roles, and many with deep affective impacts. Queer data serve as both witness and violence, bestowing solidity to both belonging and trauma. Madeline also asks, "What does it mean to create?" This may be a more precise encapsulation of this project than anything I have offered thus far. This dissertation aimed to look at the ways in which queerness and data are co-created by one another. It aimed to dissolve some of the conceptual and material borders that place queerness as solely the object of data and data as solely a method of pure documentation, but to instead see how both inform and transform one another.

During the writing of this dissertation, questions about the politics of counting felt all the more germane as debates around numbers blasted on to the national consciousness in the United States. The COVID-19 pandemic splashed numbers on to the front pages of news websites and social media posts as far as the eye could see. Numbers of diagnoses, numbers of deaths, ICU beds filled, and percentages of positive tests grasped to represent the severity (or unimportance, depending on who you are and what you read) of the spread. The discourse over how and why numbers could be politically weaponized became mainstream, prolific, and fervid. The debate was not only over who held the truth and which facts were accurate, but also about whether truth and facts were even morally desirable anymore. While some discussions centered on whether the numbers were accurate (Were 400,000 really dead? 500,000? Were doctors inflating the numbers to financially benefit?), many other debates questioned if numbers mattered at all. Then the 2020 election happened and counting found an additional battleground. Between the "Count every vote" and "Stop the steal" protests, the act of counting - not the system, the rules, or the policies, but *counting* itself - became the central drama of the election. News reports showed people praying outside an Arizona election center where votes were being counted, praying for a victory for Donald Trump while armed protesters glared through the windows. In Philadelphia, speakers boomed a heavy bass line outside vote counting location as an all-day dance party hoped to boost morale and support the continued counting. The same election workers whose work often goes unremarked upon in most elections became representative of a deep political debate over what it means to count and be counted. The attempted coup at the Capitol on January 6, 2020 was in part spurred on by the belief that the election numbers were not only wrong, but also lies. In a turn of events that I wouldn't have been predicted when I began researching the politics of counting, armed armed insurrectionists were mobilized by what was explicitly discussed as a disagreement about quantification methods. Of course, it was about more than counting. It always is. Counting is also a method of claiming immutability, objectivity, and truth, and such values carry critically heavy stakes. This dissertation works to expose how these stakes are mobilized in the world of queer health.

Queer data were centered in this project not because they are necessarily categorically different from other forms of knowledge, but because of the way such data can expose a fluidity of bodily and identificatory boundaries especially in relation to the institutional, scientific, and medical logics. The analysis offered through this work can hopefully be extended to examine the sticky processes of all types of quantification, as Geoffrey Bowker and Susan Leigh Star remind us in their book *Sorting Things Out: Classification and Its Consequences* when they stress the importance of looking at “the creation and maintenance of complex classifications as a kind of work practice, with its attendant financial, skill, and moral dimensions” (Bowker & Star, 2000). Genevive Bell importantly describes how “data will resist being tidied up. Data will be messy” (Bell, 20). Even with the expansive and fluid methodologies of anthropology, it is seductive to see this project as one that participates in such tidying up. To offer a “clean” analysis of queer data that assesses the accuracy or inaccuracy of data, labeling data processes as good or bad, is tempting since it could offer some security and even opportunities to propose more affirming, effective, or accurate methods of data collection. Throughout this work though, I have instead tried to stay with the mess. I have found that centering the messiness of quantification and of queerness, and respecting the resistance both show to a tidy, singular analysis allows the ethnographic objects I explore (even, or especially, those that seem most sterile and unmoving, like software or paper forms) to exist in all their lively, slippery, and contradictory forms.

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