



Dropdown rights: Categorizing transgender discrimination in healthcare technologies

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ABSTRACT

This study analyzes how U.S. healthcare organizations implemented legal requirements to treat patients in a manner consistent with their gender identity under Section 1557 of the Affordable Care Act. The ways that healthcare organizations determine gender and track complaints constitute socio-technical systems for compliance, and they shape what discrimination protections look like on the ground. We interviewed grievance handlers about how they use information technologies to process possible civil rights claims from patients and argue that their work demobilizes and erases civil rights, especially claims such as transgender harassment. Mobilized physician-led implementation groups, by contrast, enacted a version of gender identity recognition by tracking identities and bodies in electronic medical records and material objects such as specimen labels. Default structures—the dropdown menus of healthcare software—both shape and are shaped by professional norms, financial incentives, and conceptions of justice and deservingness. These socio-technical structures allow conflicting stories of transgender rights to continue on in different parts of the healthcare organization, making it difficult for law to transform healthcare delivery.

1. Introduction

Transgender and/or non-binary people¹ report high levels of discrimination in medical care, including insurance denials or exclusions for gender affirming care such as surgery and hormones, harassment by care providers such as being called the wrong name or addressed as the wrong gender, being outed by these practices, misdiagnoses or non-recognition of health conditions (Stroumsa et al., 2019), and receiving dehumanizing “freak” treatment through unnecessary questioning, probing, or exhibiting of their bodies (Grant et al., 2011; Nordmarken and Kelly, 2014; Shuster, 2021). Experiences of discrimination drive trans people from care (Glick et al., 2018). Concern over the health consequences of these experiences has driven policy change, most notably the transgender-inclusive interpretation of Section 1557 of the Affordable Care Act (ACA), 2010, the antidiscrimination clause of the health care law that prohibits discrimination on the basis of sex.

The trans-inclusive Section 1557 provision requires “treating individuals in a manner consistent with their gender identity” in health

care (Department of Health and Human Services, 2016). But to treat someone in a manner consistent with their gender identity in a health care setting, one must first know what that patient’s gender identity is. One must have a way of seeing and tracking when transgender people seeking care experience discrimination. Enacting civil rights in health-care means adapting systems to gather these forms of knowledge: managing complaints, “determining gender” (Westbrook and Schilt, 2013) in common interactions with frontline staff (signing in at the registration desk), and delivering clinical care focused on the body and its organs (determining who needs a cervical cancer screening).

This article examines the socio-technical implementation of civil rights in health care, focusing on the information technologies that administrators and providers use to record and share information about patients’ gender identities and the problems patients have in their care settings. These socio-technical systems shape the reality of civil rights protections for gender identity in healthcare. I ask how objects are “handled in practice” (Mol, 2002, 5) and how do compliance professionals produce medico-legal practices within their organizations (Edelman, 2016)? Marc Berg and Geoffrey Bowker point out that

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¹ I begin with the term transgender and/or non-binary people to capture the widest range of people who may seek gender affirming medical services and to indicate diversity within this group about how they identify and appear. The systems studied here do not capture non-binary people’s experiences well and so I do not always repeat the full phrase.

artefacts such as “[t]he medical record produce [] organizations that can configure their own records such that a privileged set of stories (due process, medical science, nursing efficiency) can be told again and again” (1997, 532). What then, are the privileged set of stories about transgender and/or non-binary patient rights in grievance management systems, patient satisfaction survey databases, sexual orientation and gender identity (SOGI, pronounced so-gee) forms, and trans patient organ inventories?² These stories filter through categories, sorting what the problem is and describing who the body and the identity—the subjects of civil rights—are.

The idea that health care records should include a patient’s gender identity and sexual orientation is fairly new. A 2011 Institute of Medicine (IOM) report on LGBT health recommended that SOGI data collection be part of “meaningful use” of electronic medical records (Institute of Medicine, 2011). Federal regulations subsequently required that demographics in EMR include SOGI by 2018 (Department of Health and Human Services, 2015). The earliest implementers were federally funded health centers, which the Health Resources and Services Administration (HRSA) required to report SOGI data in 2016 (Bowers, Acting Associate Administrator for Primary Care (HRSA) 2016). The General Social Survey (GSS) also began to ask about gender identity and sex assigned at birth in 2018, creating the first nationally representative survey sample (Lagos and Compton, 2020). This study examines organizations, from laggards to the early adopters, as they work out these dawning legal obligations to “treat individuals in a manner consistent with their gender identity.”

But beyond this phrase, what is the civil right at stake here? When the ACA passed in 2010, it contained a cryptically short anti-discrimination clause that listed sex discrimination for the first time in an application to healthcare settings (meaning it protects patients, since employees are already covered by Title VII of the Civil Rights Act of 1964). The text of the law simply lists other pre-existing civil rights laws for its coverage (such as Title VI for race, the Age Act for age, and Section 504 of the Rehabilitation Act for disability), and its reference to Title IX ushered in sex (2010). Section 1557 implementation reaches far, including every federally funded healthcare entity with 15 employees or more, including nursing homes, blood and tissue banks, and pathology labs, as well as the more heavily trafficked hospitals and clinics studied here. The Obama administration interpreted sex discrimination to include gender identity, making Section 1557 implementation into one of the most potentially transformative changes in US civil rights law. The Trump administration attempted to undo the transgender rights protections of Section 1557 through administrative rulemaking (subsequently tied up in court), but the clause itself remains and the Supreme Court’s 2020 ruling that transgender discrimination is sex-based discrimination seems likely to promote trans inclusion in the ACA (*Bostock v. Clayton County* 2020). It is worth noting, however, that there is no general right to healthcare in the U.S.

Regulations required every regulated site to appoint someone to handle Section 1557 complaints (Department of Health and Human Services, 2016). I analyze the position and perspectives of these grievance handlers, mostly patient satisfaction employees situated within the customer service side of the hospital system, in detail elsewhere (Kirkland and Hyman, 2021). I move to their systems for recognition here: tracking problems and their possible link to identity categories and gender identity recognition in records, on objects like wristbands, and in organ inventories. I argue that Section 1557 has turned out to be an easily coopted demobilization system, as rights typically fail to appear in the grievance management software drop-down menus, but also that it has prompted creation of other recognition systems, as electronic record-keeping shifted to make treating transgender people with knowledge and dignity possible. These adaptations are how civil rights

policy becomes real on the ground and are also how it presses medical settings to re-do gender.

2. The drop-down menu in organizational rights culture

The work of rights in healthcare has technological, organizational, and material dimensions (Brennan and Suchman, 2020). I identify four primary meeting points for transgender civil rights and healthcare on the ground within healthcare systems: (1) when grievance handlers enter and process patient complaints (about anything, but including what could count as a civil rights violation based on gender identity), (2) when those same professionals scrutinize and learn from their patient satisfaction survey reports, (3) when health care workers determine gender identity for patients in electronic medical records (EMR) and on material objects that track identity such as lab specimen stickers or inpatient bracelets, and (4) when clinicians use organ inventory records to try to recognize and provide the best patient care for trans bodies. The categorizing work in these grievance management systems, documentation systems, and inventories constitutes a political and moral order (Bowker and Star, 1999) for determining gender (Westbrook and Schilt, 2013) enacted in part through handling objects in practice (Mol, 2002). Most scholarly attention to the sociology of medical records has focused on the clinical record and its use by doctors to construct patients and organize medical work (Berg, 1997; Berg and Bowker, 1997; Timmermans and Berg, 2003). Scholars have carefully avoided attributing too much determination to material objects or information technologies or overstating the case for human agency over tools by recognizing their balance and interplay. Drawing on these lines of research, my question here becomes, what possibilities for action do objects like drop-down menus or chart stickers afford (Allen, 2013)? Moving the question into the research on rights and legality in organizations, it becomes, what possibilities for law in action do the drop-down menus in healthcare organizations open up or foreclose?

Westbrook and Schilt’s (2013:39) analysis of cisgender people fitting transgender people into “previously unquestioned systems and locations” examined employment laws, birth certificate change policies, and sports participation. This article analyzes the systems and workflows through which healthcare systems at least attempt to capture problems generally (complaint tracking software and patient satisfaction surveys) and where providers wrangle with correct recognition (recording SOGI in the medical record and adding an organ inventory). The sociology of transgender and/or non-binary people’s lives is nascent but quickly growing (Schilt and Lagos, 2017) and recent work on health care interactions reveals that health care providers who deliver gender affirming care both shape and react to transgender and/or non-binary people’s needs in dynamic ways, some more affirming than others (Pearce, 2018; shuster, 2019; Plemons, 2017; shuster, 2021). Transgender people use technologies to connect and remake dominant narratives about their medical experiences (Haimson, 2020), but here we are studying the other side: the health care workers with varying levels of awareness about transgender people who use socio-technical systems to manage and create what they will be understood to deserve. The administrators and providers we studied are overwhelmingly “gender normals” (Schilt and Westbrook, 2009) whose behavior enacts law on the ground, that is, cisgender people who encounter transgender and/or non-binary people and make decisions about their rights.

For everyone involved, coming to understand and name a problem as discrimination or as a rights violation is a complex knowledge process that occurs on organizational, material, and technological levels (Mol, 2002) and may never occur (Levitsky, 2014). Sociological scholars have documented how claims about conduct that is likely illegal discrimination ends up sorted into other buckets such as poor communication (Berrey, 2015; Berrey et al., 2017; Edelman, 2016), but with less attention to how material objects and technological systems mutually constitute rights in healthcare settings (but see Brennan and Suchman, 2020; Suchman, 2017). Research on rights within healthcare settings

² I use both “patient” and “person seeking care” to reflect both the way the institution regards someone and their agency.

such as HIV clinics, neonatal intensive care units, and the experiences of fat people seeking careshows how rights struggle to gain traction in health care, where other narratives such as care and responsibility hold much more sway (Heimer and Gazley, 2012; Heimer and Morse, 2016; Heimer et al., 2005; Heimer and Staffen, 1998; Kirkland, 2009). For example, concern for quality and safety in healthcare, certainly dominant internal frames for organizations themselves (Allen et al., 2016), might hinder rights recognition by framing rights violations as either low quality care or safety risk. The case of SOGI and transgender bodily recognition here shows a way past the question of *whether* rights appear and could drive action and into the *how*, through socio-technical forms of recognition and non-recognition.

Brennan and Suchman’s (2020) mapping of the dynamics of relationships between law, technology, and healthcare organizations helps frame why civil rights are so easily swallowed up by other organizational practices. Technological innovation in healthcare, such as the move to electronic medical records from paper files, can be consistent with prior institutional commitments or it can disrupt them, and these changes can occur within the clinical or the administrative domains. Socio-technical changes that are consistent with pre-existing practices are likely to stay closely coupled with the way things are already done, giving law little power to change practices. Is entering SOGI data into a patient’s medical record consistent use, perhaps just re-imagining the “nickname” field as “preferred name”? Is an organ inventory just helpful clinical specification? Gender identity recognition as a healthcare civil rights provision did not require disruptive technological usages in either administration or clinical care, I will argue, and so the organizational effects of legal change through these processes alone was limited. Moreover, translation work between professional domains would be needed for gender identity recognition under Section 1557 to produce robust change (Hoffmann, 2019; Kellogg, 2014; Morse, 2019), and we found that ossified status divisions between the clinical and the administrative remained. Institutional entrepreneurs (Dimaggio, 1988) can also use the occasion of a new law like Section 1557 to push along their objectives, however, and we found some push for full-scale organizational capacity to respectfully treat transgender and/or non-binary people. These actors, like the pro-breastfeeding managers Elizabeth Hoffmann calls “Allies Already” in her study of workplace lactation compliance, drive and shape compliance in their organization (2019).

3. Methodology and data

We used a qualitative interview study design to capture civil rights implementation by Section 1557 coordinators (or, if the site was non-compliant and had not appointed anyone, the person who would handle complaints generally) and other medical actors. The research team began by constructing a dataset of hospitals (excluding specialty sites such as psychiatric hospitals), ambulatory surgical centers, and a subsample of Federally Qualified Health Centers (FQHCs) in Michigan, Alabama, northern California, and the five boroughs of New York City plus a few selected upstate areas. These locations were selected to maximize political variation in transgender rights acceptance. We chose non-specialty hospitals because these are simply the largest and most obvious healthcare sites that people may interact with that are most likely to have an organized response to the new Section 1557 law in place. We added ambulatory surgical centers because they have a different organizational structure (often physician-owned with a much more streamlined administrative structure but still interacting with a lot of patients). FQHCs are an interesting type of site because they are federally funded to serve low income people and were required to gather SOGI by the Obama administration in an early roll-out of Section 1557 compliance. They also have a simpler organizational structure at each site than a larger hospital and were arguably better informed about anti-discrimination compliance because early regulation to capture gender identity in records was aimed at their operations.

A team of 7 researchers called all sites in the dataset between May

2017 and March 2019, asking to speak to Section 1557 coordinator on their website, and if there was not one listed, the person who handles patient complaints (744 contacts; n = 65 interviews). If it was clear that patient complaints would come to that person, we considered him or her the site’s grievance handler even if no one had been assigned the role (that is, a non-compliant site). Interviewers were the author and doctoral students in Sociology (in Michigan, New York, and California). Interviewers included two transgender men and four cisgender women. Interviewers followed a detailed written protocol for soliciting interviews starting with a phone call to the number listed as Section 1557 coordinator on the facility website. The PI/author pilot tested the protocol and interview script and adjusted the directions and wording before the doctoral students began work. Interviewers kept detailed call logs describing the outcome of each contact attempt. Interviews consisted of semi-structured questions about the person’s professional life and daily work. We did not presume that the grievance handler would recognize problems as discrimination, but rather sought to map how something would come to be seen as any kind of problem and then handled. Interviewing took place mostly by phone (44), but some were in person (15). Interviews were recorded, professionally transcribed, and coded using Dedoose software and a grounded theory approach, with the 2 coders achieving inter reliability scores of 0.73 and 0.85. All personally identifying information has been replaced with pseudonyms (IRB #HUM00120522).

Fifty-nine interview subjects were Section 1557 implementers, of which 43 (73%) were the primary grievance handler at their facility. Table 1 depicts their roles in the organization. The other 6 were people we reached through snowball sampling, asking the first person who else was helping with 1557 implementation and then seeking out those people. Hospitals that were taking Section 1557 seriously typically had a committee working on implementation, whereas those not yet complying only had whoever was already in charge of patient problems. Of the 43 implementors who were their facility’s primary grievance

Table 1
Interviewee professional roles.

<u>Roles as Grievance Handler</u>	Count	Percent
Patient experience overall	24	41%
a. Patient relations	11	19%
b. Patient advocate	7	12%
c. Patient experience	4	7%
d. Patient representative	2	3%
e. Customer relations	2	3%
Risk management	9	16%
Compliance & accreditation	7	12%
Health services administration	6	10%
Civil rights coordinator	4	7%
Privacy officer/HIPAA	4	7%
Recipient rights officer	4	7%
CEO/Executive Director	3	5%
Diversity, Equity & Inclusion	2	3%
Nursing/Nurse supervision	2	3%
Data and information management	2	3%
Customer relations	2	3%
Interpreter services	1	2%
Social work	1	2%
Grievance analyst	1	2%
Office manager	1	2%
Ethics	1	2%
	86	(individuals held multiple roles)
<u>Roles beyond Grievance Handling</u>		
Project manager for 1557 implementation	1	
Clinical social worker and manager	1	
SOGI expert in EMR corporation	1	
IT coordinator for EMR in hospital	1	
Physician	1	
Medical resident	1	
	6	

handler, only 14 had been specifically designated as Section 1557 civil rights coordinator and knew they had this role. The remaining 29 were people who worked in organizations that had not yet named a 1557 coordinator, but who would most likely be assigned the 1557 role when their organization complied with that aspect of the regulations. Other implementers were physicians or other clinicians, project managers, or working in electronic medical records and the IT department, reached through snowball sampling within organizations. A majority (71%) of interview subjects worked in the domains of patient relations, risk, compliance, and quality assurance. Nursing was the most highly represented educational background for grievance handlers (37%), with the rest comprised of a wide range of professional and bachelor's-level educational backgrounds without clinical training in a medical field. Notably, there were only 2 attorneys hired as grievance handlers in our sample.

A total of 744 contacts yielded 65 interviews, about an 8% response rate. Despite our low response rate and non-generalizable sample, I argue that because the regulatory and accreditation requirements are fairly uniform nationwide and because nearly all organizations used similar feedback software and an EMR system, described similarly and in accord with clear professional norms, the uses of problem-tracking software and EMR described here likely hold within most healthcare organizations in the U.S. In other words, people were understandably reluctant to grant an interview to talk about discrimination in their organizations, but the work flows and systems analyzed here are not unique to our respondents and would also structure non-respondents' workplaces. At the same time, the lack of recognition and response is itself data. First, any patient trying to phone in a complaint would also face the same morass of voicemail boxes. Second, the lack of uptake is a similar type of non-recognition to our substantive findings: raising civil rights problems simply fails to fit well within healthcare organizational work pathways.

We were not able to view confidential patient information in the grievance processing software programs directly. Sharing these data with researchers would violate patient privacy rights under the Health Insurance Portability and Accountability Act (HIPAA) of 1996. Also, health care organizations are protected from having to disclose risk management reports in litigation in order to encourage them to discover mistakes and respond internally, so these data could not be disclosed without risking that protection. This research area is not very accessible to scholars (except perhaps as embedded ethnography, which is not our method and which has other limitations). We learned what categories were built into their drop-down menus by asking, and some people read directly from their screens while on the phone with the interviewer. Future work could begin with the IT companies rather than care sites, adopting other study designs that could overcome the significant access barriers we encountered.

3.1. The drop-down menus in grievance tracking software: what kind of problem and where did it happen?

The socio-technical systems sort, alert, and remind grievance handlers as they do the work of moving along and resolving complaints. The software classifies patient problems in two main ways: (1) what kind of problem and (2) where in the organization it happened. These stories are about improving quality and safety by seeing problems and apportioning blame. The first and most important categorical division that tells "what kind?"; reflected in everything from the software itself to the organization of the professions within healthcare, is between the patient experience side and the clinical or risk side of problem management. Debra, a nurse and patient relations manager at a Catholic hospital in Alabama, explains the bifurcation:

Well, there's two sides to [our] event reporting system. One is the safety side, which would be, like if the patient fell out of the bed, or if patient got a wrong medication dose. Or any type of event that was

an unforeseen thing that could impact the patient clinically. The other side of the event reporting system is called the feedback side. And that's my side. That's where you would enter complaints, grievances, inquiries, suggestions, that kind of thing.

Potential civil rights claims fall under the personal, the experiential, and the non-medical side, which is lower in status and maintained by a cadre of patient experience specialists who are highly responsive yet rarely able to do much of anything to remedy a rights violation (Kirkland and Hyman 2021). The clinical side is the risk management side, watching for possible medical mistakes that could blow up into lawsuits. The feedback side is most concerned with patient satisfaction scores, while the risk side is most concerned with the law's external and more threatening forces. Civil rights claims thus become de-mobilized legally, with literally no place in the drop-down menus that most grievance handlers described. A few reported adding an option called Section 1557, but overwhelmingly the categories described have no obvious relation to any civil rights category, identity, or cognizable harm, and as I show, many grievance handlers resisted and denied this use of their system.

Karen describes how their system routes problems where they should go:

It has very specific drop-downs where any employee can go in at any time of the day and place a complaint, a compliment, into that system. So the complaint comes in to service leader A at hospital number 1, and it relates to the intensive care unit. So it'll automatically fire to Service Excellence and to the ICU leader. So there are auto-firing algorithms. While the Service Excellence leader is reading that complaint, it may also involve another department. Maybe it's pharmacy, for example. So the Service Excellence leader can then, quote-unquote, "task" that pharmacy leader to review the case as well. It's like forwarding an email, for lack of a better description.

These two tracks work together to deliver healthcare safely, with reasonably high quality or at least avoiding costly mistakes, and to evade fines and penalties.

Many interviewees mentioned tracking software by RL Solutions, now RL Datix. This private vendor has over 5000 institutional customers across 19 countries (Gaurav, 2020, 124). It covers 75% of incident reporting in the UK health system, and in the US its customers include the Veterans Administration, The Cleveland Clinic, Mass General, Duke, Johns Hopkins, and New York-Presbyterian (Regan, 2019). The RL Solutions brochure tells hospitals (2020) to "[u]se your data to prioritize patient advocacy and service excellence initiatives... [for] better patient satisfaction scores and lower readmission rates, which drives better healthcare reimbursement." The software reflects the separation of its "Feedback and Risk modules," by offering "integration... to minimize rework, for example, if a grievance reveals that an incident took place." An incident is a risk management event that could trigger a fine or a lawsuit, while a grievance may remain simply "Feedback." Nancy told us how she uses their RL Solutions software:

I receive on the average of maybe twelve [complaints] a month. There's predetermined categories. There is a dropdown box in this software that I was talking about that does classify, say, if somebody, you know, lost something, lost an item, then that goes under service recovery. Replace item, whatever. If they call angry and they tell us to do something, I will put that in and close it right away. And service recovery and facilitation. So those are your classifications. [What kinds of complaints are common?] Um, treatment by staff. A lot of it is not giving the medication that they want. Length of wait in the Emergency Room is a big one. Patients are not wanting to pay their deductible. Wait time and treatment by staff is our two largest complaints.

FQHC managers were indeed much more aware of their patients' vulnerable statuses, such as being low income or trans. However, they

were not any more likely to have ways of recognizing civil rights violations set up in their work routines. They also use similar grievance tracking software. June, who handles complaints at a FQHC, describes the categories they use for classifying complaints:

Was this about a prescription? Was it about an office visit? Is it about the site? Was it about communication? So themes kind of fall in those bigger categories. Did they have to wait too long? Were they treated rudely? So we have lots of themes [Are there any themes that are specific to Section 1557?]. No.

Jan, another FQHC grievance handler, gave very specific details about their complaint categories, also differentiating between “patient concerns, like let’s say somebody slipped in the parking lot” and “clinical concerns”:

[Is there any way you could tell me the categories?] Let’s see ... [reading from software interface] For just general patient concerns, it can be categories under Access to appointment. Billing. Confidentiality. Clinical care. Delay in referral. Facility. Medical records. Interpreter. Lab diagnostic results. Narcotics. No return phone call. Parking lot. Prescription. Staff discourteous or disrespectful. Telephone system. And the last one is wait time. I believe it’s just one general generic policy [to address all these categories].

If a person seeking care were to complain about discrimination in the form of harassment from a care provider, for example, it would become “staff discourteous” and be routed to the staff the part of the hospital where the incident occurred.

The selection of a category that the problem “is about” is content-free and seemingly neutral. If one is waiting longer, not getting return phone calls, not getting appointment spots, and so on because of one’s identity, then that critical detail would be buried in the notes or fall away entirely. We never heard of an “about” category called racism, harassment, mis-gendering, or anything similar. As we discovered when we probed for the intersection of patient identity data and problem reporting, there is a strong norm against particularizing patient care and satisfaction problems by civil rights identity category. Jessica, a patient relations specialist at a Catholic hospital in Michigan, explains how discrimination complaints fit into the tracking software for problems of all kinds:

And then so within MIDAS [their tracking software], there are some general categories that things are sort of classified into. So if it’s a staff complaint you would mark it as staff, and then you could further delineate beyond that what specifically it is. Is it, you know, a communication issue? Is it a discharge issue? Is it a wait time issue? A lot of those different categories. We do track like a discrimination complaint, or an ADA complaint or, there’s also those buckets of lost belongings complaint. You know, food complaints, facility complaints, or is it a complaint made against a person, so a staff member, a clinician, or a physician.

Jessica moves so quickly from “discrimination” to “lost belongings” in her list that it is clear that discrimination is one of many problems in a jumble.

Sorting this jumble is important because it shows where in the organization the problems arise. Distinguishing types of problems (civil rights versus lost belongings, perhaps) is less important than distinguishing places. We asked Karen about how she analyzes patient satisfaction survey data. She replied:

Multiple, multiple ways. We create a score card by unit, by hospital, by system, so that we can see at the most granular level what is going on, what our patients’ voice is telling us. We aggregate the comments. We are able to, also through pivot tables, look at point of entry. Did the patient come through the ER, what was that score? We

can filter it by just CMS [patient satisfaction] surveys. We can filter it by day of the week, time of the day, shift, et cetera. We use it based on DRGs [diagnosis-related groups] to look at patient satisfaction for maybe our ortho population, neuro population, by provider. There’s a number of ways that we, you know, slice and dice the data.

The patients are unknowing pointers to spots of poor care, and they matter when there are enough of their complaints (lumped together) to focus in on problematic sites for healthcare administrators.

4. Slicing and dicing patient satisfaction survey data: “irrelevant” identities and “moving those scores”

The [Affordable Care Act \(ACA\), 2010](#) increased pressure on health-care organizations to pay attention to patient satisfaction by tying patient satisfaction survey outcomes to Medicare reimbursements under its Hospital Value-Based Purchasing Program ([Kahn and Salzberg, 2019](#); [Mehta, 2015](#)). So while hospitals still compete for patients whose private insurance pays well, they now also have to worry about avoiding cuts to public payments. The 32-item survey is the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS, pronounced “H-caps”), and CMS publishes the results on a website called “Hospital Compare” ([Centers for Medicare and Medicaid Services n.d.](#)). Providers use an outside vendor such as Press Ganey for these surveys ([Staff, 2016](#)). When the interviewer asked Peggy about using patient scores to pinpoint possible dissatisfaction in protected civil rights categories such as sex, she pivoted immediately back to the need for high scores to avoid financial penalties:

[On this general patient satisfaction survey, have you ever calculated, like, men rate patient care more highly than women, or things like that?] You know, we can. We have the ability to do that. Right now we go by our top box score, which is the, you know, always or the nines or the tens. Anything less than those do not qualify and Medicare takes back money from us at the end of the year. Every hospital, that’s what they do. So they drive organizations to provide the most best customer service and care, because if you don’t, then they’re going to be taking back, you know, money.

Grievance handlers care about certain markers of good care that are internally meaningful to the organization, but would not be likely to correspond to a patient’s description of a civil rights violation. Jamie described breaking up scoring by patient race or sex as “irrelevant” because “as a whole, I need to move those scores.” She elaborated:

[I was just wondering if you guys ever analyze scores on the basis of sex or race or any of these identity categories.] You can run the report and base it off of race, sex, gender. I don’t believe there’s any like transgender checkbox. But as far as me running a report like that? No, because it wouldn’t be, um, statistically significant for the results in the reports I’m trying to run. It’s not what I’m looking for. I’m looking for data about how to improve our scores in different domains such as hospital responsiveness, nursing communication, and medication communication. So to break it up by gender or break it up by orientation, it would be irrelevant, because as a whole, I need to move these scores.

We also asked Erica, an African American working at a Catholic hospital in Michigan, if she tracks patient complaints by race, gender, or age. She replied that she usually does not look at it at all because she does not feel that it’s important. “It’s overall care that we provide for the patient, the individual. To me it doesn’t matter if it’s a woman, male, child, grandmother. It’s a patient who came in for help, and it’s our job to do that for them,” she says.

We saw in the first story that there is no drop-down for problems labelled civil rights or discrimination problems in the technobureaucratic practices of patient complaint handling, and that the focus is on places that produce a jumble of problems, not distinctions

between types of problems that include civil rights violations and harassment alongside lost dentures. Here we see a second story, about how the homogenized individualization of the best care for every patient erases attention to groups who experience more healthcare discrimination. Every patient is the same in the sense that they all need the best care, and thus differentiating by identity categories (are trans patients treated worse?) does not make sense.

Most people denied receiving complaints from transgender people, though there were some. When someone complained in a way that seemed to mirror the grievance handler's own approach in minimizing conflict, these interactions could be much more valued. Transgender people who presented as authentic selves on journeys rather than assertive rights-claimers were able to put the grievance handler at ease. This work is an example of patient impression management (Pryma, 2017; Kimport et al., 2016; Chiarello, 2019) and diffuses what Shuster (2017) calls "discursive aggression," constructing the grievance process as positive rather than antagonistic. June, a compliance officer at a FQHC in Michigan, described a positive interaction with a transgender patient who "never talked about feeling discriminated against or disrespected," but instead "just said, it would be more comfortable for me if my case manager would refer to me by the name that I prefer." She explained that the patient had been "very wonderful in this situation in explaining why this was so important to them, and where they were in their journey." Describing it as "actually a really good situation," June concludes that "when people have complaints, it doesn't have to be a situation where you become adversaries."

5. Enacting rights in electronic medical records and organ inventories

Even though Section 1557 requirements to have a grievance handler and a complaint process were new under the 2016 regulations, we frequently heard things like "Oh, we have already been doing that" and "It didn't require anything new" at healthcare sites that did not sound to us like they had taken any new steps to enact transgender health care rights. As we explain elsewhere (Kirkland and Hyman, 2021), these grievance handlers simply considered their compliance with Medicare and Medicaid requirements for a complaint process to be the same as civil rights compliance. Under minimal regulatory compliance—putting up some signage, designating a coordinator, and having a grievance policy—that is indeed all that would seem necessary.

The alternative is "beyond compliance," (Gunningham et al., 2004) which takes seriously what is needed to treat people in a manner consistent with their gender identity. This example of beyond compliance is active, not passively responding to grievances, but nonetheless enacted through the material and technological structures and categories of the healthcare organization. Beyond compliant organizations formed committees to track every appearance of gender identity categorization throughout their system: the records, the specimen labels, the ID bracelets, the in-room white boards, the registration process, the bills, the insurance claims. The mobilized employees were driven by ideals of good patient care for trans people that is clinically well grounded in correct information about bodies and identities. The paradigmatic institutional entrepreneur we encountered was a young, cisgender woman clinician working in a larger hospital hoping to earn recognition for its transgender care. These entrepreneurs did not talk in terms of rights, either. They framed transgender recognition as patient safety and good care, enacted through information technologies, interpersonal communication, and clinical interactions.

Working with technologies to achieve proper transgender patient recognition was both a result and a driver of mobilization. Jean Marie, who runs a small rural FQHC that was required to implement SOGI documentation as a condition of their funding from HRSA, explains how that data collection requirement touched off an education process throughout her organization:

Once you start [documenting SOGI], then it opens up the door to other things, the discrimination, the healthcare aspects of it, that kind of thing. Our front office supervisor has been to some conferences and seminars on how to collect that data. Our providers have been involved in some education as far as treatment and you know, transgender and that kind of thing, stuff that was put on by the LGBT community.

Actualizing transgender patient rights took the form of organizational advocacy to change the objects that materialize gender identity. Dr. Byrd, a medical resident who joined her large hospital's 1557 implementation committee, related how hard it was to change the name on the precious real estate of the lab specimen stickers:

We have these stickers that print out that get pasted on specimens, on people's labs. Some medical assistants used to call people from the waiting room, and until about a month ago, those only had legal name on them. And it was a whole long bureaucracy. It's a tiny space on a sticker and various groups want to claim that space to put certain markers on there that help their particular group. But [the 1557 committee] advocated and finally got "preferred name" on those stickers.

Dr. Byrd described going around to different groups in the hospital, bringing problems about gender misrecognition to their attention. "Security is a really good example where I was like, I don't know who I'm going to run into in Security," she recalled.

And we identified some major problems, like currently if a visitor checks in, they have to provide a government issued ID and that ID gets scanned. And then whatever name is on that ID populated onto a badge that that person has to wear. And there's no way for the Security personnel to change the name that appears on the badge. So if a trans person, for example, has an ID that does not match the name that they use, and maybe their appearance, they could potentially be outed by this badge that they're supposed to wear. When I pointed [this] out to Security, they identified it as a huge problem that needed to be fixed immediately, and called the software company and are in the process of making a change, so that last name only will appear, because we had this conversation.

Getting transgender recognition right in EMR was the biggest problem for organizations. Some hospitals had the resources to create their own gender identity forms in EMR as the early requirements were enacted, but many relied on the corporate providers to update their software. Dave is a transman who works on SOGI implementation at a major national EMR company. He has been the go-to person for clients to call when either "the organization just had their first out trans patient" and "something goes wrong" or when "there is a trans employee or some employee that, you know, kind of is an ally of the trans community and they are pushing their organization to do something." He described how people in hospitals pushed for SOGI recognition in their EMR:

It's an analyst who works with the software or, you know, not someone very high up on the food chain kind of pushing [better SOGI documentation], telling their organization, "You know, this is patient safety. We're not treating these patients correctly and we need to do so." Or they might be nurses. Some of the organizations, they have like an LGBT employee group, and that group will get together and discuss, "Hey, our software isn't really that great for LGBT patients," and they'll approach their executives and say, "We've been talking about this. We know we can do more. Can we get started on that process?"

Before 2018, he explained, all institutional customers had access to a smart form that would collect SOGI information and an organ inventory. But as of their 2018 product release, SOGI and the organ inventory are opt-out, that is, baked into the default program that every client gets.

“We did that deliberately,” Dave says, “because this is a patient safety issue.”

Susan is part of the gender identity working group at her large hospital, working in the IT department on adaptations to their electronic medical records system for SOGI. Before the new build that Dave worked to develop was available, she helped design her hospital’s form and still works on modifying it. She explained how gender identity options look in their system:

[So on the gender identity form, is that a write in or is it a drop down?] I could show you. It is a drop down. See, we got the list of gender identities. If you’re not one of these gender identities, you choose “Other,” then you need to document what did the patient say their gender identity is. And same thing with pronouns. We’ve got some people, their pronouns are zi, like Z-I. Gosh, I don’t know what that is. We don’t have that on ours because it’s not very common. Non-binary was one that we added after a while, because we did have more than a handful of patients that indicated that’s what they were. Like every six months, I’ll run the report and see is there’s something that’s showing up in “Other” that shows up frequently, then maybe we should add it as to one of our choices.

Tellingly, Susan’s IT work on the gender identity recognition interpretation of Section 1557 does not interact with the patient-driven complaint side or the satisfaction surveys. “[When you guys do HCAHP surveys, or if they’re in your event reporting system, like if there are complaints and grievance filed, do those interface with the medical records?] I don’t really know what HCAHPs is. [The patient experience

surveys.] They’re not in here at all. This is just really medical information. Those have their own separate databases.”

Accurate SOGI recognition is part of determining gender that everyone who uses EMR to interact with and name a patient would need. Clinicians wanted more, though, because for them proper care involves both the story of proper interpersonal gender determination but also caring the for body parts one has regardless of their role in lived gender identity. We interviewed several trans-affirming doctors and other clinicians who were active in their hospital’s 1557 committees, and they explained how EMR and organ inventories work to affirm trans rights and to provide the best care. Lisa, a doctor at a beyond compliant urban hospital, explains: “At the end of the day who you are or your gender identity is not always going to line up with your anatomy. What I really care about is what is the anatomy that you have. If you’re a guy but you still have a cervix, we need to do a PAP smear.” Fig. 1 shows a screen shot of a SOGI form and organ inventory that we gathered from an interview subject.

6. Conclusion: how socio-technical systems enable conflicting stories

The people in healthcare organizations whose job it is to recognize and address civil rights violations against patients—the Section 1557 grievance handlers—are poorly equipped to do it well. They are passive recorders of what could be transgender discrimination cloaked in other terms like “rude staff” or “miscommunication.” A few interviewees mentioned having a Section 1557 drop-down menu option or simply routing anything that sounded like it implicated an identity category to

Gender Identity and Sexual Orientation Form

Gender Identity

Patient's gender identity (Please receive patient's permission before documenting): Woman or Girl, Man or Boy, Trans Woman, Trans Man, Other, Choose not to disclose, Genderqueer, Two-Spirit, Nonbinary

Patient's sex assigned at birth: Female, Male, Unknown, Not recorded on birth certificate, Choose not to disclose, Uncertain, Intersex

Patient's pronouns (Please receive patient's permission before documenting): she/her/hers, he/him/his, they/them/theirs, patient's name, decline to answer, other

Steps patient has taken to transition, if any: presentation aligned with gender identity, preferred name aligned with gender identity, legal name aligned with gender identity, legal sex aligned with gender identity, medical or surgical interventions

Patient's future plans to transition, if any: [Rich text editor]

Hormone Therapy: Cross-sex hormone therapy, current user, Cross-sex hormone therapy, past user

Organ Inventory

Organs the patient currently has: breasts, cervix, ovaries, uterus, vagina, penis, prostate, testes

Organs present at birth or expected at birth to develop: same as current organs

Organs hormonally enhanced or developed: breasts

Organs surgically enhanced or constructed: breasts, vagina, penis

Therapist Information

Therapist name: [Text input]

Therapist phone number: [Text input]

Sexuality

Patient's sexual orientation (Please receive patient's permission before documenting): Lesbian or Gay, Straight (not lesbian or gay), Bisexual, Something else, Don't know, Choose not to disclose, Pansexual, Asexual

Fig. 1. Example of sexual orientation and gender identity (SOGI) and organ inventory in EMR.

their diversity officer. Overall, we found that across contexts, grievance handlers use very similar work tools in similar ways. These tools are not designed to obfuscate civil rights claims; they are designed to flag and push along ordinary problems while alerting administrators to legal risk. But they create stories of non-problems through lack of a place in the dropdown menu as well as through the homogenizing story of the best care for every patient regardless of identity. This refusal to consider identity traits as meaningful (let alone racism and misogyny awareness) is an enactment of so-called color blindness, in which doing justice to someone is supposedly accomplished by ignoring their salient identity traits. Under this view, every patient is equally special but none of them are more deserving of good care than any other.

Additionally, the division between “incidents” that comprise real risks and “feedback” that endangers patient survey scores forces an awkward division between poor treatment or harassment and the real health damage that can occur, perhaps later on or because the person does not return to care. It is focused on what regulations make important to hospitals, but it does not reflect a coherent view of how discrimination might harm people’s health. The hope was that Section 1557 would address health disparities, under the assumption that certain groups were receiving worse care or being mistreated and that a rights-based remedy could help undo that. I have shown that some commonplace forms of rights denialism that have been well documented in other contexts have unique appearances in healthcare. Rights denialism combines with the dynamics of color blind racism (Bonilla-Silva, 2006), encoded and reproduced through the socio-technical systems of problem management in hospitals.

The organ inventory is importantly different. It is an example of how taking a person apart and seeing them as dissembled or out of alignment with their lived gender is not necessarily an undignified view of personhood (though it often is) (Singh and Moore, 2020). By contrast, grievance handlers often spoke of treating “the whole person,” which they meant to be dignifying but also hewed closely to denying that minority identity might explain poor treatment. Grievance records and satisfaction surveys did not track trans experiences well at all, while EMR entries recognize both the current gender identity and the organs that may fail to match it. These records are an example of Brennan and Suchman’s consistent technology and also a boundary object (Star and Griesemer, 1989), easing use of these conflicting ways of doing gender recognition for different kinds of medical workers, from the patient relations staff to the physicians to the registration staff. The most knowledgeable and trans-affirming providers used the organ inventory in the EMR to flip the story of proper recognition from what it would be at the registration desk, for example. The frontline staff person needs to determine gender socially and affirm the patient’s “preferred name,” while the care provider needs to do that, too, but also to see past the person’s gender identity to their organs linked to sex at birth. Because these technologies are consistent with pre-existing organizational priorities, the privileged set of stories about transgender lives in healthcare conflict with each other, even down to whether tracking identity even matters. This multifarious uptake means that in its socio-technical implementation, the transgender inclusive Section 1557 has not been powerful enough to set its own terms.

Credit author statement

This is a sole authored piece. I am the originator of the concept, the grant PI, the supervisor of all my research assistants, and the sole writer of the text of the article.

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