Arguments for Enabling Patient Feedback Mechanisms in EHR and Health Data

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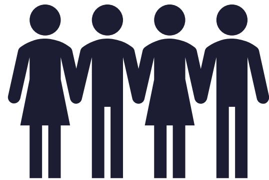
Infoway SGWG, 3/25/2025

UNDERSTANDING THE EXPERIENCE OF HEALTH CARE FOR TRANS AND GENDER DIVERSE POPULATIONS



Current estimates: 1–2 million persons in the US

Gender affirming care has broad acceptance in US medical procedures and insurance provision

Improving the quality of health data for trans + populations has been considered essential for addressing barriers to care

MY BACKGROUND

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ORIGINAL PAPER

The provenance of trans/gender: on the subject's willful disappearance from the record

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Abstract
In recent years, health and government information systems have made gender variance more visible and countable in the records. However, being counted has created novel forms of vulnerability for transgender and gender-diverse populations. This paper explores the complexity of records in exposing vulnerabilities of marginalization, illustrating how recordkeeping practices may contribute to erasure and stigma and reproduce systems of social disenfranchisement. The paper introduces the con-

Invisible Bodies:

Representing Gender and Gender Variance in Medical Records and Health Data

by

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Doctor of Philosophy in Information Studies

University of California, Los Angeles, 2018

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Prior to 2010, there was virtually no population-based health data on trans and gender variant populations at the federal, state, or local level in California. This population was completely invisible in health data. This research project took the formation of such an odd silence in the data as the motivation to form a qualitative approach to studying how gender has been encoded in medical records and health data in California. The project focused on identifying which aspects of gender were able to be recorded and what aspects were not able to be represented within the affordances observed in the recordkeeping structures. The

WHY WORRY ABOUT STIGMA IN RECORDS?

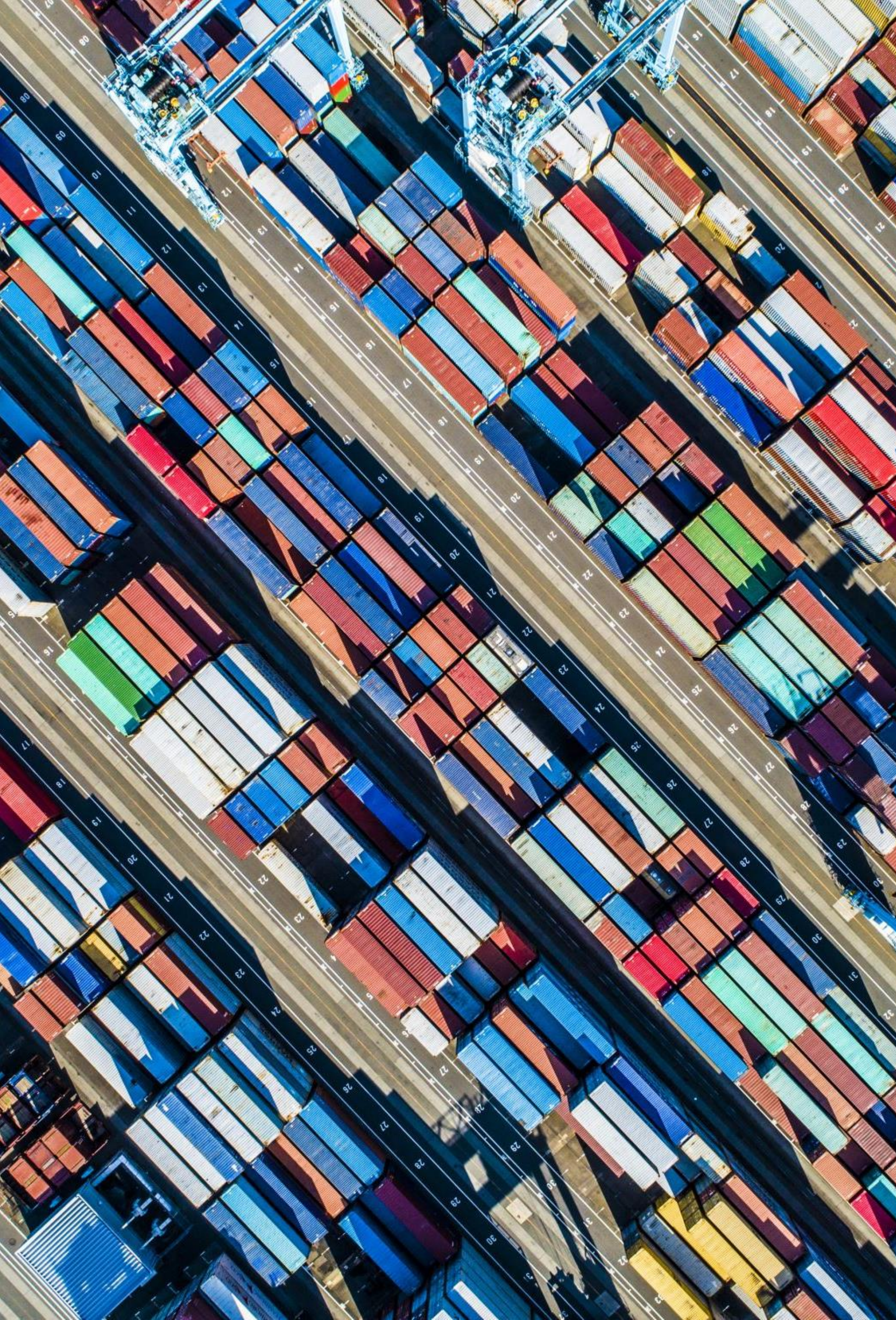
Historically marginalized population

Reports of high rates of denials of care, avoidance of care, and problematic care interactions

Complex barriers to care

Poor health outcomes and higher rates of disease

Health records with a complex history of breakdowns, dysfunction, marginalization and stigma



CONCEPTUALIZING STIGMA

"Stigma involves no so much a set of individuals who can be separated into two piles, the stigmatized and the normal, **as a pervasive two-role social process in which every individual participates in both roles**, at least in some connections and in some phases of life. **The normal and the stigmatized are not persons but rather perspectives.** These are generated in social situations during mixed contacts by virtue of the unrealized norms that are likely to play upon the encounter." (p. 137-8)

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

STIGMA IN MEDICAL RECORDS: PARALLEL REPORTS OF TESTIMONIAL INJUSTICE

- Testimonial Injustice: “that which occurs when a speaker receives an unfair deficit of credibility due to prejudice on the part of the hearer”. (Beach et al 2021)
- Beach et al (2021) found more markers of disbelief in the medical records of Black compared to White patients, suggesting that Black patients may be subject to systematic bias against their credibility. The research refers to this type of bias as a form of testimonial injustice.
- Barcelona et al (2024) tested the premise that concerns expressed by Black patients are more likely to be dismissed or ignored than White patients and found evidence to support their claim

STIGMA AS DISCREDITING/DISCREDITABLE

- Depictions of trans and gender diverse voices as inherently deceptive are a widespread and longstanding finding in media and cultural studies (Currah et al. 2006; Stryker 2008; Beauchamp 2011; Cifor and Rawson 2023).
- Trans and gender diverse populations shoulder the social burden of biases around assumptions of deceit, social pathology and deception (Hale 1998; Sloop 2000; Beauchamp 2009).

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STIGMA IN MEDICAL RECORDS

Alpert et al (2023) interviewed 20 patients and 10 providers about their experiences with reviewing their electronic health records. They concluded:

“various aspects of clinicians’ notes contradict, blame, or stigmatize patients, across multiple axes of oppression” while “certain medical customs set the stage for marginalizing, objectifying, and pathologizing transgender people.” (p. 970).

Alpert, A. B., Mehringer, J. E., Orta, S. J., Redwood, E., Hernandez, T., Rivers, L., Manzano, C., Ruddick, R., Adams, S., & Cerulli, C. (2023). Experiences of transgender people reviewing their electronic health records, a qualitative study. *Journal of General Internal Medicine*, *38*(4), 970–977.

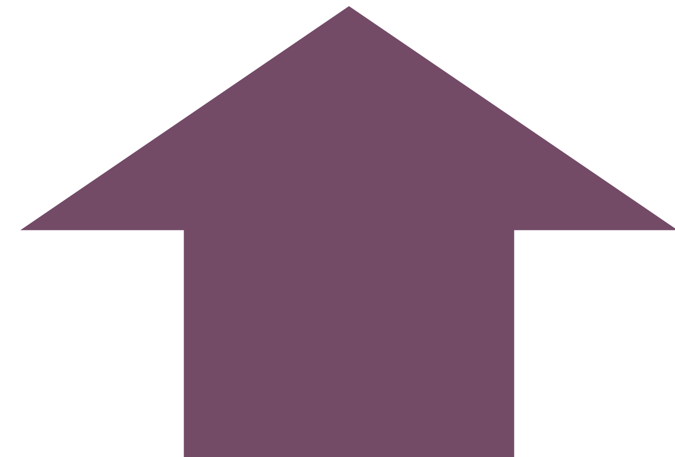
TENSIONS IN THE RECORDS

Records as social artifacts:

- Records are "active sites where social power is negotiated, contested, confirmed"
- recordkeeping practices may create complex vectors of vulnerability and disadvantage for entire populations.

Traditional recordkeeping premises:

- "records are authentic as to procedure and impartial as to creation because they are created as a means for, and as a by-product of, action, and not for the sake of posterity."
- "neutral repositories of facts"



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HISTORY OF DISCRIMINATION

- "What we have learned from 15 months of direct service and close to 500 transgender patients accessing care on a regular basis—is that transgender people face entrenched discrimination and abject denial of care within the health care system" (Sussman et al. 2015).
- "Doctors' offices, hospitals, and other sources of care were often unsafe spaces for study participants. **Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room, or other medical setting** and 2% of the respondents reported being physically attacked in a doctor's office…Unfortunately, **our data shows that doctors' knowledge of a patient's transgender status increases the likelihood of discrimination and abuse**... up to eight percentage points depending on the setting" (Grant et al 2011).

Sussman, R., Vargas, F., Kennedy, A., Dasgupta, S., & Mangia, J. (2015). *Discrimination and Denial of Care: The Unmet Need for Transgender Health Care in South Los Angeles*. St. John's Well Child and Family Center.

Grant, J. M., Mottet, L. A., Tanis, J., Harrison, J., Herman, J. L., & Keisling, M. (2011). *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. National Center for Transgender Equality and National Gay and Lesbian Task Force.

A FRAMEWORK OF ‘HOSTILE RECORDKEEPING’

Existing literatures lack the vocabulary to describe interactions which produce records which devalue and exhibit hostility toward the subject’s voice.

This paper introduces the concept of ‘hostile recordkeeping practices’ to refer to the production of records anchored in a **disregard of harm toward the subject, records based on an assumption of mistrust, and records created with a deliberate indifference of care.** (p. 11)

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JANE FRY: ON THE RECORDS (1974)

- "According to Jane, most of her problems are not internal, but rather are imposed by others… her problems do not stem from the fact that she wants to be a woman, but from the reactions others have to that desire… Her problems are compounded by having to deal with a system of authority and power which systemically prevents her from becoming what she knows she is." (p. 214)
- "Her reluctance to accept their [psychiatrists'] interpretation…is devalued as being a manifestation of her inability to accept the 'cause' of her problems and is considered further evidence of her illness." (p. 216)

Fry, J. (1974). Conclusion: On the Records. In R. Bogdan (Ed.), *Being different: The autobiography of Jane Fry.* (pp. 213–233). Wiley.

Q: WHOSE VOICE IS IN THE RECORD? (2020)

- Nurse:
  - "Personal hygiene & grooming is poor. Showers but does not use soap. … Sleep and appetite are good. Patient told staff that they wanted to use their menstrual cup. (Patient does not have a uterus due to being a trans gender male to female). Unknown what they wanted to use if for."
- Patient:
  - "I had terrible PMS and was bleeding heavily, so I asked about some menstrual supplies from my belongings. Rather than being concerned about a potential source of abdominal bleeding or identifying an error in the record, nurses informed me that I did not have a uterus and that I did not require access to menstrual products. I resorted to stuffing paper towels down my pants with the embarrassment of a thirteen-year-old."

Q: WHOSE VOICE IS IN THE RECORD?

- Nurse 1:
  - "Client very focused on her medications…States she is nausea [sic] and feels sick due to missing her medications. Still waiting for our Pharmacy to deliver some. Med Nurse has spoken with them several times today, awaiting delivery."
- Nurse 2: Educational Needs Assessment
  - Patient's requests for access to [above prescribed] medications is described in the educational needs assessment as a probable learning disability. The nurse does this via labeling the patient's reports of symptoms of illness as "histrionic," "somatic," "beliefs about personal health" and designating them as a "barrier to learning."
- Patient:
  - "I have several undergraduate and graduate degrees, some with honors. I was valedictorian twice."

Q: WHOSE VOICE? (CONT'D)

- Nurse's Summary of Findings:
  - "Patient requires further psychiatric evaluation of psychiatric diagnoses…**that impair the patient's ability to communicate effectively and engage in behaviors within the social norms".**
- Patient's Summary of Findings:
  - "Four days after admission I saw a second psychiatrist who took the time to listen. We discussed my preferred name, pronouns, and he evaluated the presentation of psychiatric symptoms. He did not find evidence of delusions, suicidal ideation or evidence of harming others. He revised the psychiatric diagnosis from psychosis to adjustment disorder, citing stress in my personal life as a contributing factor."

HEALTH INTERACTIONS THROUGH THE LENS OF PARTICIPATIVE RECORDKEEPING

- EHRs are now incorporating Patient Generated Health Data
- Broad recognition that the joint sharing of information between provider and patient is a key element of medical interactions
- The practice of medicine is fundamentally collaborative, both between provider and patient and jointly across health systems
- What 'matters' to the patient is increasingly recognized as a key feature of high-quality care
- Recordkeeping frameworks around 'Rights in the records'

STANDARDS TO PROTECT PATIENTS FROM HARMFUL RECORDS

Enable	Enable collaboration between patient and provider on the management of patient records
Enable	Enable patient control over sharing sensitive data
Allow	Allow patients to flag incorrect information, misinformation, and biased information from their medical records for review and redaction
Allow	Allow patients to give feedback on the records created about them
Allow	Allow patients to indicate if records are non-representative of their condition
Allow	Allow patients to build trust and credibility with their providers through collaboration on their records