TrueLife Health — Perspectives · Humanistic Charting

The Inequitable Distribution of Being Seen

Why invisibility is a health equity crisis — and what our study found

When ninety-five percent of patients report that their healthcare providers do not see them as they see themselves, we are not facing a communication problem. We are facing an equity crisis: the inequitable distribution of being seen as human within healthcare systems. The electronic health record — designed to standardize and improve care — has paradoxically become a barrier between patients and providers, reducing complex human beings to diagnostic codes and problem lists. And like every burden healthcare distributes, this one is not distributed evenly.

What thirty-eight people told us

We interviewed thirty-eight patients across seven facilities of New York City Health + Hospitals and asked two questions: how do you see yourself — and is that who your providers see? Thirty-six said no. They did not describe rude clinicians or clinical errors. They described a structural experience of being pre-read: encountered through their labels before they could be encountered as themselves. A 72-year-old physician — herself a doctor — told us: “It wouldn’t matter what my accomplishments were. I would be a Black woman to be disdained and disrespected and talked down to.” A jazz pianist living with bipolar disorder: “Once they know my diagnosis, my personhood falls off a bit.” A mother hospitalized with pancreatitis distilled everything the system fails to ask into six words: “Please take care of me. Think of my children.”

Why this is equity, not etiquette

Being seen is not a courtesy layered on top of care; it is an input to care. When patient identity is reduced to a record abstraction, trust erodes, communication falters, adherence declines, and outcomes suffer. For patients carrying stigmatized diagnoses — substance use disorder, sickle cell disease, serious mental illness — the effect amplifies: stereotypes embedded in prior documentation shape future encounters before a word is exchanged. The chart becomes a reputation, and the reputation arrives in the room first.

The equity literature has begun to quantify what patients have long felt: our measurement frameworks can identify *who* experiences disparate outcomes, but they lack mechanisms to understand *why* — the lived experiences and contextual factors that drive disparity. Single-axis interventions fail because disadvantages compound across the constellation of characteristics that make up a person. Which is precisely the point: the unit of equity is the whole person, and the system has no instrument for whole persons.

If healthcare equity means ensuring all patients have the opportunity to achieve their best health, then it must begin with ensuring all patients have the opportunity to be seen as fully human. The systematic

invisibility our participants described is a foundational form of inequity — one that underlies and amplifies every other disparity. Until it is addressed, other equity interventions will remain incomplete: precision poured into a system that has already decided who it is treating.

The correctable failure

The hopeful finding is that this is an *architectural* failure, not a human one — and architecture can be rebuilt. When the Humanistic Charting instrument put patients' self-descriptions in front of clinicians — one page, thirty seconds to read — the published pilot showed every measured care-experience metric significantly improving, with the largest gain exactly where the equity failure lives: patients' rating of "my clinician knew important information about my life" rose from 3.3 to 4.7 of 5. Clinicians gave the tool a Net Promoter Score of 83. Being seen, it turns out, is deliverable — collectible, chartable, and reproducible — once someone builds the place in the record where a person can exist.
That is the claim beneath all of this work: visibility is not a virtue we exhort clinicians toward. It is infrastructure — and its absence has been falling, invisibly, on the same people everything else falls on.

Drawn from the Humanistic Charting qualitative study (Montgomery, Landon, Wei — NYC Health + Hospitals) and the published pilot (JACEP Open, 2025). Part of TrueLife Health.