Catchment Area Patient and Community Perspectives on Collecting and Sharing Intersectional Identity Data Across Health Information Systems

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1. Background
To achieve health equity, health systems, including cancer hospitals and care networks, are collecting more granular data around social and structural drivers of health. Health systems have revisited their Race, Ethnicity, and Language (REL) data collection practices to ensure evidenced-based collection. They have also sought to collect Sexual Orientation and Gender Identity (SOGI) data, since studies have consistently demonstrated poor health among sexual and gender minority communities. We used community- and patient-centered research approaches to investigate collection and use of these data, with a focus on helping health systems translate research findings into health equity practice.

2. Goals
Our goals were to understand community and patient perspectives on collection and use of their race, ethnicity, and SOGI data. The catchment area for our cancer center and affiliated cancer hospital is the state of Connecticut.

3. Solutions and Methods
Synergizing across research efforts, we analyzed and triangulated data from multiple sources to better understand community and patient perspectives around collection and use of data.
1. Community Perspective
    a. Using the 2022 DataHaven Community Wellbeing Survey data of 1,034 randomly selected adult Connecticut residents, we examined factors associated with comfort with disclosing and automatically sharing REL and SOGI data across health care settings. We used unadjusted and adjusted logistic regression models to examine associations between various factors and comfort with disclosing and sharing
2. Patient Perspective
    a. In 2021, we interviewed 23 patients to understand their perspectives on quality of care and the collection and use of REL data
    b. In 2024, we administered a MyChart survey to examine perspectives on the collection and use of SOGI data with health care systems

4. Outcomes

Source	REL Data	SOGI Data
Catchment Area	• 88% comfortable disclosing at a hospital • Hispanic/Latino people are least comfortable disclosing • 82% comfortable sharing automatically with other health providers • Black/African American and AI/AN people less comfortable sharing automatically • Trust in clinician associated with comfort	• 96% comfortable disclosing at a hospital • Hispanic/Latino, Black, and AI/AN people are less comfortable disclosing • 78% comfortable sharing automatically with other health providers • Trust in clinician associated with comfort
Patient Views	• "You should have the ability to [add personal REL] ...on MyChart. '...What do you identify as?' I guess that would be the best way to give people maximum control and not feeling uncomfortable with the provider assuming or having to disclose something to them that you don't want to disclose in person"	• "There have been multiple, high-profile data breaches affecting patient information. It makes no sense to pretend that my medical data will ever be fully confidential or anonymous" • "Not all [providers] are accepting of LGBTQ+" • "Sexual and gender identity should be private...only for those that need to know"

5. Lessons Learned and Future Directions

Patients and communities view the collection and use of REL and SOGI data differently. The majority of residents are comfortable sharing REL and SOGI data with their hospital but are concerned about automatic sharing of these data to other health systems, lack of control over these data, and potential misuse of data.