Attitudes Regarding Automatic Sharing of Race, Ethnicity, and Language Data Between Healthcare Settings

Noah Brazer, Baylah Tessier-Sherman, Deron Galusha, Sakinah C Suttiratana, Corrine Liu, Katherine K Kim, Mark Abraham, Marcella Nunez-Smith, Karen H Wang

Submitted to: Interactive Journal of Medical Research
on: October 07, 2024

Table of Contents

Attitudes Regarding Automatic Sharing of Race, Ethnicity, and Language Data Between Healthcare Settings

Noah Brazer[1]; Baylah Tessier-Sherman[1]; Deron Galusha[1]; Sakinah C Suttiratana[1]; Corrine Liu[1]; Katherine K Kim[2]; Mark Abraham[3]; Marcella Nunez-Smith[1]; Karen H Wang[1]

[1]Yale School of Medicine New Haven US
[2]University of California Davis School of Medicine Sacramento US
[3]DataHaven New Haven US

Corresponding Author:
Karen H Wang
Yale School of Medicine
333 Cedar Street
New Haven
US

Abstract

Background: Little is known regarding patient attitudes toward automatic sharing of race, ethnicity, and language (REL) data in healthcare settings despite the universal practice of data sharing across healthcare institutions and providers.

Objective: Assess public comfort with disclosing and automatically sharing REL data in healthcare settings.

Methods: Using the 2022 DataHaven Community Wellbeing Survey from 1,034 adult Connecticut residents, we examined factors associated with public comfort with disclosing and automatically sharing REL data across healthcare settings. We generated unadjusted and adjusted logistic models to examine associations between factors and responses to the data-sharing questions.

Results: Hispanic/Latino respondents were less willing to disclose REL data compared to White respondents ($p<0.001$). Individuals who sometimes trust healthcare providers ($p=0.019$) or rarely/never ($p=0.040$) were less willing to disclose REL data than those who almost always. African American/Black ($p=0.004$) and American Indian/Alaska Native ($p<0.001$) individuals were less likely to share REL data automatically than White individuals. Those with poor/fair self-rated health (SRH) versus very good/excellent were less likely to automatically share REL data ($p=0.010$). Individuals with less trust in their healthcare providers were less likely to automatically share REL data.

Conclusions: Racial and ethnic identity, SRH, and trust in healthcare providers affect willingness to share REL information with providers and other health systems.

(JMIR Preprints 07/10/2024:67288)
DOI: https://doi.org/10.2196/preprints.67288

Original Manuscript

Title

Attitudes Regarding Automatic Sharing of Race, Ethnicity, and Language Data Between Healthcare Settings

Noah Brazer[1], Baylah Tessier-Sherman[1], Deron Galusha[1], Sakinah C. Suttiratana[1], Corrine Liu[1], Katherine K. Kim[2], Mark Abraham[3], Marcella Nunez-Smith[1], Karen H. Wang[1]

1. Equity Research and Innovation Center, Yale School of Medicine, New Haven, CT 06510
2. University of California Davis School of Medicine, Sacramento, CA 95817
3. DataHaven, New Haven, CT 06511

Abstract

Background: Little is known regarding patient attitudes toward automatic sharing of race, ethnicity, and language (REL) data in healthcare settings despite the universal practice of data sharing across healthcare institutions and providers.

Objectives: Assess public comfort with disclosing and automatically sharing REL data in healthcare settings.

Methods: Using the 2022 DataHaven Community Wellbeing Survey from 1,034 adult Connecticut residents, we examined factors associated with public comfort with disclosing and automatically sharing REL data across healthcare settings. We generated unadjusted and adjusted logistic models to examine associations between factors and responses to the data-sharing questions.

Results: Hispanic/Latino respondents were less willing to disclose REL data compared to White respondents ($p<0.001$). Individuals who sometimes trust healthcare providers ($p=0.019$) or rarely/never ($p=0.040$) were less willing to disclose REL data than those who almost always. African American/Black ($p=0.004$) and American Indian/Alaska Native ($p<0.001$) individuals were less likely to share REL data automatically than White individuals. Those with poor/fair self-rated health (SRH) versus very good/excellent were less likely to automatically share REL data ($p=0.010$).

Individuals with less trust in their healthcare providers were less likely to automatically share REL data.

Conclusions: Racial and ethnic identity, SRH, and trust in healthcare providers affect willingness to share REL information with providers and other health systems.

Introduction

Patient data collection pertaining to race, ethnicity, and language (REL) was first mandated in the U.S. as part of the Civil Rights Act of 1964 as a means to document race-based discrimination in healthcare settings and drive institutional and social change.[1] This groundbreaking legislative change was one of the first steps to improve healthcare disparities among racially and ethnically minoritized people, who face marginalization because of systematic oppression. In recent years, REL data collection has become digitized following the passing of the Health Information and Technology for Economic and Clinical Health Act (HITECH) in 2009, which used monetary incentives to encourage the use of electronic health record (EHR) systems.[2] Despite being codified as a federal mandate, REL data collection for patients is not always implemented systematically in healthcare settings nor always accurate.[3] During the initial height of the COVID-19 pandemic, race and ethnicity data were missing from as many as 56% of reported cases at certain points in time for various public health surveillance data.[4] As a result, healthcare and public health systems, and state government agencies have invested in ensuring improved REL data collection in health.[5,6]

Though race and ethnicity data collection in healthcare systems is the main mechanism to examine quality of care across diverse populations based on racialized identities, there have been long-standing challenges to implementing collection.[7] These challenges include concern among clinical staff with asking patients about their information, training clinical staff on the importance of data collection, and patient understanding of how these data will be used.[7] Beyond individual system-level quality improvement efforts, health systems have been using and sharing this information with other systems for health information exchange across health care settings.[8]

While data sharing across health systems and organizations serves as both a mechanism to support public health and streamline care for patients, it may occur without patients' knowledge and/or explicit consent.[9-11] Several prior studies have specifically examined patients' preferences regarding sharing of health data with other clinical providers, finding that patients prefer to be asked permission before having their data shared electronically outside of emergency contexts and that patients who are unwilling to share their data automatically with other healthcare providers cited concerns about potential breaches in security.[12-14] Although these studies focused on the automatic sharing of general health data, little is known about how patients in the U.S. feel about sharing specific aspects of their medical records, such as REL data, that are embedded in their EHR.[15,16] While one study revealed no significant difference in patient willingness to automatically share general health data to clinical providers based on patients' race and ethnicity identity groups, patient perspectives on REL data sharing based on patient's race and ethnicity was not explored.[17]

This study aims to understand how community members feel about having their REL data collected and automatically shared with healthcare systems and whether there are differences in their preferences based on their racial and ethnic identities.

Methods

Data Source and Sample

This study involved analysis of cross-sectional data from the 2022 DataHaven Community Wellbeing Survey.[18] Survey data were collected by the Siena College Research Institute via phone interviews between August 1 and August 28, 2022. The dataset includes 1,196 respondents randomly selected Connecticut residents aged 18 or older, to inform state-level estimations of resident well-being, equity, and quality of life, as previously described.[18] Respondents represented all 169

Connecticut towns. We followed the STROBE guidelines for a cross-sectional study for reporting.[19]

Measures

Outcome Variables

The outcome variables for this study were two questions that were added to the 2022 DataHaven Community Wellbeing Survey. The first question was: Patients are often asked their race and ethnicity at a hospital or clinic. Are you OK sharing this information at a hospital or clinic? Response options were "Yes" or "No". The second question was: If you were offered the choice to have your race/ethnicity/language information automatically shared electronically with the different places where you receive medical care, how likely would you be to agree to it? This question was adapted from a prior study.[12] Response options fell along a 4-point Likert scale from "Very likely" to "Very unlikely". "Very likely" and "Somewhat likely" were collapsed into one category, while "Somewhat unlikely" and "Very unlikely" were collapsed into one category.

Covariates

The covariates for this study were race and ethnicity, gender, age, primary language, reporting of chronic disease, self-rated health (SRH), trust in healthcare provider, and prior experience with discrimination in healthcare settings. We selected these covariates as prior research suggests they may influence the relationship between a person and their comfort with sharing personal data for either research or healthcare use.[13,20-22] Race categories were African American or Black, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, White, and Other/something else. Ethnicity categories were Hispanic or Latino and not Hispanic or Latino. Asian and Native Hawaiian or Other Pacific Islander were collapsed into one category because of small sample size. Individuals who reported more than one race and/or Hispanic or Latino ethnicity were placed into the category associated with whichever race or ethnicity they chose that has the least representation in Connecticut, based on previous research, to enumerate small populations.[31] Chronic disease information was collected by asking respondents about the following conditions:

high blood pressure or hypertension, diabetes, heart attack, also called myocardial infarction, angina or coronary heart disease, stroke, and asthma. Respondents who indicated they had any of the conditions were grouped into one category. Respondents with “Excellent” or “Very good” SRH were grouped into one category, while those with “Fair” or “Poor” SRH were grouped into one category. Trust in healthcare providers was collected by asking how often the following statement was true: I trust that my healthcare provider is trying to do what is best for me. Response options were “Almost always,” “Sometimes,” “Rarely,” and “Never.” “Rarely” and “Never” were collapsed into one category. Prior experience of discrimination in healthcare settings was collected by asking: When seeking health care, have you ever been treated with less respect or received services that were not as good as what other people get?

For our analytic approach, we first conducted univariate analysis to describe survey participants who had any data available for analysis (n=1,196). We then removed participants who were missing outcome data (n=69) or covariate data (n=93), leaving a final analytic sample of 1,034. We conducted unadjusted and adjusted logistic models to compare demographic characteristics and responses to the data-sharing questions and to determine the independent predictors of our outcomes. We entered covariates with a p-value <0.20 into the multivariable regression models using backward elimination. Correlations between covariates were examined, and no significant collinearity was observed. All analyses were conducted using SAS Version 9.4 (SAS Institute, Cary, NC).

Results

Among the sample of 1,196 adult Connecticut residents aged 18 years or older who were randomly selected to participate in the 2022 DataHaven Community Wellbeing Survey, half of the respondents identified as female (**Table 1**). The majority of residents surveyed were White (68.4%), followed by African American or Black (14.6%), Hispanic or Latino (8.4%), Asian or Native Hawaiian or Other Pacific Islander (Asian/NHOPI) (3.3%), and American Indian or Alaska Native

(AI/AN) (2.2%). This population slightly overrepresented White, African American or Black, NHOPI, and AI/AN groups while underrepresenting Asian and Hispanic or Latino groups relative to the Connecticut population reported in the most recent census.[23] In the cohort, 22.0% of individuals were between the ages of 18 and 39. Only a small percentage of the participants did not speak English as their primary language (5.4%). The majority of respondents reported excellent or very good SRH (53.1%), and more than half reported a chronic disease condition (55.9%). Most participants reported almost always trusting their healthcare provider (78.5%), and the majority did not have a prior experience of discrimination in a healthcare setting (82.8%). Most participants were willing to share race and ethnicity data at a hospital or clinic (88.6%) and were willing to share REL data automatically (82.9%) (**Table 1**).

Unadjusted models suggested that willingness to share race and ethnicity data at a hospital or clinic was associated with a respondent's race/ethnicity, gender, primary language, and how much they trust their healthcare provider (**Table 2**). In the multivariate logistic regression model, Hispanic/ Latino participants were significantly less willing to share their race/ethnicity data compared to White participants (adjusted odds ratio (AOR)=0.034; 95% CI: 0.20, 0.60) (**Table 2**). Female respondents were more willing to share their race and ethnicity data compared to male respondents (AOR=1.59; 95% CI: 1.07, 2.38). Individuals who reported they only sometimes (AOR=0.57; 95% CI: 0.35, 0.91) or rarely/never (AOR=0.41; 95% CI: 0.17, 0.96) trust that their healthcare provider has their best interest in mind were associated with a lower willingness to share race and ethnicity data compared to those who almost always trust their healthcare provider.

In unadjusted models, an individual's willingness to automatically share REL data with various healthcare locations was associated with their race/ethnicity, SRH, and how much they trust their healthcare provider (**Table 3**). In the multivariate logistic regression model, African American/ Black (AOR=0.53; 95% CI: 0.34, 0.81) and AI/AN respondents (AOR=0.21; 95% CI: 0.09, 0.52) were significantly less likely to share their REL data automatically compared to their White counterparts (**Table 3b**). Individuals who reported they only sometimes (AOR=0.50; 95% CI: 0.33, 0.76) or rarely/never (AOR=0.34; 95% CI: 0.16, 0.73) trust that their healthcare provider has their best interest in mind were also significantly less likely to automatically share REL data than those who almost always trust their healthcare provider. Respondents with fair/poor SRH were also significantly less likely to automatically share REL data compared to those with very good or excellent SRH (AOR=0.58; 95% CI: 0.38, 0.88).

Discussion

Principal Results

In general, the large majority of Connecticut respondents are comfortable disclosing their race and ethnicity and having their REL data shared automatically. However, racially and ethnically minoritized individuals are less comfortable disclosing REL information at hospitals and clinics and having their REL data automatically shared with health institutions where they receive care. As compared to White respondents, Hispanic or Latino respondents were the least comfortable with disclosing their REL data, while Black or African American and AI/AN respondents were less likely to grant permission to have their REL data to be automatically shared between medical providers.

Comparison with Prior Work

While previous studies showed no significant difference in respondents' willingness to automatically share general health data between race and ethnicity identity groups,[12] the results of this study add a more nuanced view of specific data elements within the EMR that certain minoritized individuals feel less inclined to share automatically. It is possible that prior studies saw no significant difference in willingness to automatically share general health data because respondents were not explicitly informed about all the sensitive data that comprised their EMR, such as REL data. Additionally, the previous studies were conducted in California which has a substantially different representation of race and ethnicity both in the survey samples and the state population than in the current study in Connecticut, with higher representation of Hispanic or Latino respondents and lower representation of Black or African American respondents. In the U.S., Black, Indigenous, and Latino communities have faced discrimination when accessing healthcare systems leading to poorer health outcomes and healthcare delivery than their White counterparts.[24,25,26] These discriminatory experiences may contribute broadly to less comfort regarding REL data collection and automatic sharing, although we did not see a significant association between individual reports of discrimination in healthcare and comfort with REL disclosure and automatic sharing.[27]

The finding that lower SRH was independently associated with a decreased willingness to share REL data automatically warrants further examination. Past studies have demonstrated a relationship between race and ethnicity and SHR.[28-30] Furthermore, studies investigating the relationship between SHR and likelihood to share data with physicians have shown that those with lower SRH are more likely to share information with their physician.[31,32] Given the findings of this study, it may be possible that individuals with lower SRH may be more comfortable with sharing general health data specifically for treatment purposes but draw the line at sharing REL data. Follow-up studies could further explore relationships between one's social identities, health status, and sharing of information.

Our finding that trust in healthcare providers is highly associated with comfort with sharing is consistent with past studies that have established a link between patient trust in their provider and willingness to disclose or share health information.[20,33] Additionally, a previous study found differences in health information seeking behavior of individuals by race and ethnicity, with Black and Hispanic individuals more trusting of health information from media, charitable organizations, and religious organizations compared to White individuals and Hispanic individuals less trusting and willing to seek information from doctors compared to White individuals.[34] The results of our study further highlight the importance of trust between patient and provider and reveal that individuals with decreased levels of trust in their healthcare providers, for whatever reason, may be hesitant to disclose and share any data, whether health-specific or demographic.

Limitations

This study had several limitations. Namely, the number of individuals identifying as AI/AN or NHOPI was very low, which affected the statistical analyses. Given that individuals who identify as AI/AN or NHOPI tend to be minoritized in most areas of the U.S., a larger cohort would be needed to better understand the nuances of comfortability with REL data disclosure and sharing among these communities. Further, the population of Connecticut is not representative of that of the US, and therefore, generalizations made while using these results should be done with caution.

Conclusions

The results of this study have implications for how we operationalize health information exchange across clinical and public health settings in the current discussion of how to most effectively enhance the nationwide health data ecosystem and standardize social and structural drivers of health data.[35] This study suggests that nuances exist in how people think about race and ethnicity data and data sharing. More work is needed to gauge whether patients have an understanding of what components comprise their health record, which of these components may be shared, and with whom the data are being shared. People’s experiences with healthcare systems likely influence their comfort with sharing sensitive data and their comfort with that data being shared automatically with other health settings.

Table 1: Survey Participant Characteristics and Responses (n=1,196)

	n	%
Race/Ethnicity		
African American/Black	175	14.63
American Indian/Alaska Native	26	2.17
Asian/Native Hawaiian or Other Pacific Islander	40	3.34
White	818	68.39
Hispanic/Latino	101	8.44
Missing	36	3.01
Age (years)		

18-39	264	22.07
18-39	264	22.07
40-64	428	35.79
65+	455	38.04
Missing	49	4.10
Gender		
Female	602	50.33
Male	591	49.41
Other	3	0.25
Trust healthcare provider		
Almost always	939	78.51
Sometimes	194	16.22
Rarely/Never	42	3.52
Missing	21	1.76
Self-rated overall health		
Excellent/Very good	635	53.09
Good	338	28.26
Fair/Poor	219	18.31
Missing	4	0.33
English as primary language?		
Yes	1122	93.81
No	64	5.35
Missing	10	0.84
Any chronic disease reported?		
Yes	668	55.85
No	519	43.39
Missing	9	0.75
Prior experience with discrimination		
Yes	170	14.21
No	990	82.78
Don’t know	29	2.42
Missing	7	0.59
Okay sharing race/ethnicity?		
Yes	945	88.57
No	122	11.43
Likelihood to automatically share REL data		
Very likely/Somewhat likely	885	82.94
Somewhat unlikely/Very unlikely	182	17.06

Table 2: Association between Individual Characteristics and Comfort with Disclosing Race and Ethnicity at Hospitals or Clinics

Demographic Characteristic	Unadjusted		Multivariable (adjusted)	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Race/Ethnicity				
White	Reference		Reference	
African American/Black	0.62 (0.36,1.04)	0.071	0.61 (0.36,1.04)	0.067
American Indian/Alaska Native	0.33 (0.12,0.93)	0.035*	0.40 (0.14,1.15)	0.089

Asian/Native Hawaiian or Other Pacific Islander	0.47 (0.19,1.17)	0.11	0.56 (0.22,1.43)	0.23
Hispanic/Latino	0.32 (0.18,0.56)	<0.001***	0.34 (0.20,0.60)	<0.001***
Age				
18-39 years	Reference		N/A	
40-64 years	0.93 (0.55,1.54)	0.77		
65+ years	0.94 (0.57,1.56)	0.81		
Gender				
Male	Reference		Reference	
Female	1.60 (1.08,2.36)	0.018*	1.59 (1.07,2.38)	0.022*
Trust healthcare provider				
Almost always	Reference			
Sometimes	0.52 (0.33,0.83)	0.006**	0.57 (0.35,0.91)	0.019*
Rarely/Never	0.33 (0.14,0.75)	0.008**	0.41 (0.17,0.96)	0.040*
Self-rated overall health				
Excellent/Very good	Reference		N/A	
Good	0.88 (0.56,1.38)	0.59		
Fair/Poor	0.78 (0.47,1.27)	0.31		
English as primary language				
Yes	Reference		Reference	
No	0.33 (0.18,0.62)	<0.001***	0.57 (0.28,1.18)	0.13
Any chronic diseases reported?				
No	Reference		N/A	
Yes	0.78 (0.53,1.16)	0.22		
Prior experience with discrimination in healthcare?				
No	Reference		N/A	
Yes	1.28 (0.70,2.34)	0.4304		

*, p<0.05; **, p<0.01; ***, p<0.001

Table 3: Association between Individual Characteristics and Willingness to Automatically Share REL Data with Different Healthcare Locations

Demographic Characteristic	Unadjusted		Multivariable (adjusted)	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Race/Ethnicity				
White	Reference		Reference	
African American/Black	0.50 (0.33,0.76)	0.001**	0.53 (0.34,0.81)	0.004**
American Indian/Alaska Native	0.16 (0.07,0.39)	<0.001***	0.21 (0.09,0.52)	<0.001***
Asian/Native Hawaiian or Other Pacific Islander	0.79 (0.32,1.95)	0.61	0.92 (0.36,2.31)	0.86
Hispanic/Latino	0.82 (0.45,1.48)	0.50	0.97 (0.53,1.78)	0.92
Age				
18-39 years	Reference		N/A	
40-64 years	0.70 (0.45,1.09)	0.12		
65+ years	0.80 (0.51,1.26)	0.34		

Gender				
Male	Reference		N/A	
Female	0.95 (0.69,1.32)	0.76		
Trust healthcare provider				
Almost always	Reference			
Sometimes	0.49 (0.33,0.74)	<0.001***	0.50 (0.33,0.76)	0.001**
Rarely/Never	0.24 (0.12,0.50)	<0.001***	0.34 (0.16,0.73)	0.006**
Self-rated overall health				
Excellent/Very good	Reference		Reference	
Good	1.20 (0.79,1.81)	0.001**	1.26 (0.82,1.92)	0.29
Fair/Poor	0.52 (0.35,0.77)	0.39	0.58 (0.38,0.88)	0.010*
English as primary language				
Yes	Reference		N/A	
No	0.94 (0.47,1.90)	0.87		
Any chronic diseases reported?				
No	Reference		N/A	
Yes	1.20 (0.86,1.67)	0.28		
Prior experience with discrimination in healthcare?				
No	Reference		Reference	
Yes	0.68 (0.44,1.06)	0.092	0.99 (0.61,1.60)	0.97

*, p<0.05; **, p<0.01; ***, p<0.001

Acknowledgments

We thank the team at DataHaven for collecting the data and making it available to us.

Conflicts of Interest

We have no conflicts of interest to disclose.

Abbreviations

Race, ethnicity, and language (REL); self-rated health (SRH); Health Information and Technology for Economic and Clinical Health Act (HITECH); electronic health record (EHR); coronavirus disease 2019 (COVID-19); Strengthening the Reporting of Observational Studies in Epidemiology (STROBE); Native Hawaiian or Other Pacific Islander (NHOPI); American Indian or Alaska Native (AI/AN)

Data Availability

The datasets used or analyzed in this study are available from the corresponding author upon reasonable request.

References

1. Title VI of the Civil Rights Act of 1964 (1964).
2. Health Information Technology for Economic and Clinical Health Act. In: Services USDoHaH, editor. 2009.
3. Filice CE, Joynt KE. Examining Race and Ethnicity Information in Medicare Administrative Data. *Med Care*. Dec 2017;55(12):E170-E176. doi:10.1097/Mlr.0000000000000608
4. Jennifer W. Tsai RK, and Emily Laflamme. Death by missing data: Uncollected racial and ethnic pandemic data will drive inequities for decades to come. Accessed April 1, 2024. https://www.statnews.com/2023/01/30/covid-19-missing-data-race-ethnicity-drive-inequities-decades-to-come/
5. Weissman JS, Adler RR, Betancourt J, et al. How Hospitals Are Addressing The Effects Of Racism: A Mixed- Methods Study Of Hospital Equity Officers. *Health Affair*. Oct 2023;42(10):1402-1410. doi:10.1377/hlthaff.2023.0047
6. An Act Equalizing Comprehensive Access to Mental, Behavioral and Physical Health Care in Response to the Pandemic. In: Assembly CG, editor. 2021.
7. Hasnain-Wynia R, Baker DW. Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions. *Health services research*. 2006;41(4p1):1501-1518.
8. Holmgren AJ, Esdar M, Hüsers J, Coutinho-Almeida J. Health Information Exchange: Understanding the Policy Landscape and Future of Data Interoperability. *Yearbook of Medical Informatics*. 2023;32(01):184-194.
9. Kalkman S, van Delden J, Banerjee A, Tyl B, Mostert M, van Thiel G. Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *J Med Ethics*. Jan 2022;48(1):3-13. doi:10.1136/medethics-2019-105651
10. Kim J, Kim H, Bell E, et al. Patient Perspectives About Decisions to Share Medical Data and Biospecimens for Research. *Jama Netw Open*. Aug 2019;2(8)doi:ARTN e199550
10.1001/jamanetworkopen.2019.9550
11. Shapiro JS, Mostashari F, Hripcsak G, Soulakis N, Kuperman G. Using Health Information Exchange to Improve Public Health. *Am J Public Health*. Apr 2011;101(4):616-623. doi:10.2105/Ajph.2008.158980
12. Kim KK, Joseph JG, Ohno-Machado L. Comparison of consumers’ views on electronic data sharing for healthcare and research. *Journal of the American Medical Informatics Association*. 2015;22(4):821-830. doi:10.1093/jamia/ocv014
13. Ancker JS, Edwards AM, Miller MC, Kaushal R. Consumer perceptions of electronic health information exchange. *American journal of preventive medicine*. 2012;43(1):76-80.
14. Medford-Davis LN, Chang L, Rhodes KV. Health information exchange: what do patients want? *Health informatics journal*. 2017;23(4):268-278.
15. Stone MA, Redsell SA, Ling JT, Hay AD. Sharing patient data: competing demands of privacy, trust and research in primary care. *British journal of general practice*. 2005;55(519):783-789.
16. Patil S, Lu H, Saunders CL, Potoglou D, Robinson N. Public preferences for electronic health data storage, access, and sharing - evidence from a pan-European survey. *Journal of the American Medical Informatics Association*. Nov 2016;23(6):1096-1106. doi:10.1093/jamia/ocw012
17. Kim KK, Sankar P, Wilson MD, Haynes SC. Factors affecting willingness to share electronic health data among California consumers. *BMC Medical Ethics*. 2017/04/04 2017;18(1):25.

doi:10.1186/s12910-017-0185-x
18. Institute DaSCR. *DataHaven Community Wellbeing Survey*. 2023. Accessed November 15, 2023. https://www.ctdatahaven.org/reports/datahaven-community-wellbeing-survey
19. Cuschieri S. The STROBE guidelines. *Saudi journal of anaesthesia*. 2019;13(Suppl 1):S31-S34.
20. Iott BE, Campos-Castillo C, Anthony DL. Trust and Privacy: How Patient Trust in Providers is Related to Privacy Behaviors and Attitudes. *AMIA Annu Symp Proc*. 2019;2019:487-493. Accessed 2019. http://europepmc.org/abstract/MED/32308842
https://europepmc.org/articles/PMC7153104
https://europepmc.org/articles/PMC7153104?pdf=render
21. Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M, Wei E. The Invisible Work of Personal Health Information Management Among People With Multiple Chronic Conditions: Qualitative Interview Study Among Patients and Providers. *J Med Internet Res*. Jun 2015;17(6)doi:ARTN e137
10.2196/jmir.4381
22. Thompson HM. Patient Perspectives on Gender Identity Data Collection in Electronic Health Records: An Analysis of Disclosure, Privacy, and Access to Care. *Transgend Health*. 2016;1(1):205-215. doi:10.1089/trgh.2016.0007
23. Bureau USC. QuickFacts: Connecticut. Accessed May 22, 2024, https://www.census.gov/quickfacts/fact/table/CT/
24. Williams DR, Mohammed SA. Discrimination and racial disparities in health: evidence and needed research. *J Behav Med*. Feb 2009;32(1):20-47. doi:10.1007/s10865-008-9185-0
25. Nelson A. Unequal treatment: confronting racial and ethnic disparities in health care. *J Natl Med Assoc*. Aug 2002;94(8):666-8.
26. Quality AfHRa. *National Healthcare Quality and Disparities Report*. Vol. 22-0030. 2022.
27. Haley JM, Dubay L, Garrett B. Implementing Revised Federal Race/Ethnicity Data Standards Won't Sufficiently Address Health Inequities. *Health Affairs Forefront*. 2024;doi:10.1377/forefront.20240828.438120
28. Williams DR, Mohammed SA. Racism and health I: Pathways and scientific evidence. *American behavioral scientist*. 2013;57(8):1152-1173.
29. Garcia JA, Sanchez GR, Sanchez-Youngman S, Vargas ED, Ybarra VD. Race as lived experience: the impact of multi-dimensional measures of race/ethnicity on the self-reported health status of Latinos. *Du Bois review: social science research on race*. 2015;12(2):349-373.
30. MacIntosh T, Desai MM, Lewis TT, Jones BA, Nunez-Smith M. Socially-assigned race, healthcare discrimination and preventive healthcare services. *PloS one*. 2013;8(5):e64522.
31. Ivanov A, Sharman R, Rao HR. Exploring factors impacting sharing health-tracking records. *Health Policy Techn*. Sep 2015;4(3):263-276. doi:10.1016/j.hlpt.2015.04.008
32. Kim J, Im E, Kim H. From intention to action: The factors affecting health data sharing intention and action. *Int J Med Inform*. Jul 2023;175doi:ARTN 105071
10.1016/j.ijmedinf.2023.105071
33. Maiorana A, Steward WT, Koester KA, et al. Trust, confidentiality, and the acceptability of sharing HIV-related patient data: lessons learned from a mixed methods study about Health Information Exchanges. *Implementation Science*. 2012/04/19 2012;7(1):34. doi:10.1186/1748-5908-7-34
34. Fareed N, Swoboda CM, Jonnalagadda P, Walker DM, Huerta RT. Differences Between Races in Health Information Seeking and Trust Over Time: Evidence From a Cross-Sectional, Pooled Analyses of HINTS Data. *Am J Health Promot*. Jan 2021;35(1):84-92. doi:10.1177/0890117120934609journals.sagepub.com/home/ahp
35. Seidman G, AlKasir A, Ricker K, Lane JT, Zink AB, Williams MA. Regulations and Funding to Create Enterprise Architecture for a Nationwide Health Data Ecosystem. *Am J Public Health*. Feb

2024;114(2):209-217. doi:10.2105/Ajph.2023.307477