Data Governance: Essential for Timely Decisions in an Era of Changing Social Policy

Sensitive Data & Equity Considerations for Data Governance

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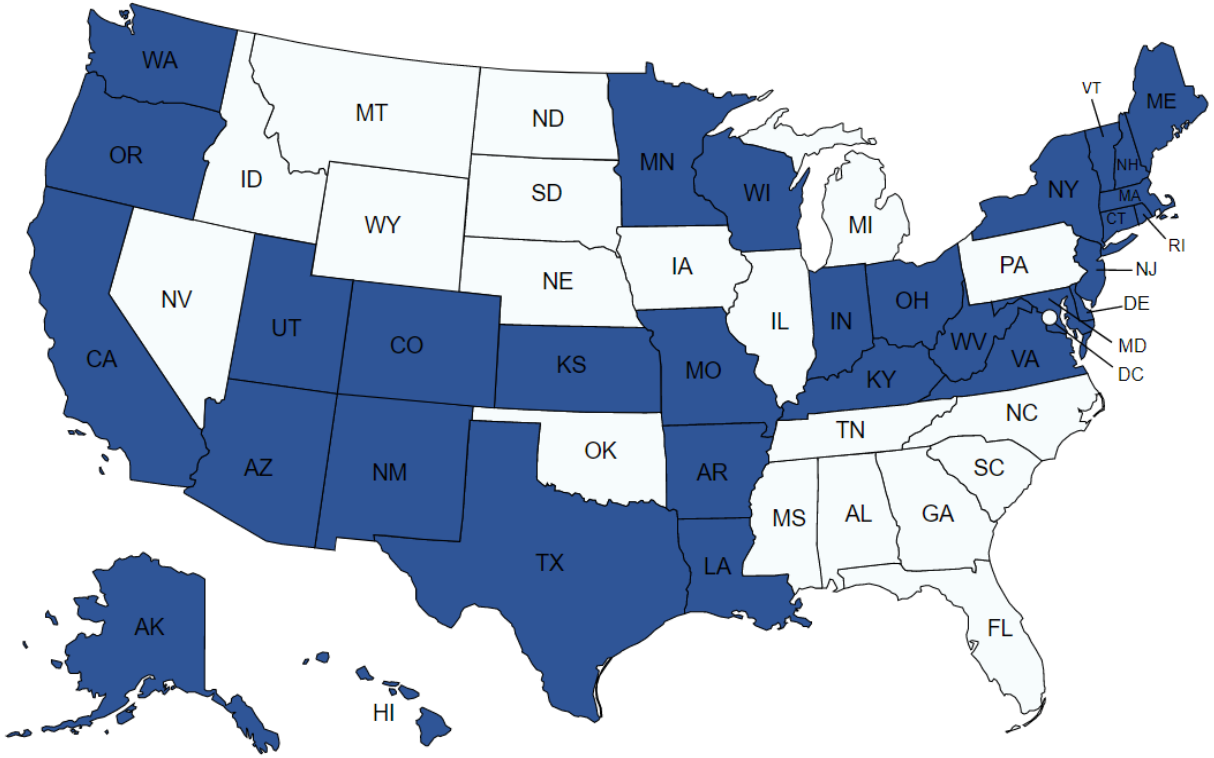
About Freedman HealthCare

- Founded in 2005
- Focus on state and nonprofit health data initiatives
- Experienced APCD managers and data scientists
- APCD and Integrated Data System lifecycle expertise:
  - Stakeholder engagement
  - Statutes & rules
  - Data Management Vendor SOWs
  - Quality & validation
  - Analytics & reporting
  - Access & use policies
  - Funding & sustainability



FHC has experience in more than 30 states

FHC Team

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Agenda for Today

- Sensitive Data
- Entity & Financial Information
- Better Data to Support Equity Analyses
- Best Practices & Lessons Learned

Sensitive Data

Patient/Member Information

- Protected Health Information (PHI) – HIPAA terminology
  - Subset of Individually Identifiable Information (III)
  - Could be used alone or with other data to identify individuals

PHI Includes:

- Names
- Postal address information
- Person specific identifiers
  - Social Security Number
  - Medical record, account, or beneficiary numbers
- Detailed date information (with day/month detail)
  - Date of birth
  - Dates of service, admission, discharge

Data Governance to Protect Privacy

- Entities often rely on HIPAA to guide policy and process development
- Establish a Data Release Committee to provide independent, expert panel review and recommendations on data requests
- Create data products for different uses and users

Data Products

De-identified Data sets

- No PHI

Limited Data sets

- Indirect identifiers
- Only dates & 5-digit zip

Identifiable Data sets

- Requires a detailed Data Use Agreement (DUA) and Data Management Plan
- Limit to minimum data necessary, justified based on project purpose
- Require Institutional Review Board or similar review & approval

Sensitive Conditions & Vulnerable Populations

- HIV/AIDS
- Alcohol & Substance Use Disorder
- Reproductive & Women's Health, Abortion, Family Planning
- Mental & Behavioral Health Services
- Genetic Testing
- Sexually Transmitted Diseases (STDs)
- Gender Affirming Care
- Rare Diseases & Conditions
  - Tuberculosis
  - Hemophilia

Data Governance Best Practices

- Limit access to information on sensitive conditions and vulnerable populations
  - Require justification based on project purpose/specific research questions
  - Mask provider identities including name, location, etc.

- Review reports, presentations, etc. prior to publication to prevent release of provider identities and locations

- Data Use Agreement establishes detailed terms and conditions for access, use, and reporting

Entity & Financial Information

Entity & Financial Information

Entity & Financial Information (EFI) Includes:

- Payer and Provider Identifiers - name, address, license numbers
- Detailed Payment Information:
  - Charged and allowed amounts
  - Plan paid, patient responsibility (copay, coinsurance, deductible)

EFI Value:

- Supports many high-value uses, e.g., cost variation, system performance
- Unlikely to impact patient privacy - not generally considered sensitive
- Release may put certain types of providers at risk, e.g., women’s reproductive health, family planning/abortion, gender affirming care

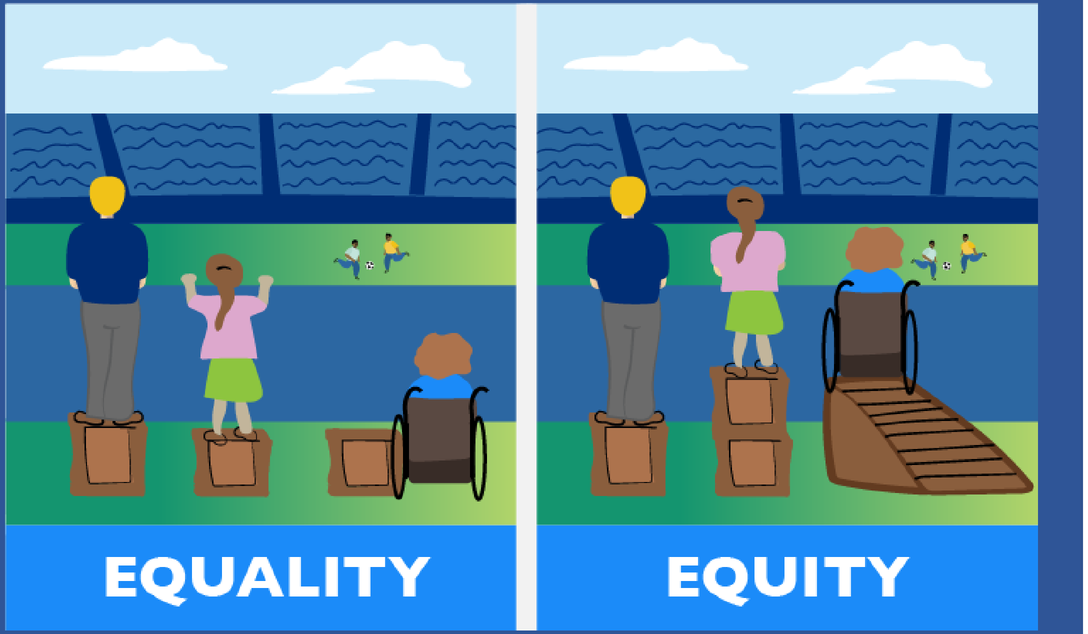
Data Governance & EFI

- Data entities have historically taken a conservative approach
  - Limited release of detailed EFI, justified based on project purpose
  - Aggregate the data, limit reporting to average or median paid amounts
  - Payer and/or provider identities & locations "masked"

- Federal Law & Policy is changing
  - Created historical incentives for entities to be cautious
  - Recent changes have created new opportunities:
    - Hospital transparency rule – effective January 1, 2021
    - Insurance transparency rule – phase in period 2022-2024
    - Department of Justice (DOJ) withdrawal of outdated Statements of Antitrust Enforcement Policy in Health Care – February 2023

Better Data to Support Equity Analyses

Health Equity

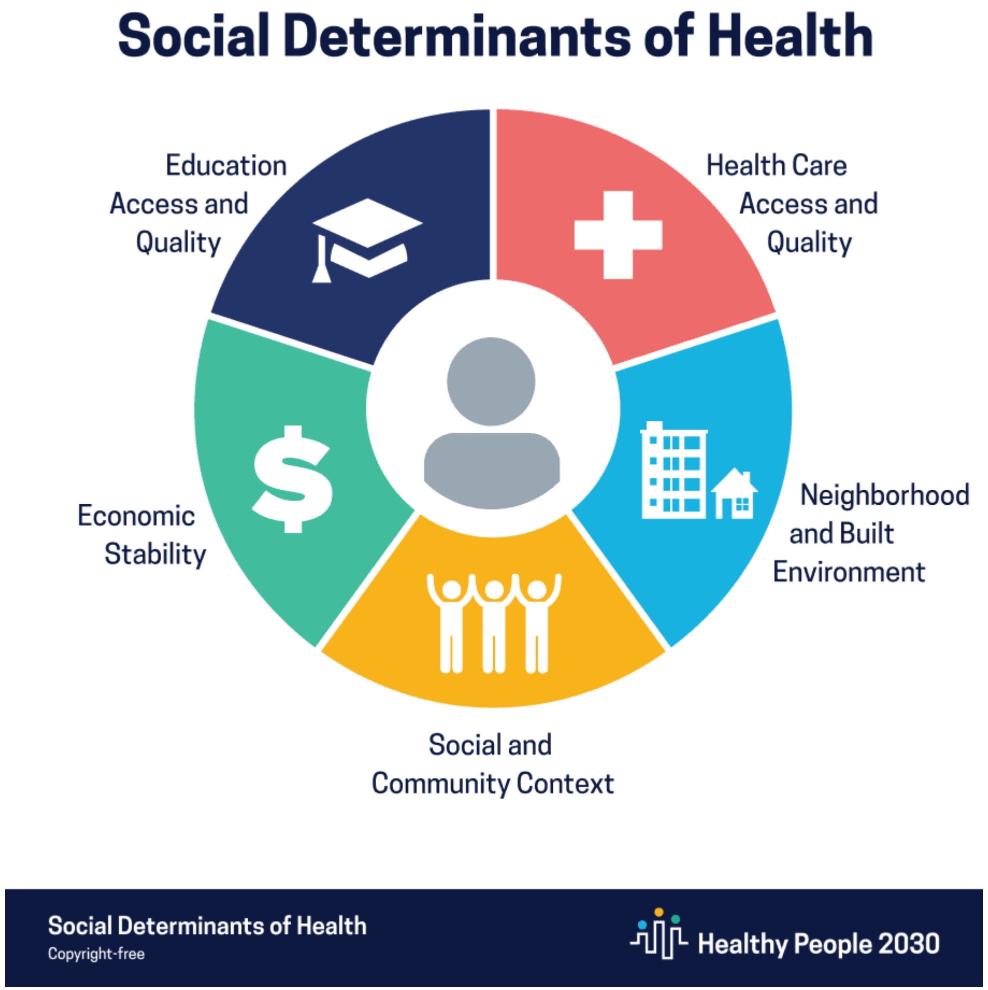


"Health equity means the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of *race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language or other factors* that affect access to care and health outcomes."

- Centers for Medicare & Medicaid Services (CMS)

Data to Inform Equity Analysis

- To generate value related to Equity issues, entities must collect complete & accurate information on:
    - Race & Ethnicity
    - Disability
    - Sexual Orientation
    - Gender Identity
    - Socioeconomic Status
    - Geography
    - Preferred Language
- Individual sources often lack robust data in these areas
- Collection of “good” data helps minimize bias in analysis & reporting.



Equity Data – High Value Uses

1. Identify disparities in health outcomes among different groups.
2. Inform decision-making & targeted interventions for disadvantaged communities.
3. Monitor progress in reducing health disparities.
4. Allocate resources more efficiently to address healthcare inequities.
5. Promote patient-centered care that considers social determinants of health.
6. Enhance research and innovation for diverse populations.
7. Identify and address root causes of health disparities.
8. Engage communities and build trust through effective data governance.
9. Advocate for policy changes that promote more equitable access to healthcare and support services.

Collection of Race & Ethnicity Data

- Essential for effective, patient-centered, timely, efficient, and equitable care.
- Most data collection tools attempt to capture Race and/or Ethnicity data.

Race

American Indian or Alaska Native

Asian

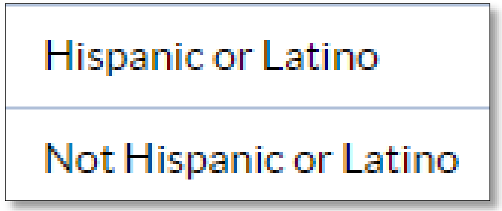
Black or African American

Native Hawaiian or Other Pacific Islander

Other Race

White

Ethnicity



Hispanic or Latino

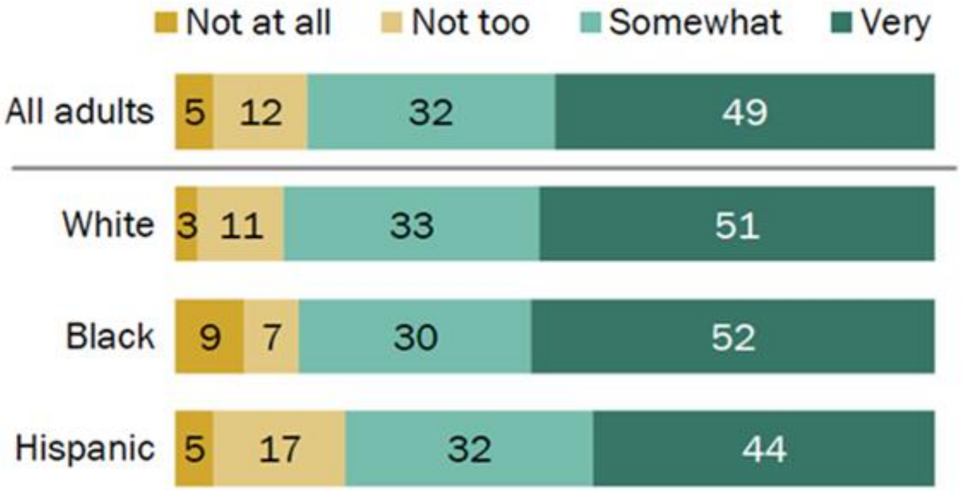
Not Hispanic or Latino

Race & Ethnicity Data Considerations

- Patient Reluctance
- Cultural Sensitivity
- Complexity and Diversity
- Data Inaccuracy and Misclassification
- Limited or Ambiguous Options
- Data Integration Issues
- Data Privacy and Confidentiality Concerns
- Changing Self-Identification
- Disparities and Bias
- Interpretation and Data Analysis
- Regulatory and Policy Challenges

About half of U.S. adults say census questions reflect own identity very well

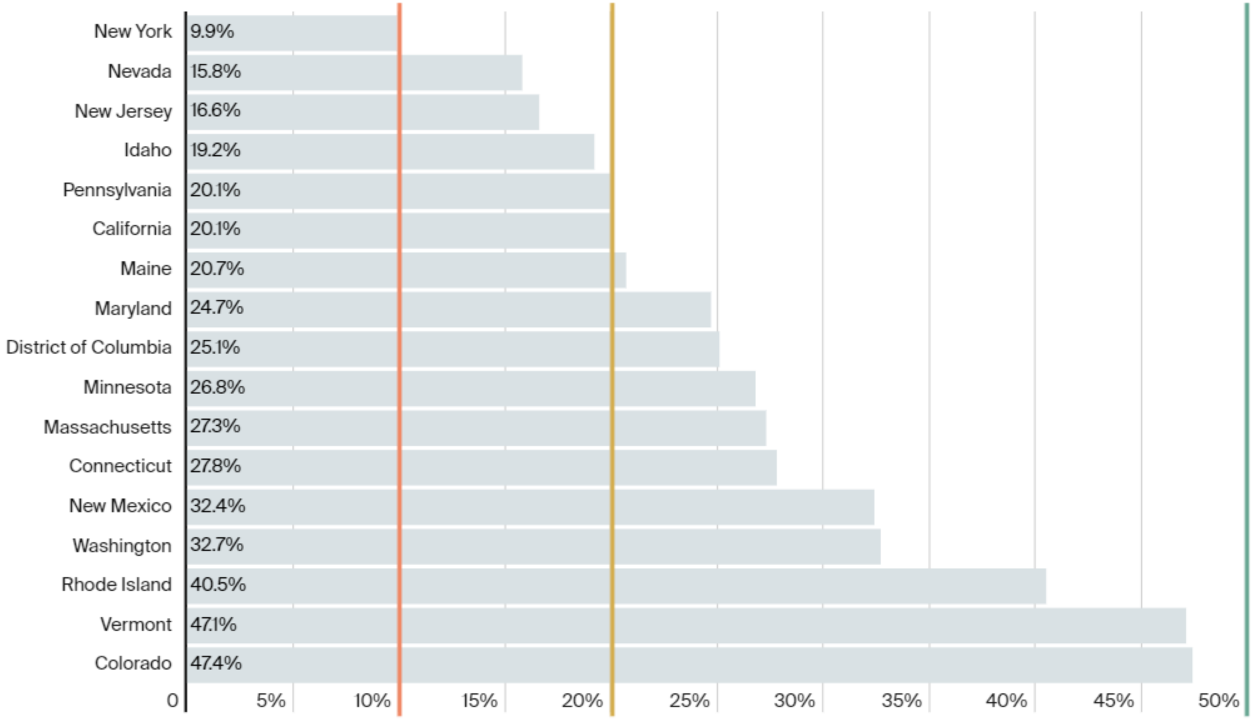
% saying the census race and ethnicity questions reflect how they see their race and origin ____ well



Note: White and Black adults include those who report being only one race and are not Hispanic. Hispanics are of any race. Share of respondents who didn't offer an answer not shown.
Source: Survey of U.S. adults conducted Jan. 3-13, 2020.
"Black and Hispanic Americans See Their Origins as Central to Who They Are, Less So for White Adults"

PEW RESEARCH CENTER

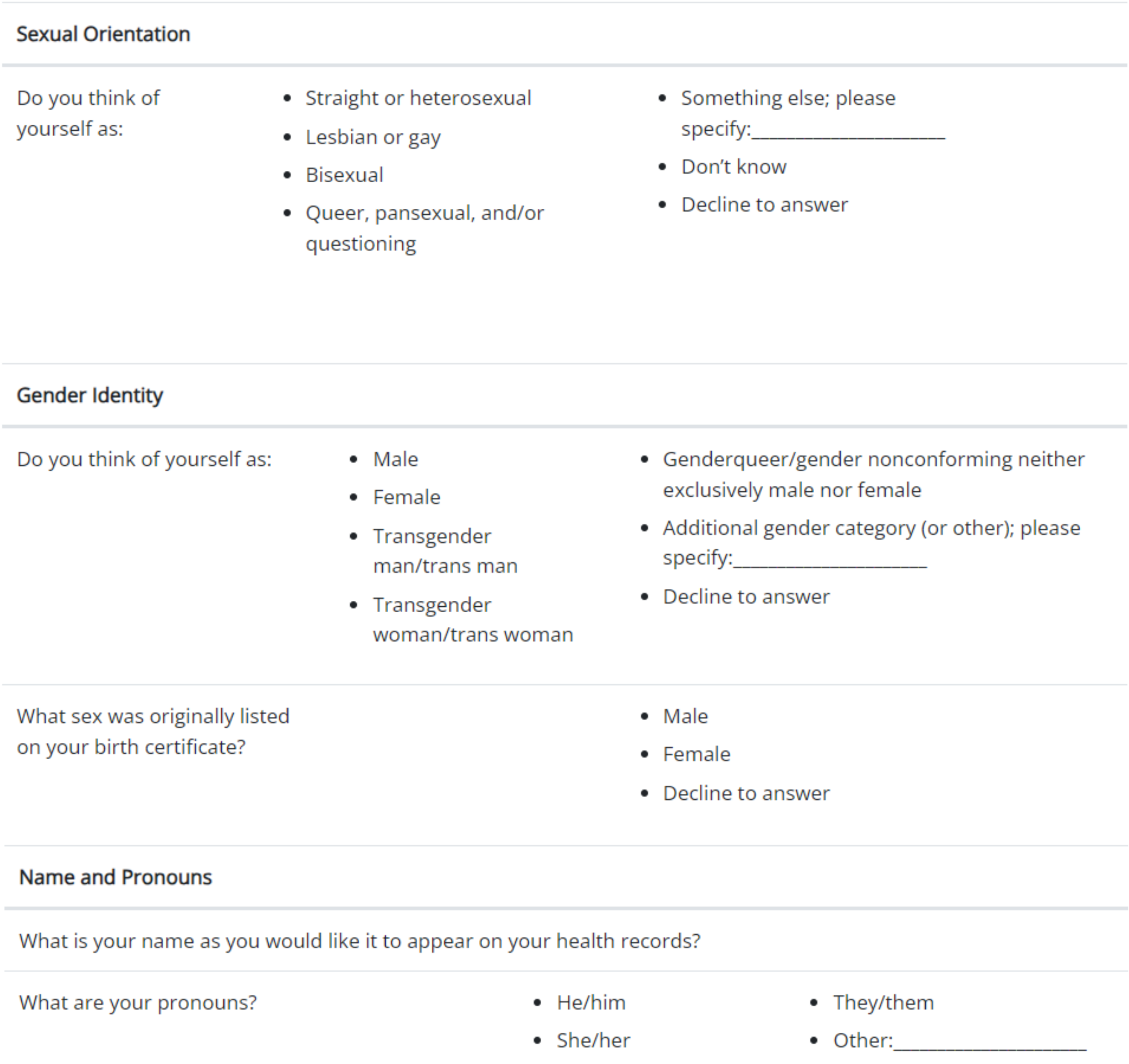
Percent of Enrollees with Missing Race or Ethnicity Data in State-Based Marketplaces During the 2022 Open-Enrollment Period Compared to Level of Concern for Impeding Analysis



(Commonwealthfund.org, 2022)

Collection of Sexual Orientation & Gender Identity Data

- Sexual Orientation and/or Gender Identity (SOGI) data are not always found in data collection tools.
- Without this information, lesbian, gay, bisexual, and transgender (LGBTQ+) patients and their specific health needs cannot be addressed.



Sexual Orientation

Do you think of yourself as:

- Straight or heterosexual
- Lesbian or gay
- Bisexual
- Queer, pansexual, and/or questioning
- Something else; please specify:_________________
- Don't know
- Decline to answer

Gender Identity

Do you think of yourself as:

- Male
- Female
- Transgender man/trans man
- Transgender woman/trans woman
- Genderqueer/gender nonconforming neither exclusively male nor female
- Additional gender category (or other); please specify:_________________
- Decline to answer

What sex was originally listed on your birth certificate?

- Male
- Female
- Decline to answer

Name and Pronouns

What is your name as you would like it to appear on your health records?

What are your pronouns?

- He/him
- She/her
- They/them
- Other:___________________

Sexual Orientation & Gender Identity (SOGI) Terminology

- What is LGBTQ+?
  - An acronym that typically stands for lesbian, gay, bisexual, trans, queer, questioning. Longer variations of this acronym include LGBTQIA which include intersex and asexual; however, LGBTQ is the most common written acronym.
- What is Gender Identity?
  - One's innermost concept of self as male, female, a blend of both, or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.
- What is Transgender?
  - Transgender is an umbrella term used to describe people whose gender identity and/or gender expression differ based on the sex they were assigned at birth. Transgender people have diverse sexual orientations, gender expressions, and gender identities, and transgender identities do not depend on physical appearance or medical procedures.
- What is Cisgender?
  - Describes someone whose internal sense of gender corresponds with the sex the person was identified as having at birth. Most people can be described as cisgender, or cis. If the pronouncement at your birth was—*It's a girl!* or *It's a boy!*—still feels accurate, then you are cisgender.

SOGI Data Considerations

Patient Reluctance

Privacy and Confidentiality Concerns

Healthcare Provider Training

Data Accuracy and Completeness

Data Integration Challenges

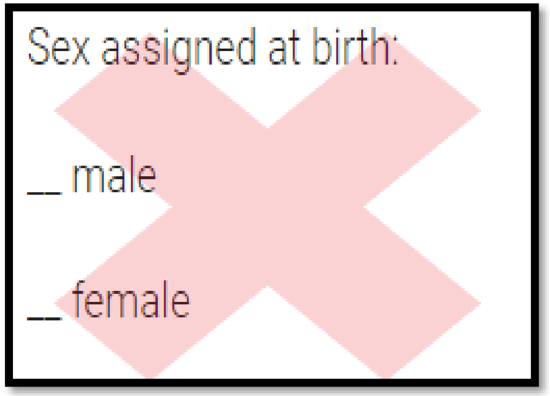
Bias and Misclassification

Legal and Policy Issues

Data Disparities

Institutional Resistance

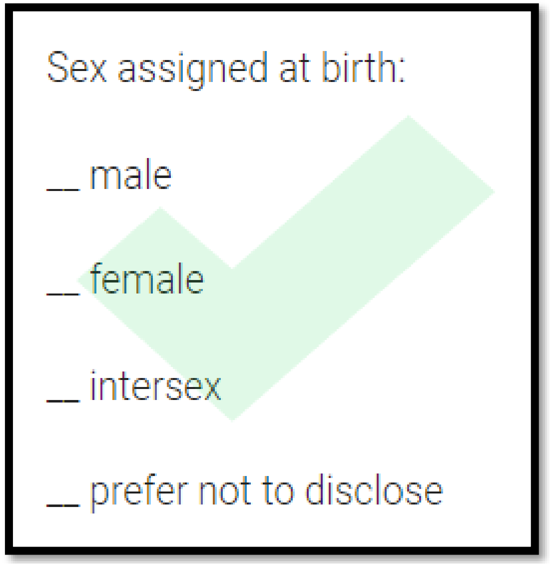
Lack of Standardization



Sex assigned at birth:

__ male

__ female



Sex assigned at birth:

__ male

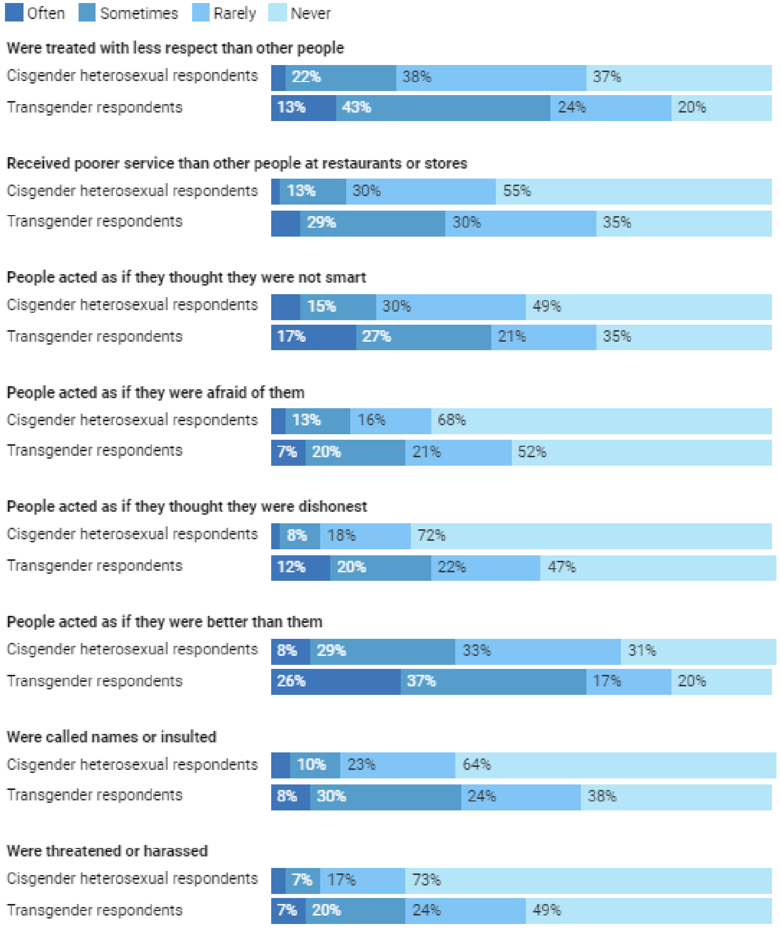
__ female

__ intersex

__ prefer not to disclose

4 in 5 transgender adults report being treated with less courtesy or respect than their cisgender heterosexual counterparts

Shares of transgender and cisgender heterosexual adults who reported poor treatment in various spaces, 2016–2018



Hover over or click to see values.
Note: *Totals may be larger than 100 due to rounding.*

Chart: Center for American Progress • Source: Ilan H. Meyer, "TransPop, United States, 2016-2018" (Los Angeles: University of California, Los Angeles, Williams Institute, 2021), available at https://www.icpsr.umich.edu/web/ICPSR/studies/37938/summary.

Transgender adults are 4 times as likely as cisgender heterosexual adults to report making at least 1 suicide attempt in their life

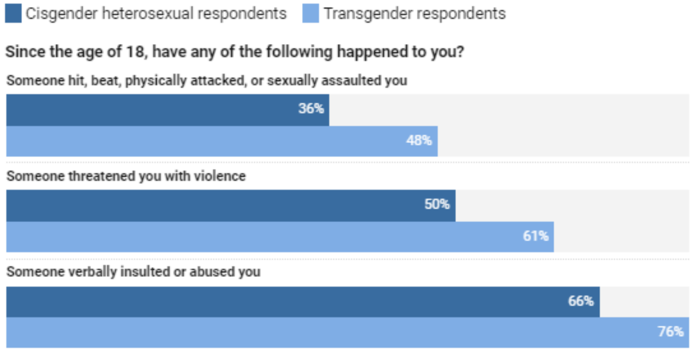
Shares of transgender and cisgender heterosexual adults who reported suicidal ideation, suicide attempts, and self-harm during their lifetime, 2016–2018

Hover over or click to see values.

Chart: Center for American Progress • Source: Ilan H. Meyer, "TransPop, United States, 2016-2018" (Los Angeles: University of California, Los Angeles, Williams Institute, 2021), available at https://www.icpsr.umich.edu/web/ICPSR/studies/37938/summary.

Half of transgender adults report being physically attacked or sexually assaulted at some point in their lives

Shares of transgender and cisgender heterosexual adults who reported verbal or physical abuse in their lifetimes, 2016–2018



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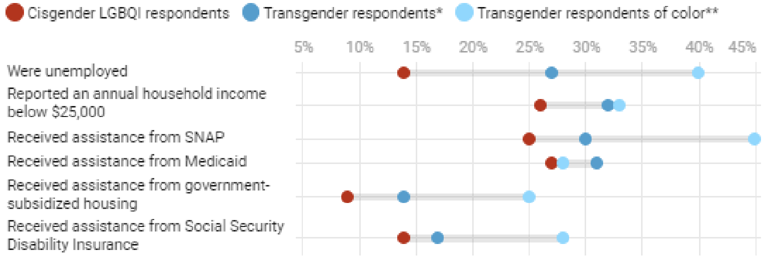
1 in 3 transgender adults report an annual household income below $25,000

Shares of transgender and cisgender LGBQI adults facing unemployment or receiving benefits assistance, 2020



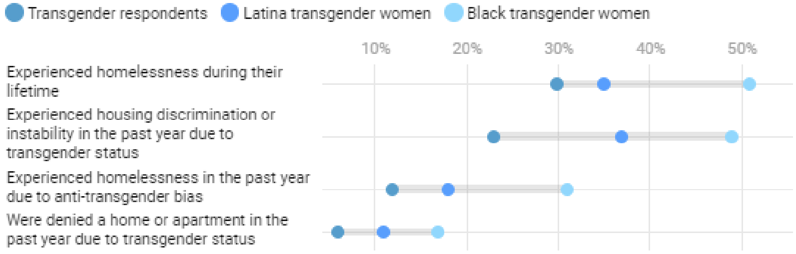
** The statistics for transgender individuals include nonbinary, gender-nonconforming, genderqueer, and agender respondents.*
*** For the purposes of this survey, people of color include Black, Hispanic, Asian, and multiracial individuals as well as those identifying as "other, non-Hispanic."*

Hover over or click to see values.

Chart: Center for American Progress • Source: Center for American Progress and NORC at the University of Chicago nationally representative online survey of 1,528 LGBTQ+-identifying individuals, June 2020, on file with the authors.

Nearly 1 in 3 transgender adults have experienced homelessness during their lifetime

Shares of respondents to U.S. Transgender Survey who reported experiences of housing discrimination and homelessness, 2015



Hover over or click to see values.

Chart: Center for American Progress • Source: Sandy E. James and others, "The Report of the 2015 U.S. Transgender Survey" (Washington: National Center for Transgender Equality, 2016), available at https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

Addressing Considerations and Challenges

- Patient Education and Engagement
- Provider Training on Cultural Competency
- Standardized and Inclusive Data Collection
- Data Accuracy and Privacy
- Identifying Disparities, Not Reinforcing Stereotypes
- Consider Social Determinants of Health

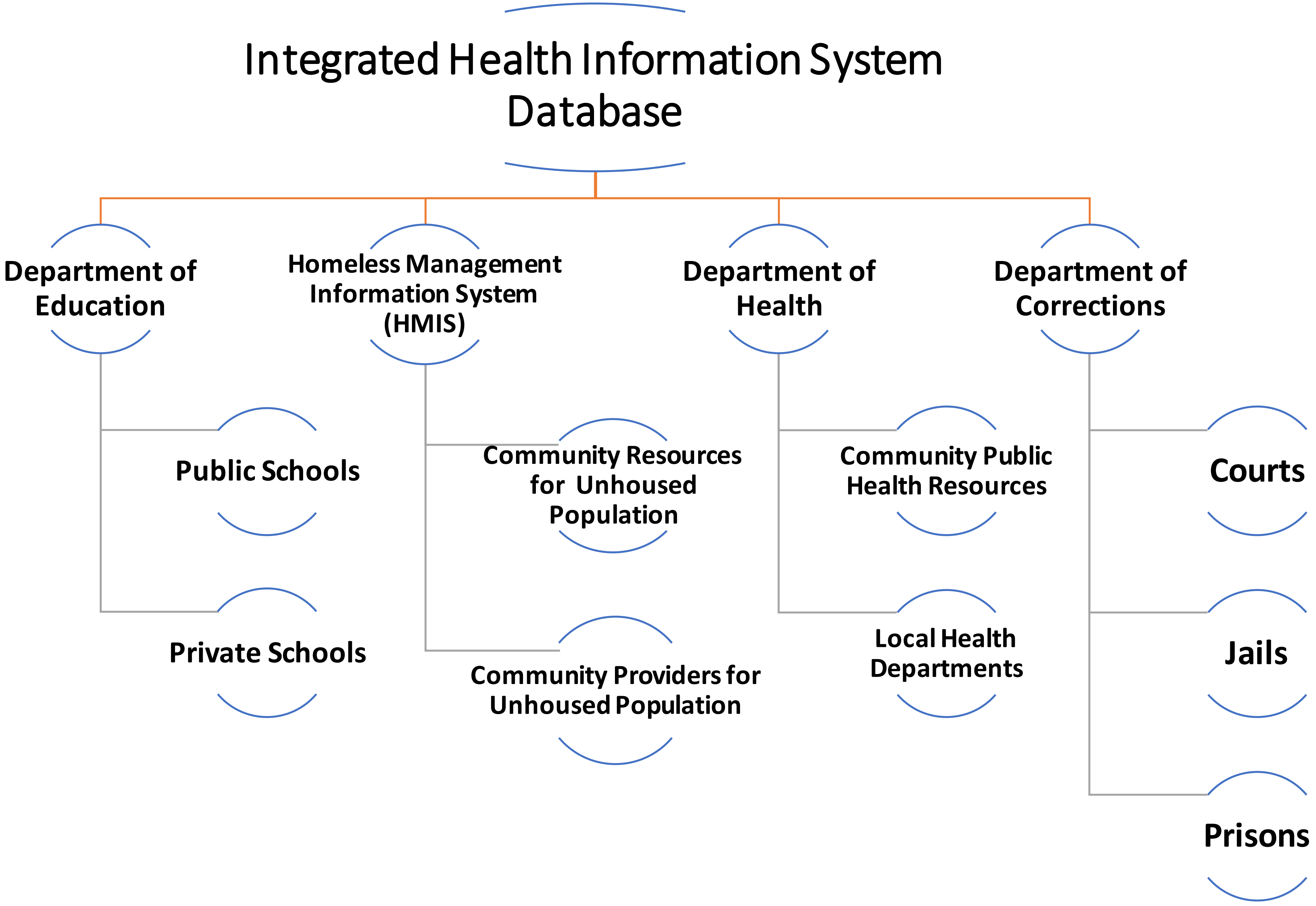
The Future of Data: Integrated Health Information Systems (IHIS)

Integrated Health Information Systems

- An Integrated Health Information System, establishes a robust network that interconnects health-related data at both the individual and family levels, spanning across diverse state agencies and healthcare providers.
- Its core purposes are to fortify healthcare delivery, bolster public health monitoring, and drive medical research advancements by fostering the seamless integration and sharing of critical health data.

People are not slices of data.
We are whole human beings,
raised in families,
rooted in communities,
and bearing our history.

What does an IHIS database look like?



- Integrated Health Information System Database
  - Department of Education
    - Public Schools
    - Private Schools
  - Homeless Management Information System (HMIS)
    - Community Resources for Unhoused Population
    - Community Providers for Unhoused Population
  - Department of Health
    - Community Public Health Resources
    - Local Health Departments
  - Department of Corrections
    - Courts
    - Jails
    - Prisons

IHIS: Key Features and Benefits

- Comprehensive Data Integration
- Person-Centric Approach
- Improved Care Delivery
- Public Health Monitoring and Management
- Research and Innovation
- Reduce Duplicative Efforts
- Enhance Data Security and Privacy
- Interoperability and Data Exchange

IHIS
in Practice

Imagine: Data from sources such as Medicaid, Department of Health, Department of Labor & Training, Department of Education, HMIS all stored within the same system.

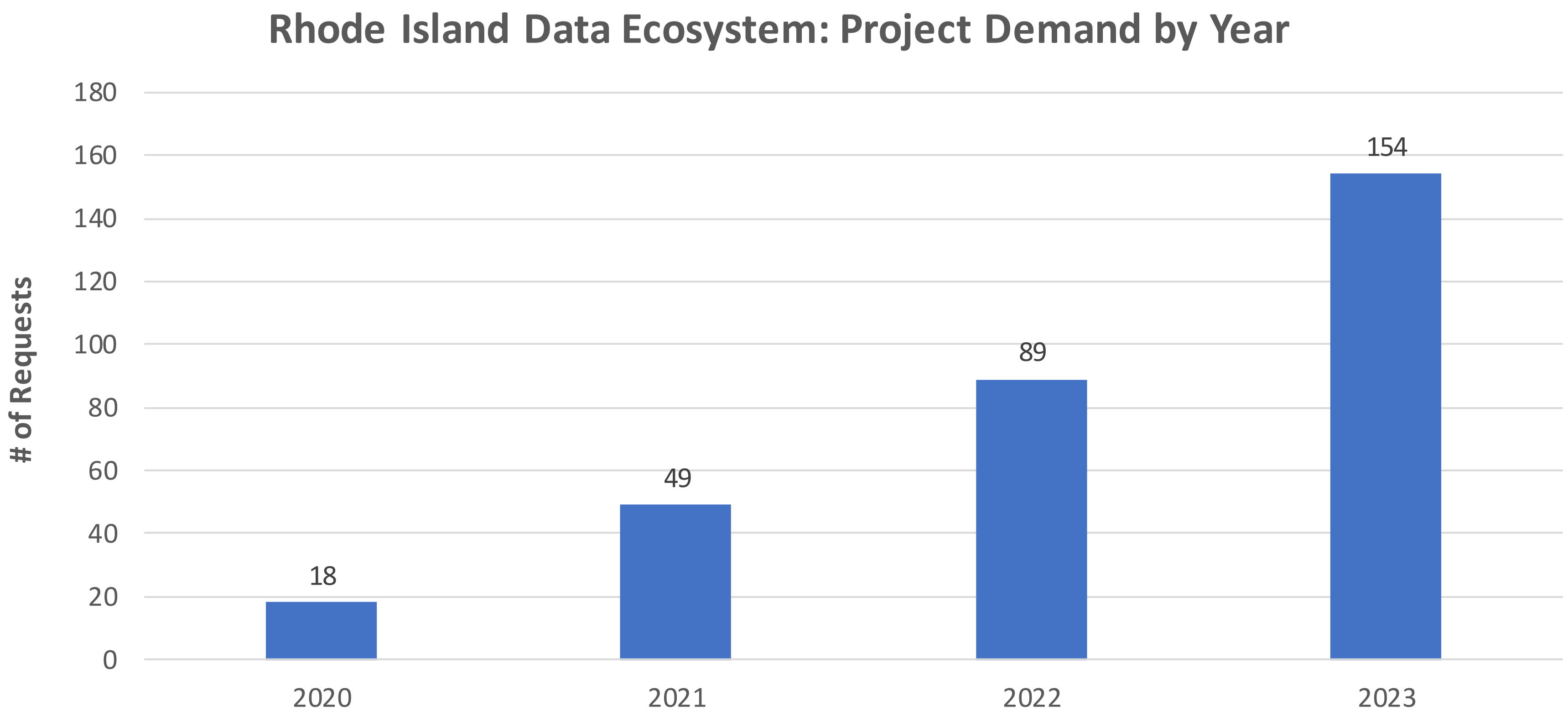
Think: How could access to an Integrated Health Information System help you in your current work?

Practice: The transgender population faces unique health disparities, including challenges related to accessing gender-affirming healthcare, mental health support, and culturally competent services. To address these inequities, a healthcare organization implements an Integrated Health Information System (IHS) with a focus on transgender-inclusive care.

In Practice: Transgender Population

Medicaid & Insurance	Department of Education	Department of Labor & Training	HMIS	Department of Health
• Population • Demographics	• Education Level • Test Scores	• Employment Status • Wages	• Housing Status	• Conditions • Health Behaviors • Vaccinations

Future of Data Use



If you build it, they will come

Best Practices & Lessons Learned

- Robust Data Governance Framework
- Community Engagement
- Transparent Information
- Inclusive Categories
- Response Options
- Data Usage Communication
- Contextual Storytelling
- Regular Review of Methods
- DON’T SHARE IDENTIFIABLE INFORMATION

Thank you!

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