



FOUNDATION FOR Health Care Quality

Improving health outcomes through collaboration, data, and finding common ground

Storing and Sharing Data Recommendations

June 2023

Background

The first step to eliminating health disparities and address upstream drivers of health outcomes is to measure disparities using demographic data.ⁱ Data are essential for identifying disparities, directing efforts and resources, and establishing accountability.ⁱⁱ While many health care stakeholders understand the importance of collecting demographic data, challenges related to the collection and sharing of these data can prevent accurate measurement of disparities.ⁱⁱⁱ Additionally, current demographic data standards do not capture granular ethnicity and language fields, and the collection of sociodemographic data presents may present ethical concerns for patient autonomy and data ownership.^{iv,v}

The Storing and Sharing Data workgroup aims to develop demographic and social need data collection and sharing strategies to inform better care. Focus areas for the storing and sharing data workgroup are highlighted in **Table 1**.

Table 1: Storing and Sharing Data Focus Areas

Focus Area	Goals
Socio-Demographic Data Standards	<ul style="list-style-type: none">• Offer potential standards to collect demographic and social need information.• Recommend areas of improvement for demographic data standards
Use Cases	<ul style="list-style-type: none">• Recommend standard use cases for organizations to meet using their data collection and sharing capabilities.
Common Capabilities	<ul style="list-style-type: none">• Describe the common capabilities of interoperable data systems.• Offer recommendations for achieving the common capabilities.
Interoperability	<ul style="list-style-type: none">• Point to interoperability standards for health data systems.• Recommend additional steps for ensuring data can be used for individual patient care, population health management, research, and quality improvement processes.
Guiding Principles and Ethical Considerations	<ul style="list-style-type: none">• Consider ethical data use and collection considerations.• Provide examples of existing regulations governing data sharing.• Trust and transparency

Recommendations

Demographic and Social Need Data Standards

- As a general principle, collect the minimum data necessary to identify and meet needs. Needs could include identifying and addressing inequities. Ensure individual sociodemographic data is collected on a voluntary, self-reported basis.
- Collect demographic data on health related social needs (at least housing, food security, and transportation); race, ethnicity, and language (REaL), sexual orientation and gender identity (SOGI), and disability.
 - Consider collecting additional demographic data on nativity, socioeconomic status (SES), veteran status, or other indicators for disparities.
- Borrow from the Gravity Project’s terminology workstream to code for social need information. The Gravity Project offers standard social need codes that can be linked to specific domains or assessment tools.
- Collect race and ethnicity data in a way that meets the needs of the community. Ensure data fields can be mapped to OMB standards to ensure usability of aggregate data. Stay up to date with upcoming changes to OMB standards for race and ethnicity.
 - Consider collecting more granular ethnicity categories using the CDC’s expanded ethnicity list that roll up into the OMB categories.
 - Allow individuals to choose multiple races. Ensure the “multiracial” category can be disaggregated into the individual racial categories.
- Develop data fields for primary/preferred language.
 - Consider borrowing fields from the Census Bureau
- Develop sexual orientation and gender identity data fields.
 - Consider borrowing from Fenway or Human Rights Campaign standards.
- Develop disability data fields.
 - Consider borrowing from the Census Bureau or the Oregon Health Authority standards.

Table 2: Potential Sources of Demographic and Social Need Data Standards

Demographic Data Category	Potential Source
Social Need Data	Minimum Domains: <ul style="list-style-type: none"> • Housing Security, Food Security, Transportation Standards and Terminology: • Gravity Project Terminology Workstream
Race and Ethnicity	Minimum Standards: <ul style="list-style-type: none"> • OMB Potential Expanded Categories: <ul style="list-style-type: none"> • CDC Expanded Ethnicity List (rolls up to OMB categories)
Language	<ul style="list-style-type: none"> • American Community Survey (Census) • ISO 639.2

Sexual Orientation and Gender Identity	<ul style="list-style-type: none"> • Fenway Institute • Human Rights Campaign
Disability	<ul style="list-style-type: none"> • American Community Survey (Census) • Oregon Health Authority

Use Cases

- Ensure data systems and workflows are capable of storing and sharing data related to at least these three use cases:
 - Documenting social need and sociodemographic data (Data Collection)
 - Documenting and tracking social need-related interventions (Patient Care/Referrals)
 - Gather and aggregate social need and sociodemographic data for uses beyond point of care (Generic Consumption).
- The [Gravity Project Use Case Package](#) provides detailed information, including actors and actions, about these three use cases for social need.

Common Capabilities

- Common capabilities required for interoperable sociodemographic data systems can be sorted into the three use cases described above: data collection, patient care/referrals, and data aggregation for generic consumption. Potential common capabilities to meet each use case are listed below.

Table 3: Common Capabilities for Sociodemographic Data Collection and Consumption

Use Case	Common Capabilities
Overarching Capabilities	<p><u>Must Have</u></p> <ul style="list-style-type: none"> • A centralized Master Patient/Person Index (MPI) with referential matching to ensure that patient information can be consistently resolved to a single individual. • Various forms of data storage to support the persistence of data. <p><u>Nice to Have:</u></p> <ul style="list-style-type: none"> • A Consent Management solution to manage visibility of sensitive data. • An Eventing capability to notify interested parties in real time or near real time when a particular event has occurred, such as notifying providers when a patient screens positive for social need, or notifying clinicians when a referral is completed.
Data Collection	<p><u>Must Have</u></p>

	<ul style="list-style-type: none"> • A Single Sign-On (SSO) solution to manage identity and access for both provider and patient users. • A Set of APIs to provide backend functionality for the Web Portal and for direct system-to-system interactions between organizations other systems and for workflow automation. • A Workflow Orchestration/Automation solution to manage the ingestion of sociodemographic screening data.
<p>Patient Care/Referrals</p>	<p><u>Must Have:</u></p> <ul style="list-style-type: none"> • A Workflow Orchestration/Automation solution to manage communications about the organization’s social need interventions, specifically related to closed-loop referrals. • A set of APIs for system-to-system interactions with external social service partners that receive referrals. <p><u>Nice to Have:</u></p> <ul style="list-style-type: none"> • A Web portal solution that offers patients access to a community information exchange or social service resource locator.
<p>Generic Consumption</p>	<p><u>Must Have:</u></p> <ul style="list-style-type: none"> • A Set of APIs for system-to-system interactions that allows systems to respond to queries from authorized partners and communicate with external/federated systems for the automated consumption and delivery of data products. • Ability to respond to custom data requests • Ability to provide subscriptions to specific data products on a recurring basis. • An Analytics capability for research, consumption of data without requiring the use of APIs.

- Additional recommendations to ensure data systems are capable of addressing social need and health equity include:
 - Patient Data Collection: ensure that the electronic health record (EHR) (or other data system) is capable of collecting sociodemographic data.
 - Consider EHR-based social need assessment tools that allow real-time collection of patient social need. Leverage existing standards as recommended in the data standards section.
 - Ensure granular race and ethnicity data fields are capable of being re-aggregated into standard categories without information loss or flattening in-group disparities.

- Social Service Referral Management: link the data system to a closed-loop referral system where possible.
 - Consider leveraging investments in private community information exchanges if feasible and appropriate.
 - Consider alternative pathways for community referrals, such as the Connect2Care program out of HealthierHere.
- Analytics and Reporting: ensure sociodemographic data is available for population health data aggregation. Use FHIR standards for data exchange.
- Implementing common capabilities will require investment and planning outside of the IT system.
 - Invest resources in IT personnel and capacity to implement common capabilities.
 - Develop an internal data governance structure that participates in broader data sharing.

Achieving Interoperability

- Use existing [HIMSS](#) models to track and improve on interoperability:
- Beyond existing interoperability metrics, ensure that data systems respond to queries for sociodemographic data by authorized partners.
- Ensure data systems are FHIR-compliant, the nationally accepted exchange standard. Use the [Gravity Project's FHIR Implementation Guide](#) for more information about shifting to FHIR, especially for demographic information.

Guiding Principles and Ethical Considerations

- Develop policies and principles for data ethics. Consider processes for data collection, data integrity, reporting practices, and analysis practices.
- Key ideas to keep in mind include:
 - Autonomy: allow the individual to have ownership over their personal information. Obtain consent for collecting data.
 - Transparency: provide public information about how data is stored, shared, and used.
 - Privacy: ensure data systems are capable of securely storing personal health information and/or other personally identifiable information.
 - Intention: ensure the intentions of data collection are ethical, for example, to reduce inequities and improve outcomes, and assess the intention behind the collection of each new piece of data.
 - Outcomes: even with good intentions, ensure that data analysis, reporting, and use do not lead to inadvertent harm to individuals or groups of individuals.
- Additional concepts when working with healthcare data include:
 - Data sovereignty: in general, data sovereignty is the idea that data are subject to the laws and governance structures of the nation where they are collected. This is especially important when collecting data on tribal populations. When collecting data on tribal populations, partner with tribal organizations to better understand tribal priorities.

Stakeholder Roles and Responsibilities

Each stakeholder plays several roles in the health and social care ecosystem. This list (adapted from the Robert Wood Johnson Foundation Raising the Bar Report) provides several suggested actions for specific stakeholders to take depending on their role. The actions suggested are not in chronological order. Stakeholders are invited to develop an action plan to achieve the objectives relevant to their organization.

Leaders: C-suite executives, directors, and managers in charge of setting priorities and allocating resources

Goal: Commit necessary resources to incorporate sociodemographic data standards and facilitate interoperability.

- 1.1: Develop multi-year plans to adopt sociodemographic data standards for REaL, SOGI, disability, and social need data.
- 1.2: Commit the necessary resources to achieve FHIR interoperability, especially related to social need data sharing.

Health Care Providers: Physicians, other clinicians, and other providers responsible for treating and managing patients.

Goal: Incorporate standard sociodemographic data into workflows wherever possible.

- 2.1: Actively promote and facilitate sociodemographic data standards.
- 2.2: Establish and sustain a trusting environment with patients and staff that prioritizes whole-person care and explains why data collection is important.

Employers: Any organizations that support and manage staff, human resource departments.

Goal: Understand the workforce's social need and demographic makeup to better support employees.

- 3.1: Develop a voluntary social need screening process for employees to better understand how to support staff through the employee life cycle.

Partners: Organizations that facilitate relationships across multiple sectors to achieve equity.

Goal: Engage with community organizations and other healthcare organizations to build social need aggregation capabilities.

- 4.1: Engage with community organizations and peer institutions to develop plans for data sharing and transparency.
- 4.2: Build trusting relationships with individuals and organizations.
- 4.3: Include transparency around social need screening practices and the use of data.

Advocates: People and organizations who advocate for greater change.

Goal: Advocate for greater interoperability capabilities and data transparency.

- 5.1 Actively push for and adopt upcoming interoperability standards.
- 5.2: Use your organization's power and influence to advocate for greater data collaboration and transparency.

Purchaser: Organizations in charge of purchasing benefits for their employees, staff, or other clients.

Goal: Engage with interoperability efforts.

- 6.1: Develop strategies to align plan/purchaser sociodemographic data fields with healthcare organization data fields.

Insurer: Organizations that manage health plans for enrollees.

Goal: Participate in interoperable data systems across public and private partners.

- 7.1: Develop multi-year plans to adopt sociodemographic data standards for REaL, SOGI, disability, and social need data.
- 7.2: Commit the necessary resources to achieve FHIR interoperability, especially related to social need data sharing.
- 7.3: Participate in data aggregation and data sharing agreements to facilitate population health reporting of sociodemographic data for quality improvement purposes.

Regulators and Policy: Organizations and people in charge of developing policy that governs healthcare organizations and regulating/enforcing these policies.

Goal: Incorporate sociodemographic data into interoperability requirements and maintain updated benchmarks for data and interoperability.

- 8.1: Develop standard codes for social need and update demographic standards for race, ethnicity, sexual orientation, gender identity, and disability.
- 8.2: Aid organizations that are adopting new data standards and data systems.
- 8.3: Provide guidance for updating sociodemographic data standards.

Population Health: Organizations that collect population-level data and focus on multi-sector partnerships to advance health.

Goal: Aggregate sociodemographic data for reporting and transparency purposes.

- 9.1: Facilitate partnerships and alignment around sociodemographic data standards.
- 9.2: Aggregate sociodemographic data for population health reporting purposes.

Tools and Resources

- General:
 - [HHS Implementation Guidance on Demographic Data Collection](#)
 - [CDC Inventory of Resources for Standardized Demographic and Language Data Collection](#)
 - [AHRQ Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#)
- Data Standards
 - Social Need
 - [Terminology Workstream \(for data standards, especially related to social need\)](#)
 - Race/Ethnicity
 - [US Office of Management and Budget \(OMB\)](#)
 - [Centers for Disease Control and Prevention \(CDC\)](#)
 - [CDC Expanded Race and Ethnicity Code System](#)
 - Sexual Orientation and Gender Identity
 - [Fenway Health SOGI Data in EHRs](#)
 - [Human Rights Campaign \(HRC\) SOGIE* Data Collection](#)
 - Disability Standards
 - [US Census Bureau Disability Data](#)
 - [Oregon Health Authority \(OHA\) Race, Ethnicity, Language, and Disability](#)
- Health Equity Planning Guides (often include data strategies)
 - [American Medical Association \(AMA\) Strategic Plan to Advance Health Equity](#)
 - [Institute for Healthcare Improvement \(IHI\) Health Equity Resources](#)
 - [American Hospital Association \(AHA\)](#)
- Interoperability Standards
 - [Healthcare Information and Management Systems Society \(HIMSS\)](#)
 - [FHIR Implementation Guide \(for using exchange standards\)](#)
- Ethics and Guiding Principles
 - [Robert Wood Johnson Foundation: Equity Centered Data Systems](#)
 - [Urban Indian Health Institute](#)
 - [AHIMA: Policy Statement on Social Need Data](#)

References

ⁱ Douglas M, Dawes D, Holden K, & Mack D. 2015. Missed Policy Opportunities to Advance Health Equity by Recording Demographic Data in Electronic Health Records. *Am J Public Health*. 105(3):S380-S388. doi: 10.2105/AJPH.2014.302384

ⁱⁱ Artiga S. 2021. Advancing Health Equity Requires More and Better Data. *Kaiser Family Foundation*. Accessed June 2022. Available: <https://www.kff.org/policy-watch/advancing-health-equity-requires-more-better-data/>

ⁱⁱⁱ Agency for Healthcare Research and Quality. 2018. Improving Data Collection across the Health Care System. *AHRQ*. Accessed June 2022. Available: <https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata5.html>

^{iv} Institute of Medicine (US) Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement; Ulmer C, McFadden B, Nerenz DR, editors. Washington (DC): National Academies Press (US); 2009.

^v Wade, D. 2007. Ethics of collecting and using healthcare data. *BMJ*. 334(7608):1330-1331. doi: 10.1136/bmj.39247.679329.80