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NATIONAL ASSOCIATION OF HEALTH DATA ORGANIZATIONS

Social Determinants of Health:

APCD and Hospital Discharge Data Standards and Collection Practices

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The Need for Better Data Collection

The COVID-19 pandemic underscored the need for a modernized public health data infrastructure, particularly to accurately measure and report disparate outcomes. Modernizing the often disjointed health data infrastructure requires the commitment and support of national, state, and local governments, as well as private and civil public health stakeholders, health care delivery systems, and health data stewards.

The National Commission to Transform Public Health Data Systems made several recommendations for state governments to achieve these necessary improvements, including:[1]

- **Ensure that state policies for public health data collection, sharing (including balancing privacy and transparency), and analysis are equity-driven and explicitly call out the influence and consequences of structural racism and other inequities on health.**
- Partner with local health departments and departments that provide public health data (e.g., social services data) to consider new models of collaboration to improve efficiency and timeliness of decision-making and action at both state and local levels.

The commission's recommendations also call on other sectors to act:

- **Businesses can support standards development for exchanging and use of public health data collected by the private sector,**
- **Healthcare systems can collect social determinants of health data using standardized questions and diagnosis codes,**
- Nonprofits can build trust in data as a public good in the community and develop data-sharing strategies where appropriate and where there is a benefit, reciprocity, and equitable access, and
- Professional associations can develop strategies to improve data completeness and quality, particularly for equity and drivers of health and well-being.

These recommendations are all made alongside the broad recommendation to make Federal investments for standards-based and interoperable data infrastructure.

[1] From *Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems,* by Robert Wood Johnson Foundation, 2021. (https://www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html)

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Development of Standardized Ways to Collect Data

HIPAA established the processes and governance for establishing standard health data formats and exchange technology.[2,3,4] However, one challenge in creating comprehensive and aligned data systems across sectors is that there is no single "responsible party" for creating definitions and guiding the "best" way to collect data related to the various demographic and social constructs that are associated with health inequity. Activities in areas in which data collection needs to occur are summarized below.

Race

In 2011, HHS recommended data standards for race, ethnicity, sex, primary language, and disability status to support the implementation of a section of the Affordable Care Act intended to eliminate health disparities in America. In alignment with standard classifications published by the Office of Management in Budget,[5] HHS implementation guidance provides additional granularity for Hispanic and Asian subcategories that were tested and used for the American Community Survey and the 2010 Decennial Census.[6]

Sexual Orientation and Gender Identity

In 2020, the Fenway Institute's National LGBTQIA+ Health Education Center program published updated guidance on collecting data on sexual orientation and gender identity (SOGI).[7] The Bureau of Primary Health Care at the Health Resources and Services Administration (HRSA) approved the definitions recommended by the Fenway Institute for use in the Health Center Program Uniform Data System (UDS).[8] The same guidance was shared with the Association of State and Territorial Health Officers (ASTHO) in an open letter signed by a coalition of more than 100 organizations representing LGBTQ health policy advocates in December 2020,

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[2] The Accredited Standards Committee (ASC) X12 Subcommittee X12N is an American National Standards Institute (ANSI) accredited organization responsible for developing and maintaining components of ASC X12 Standards used for health insurance industry activities, including those performed by commercial and government health care organizations.

[3] The National Council for Prescription Drug Programs (NCPDP) is an ANSI-accredited standards development organization maintaining standards to improve communication within the pharmacy industry.

[4] Health Level 7 International (HL7), an ANSI-accredited standards development organization, created Fast Healthcare Interoperability Resources (FHIR) for exchanging electronic health records.

[5] From *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity,* by Office of Management and Budget, 1997. (https://www.govinfo.gov/content/pkg/FR-1997-10-30/pdf/97-28653.pdf)

[6] From *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*, by Office of the Assistant Secretary for Planning and Evaluation, 2011. (https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0)

[7] From *A Guide for Collecting Data on Sexual Orientation and Gender Identity,* by National LGBT Health Education Center, The Fenway Institute, 2020. (https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf)

[8] From *Uniform Data System 2022 Manual, Health Center Data Reporting Requirements,* by Health Resources and Services Administration, 2022. (https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/2022-uds-manual.pdf)

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including the Human Rights Campaign which had developed earlier guidance on SOGI data collection.[9,10] The ONC formally incorporated the same SOGI questions and values into USCDI version 2 in July 2021.[11,12]

Social Determinants of Health

The ICD-10 Clinical Modification (ICD-10-CM) is a source of diagnosis codes required for medical coding by HHS since 2015.[13] ICD-10-CM includes a range of codes for factors influencing health status and contact with health services. Some of these can be used to capture data about SDoH. Categories of SDoH-related ICD-10-CM codes are often referred to as "Z-codes" because they begin with the letter Z.[14,15,16]

In March 2021, the Gravity Project, a multi-stakeholder public collaborative convened by HL7, a health information standards developing organization, presented a proposal at the ICD-10 Coordination and Maintenance Committee Meeting to integrate new codes aligned with standardized screening questions and answers such as PRAPARE, the Accountable Health Screening Tool, or the Health Leads Screening Tools.[17]

In 2022, ONC began hosting monthly SDoH Information Exchange Learning Forum webinars convening health care providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to

[9] From *LGBTQI Inclusion in COVID-19 Data Collection & Vaccination Planning,* by The Fenway Institute, 2020. (https://fenwayhealth.org/wp-content/uploads/12.21.20-ACIP-LGBTQI-Data-Vaccination-Letter.pdf)
[10] From *SOGIE* Data Collection*, by Human Rights Campaign Foundation, 2017. (http://assets2.hrc.org/files/assets/resources/HRC_ACAF_SOGIE_Data_Collection_Guide.pdf)
[11] The USCDI is overseen by the Office of the National Coordinator (ONC), the federal entity with governance over electronic health records. The USCDI elements are required for all Certified Electronic Health Record Technology (CEHRT) products. The certification process overseen by CMS and ONC intends to promote interoperability in the health data ecosystem. The USCDI specifications are incorporated into HL7 FHIR.
[12] From *United States Core Data for Interoperability, Version 2*, by The Office of the National Coordinator for Health Information Technology, 2021. (https://www.healthit.gov/isa/sites/isa/files/2021-07/USCDI-Version-2-July-2021-Final.pdf)
[13] From *HIPAA Administrative Simplification: Modifications to Medical Data Code Set Standards To Adopt ICD-10-CM and ICD-10-PCS*, by Department of Health and Human Services, Office of the Secretary, 2009. (https://www.govinfo.gov/content/pkg/FR-2009-01-16/pdf/E9-743.pdf)
[14] From *Utilization of Z Codes for Social Determinants of Health among Medicare Fee-for-Service Beneficiaries, 2019*, by Centers for Medicare & Medicaid Services, Office of Minority Health, 2021. (https://www.cms.gov/files/document/z-codes-data-highlight.pdf)
[15] From *Provider Update, ICD-10 Codes to Identify Social Determinants of Health,* by John Hopkins Medicine, 2021. (https://www.hopkinsmedicine.org/johns_hopkins_healthcare/providers_physicians/resources_guidelines/provider_communications/2021/PRUP135_ICD10-km.pdf)
[16] From *ICD-10-CM Coding for Social Determinants of Health,* by American Hospital Association, 2022. (https://www.aha.org/system/files/2018-04/value-initiative-icd-10-code-social-determinants-of-health.pdf)
[17] From *ICD-10 Coordination and Maintenance Committee Meeting*, by Centers for Disease Control and Prevention, 2021. (https://www.cdc.gov/nchs/data/icd/March-2021-proposal-packet-508.pdf)

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share lessons learned, promising practices, and challenges related to exchanging SDOH data.[18] This aligns with a recommendation from the National Committee on Vital and Health Statistics (NCVHS) to the Secretary of Health and Human Services that ONC be given expanded authority to coordinate SDoH data standardization efforts across HHS agencies.[19] Recommendations NCVHS made to the Health Information Technology Advisory Committee (HITAC) in 2021 specifically mention consistent standards for, "race, ethnicity, disability condition and resulting impacts, sexual orientation, preferred language, SOGI, and data for SDOH."[20]

Summary of Demographic and SDoH Data in Standard Insurance Transactions

- ASC X12, a standards development organization for insurance and other transactions, includes diagnosis code fields that allow providers to send ICD-10-CM Z-codes capturing a patient's SDoH to an insurance carrier or payer.
- ASC X12N 834 (enrollment) and 270/271 (eligibility) transactions:
  - Require the member's sex, although ASC X12N specifications conflate sex assigned at birth and gender by using standard values for sex to describe a subscriber or member's "gender".
  - Situationally include member's language if required for compliance with implementation guidance.
  - Include race and ethnicity elements that are "not used."
  - Do not provide guidance for SOGI data exchange.
- Given that the National Council for Prescription Drug Programs (NCPDP), a standards development organization providing healthcare solutions, relies on X12N 834 and 270/271 transactions for member enrollment and eligibility data, the same limitations on demographic data on the enrollment and eligibility transactions for medical insurance apply to pharmaceutical records.

[18] From *ONC's Social Determinants of Health Information Exchange Learning Forum,* by The Office of the National Coordinator for Health Information Technology, 2022. (https://www.healthit.gov/news/events/oncs-social-determinants-health-information-exchange-learning-forum)

[19] From *Recommendations to Modernize Adoption of HIPAA Transaction Standards,* by National Committee on Vital and Health Statistics, 2022. (https://ncvhs.hhs.gov/wp-content/uploads/2022/08/Recommendation-Letter-Modernize-Adoption-of-HIPAA-Transaction-Standards-508.pdf)

[20] From *Final Report of the Health Information Technology Advisory Committee's Public Health Data Systems Task Force 2021,* by Health Information Technology Advisory Committee, 2021. (https://www.healthit.gov/sites/default/files/page/2021-08/2021-07-14_PHDS_TF_2021_HITAC%20Recommendations%20Report_Signed_508_0.pdf)

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The Current State of Data Collection

Despite being included in health data standards used for different purposes (e.g., health insurance records, pharmacy claims, electronic health records), REaL, SDoH, sex, and SOGI fields are often not populated because they are undefined or not used in standard implementation guidance. This suggests misaligned incentives across stakeholders using standards; more specifically, the unused demographics and SDoH data elements imply they are currently unnecessary for most relevant business transactions (e.g., health insurance claims adjudication and provider-oriented population health management). For example, according to the AHA Institute for Diversity and Health Equity, "most hospitals (82 percent) currently collect data on their patients' race and ethnicity, and 67 percent collect information on the patient's primary language. However, the data are not collected in a systematic or standard manner and are often not shared, even between different departments within the same hospital."[21]

In a survey of twenty-two all-payer claims database (APCD) and hospital discharge data (HDD) programs, most respondents are not defining data collection for their APCD and HDD programs using national standards, or are perhaps unaware of standard definitions, with the exception of most HDD programs using the standard hospital billing claim (i.e., UB-04) in data submission guidance. The APCD Council, a collaboration between the National Association of Health Data Organization (NAHDO) and the Institute for Health Policy and Practice at the University of New Hampshire, created the APCD Common Data Layout (APCD-CDL™) with national health insurance standards as the core structure for development, particularly X12N Post-Adjudicated Claims Data Reporting (PACDR). The APCD-CDL™ includes data elements for a member's sex (under the misnomer "gender" in alignment with the X12N 271 transaction guide, a known issue by HL7 and X12 that is addressed in APCD-CDL™ version 3),[22] race, and ethnicity (using CDC guidance in alignment with the external codes for a "not used," or not required, data element in the X12N 834 transaction).[23] However, the APCD-CDL™ does not include data elements for SOGI because standard health insurance transactions do not include SOGI.

[21] From *Why Collect Race, Ethnicity and Primary Language,* by American Hospital Association, Institute for Diversity and Health Equity, 2022. (https://ifdhe.aha.org/hretdisparities/why-collect-race-ehtnicity-language)
[22] From *The Gender Harmony Project*, by R. McClure, 2022. (https://confluence.hl7.org/display/VOC/The+Gender+Harmony+Project)
[23] From *CDC Race and Ethnicity Code Set – Version 1.0,* from Centers for Disease Control and Prevention, n.d. (https://www.cdc.gov/nchs/data/dvs/Race_Ethnicity_CodeSet.pdf)

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One APCD respondent described why their organization deviates from national standards when defining data collection:

> *The main reason is that much of the social determinant of health data needed for research does not apply to claims adjudication and therefore not available/not included/not collected on claims and enrollment transaction standards. I have also heard that there is hesitancy on the part of insurance companies to request this information for fear of appearing discriminatory.*

The respondent's point that SDoH data are not needed for claims adjudication and, thus, unavailable for collection suggests potentially misaligned incentives that might explain why CMS and the respondents in this survey observe relatively low rates of SDoH diagnosis code utilization. Indeed, demographic and SDoH data have not typically been necessary for claims adjudication in the past, but this overlooks that SDoH data could be collected through wider use of the ICD-10-CM Z-codes in standard insurance transactions (i.e., X12N), and that demographic data are in health data standards for interoperability (i.e., USCDI).

Summary

APCD and HDD programs' data collection (and quality) typically reflect standard medical and pharmacy insurance EDI transactions with exceptions often due to data collection requirements in state law or regulation. However, industry stakeholders exchanging data might have different business needs, incentives, and methods for data storage. Health data organizations should not expect that including demographic and SDoH data elements in data submission guidance is sufficient to collect useful data.

A mechanism for collecting SDoH data exists in the standard insurance data lifecycle (i.e., ICD-10-CM on an X12N transaction between provider and payers). Some demographic data (e.g., sex, race, and ethnicity) exist in the insurance data lifecycle too, but others (e.g., SOGI) exist in the larger health data ecosystem using other standards for interoperability (i.e., USCDI and HL7 FHIR). Even when these data exist, it is important to consider whether the fields are used by industry (e.g., providers and payers) and how they are collected (e.g., self-report).

Health data organizations must strike a balance between the need for demographics and SDoH data to support innovative analyses of health equity and disparities, and alignment with national standards that were not developed specifically for public health. Industry-wide standards organizations often need more time than APCD and HDD programs to make changes. In that way, DMSOs might want to know the experience of APCD and HDD programs, but cannot change their processes as quickly, as the industry needs may not be aligned with state and local public health data needs.

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Based on these findings come the following recommendations:

1. Whenever possible, health data programs should leverage industry standards for exchanging health data.

Where the relevant industry standards come up short (e.g., X12 transactions missing SOGI data), there is an opportunity to plan for or pursue the collection of data elements using alternate standards that are more complete, although that may require accepting data from a different origin point or source. There should also be an ongoing effort to encourage data standards maintenance organizations to address any shortcomings that limit the usefulness of the standards.

2. Health data programs should build the functionality in the system during implementation that accommodates secondary data or build functionality in processes that anticipate change in the future.

There are opportunities to collect reliable demographic and SDoH data from other sources. Health data systems should be technically compatible with a broad range of data sources.

3. APCD and HDD programs should consider aggregate data for small geography (e.g., Census tracts or blocks) for imputation while being mindful of limitations.[24,25]

[24] According to an ASPE report, entitled *Imputation of Race and Ethnicity in Health Insurance Marketplace Enrollment Data, 2015 – 2022 Open Enrollment Periods*, "limitations include the imputation assumption that nonreporters are otherwise similar to self-reporters with the same names and Census block group, the use of older Census data owing to unavailability of 2020 data during the analysis, and the potential that mortgage application data may misrepresent racial and ethnic groups because of longstanding structural inequities in housing."

[25] From *Ethics and Empathy in Using Imputation to Disaggregate Data for Racial Equity, A Case Study Imputing Credit Bureau Data,* by A. Stern, A. Narayanan, S. Brown, G. MacDonald, L.D. Ford, & S. Ashley, 2021. (https://www.urban.org/research/publication/ethics-and-empathy-using-imputation-disaggregate-data-racial-equity-case-study-imputing-credit-bureau-data)

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