



MAY 2024

State Requirements for Demographic Data Reporting upon Hospital Discharge: An Overview for State Flex Programs

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KEY FINDINGS

- An environmental scan of the 45 states participating in the Flex Program revealed that most states require hospitals to report sex, race, and ethnicity demographics in hospital discharge data. Definitions and categories for these demographic characteristics, however, vary widely between states.
- Very few states require reporting of other demographic data upon hospital discharge including sexual orientation, gender or gender identity, language, disability status, or tribal affiliation.

PURPOSE

Recording and reporting demographic data in hospital encounters is crucial for identifying and addressing health outcome disparities among different populations. These data typically include indicators of race, ethnicity, and language (REL); sexual orientation and gender identity (SOGI); and sex. Collecting such data can enhance doctor-patient interactions, enable more patient-centered care, and inform more equitable distribution of resources. However, challenges persist, including lack of standardization in data collection, particularly in rural hospitals, reluctance among providers to collect such data, as well as hesitation from some patients to disclose their demographic information. Efforts to standardize data collection are essential for improving accuracy and measuring health inequities, and rural hospitals, including Critical Access Hospitals (CAHs), face unique obstacles. This brief outlines the current state requirements for collecting demographic data and highlights some CAH-specific considerations.

BACKGROUND

Recording and reporting demographic data from hospital encounters can help identify differences in health outcomes between populations and act as a starting point to address these inequities.^{1,2} Demographic data collected by hospitals primarily includes race, ethnicity, language, sex assigned at birth, sexual orientation, and gender identity. More information about collection of demographics including common definitions, categories, and tools for providers can be found in Appendix A.



Collecting demographic data can affect the quality of the doctor-patient interaction, particularly in the case of sexual orientation and gender identity (SOGI) data.³ For example, equipping providers with this information can promote a more patient-centered approach to care which facilitates accurate conversations about health and health behaviors.³ These data can also help inform broader, facility-wide decisions. During the COVID-19 pandemic, health care entities that utilized race, ethnicity, and language (REL) data were able to distribute resources more equitably and efficiently.⁴

To identify inequities and begin to address their root causes, hospitals must first have the data to identify the gaps.⁵ A few states began collecting hospital discharge data in the early 1970s which provided a standard format to report demographic data.⁷ This practice expanded in the following years to include almost all states collecting race and ethnicity data in hospital discharge data by 2015.⁶ In 1997, the U.S. Office of Management and Budget (OMB) updated their standards for classification of race and ethnicity data which separated Hispanic identity from questions about race.⁷ While lack of standardization has been a long-standing challenge for hospitals collecting demographic data,⁸ standardizing collection of socio-demographic data is a health equity priority for the Centers for Medicare & Medicaid Services (CMS) and is an important consideration for hospitals and communities aiming to identify health inequities.⁹

Accuracy in demographic data collection is important to assess patient populations and inequities. Often, databases that include demographic data include a high percentage of entries that are not useful for analysis such as “unknown race”, and these percentages are higher in observational health databases (e.g., data reported by providers) as compared to patient-provided information.¹⁰ Standardization can help improve accuracy of these data. For example, following the implementation of standardized guidelines and protocols for collection of race and ethnicity data in

New Jersey, the proportion of patients identifying as Hispanic decreased by 7%, “other” decreased by 25%, and Asian/Pacific Islander increased by 27%.¹¹

Health care facilities face some challenges when trying to improve their data collection and/or standardization. Some providers may be reluctant to collect patient demographic data based on beliefs concerning whether the information is useful and how the data will be used.¹² Importantly, previous work has found that provider beliefs about SOGI data collection and desires to accurately record these data coupled with imprecise categories in electronic health records (EHRs) may impact accuracy of data.¹³ This may apply to REL and other demographic data as well.

Rural hospitals, including Critical Access Hospitals (CAHs), often have limited resources that may make collecting and using standardized demographic data more challenging. This is reflected in previous research that found use of standardized forms for collecting race and ethnicity data is less common among rural hospitals.¹⁴ Further, low inpatient volumes (and thus fewer data points) in CAHs can make it more challenging to draw meaningful conclusions from data analysis. New quality measures from CMS in CY 2024 will require hospitals to attest to whether they collect and analyze demographic data, including race and ethnicity, to identify equity gaps.¹⁵

This report summarizes current state approaches to demographic data collection and identifies additional challenges CAHs may face in meeting state standards.

APPROACH

For this study, we conducted an environmental scan of state-level policies related to hospital collection of demographic data. The scan was completed between June and September 2023, and while it was thorough, it may not provide a completely exhaustive list of state policies. We conducted this search for all 45 states that participate in the Medicare Rural Hospital Flexibility (Flex) Program. To identify state hospital



demographic data reporting requirements, we used the following search terms: “hospital discharge reporting requirements [state]”; “hospital discharge data [state]”; “[state] hospital data race and ethnicity requirements”; “[state] hospital demographic data collection”; “[state] hospital demographic data collection requirements”. The source documents identified are included by state in Appendix B. Hospital reporting requirement resources identified in the search included: hospital reporting manuals, state legislation, state hospital association webpages, state department of health webpages, and more. Once resources were located, we identified specific requirements and definitions, when available, for race, ethnicity, sex assigned at birth, gender identity, sexual orientation, language, disability, and other demographics. We recorded the entity to which these variables were reported, as well as any notable proposed changes, COVID-specific policies, and CAH waivers or exemptions. In most cases, exemptions and exceptions relevant to hospital reporting requirements were found within these resources, but when they were not noted in these resources, we used the following search terms to attempt to locate them: “[state] hospital reporting exceptions”; “[state] hospital discharge data reporting exceptions”; “[state] critical access hospital reporting”. In many cases, no exemptions or exceptions were found. States were noted to have no exceptions when language such as “all hospitals” was used and/or exceptions to other types of data collection, but not demographic data, were found. We excluded proposed changes and COVID-specific policies in the results below as there was very little information available in the resources we identified.

It is important also to note some assumptions we made while conducting the environmental scan, particularly in how sex and gender data were defined. Using definitions from the National Institutes of Health, throughout this brief we consider “sex” to be a biological descriptor that includes features of an individual’s anatomy, physiology, genetics, and hormones; whereas “gender” is a social characteristic that includes an

individual’s identity, roles and norms, relations, and power.¹⁶ However, in practice, these are often used synonymously, including in clinical settings and in the findings of our environmental scan. In our findings, we describe the data we believe states are collecting, which does not always align with what the state said they collect. For example, when a state indicated that they collect “gender” data, but their reporting options only include M, F, and Unknown, we categorized this as patient “sex” rather than “gender”. Similarly, if a state indicated that they collect “gender” data but do not also require collection of “sex” data, we assumed they are actually collecting “sex” data. We believe this allows for more accurate comparisons between and across states. It’s also important to note, however, that at the hospital and/or provider level, there are likely to be assumptions of patients’ sex that is based on their perceived gender or gender expression.

Search results for each state were organized in an Excel spreadsheet, and findings were cleaned, summarized, and quantified.

RESULTS

We were able to find specific information about required reporting of demographic data upon patient discharge for 37 of the 45 states in the Flex Program. Their policies varied widely in the level of detail publicly available, and these findings are summarized below by topic. For the remaining eight Flex Program states (Hawaii, Idaho, Iowa, Michigan, Minnesota, North Dakota, South Dakota, and Wyoming), we were unable to find specific information about their reporting requirements.

Sex, Gender, and Sexual Orientation

Of the 37 states that had information about their required demographics for reporting, 35 require reporting of patient sex, including ten states that seem to have conflated the terms “sex” and “gender” as described above in the approach. Seventeen states indicated that their hospitals report patient “sex” but did not provide



specific details about how “sex” was defined or what options were available. Fifteen additional states use three categories of male, female, and unknown. Three states indicated a different categorization system, including specifying sex assigned at birth or additional categories of “missing”, “invalid”, or “suppressed”. Unfortunately, we were unable to find details of how those additional categories were defined by the states that used them.

Only three states indicated that their hospitals report patient sexual orientation, with two of those states not providing detail. The remaining state uses ten categories, though we were unable to find how these categories were determined.

Only two states indicated that their hospitals report patient gender identity. Both states also report patient sexual orientation. For one state, we were unable to find additional details and the other state uses seventeen options for gender identity. We were also unable to find how these gender identity categories were determined by this state.

Race, Ethnicity, and Language

Thirty-four of the 37 states that had information available appear to require their hospitals to report race data, but the categories used to collect and report these data vary widely across states. Five states report that they

use the seven OMB categories of American Indian/Alaska Native, Asian, Black/African American, Native Hawaiian/Other Pacific Islander, White, Other, and Unknown. An additional nine states use those same five main race categories but with changes such as an additional category for “two or more races” or dropping the “other” and/or “unknown” categories. Eight states use another categorization system including combining race with ethnicity categories, combining Asian and Pacific Islander into one category, or using more specific categories. For example, one state has 72 options but notes that most hospitals use the seven OMB categories.

Most states (19) indicated that their hospitals report ethnicity using the categories of “Hispanic or Latino” and “Not Hispanic or Latino.” Some of these states (13) have additional categories such as “refused”, “unknown”, or “missing”. Five other states (not included in the 19 above) combine ethnicity and race codes (e.g., White, non-Hispanic origin).

Six states indicated that hospitals report patient language data, but varied in how they define language or the options provided. One state has 50 language options for the patient’s “preferred language”, another has 46 to select for “primary” or “principal” language, two describe the category as “primary language spoken”, one defines it as “written and spoken, English proficiency”, and one we were not able to find details for.

Other Data, Reporting, and CAH Exemptions

In our search, we looked for a few other elements in state requirements that are summarized here. A few states include other demographics in their reporting requirements, including disability status (three states) and tribal affiliation (one state).

We also looked at which organizations hospitals report these demographic data to. For most states, hospitals report this information to their department of health (23 states). Six states report these data to their statewide hospital association, and seven states report

TABLE 1: Frequency of Definitions of Race and Ethnicity

Race Definition	Number of states
OMB Categories	5
OMB Categories with changes	9
Defined another way	8
Reports race but no details available about how defined	12
Total	34



to another type of data organization, which appeared to mostly be other state-run agencies. For one state, we were unable to find which organization hospitals report to.

Only one state was found to have an explicit exemption or exception for CAHs and indicates that “waiver and grant opportunities are only available to certain Critical Access Hospitals,” but no other details were available. Nine other states listed some type of exemption or extension not specific to CAHs. Three states provided deadline extensions, and the remaining six states offer more complete exemptions, some citing specifics such as “if requiring the hospital to comply with the requirements would cause the hospital financial hardship” or “eligible hospitals may apply for a waiver due to economic hardship, technological limitations not reasonably in the control of the hospital, or other exceptional circumstances.”

DISCUSSION

Demographic data for patients discharged from hospitals is one source for states, hospitals, and communities to use to identify health inequities and better understand the populations they serve. It is thus important for the state department of health, hospital association, or other organization that collects these data to provide clear guidelines for what data hospitals should collect and which relevant categories should be used for this collection. We found that eight Flex states currently have none of this information about what data is collected publicly available online, and many states provide incomplete or unclear information about hospital reporting requirements. Without clear guidance from state organizations, hospitals are unlikely to record data in the exact same ways and with the same categories. While individual hospitals may still be able to use their collected data for quality improvement internally, it becomes difficult to use the data for comparisons at the state or regional level when these categories are not comparable. This is particularly important for rural hospitals with small patient populations, where pooling discharge data from

other rural hospitals in the region may be helpful for conducting meaningful analyses, particularly to assess outcomes for marginalized populations.

Significant disagreement persists for the best practices to collect data related to race, ethnicity, and language. Nationally, OMB has identified seven race categories and three ethnicity categories which it suggests using,¹⁷ but we found that many states use different classifications. Even seemingly small modifications to the OMB suggestions, such as not including the “other race” category, can have a significant impact on hospital or state data, as patients are then forced to select another race category or may be placed in a “refused to answer” category. Of note, OMB has published revisions to these categories, including combining race and ethnicity into one question, and adding a “Middle Eastern or North African” race category.¹⁸ While standardized data offers many benefits, at the same time, states and individual communities vary greatly in their population characteristics and should maintain autonomy for some local-level data collection practices, particularly when collecting *additional* information, and provided that data can be aggregated to more widely-used categories.⁴ For example, states with larger Indigenous populations may want to collect tribal affiliation data, though this may be less of a priority in states with smaller Indigenous populations.

This analysis of state requirements related to demographic data collection reiterates the importance of collecting these data to identify, analyze, and address inequities. There is a robust body of research supporting that demographic data collection and reporting can help identify factors that lead to health inequities, bring awareness and resources to areas of need, and improve health care outcomes and overall health status for certain populations.^{1,2,19} For hospitals to address inequities, they need to first understand the composition of the population they serve and the different health outcomes specific demographic populations face. It is also important for hospitals to have the ability to compare their patient population to the



overall population of their service area to assess the extent to which they are serving residents in their communities. Once hospitals collect these data, they can identify inequities in outcomes and begin to address inequities by defining measurable goals, developing interventions based on these goals, and evaluating the outcomes of their interventions.

To best address health inequities between different demographic groups, hospitals also need to properly define populations to address specific issues. For example, ten state regulations conflate “sex” and “gender” or do not collect this data separately. This can artificially hide health inequities experienced by transgender individuals whose sex assigned at birth is used for demographic grouping, as well as for those whose sex is assumed to be their gender expression. This may not only skew the data, but also disregard the distinct health needs and structural factors that impact transgender patients’ health outcomes and access to health care.²⁰ The Centers for Disease Control and Prevention and the National LGBTQIA+ Health Education Center both recommend three separate questions to obtain sexual orientation, gender identity, and sex assigned at birth.^{21,22} The recommended response options to these questions differ across organizations, however, and may change over time to reflect terminology changes. Organizations developing standardized data collection tools or templates should strive to use the most current terms when possible, as should hospitals while also considering the makeup of their local community and how these changes may or may not be accepted.

While not specifically investigated in this study, data literacy of providers and staff plays a key role in successful collection of this information.¹² Hospital staff may be more willing and comfortable asking patients about their race, sexual orientation, and other demographics if they clearly understand the rationale for asking for this information. State agencies and the other organizations mentioned above can play a role in helping providers through training and resources, as

well as tools for hospitals to share with their patients about why these data are important. These resources may help build trust with patients who may be reluctant to disclose sensitive information, while also honoring a patient’s choice to not disclose information.

Demographic data collection practices have received increased attention nationally, including for CAHs. CMS’ new Hospital Commitment to Health Equity (HCHE) structural measure¹⁵ will be added to the Medicare Beneficiary Quality Improvement Project (MBQIP) in 2025, which is the quality reporting program for CAHs. This measure consists of attestations in five domains, one of which is focused entirely on data collection and has three sub-components. Once data from this measure become available, states can use this information to better understand their CAHs’ current practices and work with CAHs to identify areas for improvement.

When interpreting these state policies, there are a few other important features specific to CAHs to consider. Prior research suggests that while nearly all hospitals collect race and/or ethnicity data, rural hospitals are less likely to have a standard form to do so.¹⁴ One study found, however, that there was not a difference between rural and urban providers in their comfortability asking patients to identify their race and ethnicity, and that most providers were comfortable asking for this information.²³ This is encouraging for efforts to increase completion and accuracy of these data. There are also technical barriers for data collection that may be exacerbated for CAHs. Prior research has found significant variation and inconsistency of SOGI data documentation in hospital EHRs.^{24,25} There remains a lack of widely adopted standard fields and tools for SOGI data, meaning hospitals and health systems may need to customize their EHR for these purposes.²⁴ While some rural hospitals, including CAHs, may be able to do so,²⁴ CAHs are already less likely to have an advanced, comprehensive EHR to begin with, particularly if they are not system-owned, putting them at a significant disadvantage.²⁶



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It's important to recognize that this environmental scan includes policies at the state level, which is the minimum requirement states impose for their hospitals. This does not necessarily mean, however, that individual hospitals are not collecting additional data for use internally or locally.

CONCLUSION

This environmental scan underscores that states participating in the Flex Program vary widely in their requirements for hospitals to report discharged patients' demographic data. Consistent, accurate, and standardized demographic data collected from hospital discharges is an important foundational step for states and communities to identify health disparities and better serve their patients. Clear guidelines from state health departments or data organizations are crucial to ensure consistent data collection practices across hospitals and ideally, across states as well to allow for national comparisons. Discrepancies in demographic data collection practices pose challenges for data comparability and analysis. Understanding and supporting patient and provider data literacy is essential for successful data collection, highlighting the need for continued training and resources.

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This report was completed by the Flex Monitoring Team with funding from the Federal Office of Rural Health Policy (FORHP), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS), under PHS Grant No. U27RH01080. The information, conclusions and opinions expressed in this document are those of the authors and no endorsement by FORHP, HRSA, or HHS is intended or should be inferred.



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Appendix A: Resources for Collecting and Using Patient Demographic Data

Resource Name	Description
Measuring Sex, Gender Identity, and Sexual Orientation	Comprehensive resource on measuring SOGI characteristics from the National Academies of Sciences, Engineering, and Medicine.
Ready, Set, Go!	Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity from the National LGBTQIA+ Health Education Center
The National Standards for Culturally and Linguistically Appropriate Services (CLAS)	Resource from the National Department of Health and Human Services that includes 15 action steps for health care organizations to implement culturally and linguistically appropriate services and help reduce health disparities.
Data-Driven Care Delivery Toolkit	Toolkit developed by the American Hospital Association (AHA) Institute for Diversity and Health Equity (IFDHE) that includes tools for collecting, validating, and stratifying demographic data. Focuses primarily on REL data.
Building an Organizational Response to Health Disparities	Resource from the Centers for Medicare & Medicaid Services (CMS), focused primarily on REL data and includes links to other resources.
Resource of Health Equity-related Data Definitions, Standards, & Stratification Practices	CMS document that outlines recommended definitions and standards for patient demographic characteristics including race, ethnicity, sex, gender identity, sexual orientation, disability status, primary language, English language proficiency, and rurality.

Appendix B: Sources Used in Environmental Scan by State

Note: Links were active as of February 27, 2024. These are not meant to provide a complete list of resources but reflect the primary web pages where the information in this brief was found.

State	Source Description and Link
Alabama	<ul style="list-style-type: none"> Alabama Hospital Association Discharge Data Collection Program Description of Hospital Discharge Data Act
Alaska	<ul style="list-style-type: none"> Alaska Health Facilities Data Reporting Program Alaska Health Facilities Data Reporting Program Guidelines
Arizona	<ul style="list-style-type: none"> Arizona Hospital Discharge Data Reporting Specifications Manual
Arkansas	<ul style="list-style-type: none"> Arkansas Hospital Discharge Data System
California	<ul style="list-style-type: none"> Emergency Department & Ambulatory Surgery Encounter Reporting Inpatient Discharge Reporting
Colorado	<ul style="list-style-type: none"> Signed House Bill 22-1157
Florida	<ul style="list-style-type: none"> Florida Discharge Data Reporting Specifications Manual
Georgia	<ul style="list-style-type: none"> Georgia Rules and Regulations for Hospitals
Illinois	<ul style="list-style-type: none"> Illinois Department of Public Health Discharge Data Illinois Hospital Discharge Database
Indiana	<ul style="list-style-type: none"> Indiana Hospital Data Submission Portal Indiana Department of Health Hospital Discharge Data Indiana Hospital Financial Disclosure Law
Kansas	<ul style="list-style-type: none"> Kansas Hospital Discharge Data General Information Kansas Hospital Association Data Products and Services
Kentucky	<ul style="list-style-type: none"> Kentucky Health Facility and Services Data
Louisiana	<ul style="list-style-type: none"> Louisiana Hospital Inpatient Discharge Database Louisiana Administrative Code Hospital Discharge Data Submittal Guide
Maine	<ul style="list-style-type: none"> Maine Hospital Inpatient and Outpatient Data
Massachusetts	<ul style="list-style-type: none"> All Payer Claims Database and Case Mix and Charge Data Submission Massachusetts Hospital Inpatient Discharge Database
Mississippi	<ul style="list-style-type: none"> Mississippi Inpatient Outpatient Data Collection System Mississippi Healthcare Data Registry System
Missouri	<ul style="list-style-type: none"> Missouri Patient Abstract System
Montana	<ul style="list-style-type: none"> Montana Hospital Discharge Data System
Nebraska	<ul style="list-style-type: none"> Nebraska Hospital Information System Companion Guide
Nevada	<ul style="list-style-type: none"> Nevada Office of Analytics – Data Sources NRS 449.485
New Hampshire	<ul style="list-style-type: none"> New Hampshire Hospital Discharge Data
New Mexico	<ul style="list-style-type: none"> Health Information System Reporting Requirements for Healthcare Facilities and Access to Data and Reports
New York	<ul style="list-style-type: none"> Overview of Data Submission System Statewide Planning and Research Cooperative System (SPARCS) Data Governance Policy and Procedure Manual for Data Release Data Submission Compliance Protocol
North Carolina	<ul style="list-style-type: none"> North Carolina Hospital Discharge Data
Ohio	<ul style="list-style-type: none"> Hospital Registration and Reporting Requirements Ohio Hospital Association Data E-Learning
Oklahoma	<ul style="list-style-type: none"> Hospital Discharge & Outpatient/ASC Surgery Data
Oregon	<ul style="list-style-type: none"> Health Care Facility Utilization and Discharge Data Submission Requirements REALD Data Collecting and Reporting Requirements
Pennsylvania	<ul style="list-style-type: none"> Data Reporting Requirements
South Carolina	<ul style="list-style-type: none"> Data Oversight Council Definitions and Appendices
Tennessee	<ul style="list-style-type: none"> Required Data Elements and Codebook Definitions Hospital Discharge Data System
Texas	<ul style="list-style-type: none"> Discharge Reports—Records, Data Fields and Codes Health Care Facilities Exemptions from Filing Requirements
Utah	<ul style="list-style-type: none"> Utah Administrative Code 428-2-10 Utah Department of Health & Human Services Help and Manuals
Vermont	<ul style="list-style-type: none"> Reporting Manual for Vermont Uniform Hospital Discharge Data System (VUHDDS)
Virginia	<ul style="list-style-type: none"> Reporting Requirements for Patient Level Data Elements
Washington	<ul style="list-style-type: none"> New Rules for Hospital Patient Discharge Information Reporting Engrossed Second Substitute House Bill 1272 CHARS Implementation
West Virginia	<ul style="list-style-type: none"> Data Element Specifications Guide
Wisconsin	<ul style="list-style-type: none"> DHS 120.12 Data to be submitted by hospitals