HEALTH EQUITY *and* RACE AND ETHNICITY DATA

How Race and Ethnicity Data is Collected and Used

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» ABSTRACT

Over the past few decades, the United States has become an increasingly multi-cultural country.[1] As the nation's demographics change, some of the greatest challenges many health care organizations experience in providing quality health care services are knowing the patient populations they serve, identifying their patients' needs and preferences, and implementing and monitoring improvements in health and health care.[2] The collection of race and ethnicity data is considered crucial to providing quality health care for everyone.[3]

This paper examines the reasons behind collecting race and ethnicity data in health care, and how to overcome some of the obstacles that may arise in doing so. It looks at procedures that health care organizations can adopt regarding such data and current best practices around collecting, analyzing, using and reporting race and ethnicity data to complement other health equity efforts. Case study examples illustrate how some Colorado organizations participating in The Colorado Trust's Equality in Health initiative have learned to collect and use race and ethnicity data to improve the services they offer. Overall, data can be an important tool in providing quality health care services for all patients. Some of the issues discussed in the paper include:

Laws and Regulations
The national standards on Culturally and Linguistically Appropriate Services (CLAS) (see page 3) and the Patient Protection and Affordable Care Act (ACA) provide guidance and standards for how health care organizations can collect, analyze, use and report patient demographic data.

Staff Training
Organizations can help reduce barriers to collecting race and ethnicity data by facilitating discussions and training staff on data collection, its legality and uses, and how to work with patients on data collection.

Data Collection
Best practices on data collection focus on increasing patients' comfort levels by asking them to self-identify

their race and ethnicity and explaining that the data will be used to monitor quality of care. Demographics data can be recorded in a standard database and linked to clinical data as well as other quality measures to provide a more comprehensive picture of any disparities that exist.

Data Analysis

Race and ethnicity data can help health care organizations better understand whether racial and ethnic health disparities exist and, if so, if those disparities are increasing or decreasing. Organizational data review committees can review and interpret data results, consider what organizational and institutional factors may contribute to patient health disparities, identify how services can be modified and/or developed to address patient health disparities, assess the impact of culturally tailored and targeted services, and track changes in patient health disparities over time.

Data Reporting

Race and ethnicity data results can be used to validate the effectiveness of programs, demonstrate accountability, promote an organization's values and commitment to being inclusive, and justify funding. Carefully tailored messages and communications methods that consider the interests and concerns of each stakeholder group can help organizations convey the results of their work.

Contributing Factors

Many of the participants in The Colorado Trust's Equality in Health initiative expressed that a key factor to successful data collection was having leadership support and an organizational culture that is open to self-reflection and growth.

Drawing on lessons learned through the Equality in Health initiative, and existing data, this paper shares information to help health providers and leaders of health care organizations consider how they might improve their collection and use of racial and ethnic data as one means to strengthen equitable and quality health care services.

» INTRODUCTION

The prevalence of racial and ethnic health disparities has received heightened national and state visibility in the past decade. While health care organizations are working to eliminate such disparities, they nonetheless experience challenges in identifying the populations they serve, meeting their needs and monitoring improvements in health over time.[2] Improved data collection and reporting procedures could help these organizations increase awareness of health care disparities, determine appropriate strategies for reducing them and gauge the effectiveness of their efforts.[4]

Collection of these types of data is being used by government and industry as a tool to raise the quality of health care. Title VI of the 1964 Civil Rights Act prohibits recipients of federal assistance from discriminating on the basis of race or national origin. It also eliminates legal liability for health care organizations that collect and report patients' race and ethnicity for the purpose of improving care quality.[5] Since then, national reporting requirements have been developed to mandate agencies to collect this information. The 2010 Patient Protection and Affordable Care Act (ACA) aims to advance the collection of race and ethnicity data. The U.S. Department of Health and Human Services (HHS) recommends that accreditation organizations such as the Joint Commission, which accredits and certifies more than 19,000 health care organizations and programs in the country, incorporate the collection of race and ethnicity data into its standards and performance measures.[6]

In addition to meeting compliance regulations, health care organizations can collect, analyze, utilize and report patient race and ethnicity data to measure and alleviate disparities that may exist among their own service population. Identifying and tracking such disparities can lead to the development of programs better aligned with the needs and preferences of diverse communities. Monitoring the racial and ethnic

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Current Standards of Practice

The federal Office of Minority Health has developed national standards on Culturally and Linguistically Appropriate Services (CLAS) to ensure that the practices of health care organizations are culturally and linguistically accessible to all communities. Most of the 14 CLAS standards are required for all recipients of federal funds or recommended for adoption as mandates by federal, state and national accrediting agencies. Six standards apply to the collection, analysis, utilization and reporting of race and ethnicity data:[9]

■ **Standard 2:** Health care organizations should implement strategies to recruit, retain and promote at all levels of the organization a diverse staff and leadership representative of the demographic characteristics of the service area.

■ **Standard 8:** Health care organizations should develop, implement and promote a written strategic plan that outlines clear goals, policies, operational plans and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.

■ **Standard 9:** Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments and outcomes-based evaluations.

■ **Standard 10:** Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.

■ **Standard 11:** Health care organizations should maintain a current demographic, cultural and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.

■ **Standard 14:** Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

composition of patients while staying attuned to changing demographics and needs of the greater population can help health care organizations better serve diverse communities.[7,8]

In addition to the CLAS standards, section 4302 of the ACA expands current requirements for data collection and analysis by requiring standardization, collection, analysis and reporting of health disparities data.[10] By amending the Public Health Service Act, the ACA requires as of 2013 all federally funded health programs and population surveys to collect and report a variety of patient demographic data, including race and ethnicity.[11] Furthermore, as required by the provision, the HHS Secretary has established data collection standards and guidelines that can be "used, to the extent practicable, in all national population health surveys."[10] (See Appendix for the HHS Race and Ethnicity Data Standards and Implementation Guidelines.)

The HHS race and ethnicity guidelines focus on such issues as how to ask questions to get the information needed and ensure data quality. They specify which categories of race and ethnicity to use in questionnaires, and how to handle variations. Some flexibility exists for a patient to select more than one choice in each question.

The HHS guidelines also outline new minimum data collection standards for sex, primary language and disability standards. This paper and The Colorado Trust's Equality in Health initiative, however, focus on racial and ethnic disparities, recognizing that communities of color across the state continue to be disproportionately affected by disease and disability, with less of an opportunity to achieve optimal health.

≫ CHALLENGES TO COLLECTING RACE AND ETHNICITY DATA

A variety of agencies ranging from state health departments and health insurance companies to community health centers and nursing homes collect, analyze, use and report race and ethnicity data. Although having numerous stakeholders can be beneficial, this situation can also be challenging since

each entity tends to have its own reasons for and ways of categorizing, collecting and aggregating the data.[2] While the new standards developed through the ACA address this issue, other barriers should be considered.

Addressing Provider and Patient Concerns and Perceptions

A clear understanding of why it is important to collect race and ethnicity data is needed for staff of health care organizations to buy into the process. Otherwise, staff ranging from intake workers to medical providers may feel burdened by the process or be uncomfortable soliciting this information from patients. Some staff may not believe there are disparities in their practice, while others may worry that if disparities are identified, they will be accused of discrimination.[12, 13]

At the same time, patients may be hesitant to provide race and ethnicity data because of concerns around privacy and discrimination.[2] Patients may not understand why health professionals want race and ethnicity data, or they may associate providing race and ethnicity data with discrimination or misuse of the data, such as using it to find undocumented immigrants.[14] Most patients, however, believe that health care providers should collect race and ethnicity data, although minorities are less comfortable with the procedure.[11, 15] According to one study, "28 percent of patients had significant discomfort reporting their own race/ethnicity…, and 58 percent were somewhat or very concerned that their race and ethnicity information could be used to discriminate against patients." Letting patients know that the information will be used to strengthen the quality of care – rather than saying the information is mandated or required – has been shown to improve their level of comfort.[15] Common provider and patient concerns can often be addressed by facilitating discussions with staff around the importance of collecting race and ethnicity data and conducting trainings that offer guidelines and strategies for how to implement the procedure and explain the purpose to patients. Equipping staff with these skills and understanding can help organizations successfully carry out their data collection and health equity efforts.

Understanding the Legality of Data Collection

Discussions around race and ethnicity can be challenging and may be viewed as taboo or controversial topics. As racial and ethnic health

disparities remain, however, having such discussions may be necessary. Such conversations can be supported by informing staff that not only is collecting race and ethnicity data permitted under Title VI of the 1964 Civil Rights Act and the ACA, but it is also required for recipients of federal funding to ensure compliance with many statutes.

The American Recovery and Reinvestment Act of 2009 lays out expectations for the inclusion of race and ethnicity variables in electronic medical records.[2] While some health care providers may be concerned about the applicability of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, which addresses security and privacy of data among other issues, it is helpful to note that HIPAA restricts the use and disclosure of identifiable health information but does not prohibit the collection of demographic data for quality improvement efforts.[16] Setting data-collection procedures can help ensure that data collection, analysis and reporting are conducted sensitively and properly to maintain patients' privacy.

Understanding Subpopulations

The race and ethnicity data standards of the ACA specified additional subgroups that were formerly classified under "Hispanic/Latino," "Asian" and "Native Hawaiian or Other Pacific Islander."[10] While this more specific classification represents an improvement from the previous Office of Management and Budget standards, the new categories still may not fully distinguish locally relevant ethnic populations with unique cultural needs and preferences.[2] Although an organization may be limited in their capacities for collecting and analyzing an abundant number of categories, if feasible, collecting and utilizing more detailed data may prove useful in addressing disparities that exist within an organization's patient population. Although such data need to be aggregated to abide by the ACA standards, using consistent methods to identify key subgroups can be helpful.

Consistent methods can facilitate more robust analyses of relevant community demographics and inform national standards about categories that capture the full diversity of the population.[2] Adding an "other, please specify: _____" category to the ACA standards could help inform service providers about the local patient population's demographics. Similarly, as stated in the ACA standards, including instructions that inform individuals they may select "one or more"

racial or ethnic groups will provide more accurate data than a single "multiracial" category.

Using Health Information Technology

Advances in health information technology, including the transition to electronic medical records (EMRs), may aid the progression of data collection. However, without a standard procedure for designing or utilizing health IT systems, efforts for data collection, analysis and utilization are complicated by the challenges of capturing sufficient information as well as linking data from multiple sources.[17]

The first issue of insufficient information often results from inadequate space on data collection forms or in health IT systems to capture detailed race and ethnicity data.[8] While the ACA requires the separate collection of race and ethnicity data, some health IT systems only include one field for capturing both indicators.[2] Similarly, other systems are unable to handle more than one response, prohibiting patients from selecting one or more category such as "black, Hispanic."[18]

The second challenge of linking demographics data with health data can occur if demographic data are included in practice management systems, while clinical information care is captured in health IT systems.[2] Assessing quality of care across diverse racial or ethnic groups may require data from the two systems to be cross-referenced. While EMRs now
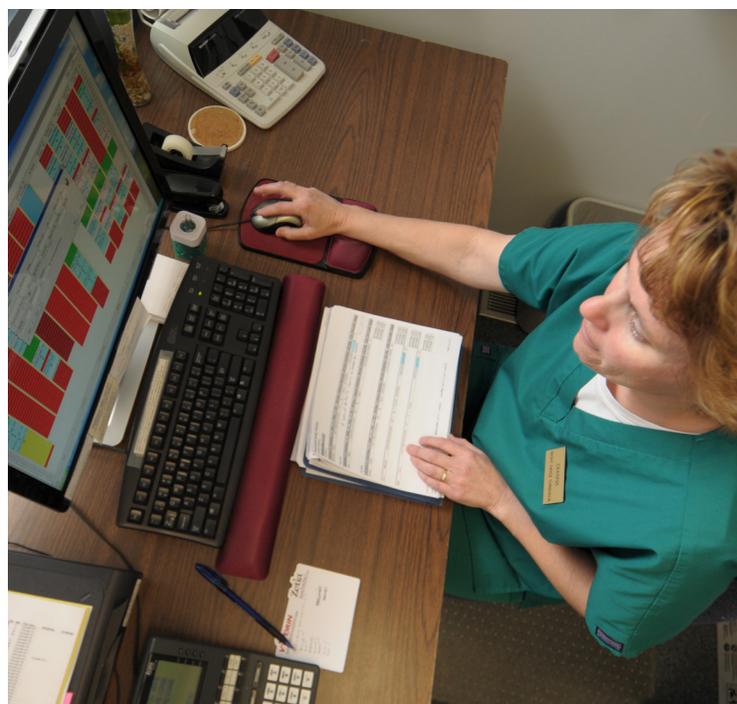
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provide a mechanism for collecting demographic data as well as clinical information in one system, many were designed solely to capture individual patient data and not for running reports that analyze population data. Despite the added administrative burden, many organizations that recognize the importance of understanding their patient demographics and corresponding health outcomes manually code and analyze the data in the absence of adequate automated systems. As health care organizations become more aware of how EMRs and other health IT systems could complement their efforts to understand racial and ethnic health disparities, they can encourage health IT and EMR companies to develop tools that can better capture and analyze patient demographic information.

Similarly, health IT systems in Colorado provide valuable data to inform quality improvement efforts. These systems could be utilized to integrate the collection and use of race and ethnicity data. For example, the All Payer Claims Database (APCD), administered by the Center for Improving Value in Health Care (CIVHC), is a comprehensive source of health care claims data from private and public payers in Colorado.[19] Going forward, some refinements could make this system an even stronger resource, such as: the inclusion of additional fields for race and ethnicity that align with new federal standards; use of the HHS Race and Ethnicity Data Standards; listing subpopulations that are relevant specifically to Colorado; the inclusion of mechanisms to ensure uniformity of race and ethnicity data collection; and more robust data for large commercial payers, Medicaid, Medicare, self-insured and small group plans.

» STRATEGIES FOR SUCCESS
Collecting Race and Ethnicity Data

Given the sensitive nature of soliciting race and ethnicity information, health care organizations may want to develop a protocol for how to collect the data. Training sessions can help staff become familiar with the protocol and comfortable with its implementation. Periodic trainings may be necessary because research on how best to collect and use race and ethnicity data is constantly evolving based on advances in health IT, the changing demographics of the United States and how individuals self-identify.

Some organizations have made recommendations, including the American Medical Association's Commission to End Health Care Disparities.[20] Current best practices on how to collect race and ethnicity data include:

- **Who provides the data.** Ask patients (or those who care for them) to identify the patient's race or ethnicity rather than inferring from observation or name.[21]

- **Where to collect the data.** Patients' race and ethnicity data can be collected during registration to ensure the information is available prior to the patient receiving services. Organizations can consider the pros and cons of different places where the data could be collected and determine the most appropriate.[21]

- **Introducing the topic.** Although some people may have concerns about how race and ethnicity data may be used, most individuals are willing to provide their demographic information. Research has demonstrated that nearly 80 percent of patients strongly agree or somewhat agree that health care providers should collect information about their patients' race and ethnicity, and nearly 97 percent feel it is important for hospitals and clinics to gather race and ethnicity data to ensure that all patients receive high-quality care.[15] To ease any uncertainties that patients may feel, however, providers can share why the data are being collected prior to asking about race and ethnicity. One study revealed that of participants who originally were uncomfortable reporting their race and ethnicity, 25 percent said the explanation about how the information would be used to monitor quality of care made them somewhat more comfortable and 26 percent said the explanation made them much more comfortable.[15] Providers will also want to inform the patient that the information will not be used against him or her in any way.

- **How to collect the data.** Under the ACA, organizations receiving federal funding are required to use the HHS racial and ethnic data standards. It is recommended that they use the ACA as a base and add more specific categories based on the populations of their local community and their patients. This step may be particularly important for a culture-based organization comprising primarily staff and board members of the racial or ethnic group(s) it serves. Categories of "other" race or ethnicity with space to list the patient's response, "refused or declined to answer" and "unknown," can also be helpful. If a patient is asked to provide the information through a written form and leaves a question blank, staff can follow up to determine whether or not the patient had difficulty understanding the question or concerns about why the question was asked. Providing an interpreter if language barriers exist can create an opportunity to explain why the data are being collected and to answer any questions or concerns the patient may have.[21]

While it is obviously unnecessary to ask patients about their racial and ethnic identity at every visit, asking again can allow patients the opportunity to change their identification or to confirm their existing identity if the recommended racial and ethnic categories change.

- **How to record the data.** Demographics data can be recorded in a standard database to facilitate aggregation and linking to clinical data as well as other quality measures.[21]

Once a data collection protocol has been developed, organizations may want to educate all staff about why the organization is collecting race and ethnicity data and how to address any concerns that patients may have. Staff members responsible for collecting the data may require additional training on implementation procedures. Additional trainings may be needed to inform existing staff about any process modifications and as needed with new employees.

Informing the community about a new system to collect race and ethnicity data can help ensure the initiative's success. Steps can include multi-language fliers around the facility, mailing brochures to existing patients, placing public service announcements or contacting media outlets.[13] Engaging community members in conversations through focus groups and community forums can help facilitate the data collection process by including them and patients as active and informed partners in the process. Discussing why the organization will collect race and ethnicity data, what patients can expect when they arrive at their appointments and how the data will be used can lead to an open dialogue about any concerns community members may have as well as create an opportunity for staff to learn about community values and needs they may not have been aware of previously.[7]

Health care organizations will also find ongoing evaluations of the data collection protocol to be useful. Staff perceptions and feedback on the process can help organizations assess their efficiency and determine if additional training is required, while patient perceptions and feedback can provide information about patients' level of comfort responding to the questions and how the process could be improved. Having supervisors listen to staff interactions with patients when race and ethnicity data are being collected could also provide valuable information about how the protocol could be improved.
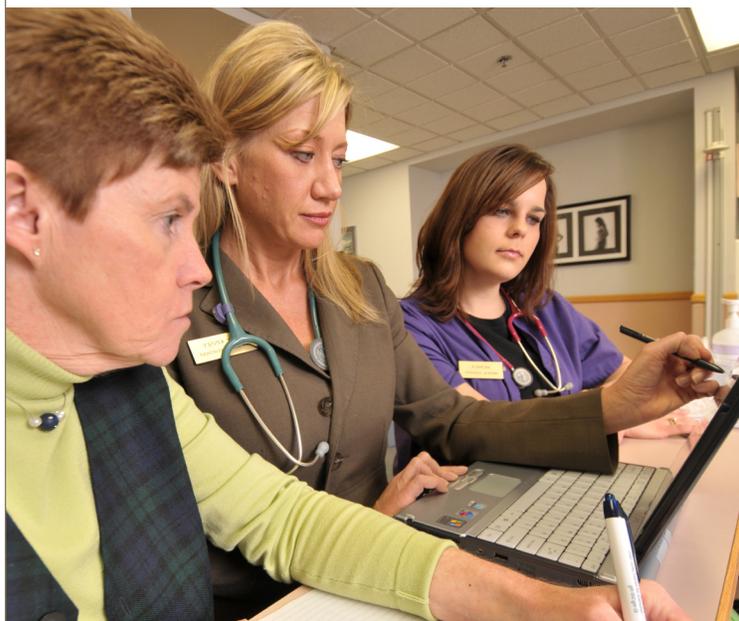
Analyzing Race and Ethnicity Data

Analyzing outcomes data (e.g., health indicators, disease rates) with patients' race and ethnicity data and satisfaction data can help organizations better align services with patients' needs and preferences. Health care organizations often have multiple data tracking systems ranging from Excel spreadsheets and Access databases to patient registration systems and electronic medical records. Before the data are collected, organizational leaders will need to consider how the data will be analyzed to ensure that the race and ethnicity information is entered into the appropriate system(s). This also requires a clear understanding of how the data will be linked to patient outcomes and satisfaction, who should have access to the data and how reports will be prepared, disseminated and utilized.

To assure the value of analyses, organizations should assess the quality of the data. Completeness of the data can be assessed by reviewing missing data as well as instances where patients declined to respond. Although patients who decline to respond should not be asked for their race and ethnicity information again, examining the rate of such responses can inform whether or not the data collection protocol may need to be adjusted and/or if additional training is required.

It can also be useful to examine responses in the "other" category. Analyzing clinical data from ethnic groups with high frequencies of responses in this category may provide important information for the organization regarding changing community demographics. Depending on the size of this population, such data could also inform decisions to add ethnic subcategories to the question and data tracking systems.

If organizations conduct outcomes and satisfaction analyses based on sampling their patient population, they should pay particular attention to the size and representativeness of the sample for smaller racial and ethnic groups. To increase the reliability of the estimates, organizations may want to oversample underrepresented populations, that is, include a greater percentage of patients from the smaller populations than the larger populations so the numbers of patients from both groups are more similar. This will allow a more detailed analysis of the effects on disparities.

Other changes worth tracking over time include differences across racial and ethnic groups and differences in rates of change across racial and ethnic groups. In examining data, health care leaders can determine such trends as what and how disease rates are changing, which populations are impacted, and whether disparities are improving or worsening.

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Equality in Health Initiative

Equality in Health (EIH) was a seven-year initiative funded by The Colorado Trust (The Trust) to reduce racial and ethnic health disparities across Colorado. Twenty-six health service organizations were selected to develop their cultural competency, receiving five-year grants from 2005-2010 or 2007-2012. The grantee organizations varied in their size, geographic location, service provisions, organizational capacity and client populations, providing The Trust and a team of technical assistance providers the opportunity to assess a number of strategies for improving health equity.

By the end of the initiative, many grantees demonstrated important changes, including increased staff, board and client diversity; implementation of cultural competency policies; enhanced methods to solicit client feedback; and adaptation of services to meet the cultural and linguistic needs and preferences of diverse communities. These changes resulted in increased usage of the organizations' services by racial/ethnic minorities, which, in turn, led to further organizational development efforts tailored to the changing community demographics.

The literature and research findings described in this report are complemented with EIH grantees' experiences specific to data collection, gleaned from interviews with executive directors of some of the grantee organizations.

Case Study on Collecting and Analyzing Data:
Colorado Total Smiles[21]

Established in 2007, Colorado Total Smiles (CTS) (formerly Total Oral Prevention Strategies) is a nonprofit located in Metro Denver that provides oral health care services to underserved communities. CTS collects race and ethnicity data from its pediatric patients through its treatment consent form. When asked to complete the consent form, patients are informed of the purpose of collecting demographic information and assured their names will not be used in the data analysis process. The racial and ethnic categories on the form align with those of the 2010 Census and also include an open-ended "other" category where patients can list an identity that is not provided. With the growing number of patients selecting "other," however, CTS plans to identify the most commonly listed racial and ethnic groups and add them to the list of provided options.

Although CTS did not experience any resistance from patients, some staff members originally were uncertain as to why the program was collecting patient demographic information and were reluctant to do so. CTS provided training on the importance of collecting race and ethnicity data to give staff a greater understanding of how the data can help improve their service to communities facing disparities. Staff

members also are able to share, not only with patients but also parents, teachers and community partners, the program's efforts to reduce racial and ethnic health disparities. In turn, some patients have expressed pleasure in contributing to the agency's efforts. The impact of the organization's willingness to take the time to explain its reasons for collecting race and ethnicity data has likely contributed to the increased response rate to this question over the years.

CTS, which has four staff members and does not have an EMR, utilizes volunteer graduate students to help enter patient demographic data from paper records into a data analysis software package. Although this prevents the organization from being able to fully integrate demographic data with medical records, it allows for more useful analyses of paper records to identify trends among patients. Race and ethnicity data are also collected on CTS' patient satisfaction survey, allowing program leaders to assess whether or not certain populations are more or less satisfied with their services than others. In addition to race and ethnicity information, CTS also collects demographic data on attributes such as language, insurance type, ZIP Code of residence and computer access. This information is then linked to race and ethnicity data. Moving forward, CTS intends to begin collecting data on oral health comorbidities (two or more diseases existing at the

same time) and is planning to adopt an organizational policy on data tracking.

Using Race and Ethnicity Data

Once patients' race and ethnicity data have been analyzed for current disparities as well as changes in these disparities over time, organizations can interpret the data and make recommendations for adding or modifying services. Interpretation of the data and the development of recommendations can be done through a variety of entities such as a committee, quality improvement department or data team. It may be helpful for such an entity to include staff representing various programs or departments of the organization in addition to organizational leaders. It may also be helpful to have representation from the organization's board of directors, the community and/or the patient population. Objectives of the group may include the following:

- Review and interpret data results

- Consider what organizational and institutional factors may be contributing to patient health disparities

- Identify how services can be modified and/or developed to address patient health disparities

- Assess impact of culturally tailored and targeted services

- Track changes in patient health disparities over time.

If significant disparities are identified, the organization may need additional methods to obtain feedback from affected communities. Gathering input through focus groups, community forums and key informant interviews may provide insights into barriers that community members face in accessing services and quality improvement efforts.

> **Gathering input through focus groups, community forums and key informant interviews may provide insights into barriers that community members face.**

Case Study on Using Data:
Metro Community Provider Network[22]

Founded in 1989, the Metro Community Provider Network (MCPN) is a nonprofit organization in the Denver Metro area that provides medical and health education services to underserved communities. Its mission is "to partner with the community to provide excellent, culturally sensitive health services to meet the needs of each individual." Over the years MCPN has grown to include 10 sites and several community-based case management programs and has one of the largest population bases of any community health center in Colorado.

With the goal of better serving disparate communities, MCPN began collecting race and ethnicity data from patients receiving diabetes case management services. The diabetes program links patients' race and ethnicity data with clinical data and assesses the results every six months. Through this analysis, MCPN has learned that the Hispanic and black patients they serve have a higher prevalence of diabetes than other racial or ethnic groups.

Data collection also showed MCPN staff that more than 60 percent of its diabetic patients self-identify as Hispanic or Latino. To better serve this population, the organization hired bicultural and bilingual staff to provide Spanish health education programs that integrate culturally appropriate recipes into the discussion about diabetes. Additionally, the data comparison from pre- to post-tests showed that while Hispanic patients understood how nutrition and exercise affect their diabetes, these patients had learned much less about blood glucose monitoring compared with their Caucasian counterparts. With health providers' wanting patients to understand the importance of measuring blood glucose levels, as well as how to use this information rather than just "follow doctors' orders," the Spanish health education programs were modified to expand discussions around blood glucose monitoring.

The Hispanic community's appreciation for these efforts has been demonstrated in patient satisfaction survey results as well as in anecdotal comments. Modifying health education and diabetes management programs to better align with the needs and preferences of diverse patients also helped MCPN improve patients' health and reduce racial and ethnic health disparities. Hispanic and black patients who had

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a higher prevalence of diabetes than white patients experienced 28 percent and 29 percent reductions, respectively; from their pre- to post-Hemoglobin A1c test levels (a lower Hemoglobin A1c test indicates better blood sugar control for patients with diabetes). Although the Hispanic and black diabetes patients served by MCPN continue to have worse health outcomes than its white patients do, efforts to utilize race and ethnicity data to identify where culturally and linguistically appropriate services are needed have helped reduce disparities that previously existed among the organization's diabetes patients.

Reporting Race and Ethnicity Data

In addition to improving programs and services, results gathered through collecting race and ethnicity data also can be used to validate the effectiveness of programs, demonstrate accountability, demonstrate an organization's values and commitment to being inclusive, and justify funding. For these reasons, it is important for organizations to share the results of analyses linking race and ethnicity data to clinical measures and satisfaction data with internal stakeholders such as staff and board, as well as with external stakeholders such as funders, government agencies, partner organizations, patients, community members and policymakers. When sharing results, health care organizations should tailor messages about the progress of their efforts to different stakeholders and identify the purpose for including a particular stakeholder, what data will relate to that audience's interests, the preferred and appropriate mode(s) for communicating data results (such as newsletters, fact sheets, webpages, emails, news stories, social media, mailings, community forums, personal communications, presentations)[23, 24] and any necessary training for staff and board members on how to communicate data results clearly.

Case Study on Reporting Data: Northside Child Health Center[25]

In 2007, the Northside Child Health Center (NCHC) was established as a school-based health center in Montrose, Colorado. NCHC provides children from birth through high school with primary care services, determination of presumptive eligibility (temporary coverage while an application is being processed) for Medicaid and the Child Health Plan Plus program (CHP+), mental health therapy and preventive oral health care services. Parents are also eligible for oral health care services. NCHC's analysis of its racial and ethnicity data revealed that approximately 66 percent of its patients seeking primary medical services were Hispanic. After sharing this information at a staff meeting, NCHC decided to make numerous changes to its organization and services. Among those changes were developing signs and print materials in Spanish, creating a bilingual telephone recording, providing opportunities for staff to learn about various cultural health beliefs among the Hispanic populations and providing more homeopathic treatment options for families.

The data also showed that the Hispanic community had a significantly lower rate of utilizing mental health services compared to primary care services. NCHC increased its mental health outreach to the community's Hispanic families and sent letters to parents that not only informed them of the clinic's services but also addressed the stigma attached to mental health in Hispanic communities.

NCHC has also shared its data results with other stakeholder groups through various methods depending on the groups' preferences: a spreadsheet for the Montrose County School District and funders, an annual report including charts and graphs with written explanations for partnering organizations and community members, and through in-person presentations to its Patient Advisory Committee and the staff of the Northside Elementary School.

≫ FACTORS CONTRIBUTING TO SUCCESS OF HEALTH EQUITY EFFORTS

The case studies illustrate the importance in familiarizing staff with practices for collecting, analyzing, using and reporting race and ethnicity data. Having good data and knowing how to use them to determine and make needed changes are key in ensuring all patients receive quality medical care. Other factors also influence an organization's effectiveness in carrying out health equity efforts.

Leadership

Leadership is an integral component of successful implementation of organizational change efforts. Leaders can be explicit about the importance of ongoing data collection as well as how the data will be used. They can demonstrate their commitment to data collection as a compliance measure and as a method for quality improvement in several ways:

- Communicating a vision for the work
- Developing an effective strategy for the collection, analysis, utilization and reporting of race and ethnicity data
- Providing the necessary support for staff to carry out the work
- Developing organizational policies that facilitate the data collection process.[27]

Learning Culture

Another key success factor for implementing data collection practices is adopting the culture of a learning organization. A learning organization is "made up of employees skilled at creating, acquiring and transferring knowledge…[who] help their firms cultivate tolerance, foster open discussion, and think holistically and systematically."[26] As noted previously, one barrier to collecting race and ethnicity data is the fear that data will reveal the existence of racial and ethnic health disparities among an organization's patient population.

Learning organizations view identified health disparities among their patient population as an opportunity to improve services. Such organizations recognize that data can be used to inform decisions about keeping or changing current practices based on their effectiveness. Having a culture that is open to self-reflection and that values tools used to provide information about areas for growth are likely to succeed in their efforts to adopt organizational practices and procedures related to the data collection provision of the ACA.

> **Learning organizations view identified health disparities among their patient population as an opportunity to improve services.**

» CONCLUSION

Collecting race and ethnicity data can provide health care organizations with useful information about their patients, including whether any racial and ethnic patient populations are experiencing disparities in their health and health care. While barriers to collecting and analyzing race and ethnicity data exist – provider and patient concerns, misperceptions around the legality of data collection, challenges in understanding subpopulations, linking data from multiple health IT systems – these challenges often can be addressed by training staff on data collection protocols, demonstrating leadership's commitment to data collection and usage, and creating an organizational environment that values reflection and growth. Collecting and using data can provide information helpful not only to patients but also to health care organizations, their staff, their communities and other stakeholders.

Health care organizations can find assistance and support for collecting race and ethnicity data from several sources. The Affordable Care Act and the Health and Human Services' standards for Culturally and Linguistically Appropriate Services provide guidance and standards for how health care organizations can collect, analyze, use and report patient demographic data. National organizations such as the American Medical Association have recommendations on practices such as how and when to ask race and ethnicity questions, and how to make patients feel comfortable providing such information. Studies show that when patients understand how the data will be used to monitor quality of care, they are more willing to participate in the data collection. When organizations put the data they collect into a database linked to clinical data and other quality measures, they are more likely to identify disparities that exist. And when they understand where any disparities lie, they can determine how to address barriers that might be impeding a population's access to health and health care.

In addition, sharing data results, as well as the organization's efforts to address racial and ethnic health disparities, with stakeholders can help validate the effectiveness of health equity programs, demonstrate accountability, justify funding and develop partnerships.

The case studies described in this paper demonstrate the gains three organizations achieved by identifying racial and ethnic health disparities among their patient populations. When the data results are then used internally and shared externally to inform the development of programs and to align services with the needs and preferences of underserved communities, race and ethnicity data can contribute to and increase the impact of health equity efforts.
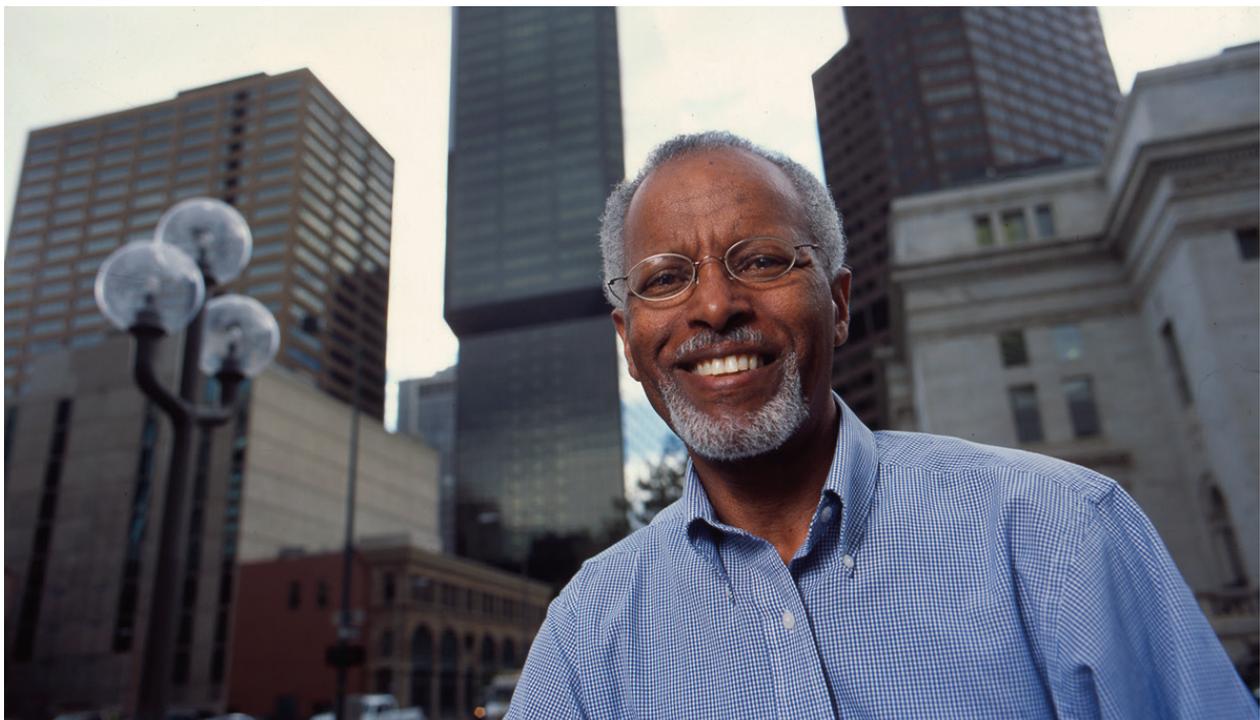
» APPENDIX

U.S. Department of Health and Human Services

Race and Ethnicity Data Standards and Implementation Guidelines[10]

- Self-identification is the preferred means of obtaining information about an individual's race and ethnicity, except in instances where observer identification is more practical. The surveyor should not tell an individual who he or she is, or specify how an individual should classify himself or herself.

- To provide flexibility and ensure data quality, separate questions for race and ethnicity should be used wherever feasible. Specifically, when self-reporting or other self-identification approaches are used, ethnicity is asked first, and then race. The standard acknowledges that this standard might not work in other contexts (e.g., administrative records.) [In some circumstances (e.g., administrative records), race and ethnicity may need to be asked and/or entered as one category.]

- The specified race and ethnicity categories provide a minimum set of categories except when the collection involves a sample of such size that the data on the smaller categories would be unreliable, or when the collection effort focuses on a specific racial or ethnic group. [Organizations should collect race and ethnicity data using the following categories unless there are so few patients who identify with any of the listed categories that the analysis of the data will be unreliable.]

  - » The Office of Management and Budget (OMB) – whose current government-wide standard served as the starting point for these new ACA standards – minimum categories for race are: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White.

  - » The OMB minimum categories for ethnicity are: Hispanic or Latino and Not Hispanic or Latino.

- When self-reporting or other self-identification approaches are used, respondents who wish to identify their multi-racial heritage may choose more than one race; there is no "multi-racial" category.

- The OMB encourages additional granularity [i.e., subcategories] where it is supported by sample size and as long as the additional detail can be aggregated back to the minimum standard set of race and ethnicity categories.

- Any other variation will have to be specifically authorized by the OMB through the information collection clearance process. In those cases where the data collection is not subject to the information collection clearance process, a direct request for a variance should be made to the OMB.

The categories for HHS data standards for race and ethnicity are based on the disaggregation [i.e., classification of subcategories] of the OMB standard used in the American Community Survey (ACS) and the 2000 and 2010 Decennial Census. The data standard for race and ethnicity is listed below. Race and ethnicity data collection applies to survey participants of all ages.

Ethnicity Data Standard

Are you Hispanic, Latino/a, or Spanish origin (One or more categories may be selected)

a. ___ No, not of Hispanic, Latino/a, or Spanish origin
b. ___ Yes, Mexican, Mexican American, Chicano/a
c. ___ Yes, Puerto Rican
d. ___ Yes, Cuban
e. ___ Yes, Another Hispanic, Latino, or Spanish origin

Race Data Standard

What is your race? (One or more categories may be selected)

a. ___ White
b. ___ Black or African American
c. ___ American Indian or Alaska Native
d. ___ Asian Indian
e. ___ Chinese
f. ___ Filipino
g. ___ Japanese
h. ___ Korean
i. ___ Vietnamese
j. ___ Other Asian
k. ___ Native Hawaiian
l. ___ Guamanian or Chamorro
m. ___ Samoan
n. ___ Other Pacific Islander

≫ ENDNOTES

1   Brittingham A, De la Cruz GP. *Ancestry: 2000*. Washington, DC: U.S. Census Bureau; 2004.

2   U.S. Department of Health and Human Services Agency for Healthcare Research and Quality. *Race, Ethnicity, and Language Data: Standardization for Health Care Equality Improvement*. http://www.ahrq.gov/research/iomracereport/reldata1.htm. Accessed December 18, 2012.

3   Perot R, Youdelman M. *Racial, Ethnic and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices*. New York, NY: The Commonwealth Fund; 2001.

4   U.S. Department of Health and Human Services. *Improving Data Collection to Reduce Health Disparities.* http://www.healthcare.gov/news/factsheets/2011/06/disparities06292011a.html. Accessed December 18, 2012.

5   Rosenbaum S, Burke T, Nath S, Santos J, Thomas, D. *The Legality of Collecting and Disclosing Patient Race and Ethnicity Data.* Princeton, NJ: Robert Wood Johnson Foundation; 2006.

6   U.S. Department of Health and Human Services Agency for Healthcare Research and Quality. *Race, Ethnicity, and Language Data: [1] Standardization for Health Care Equality Improvement*. http://www.ahrq.gov/research/iomracereport/reldata6a.htm. Accessed January 26, 2013.

7   Hasnain-Wynia R, Pierce D, Greising C, Prince V, Reiter J. Health Research and Educational Trust Disparities toolkit. http://www.hretdisparities.org/. Accessed December 18, 2012.

8   Nernez D. Health care organizations' use of race/ethnicity data to address quality disparities. *Health Affair*. 2005; 24:(2):409-416.

9   U.S. Department of Health and Human Services Office of Minority Health. *National Standards on Cultural and Linguistically Appropriate Services*. http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15. Accessed January 3, 2013.

10   U.S. Department of Health and Human Services. *Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.pdf. Accessed December 27, 2012.

11   Russell L. *Measuring the Gaps: Collecting Data to Drive Improvements in Health Care Disparities*. Washington, DC: Center for American Progress; 2010.

12   Hasnain-Wynia, R, Pierce D, Pittman M. *Who, When and How: The Current State of Race, Ethnicity and Primary Language Data Collection in Hospitals*. New York, NY: The Commonwealth Fund; 2004.

13   Weinick R, Flaherty K, Bristol S. *Creating Equity Reports: A Guide for Hospitals*. The Disparities Solution Center at Massachusetts General Hospital. Boston, MA; 2008.

14   Kandula N, Hasnain-Wynia R, Thompson J, Brown E, Baker D. Association between prior experiences of discrimination and patients' attitudes towards health care providers collecting information about race and ethnicity. *J Gen Intern Med*. 2009; 24:(7):789-94.

15   Baker D, Cameron K, Feinglass J. Patients' attitudes toward health care providers collecting information about their race and ethnicity. *J Gen Intern Med*. 2005; 20:895-900.

16   Kornblet S, Pritts J, Goldstein M, Perez T, Rosenbaum S. *Policy brief 4: Patient Race and Ethnicity Data and Quality Reporting: A Legal "Roadmap" to Transparency*. Washington, DC: The George Washington University School of Public Health and Health Services; 2008.

17   Schoenman J, Sutton J, Elixhauser A, Love D. Understanding and enhancing the value of hospital discharge data. *Med Care Res Rev*. 2009; 64:(4):449-468.

18   Coltin K. 2009. Implementation challenges for health plan collection of race, ethnicity & language data. Harvard Pilgrim Health Care. Presentation to the IOM Committee on Future Directions for the National Healthcare Quality and Disparities Reports; February 9, 2009. Washington, DC.

19   Center for Improving Value in Health Care. Colorado All Payer Claims Database. http://www.cohealthdata.org/#/aboutapcd. Accessed January 24, 2013.

20   Wynia M, Hasnain-Wynia R, Hotze T, Ivey S. *Collecting and Using Race, Ethnicity and Language Data in Ambulatory Settings: A White Paper with Recommendations from the Commission to End Health Care Disparities*. Chicago, IL: American Medical Association; 2011.

21   Colorado Total Smiles. http://www.kidsoralprevention.org/. Accessed January 6, 2013.

22   Metro Community Provider Network. http://www.mcpn.org/en/index.html. Accessed January 6, 2013.

23   Centers for Disease Control and Prevention. *Evaluation Manual: Step 6 - Ensure Use of Evaluation Findings and Share Lessons Learned: Introduction to Program Evaluation for Public Health Programs*. http://www.cdc.gov/getsmart/program-planner/Step6.html. Accessed January 4, 2013.

24   Dahlkemper L, Caughey T. Communicating about data. http://educationnorthwest.org/webfm_send/1332. Accessed January 5, 2013.

25   The Colorado Trust. *Northside Child Health Center in Montrose receives The Colorado Trust's Annual Leadership Award*. http://www.coloradotrust.org/news/news-releases/show-news-release?id=192. Accessed January 6, 2013.

26   Mayhew R. *What is a Leader's Role in an Organization with Respect to Diversity?* http://smallbusiness.chron.com/leaders-role-organization-respect-diversity-22404.html. Accessed December 11, 2012.

27   Garvin DA, Edmondson AC, Gino F. Is yours a learning organization? *Harvard Bus Rev*. March 2008.

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