Health Equity Resource Series

Data-Driven Care Delivery

Data Collection, Stratification and Use
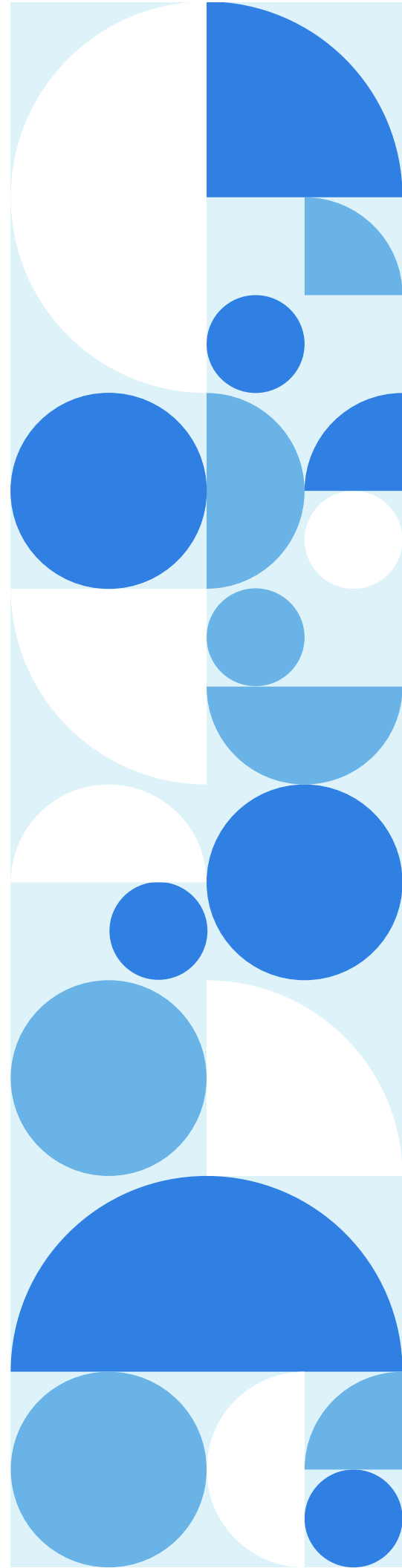
Executive Summary

The COVID-19 pandemic's disproportionate impact on people of color has accelerated the integration of health equity into health care strategy playbooks across the nation. Within health care settings, from urban to rural and from hospitals to ambulatory care sites and clinics, there is renewed focus on efforts to advance health equity. Furthermore, there is strong evidence of a commitment to ensure equitable practices are tied to the core work of improving quality and advancing health equity. To support hospitals and health systems starting from different points on their journey to strengthen health equity, the AHA's Institute for Diversity and Health Equity (IFDHE) is preparing four new guidance and resource toolkits to share evidence-based practices to inform organizational next steps. This first toolkit of our series focuses on approaches to promote data collection and stratification to improve patient outcomes. Look for additional IFDHE toolkits to be released throughout 2021.

These toolkits highlight four compelling strategies to prioritize health equity. These foundational pillars include:
- Data collection, validation, stratification and application of patient information to address disparate outcomes
- Cultural competency and implicit bias training and education
- Diversity and inclusion in leadership and governance roles
- Sustainable community partnerships focused on improving equity

Each toolkit is designed to be informative whether organizations have already deployed health equity tactics and strategies or if at the early stages of implementation. This series of toolkits also lays the groundwork for an equity roadmap to support hospitals' and health systems' efforts toward achieving high-quality, equitable care for all.

Who should be involved in this work?

Interdisciplinary teams that are organized to coordinate efforts across departments to effectively collect, validate and stratify data should use these toolkits. Strong support from senior leaders listed below is essential to encourage and reinforce actions by teams involved in the ongoing work. Titles may vary by hospitals and health systems.

- Chief Executive Officer
- Chief Operating Officer
- Chief Finance Officer
- Chief Medical Officer
- Chief Nursing Officer
- Chief Health Equity Officer
- Chief Diversity and Inclusion Officer

- Chief Compliance Officer
- Chief Quality Officer
- Patient and Family Advisory Council
- Patient Experience Officer
- Patient Services Lead
- Chief Clinical Information Officer
- Chief Information Officer

How to use these toolkits:

Recognizing there is no predetermined starting point, these toolkits are designed to meet organizations where they currently stand. Initial processes may include:
- Establishing the organization's baseline experience
- Focusing on one or two key areas to drive change
- Tracking progress over time

Examples of leading practices from hospitals and health systems across the nation are used to inspire and motivate other organizations implementing similar initiatives that impact communities so that *all people can reach their highest potential for health — this is the AHA's vision for health equity.*

Understanding the issue:

Hospitals and health systems are focused on addressing health care disparities, and this begins with understanding the unique needs of the patients they serve. For example: data and analytics allow hospital and health systems leaders and their teams to see the challenges and barriers some patients may face when accessing care. The data not only pinpoint where resources may be deployed to address gaps in access or quality of care, but data also provide deeper insights to instruct and inform intentional actions by leadership and clinical teams to support organizational strategies to eliminate disparities in care.
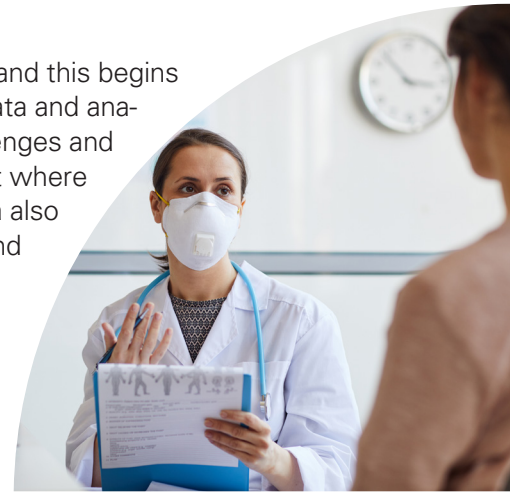
- **Addressing Health Care Disparities through Race, Ethnicity and Language (REaL) Data**
  This brief contains multiple resources and case studies of how hospitals are using REaL data to drive care improvements.

- **Collecting REaL Data to Conquer COVID-19 Podcast**
  This conversation features two health system chief diversity officers discussing their efforts to learn more about the patients they are serving through REaL data collection, stratification and utilization.

Involving the board in advancing health equity:

The role of boards in setting an agenda for advancing health equity within hospitals and health systems cannot be overstated. In partnership with executives and clinical senior leaders, they set the strategic direction for the organization through the mission, values and organizational priorities. With the appropriate collection and sharing of REaL data, boards are able to review reports and dashboards to identify disparities among patient populations and develop action plans to drive better results.

RESOURCES FOR TRUSTEES

- **Tackling Health Equity: A Two-part Podcast for Trustees**
  This two-part podcast discusses the health equity challenges that board members can expect to encounter and how best to address them. Part one covers data that should be included in board reports and dashboards to improve visibility of the issues of inequity.

- **Addressing Health Equity in the Hospital Board Room**
  To improve health equity, trustees must learn about the patients and communities served by their hospital or health system. This issue brief outlines the reasons and approaches trustees can take to enhance their understanding and conversations about health equity in the board room.

- **The Board's Role in Advancing Healthier, More Equitable Communities**
  This article provides practical strategies and collaborations trustees can consider to address and improve health equity in their community.

Getting Started:

Collect the data using a uniform framework

A uniform data collection framework provides a process improvement tool for health care organizations to systematically collect demographic data from patients or their caregivers. Using a uniform framework results in more accurate and complete data.

The elements of a uniform framework include:

1. A rationale for why the patient is being asked to provide this information.
2. A script for staff to use each time so that they ask questions in a uniform fashion.
3. A method for allowing patients to self-report their information.
4. A standardized approach for "rolling up" granular responses to the U.S. Office of Management and Budget categories for analytical and reporting purposes.
5. Assurances that the data will be held confidential and that a limited number of people will have access to the data and a mechanism to ensure compliance.

Data Validation

Working across teams, hospitals can conduct a thorough assessment of the quality of the existing patient data and understand the accuracy, completeness, uniqueness, timeliness and consistency of the data.

Accuracy	Is the data self-identified and correctly recorded? Are there differences in categorization among data sources?
Completeness	Are race, ethnicity, language and other relevant data captured across all service areas? What is the percentage of unknown, other or declined data?
Uniqueness	Are individual patients represented only once?
Timeliness	Is the data kept up to date? How often is the data updated?
Consistency	Is the data internally consistent, and do the data reflect the patient population served?

Data Stratification

By collecting and stratifying data, hospitals and health systems can analyze data to identify disparities. A Framework for Stratifying Race, Ethnicity and Language Data is a guide consisting of a five-step framework to stratify data. This framework includes the following steps:

1. Assemble a working group that is focused on health care disparities data.
2. Validate the data.
3. Identify the highest priority metrics for stratification.
4. Determine if stratification is possible on the selected metrics.
5. Stratify the data.

The table below demonstrates potential priority metrics and patient data to stratify.

Quality Metric	Data Element to Stratify
Clinical • Hospital inpatient quality reporting (IQR) measures (i.e., "core measures") • 30-day readmissions **Patient Satisfaction** • Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores **Cost and Efficiency** • Medicare Spending per Beneficiary	**Demographic** • Age • Gender • Race • Ethnicity • Language preference • Language proficiency

Other Potential Metrics:

The AHA's Health Equity, Diversity and Inclusion Measures for Hospital and Health System Dashboards can help hospitals and health systems identify metrics to track and monitor. Specific metrics to identify disparities among diverse patient populations may include: race, ethnicity and language preference, sexual orientation, gender identity, disability status and social needs data.

Data Application Case Studies

The table below highlights case studies of past AHA Carolyn Boone Lewis Equity of Care Award recipients. The Carolyn Boone Lewis Equity of Care Awards recognize hospitals and health systems that have moved beyond plans and awareness of the #123forEquity pledge to action. This award celebrates organizations that demonstrate high achievement in advancing diversity, health equity, and equitable health care as evidenced through data, leadership, cultural awareness and partnerships.

Hospital/ Health System	Challenge	Quality Metrics	Data Elements stratified	Performance Improvement Plan	Results
Atrium Health	Hispanic/Latino patients were not being screened at the same rate as other groups	REaL: Ethnicity	Cancer screening patient experience	Phone call campaign to patients, and a partnership with a Spanish newsletter to educate community members	200 additional screenings
	LGBTQ patients did not experience the organization in the same way as others	SOGI: Sexual Orientation	Patient satisfaction scores / patient experience survey	Intervention to uncover and rectify unconscious biases among staff	Policies, such as those regarding ICU visitation, were evaluated and amended to include the variety of relationships patients may have, including the LGBTQ community.

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Henry Ford Health System	Better understanding of communities it serves, especially Latinx and Arab/Chaldean populations	REaL: Coordinated with community partner (Greater Detroit Area Health Council) to launch "We Ask Because We Care" campaign.	REaL data and at least 10 clinical quality and service metrics for equity dashboard	Data collection process built into EHR for appointment scheduling. Forms also available in Arabic and Spanish	90.4% of REaL data collected (by end of 2019) 91.3% of race data, 94.8% of ethnicity data and 97.2% of language data was collected
Northwell Health	Interpretation services not being fully utilized	REaL: Language	Language preference	Established a process within Electronic health records (EHR) so that the data flows to the top banner of a patient's record	Telephonic interpretation calls increased by 465% from 51,207 to 289,615
Sutter Health	African American patients at Sutter Health had an HEI of 2.2, much higher than their counterparts who are white (1.0), Hispanic (1.1), or Asian (1.3)	REaL: Race	Emergency room visits	Created an adult asthma program in partnership with a local federally qualified health center and made it available to all African American adults at the point of contact who were seeking care for asthma in the ER	Analyzed 18 quality measures from birth to the end of life, stratified by race and ethnicity to create a snapshot of health equity across the spectrum of clinical care in six months.

Assessments:

While collecting patient data and developing performance improvement plans are crucial, it is equally important for organizations to evaluate the effectiveness of the plan and its impact on the identified disparity. The resources below provide assessment tools for program evaluation.

- **Evaluation of the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards)**
  This toolkit describes the National CLAS Standards and provides meaningful and practical guidance on delivering culturally and linguistically appropriate services.

- **Race and Ethnicity Data Improvement Toolkit**
  This toolkit includes a variety of materials including surveys, scripting for data collection teams and links to online resources.

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Discussion Guide

One of the first steps to initiate change is to look at current practices and procedures to assess where things stand. In the discussion guide below, addressing these critical questions can jump-start conversations in your health care organization about the efforts to address and prioritize diversity, inclusion and health equity. The answers may also inform steps your board and leadership can take to ensure all patients have equitable access to the highest quality health care.

We recommend tailoring the use of this discussion guide to bring your leadership team together as part of the agenda for a leadership retreat or strategic planning session. The executive staff should be prepared to answer questions from the perspective of their department's expertise and goals.

Executive Team Discussion Guide:

1. **(ALL TEAM MEMBERS)** Does our organization have a unified framework for consistently collecting data on demographics, language preference and ways information is received to improve the quality of care for all patients?

2. **(ALL TEAM MEMBERS)** Has our organization assembled a working group to focus on REaL data and health care disparities? If so, is diversity reflected among the members of the working group? (This might include age, race/ethnicity, language, work unit, gender identity, etc.)

3. **(OPERATIONS EXECUTIVE)** What steps has our organization taken to standardize the data collection process?

4. **(HUMAN RESOURCES EXECUTIVE, CNO, CMO)** Does our training offer instructions on how to ask questions related to race and ethnicity?

5. **(LEGAL/COMPLIANCE & PATIENT EXPERIENCE EXECUTIVE)** Do we offer information for patients regarding why and for what purpose REaL data will be used and collected?

6. **(PATIENT EXPERIENCE EXECUTIVE)** What protocols do we have in place for addressing concerns from patients who inquire about the collection of their demographic data?

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Leadership and Governance Discussion Guide:

1. What is your understanding of health equity, health equality and health care disparities?

2. How does our mission, vision and values align with our commitment to health equity?

3. How can health equity be incorporated into our strategic plan?

4. What are the demographics our hospital serves? What health disparities exist in our patient population and community?

5. What steps can our organization take to address care disparities? How will we assess progress on health equity?

6. What organizations can we collaborate with to improve health equity?

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Interdisciplinary Team Discussion Guide:

1. How will our organization address concerns regarding data collection from internal and external stakeholders? Has our organization identified a point of contact for these inquiries?

2. Has our organization assessed technological readiness for data collection and stratification purposes across the system?

3. Identify the ways in which our organization will guide and train staff on continuing to learn best practice as it relates to data collection. (REaL, SOGI)

4. Do we educate patients of color about support and community resources that might be available internally and externally? (SDOH)

5. Has our organization identified different modes of communication for data collection?

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APPENDIX

Building an Organizational Response to Health Disparities
This resource features a compilation of reports, guides, toolkits, training tools, webinars, books and articles regarding REaL data collection, stratification and use.
URL: https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Collection-Resources.pdf

Improving Quality and Achieving Equity: A Guide for Hospital Leaders
A guide designed to help health care leaders address disparities through change management. It also highlights model practices and recommends activities and resources that can help hospital leaders initiate an agenda for action.
URL: https://mghdisparitiessolutions.files.wordpress.com/2015/12/improving-quality-safety-guide-hospital-leaders.pdf

Race, Ethnicity, and Language Data Standardization for Health Care Quality Improvement
Foundational resource that contains important information on categorizing REAL data beyond standard OMB categories and provides guidance and examples of granular categories. Additionally, it emphasizes at minimum collecting data on a patient's spoken English language proficiency.
URL: https://www.ahrq.gov/sites/default/files/publications/files/iomracereport.pdf

Data Collection

PRAPARE Implementation and Action Toolkit
A modularized toolkit containing resources and best practices to help guide interested users in each step of implementing PRAPARE (Patients' Assets, Risks, and Experiences) to identify and act on the social determinants of health.
URL: https://www.nachc.org/research-and-data/prapare/toolkit/

New York State Toolkit to Reduce Health Care Disparities: Improving Race and Ethnicity Data
This toolkit is designed to help hospitals, ambulatory care centers, community health centers and other users understand the importance of collecting accurate data on race and ethnicity. The toolkit includes sample tools, forms, training materials, resources for implementation, frequently asked questions, patient/ consumer materials, resources for hospital leaders and quality improvement resources.
URL: https://www.albany.edu/cphce/mrt_nys_toolkit_to_reduce_healthcare_disparities.pdf

Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data
This guide includes two sections that address both collection and use of REaL data. The first section provides a four-step approach on how to obtain an accurate and usable REaL data set. The second section discusses how hospitals and care systems can use REaL data to achieve clinical, operational, financial, and population health benefits.
URL: http://www.hpoe.org/Reports-HPOE/Equity_Care_Report_August2013.PDF

Sexual and Gender Minority Clearinghouse
Resources to improve the understanding of sexual and gender minority health and disparities, and provide information on health care access, health-related risk behaviors, chronic health conditions and use of preventive services. This includes surveys with questions about sexual identity, attraction, and behavior; data on gender identity and household relationships.
URL: https://www.cms.gov/About-CMS/Agency-Information/OMH/resource-center/hcps-and-researchers/data-tools/sgm-clearinghouse/index

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SOGI Data Collection Demonstration Videos
These videos demonstrate best practices in sexual orientation and gender identity (SOGI) data collection. They address common questions and issues that arise for clinical and front-line staff when asking patients about their sexual orientation and gender identity.
URL: https://www.lgbthealtheducation.org/courses/so-gi-data-collection-training/

Do Ask, Do Tell: A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings (2020)
This toolkit provides specific SOGI questions recommended by national LGBTQ organizations. It also describes how to collect these data in electronic health record systems, how to use these data to support clinical processes, and how to train clinical staff to interact with LGBTQ patients in ways that are affirming and welcoming.
URL: https://doaskdotell.org/ehr/toolkit/

Ready, Set, Go! Guidelines and Tips For Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI) (2018)
This guide helps hospital and health systems begin to implement SOGI data collection.
URL: https://www.lgbtqiahealtheducation.org/wp-content/uploads/2018/03/Ready-Set-Go_2018.pdf

Disability Data Collection and Analysis (2015)
This training module aims to help understand the approach and guiding principles of the Washington Group on Disability Statics and deepen knowledge of how to collect and analyze disability.
URL: https://hilearngo.handicap-international.org/workspaces/176/open/tool/home#/tab/-1

ICD-10-CM Coding for Social Determinants of Health (2018):
This brief provides an overview on ICD-10 coding for SDOH. It also features a list of AHA tools and resources for hospitals, health systems and clinicians that address the social needs and the SDOH.
URL: https://www.aha.org/system/files/2018-04/value-initiative-icd-10-code-social-determinants-of-health.pdf

Screening for Social Needs: Guiding Care Teams to Engage Patients
This tool helps hospitals and health systems facilitate sensitive conversations with patients about their non-medical needs that may be a barrier to good health.
URL: https://www.aha.org/toolkitsmethodology/2019-06-05-screening-social-needs-guiding-care-teams-engage-patients