Handbook on the Collection of Race/Ethnicity/Language Data in Medical Groups

MN Community Measurement

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Introduction

In 2008, Minnesota Community Measurement (MNCM) set out to identify a common set of data elements that, if collected consistently and married with clinical results, could aid in the evaluation of disparities in health care. This data set is focused on care given in the ambulatory care setting. MNCM also wanted to learn about the implementation of the data collection process from medical groups who had already established systems for collecting such data (Early Adopters) and share the best practices of these medical groups.

MNCM convened a work group comprised of members from five Early Adopter medical groups. This Early Adopters Work Group (EAWG) worked from July, 2008 through April, 2009 to define the data elements and to clarify essential lessons learned. The result of this collaborative effort is the *Handbook on the Collection of Race/Ethnicity/Language Data in Medical Groups.* This Handbook defines the data elements and provides advice on issues related to implementation.

MNCM recommends all medical groups consider implementing a collection system in 2009. Voluntary reporting of these data elements to MNCM begins in 2010 (2009 dates of service) via the direct data submission (DDS) process along with the clinical measures. These data will be required reporting in 2011 (2010 dates of service).

Two **important notes** about the data elements and collection:

1. This Handbook establishes a **minimum** dataset for collection and reporting to MNCM. Medical groups may decide to use more detailed data categories to support care and quality management within their group. If a medical group should chose to collect more detailed data categories, the group must have a data mapping plan to roll up to the data categories defined herein for reporting purposes to MNCM.
2. If your medical group has been collecting this type of data, please contact MNCM to discuss reporting requirements at support@mncm.org.

MNCM is grateful for the time and expertise shared by the EAWG members. A full listing is provided in Appendix A.

Support for this Handbook was provided by the Robert Wood Johnson Foundation through its *Aligning Forces for Quality* initiative.

Scope and Purpose

To evaluate and reduce disparities in health care, health care providers and the organizations that work with them on quality improvement require certain data that can only be collected from patients. If Minnesota wants to analyze health care disparities statewide, the state needs a uniform data definition and a consistent collection and reporting methodology. MNCM has developed this Handbook to achieve the following objectives for care given in ambulatory care settings:

- Define and standardize the data elements to be collected by medical groups. (Reporting to Minnesota Community Measurement (MNCM) will begin, on a voluntary basis, in 2010 for services rendered in 2009. Reporting will be required in 2011 for services rendered in 2010.)
- Identify and recommend additional data elements for collection to improve care given within the medical group setting.
- Provide insights and lessons learned from several medical groups with experience in collecting these data.
- Serve as a resource and provide support to those who will lead these initiatives in medical groups across the state.

The Case for Collecting

The Minnesota Governor's Health Care Disparities Task Force[1] documented the business and clinical case for data collection as follows:

> *The Business Case*
> Minnesota has been and will continue to face changing demographics in the general population and workforce. Although Minnesota has one of the greatest rates of overall health on a national scale, Minnesota also continues to experience some of the greatest racial and ethnic health disparities in the nation. In part, this may be due to Minnesota having the greatest proportion of new immigrants in the nation. The expected future changes in demographics in the region give reason for the need of providing quality healthcare for diverse populations. Effective data collection can improve quality and cost-effectiveness of the care received by targeting limited resources where they are most needed, thereby preventing unnecessary services or tertiary services when primary care would be most appropriate. Considering a shift in workforce populations and demographics, it is in the best interest of healthcare providers to identify the various populations they are servicing to ensure quality health care and to close the gap of existing disparities in health care delivery.

> *The Clinical Case*
> Because data collection occurs at the clinical level, we communicate the results through collaborative publishing of clinical performance and outcomes at the medical group and clinic levels through Minnesota Community Measurement. Collaboration on the disparities in Minnesota strengthens working relationships by sharing ideas, thoughts and programming ideas of how to use this data to see clinical results and improvement in care. Effective data collection can improve quality and effectiveness of the care

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[1] http://www.health.state.mn.us/ommh/committees/taskforce/index.html

received by targeting resources for populations at risk for specific conditions, crucial support services such as interpreters, or preventive screenings for specific populations. Knowing the populations in the caseload is essential for clinics to plan their care and to understand cultural and economic barriers or complications to successful treatment. The data can be a tool to accelerate reducing disparities in clinical settings. Collaboration and communication is vital as it identifies that disparities do exist and that we need to take action. From a clinical perspective, it is valuable to see these improvements in care and overall health for emerging, diverse populations.

By implementing effective and consistent data collection systems within Minnesota, a wide range of initiatives will be enabled to address disparities in health care. Medical groups will be able to:

- Respond to findings like these about health care in Minnesota[2]:
  a) Cardiovascular disease rates for African Americans, Latinos and American Indians are more than 10 percent higher than the rate for Whites. African Americans die from heart disease at a rate nearly 30 percent greater than Whites.
  b) Diabetes related deaths are 1.5 to 4 times more common among African Americans, Latinos, and American Indians compared to Whites.
  c) White women have a higher incidence of breast cancer, although African American women are more likely to die from the disease.
- Monitor Minnesota health care delivery against national disparities like those reported in the National Healthcare Disparities Report[3]:
  · Blacks have a rate of new AIDS cases 10 times higher than Whites.
  · Asian adults age 65 and over are 50 percent more likely than Whites to lack immunizations against pneumonia.
  · American Indians and Alaska Natives are twice as likely to lack prenatal care in the first trimester as Whites.
  · Hispanics have a rate of new AIDS cases over 3.5 times higher than that of non-Hispanic Whites.
  · Poor children were over 28 percent more likely than high-income children to experience poor communication with their health care providers.
- Assess the impact of interventions on diverse communities as well as on the overall Minnesota population.
- Evaluate the ability of diverse communities to access needed services and receive quality health care.
- Demonstrate medical groups' performance in health care delivery to diverse patients.

The Early Adopters Work Group (EAWG) medical groups also found administrative benefits. With these data, they were able to:

- Improve staff diversity to match overall patient mix.
- Increase eligibility for grants and research dollars through deeper analysis of patient data.
- Enhance their ability to analyze their patient mix against the overall community.
- Reduce myths about the impact of certain populations on their medical group.
- Improve staff satisfaction with health improvement actions.

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[2] https://www.minneapolisfoundation.org/Publications.html
[3] http://www.ahrq.gov/qual/qrdr07.htm#toc

- Increase ability to comply with federal and state collection and reporting requirements.

Figure 1 illustrates this effort showing the collection method objectives, the data categories considered for common definition and collection, and the data value/uses.

Collection Methods:
Respectful
Effective
Integrated
Efficient
Consistent

Disparity Data

Country of Origin
Race/Ethnicity
Language
Insurance Status

Religion
English Language Proficiency
Health Literacy

Data value/use

Tailoring services at point of care

Managing Disease

Evaluating and ensuring equity

Reporting Compliance
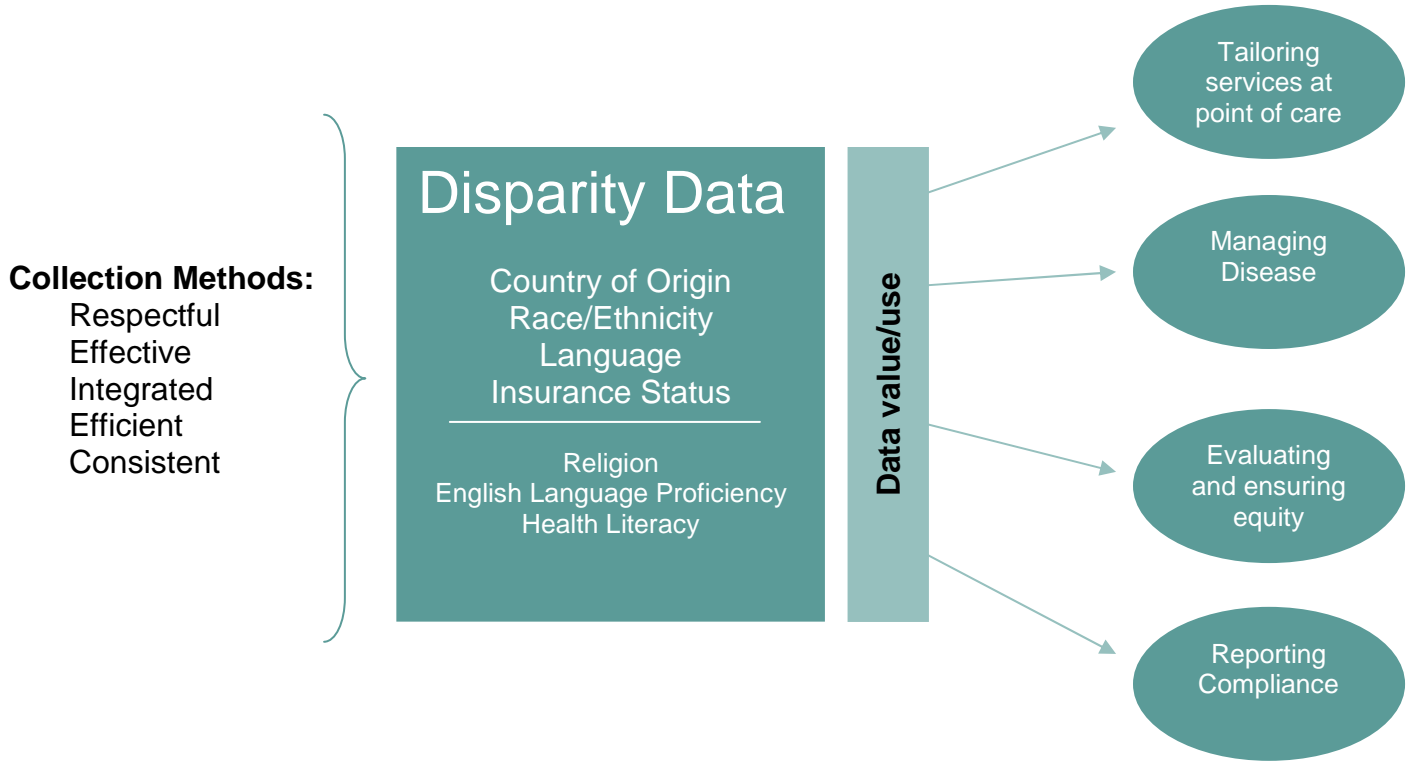
This data definition and collection is an essential first step to evaluating health care disparities and improving health for all Minnesotans.

The Data for Collection

To effectively compare results and analyze the data across medical groups in Minnesota and border counties, a standard set of data elements was needed. In the EAWG, no two medical groups were using the same set of data elements, so defining a common set of data elements became the first task. The data elements required for submission to MNCM are listed below in the section entitled *The Required Data Elements.* The section entitled *The Rationale for the Required Data Elements* provides insight into the data elements via highlights of the discussions during the EAWG sessions. The final section entitled *Other Elements to Consider* contains data elements that were discussed but will not be required for submission to MNCM. These data elements have application and value for internal quality improvement efforts and therefore medical groups may opt to collect them.

The Required Data Elements[4]

Country of Origin (including U.S. territories)
Medical groups will report a patient's country of origin (birth country). The data categories are:

Afghanistan	Congo, Republic of	Iran	Nepal	South Korea
Albania	Costa Rica	Iraq	Netherlands	Spain
Algeria	Cote D'Ivoire	Ireland	New Zealand	Sri Lanka
American Samoa				
Angola	Croatia	Israel	Nicaragua	Sudan
Argentina	Cuba	Italy	Niger	Suriname
Armenia	Cyprus	Jamaica	Nigeria	Swaziland
Australia	Czech Republic	Japan	North Korea	Sweden
Austria	Denmark	Jordan	Norway	Switzerland
Azerbaijan	Djibouti	Kazakhstan	Oman	Syria
Bahamas	Dominican Republic	Kenya	Pakistan	Taiwan
Bahrain	East Timor	Kuwait	Palestinian State (proposed)	Tajikistan
Bangladesh	Ecuador	Kyrgyzstan	Panama	Tanzania
Barbados	Egypt	Laos	Papua New Guinea	Thailand
Belarus	El Salvador	Latvia	Paraguay	Togo
Belgium	Equatorial Guinea	Lebanon	Peru	Tonga
Belize	Eritrea	Lesotho	Philippines	Trinidad and Tobago
Benin	Estonia	Liberia	Poland	Tunisia
Bhutan	Ethiopia	Libya	Portugal	Turkey
Bolivia	Fiji	Lithuania	Puerto Rico	Turkmenistan
Bosnia Herzegovina	Finland	Luxembourg	Qatar	Uganda
Botswana	France	Macedonia	Romania	Ukraine
Brazil	Gabon	Madagascar	Russia	United Arab Emirates
Brunei	Gambia	Malawi	Rwanda	United Kingdom
Bulgaria	Georgia	Malaysia	Saint Lucia	United States
Burma	Germany	Maldives	Saint Vincent & the Grenadines	Uruguay
Burkina Faso	Ghana	Mali	Samoa	Uzbekistan
Burundi	Greece	Malta	Sao Tome and Principe	Vanuatu
Cambodia	Grenada Guam	Marshall Islands	Saudi Arabia	Venezuela Virgin Islands, U.S
Cameroon	Guatemala	Mauritania	Senegal	Vietnam
Canada	Guinea	Mauritius	Serbia	Western Sahara

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[4] Data submission is voluntary in 2010 for 2009 dates of service. Data submission will be required in 2011 for 2010 dates of service.

Cape Verde	Guinea-Bissau	Mexico	Sierra Leone	Yemen
Central African Republican	Guyana	Micronesia	Singapore	Yugoslavia (former)
Chad	Haiti	Moldova	Slovakia	Zambia
Chile	Honduras	Mongolia	Slovenia	Zimbabwe
China	Hungary	Montenegro	Solomon Islands	Other (please specify) _____
Colombia	Iceland	Morocco	Somalia	Chose not to answer/Declined
Comoros	India	Mozambique	South Africa	Unknown
Congo, Democratic Republic of	Indonesia	Namibia		

Race and Ethnicity

Medical groups will report race/ethnicity based on the categories used by the federal Office of Management and Budget (OMB), which were determined to be the overall best practice. The slight variation from OMB reflects the categories recommended by the Health Research & Educational Trust (HRET) Toolkit[5] when combining race and ethnicity into one field. The data categories are:

American Indian or Alaska Native	Native Hawaiian/Other Pacific Islander
Asian	White
Black or African American	Choose not to disclose/Declined
Hispanic or Latino	Unknown

Important Note: Patients <u>must</u> self-report race and be able to select more than one category to show multi-racial status.

Language

Medical groups will report a patient's specific language preference. MNCM has set a minimum list of language categories based on the collaborative work done by the Minnesota Immigrant Task Force. Medical groups may report additional language categories if they are collecting them. The minimum data categories are:

Amharic	English	Karen	Russian	Tibetan
Arabic	French	Korean	Sign Language	Tigrinya
Bosnia	German	Laotian	Somali	Urdu
Burmese	Hearing Impaired	Mandarin	Spanish	Vietnamese
Cambodian	Hindi	Oromo	Swahili	Yoruba
Cantonese	Hmong	Polish	Tagalog	Other _____
Chinese	Japanese	Romanian	Thai	Declined
				Unavailable/Unknown

Insurance Coverage

Medical groups will report insurance coverage based on the patient's insurance coverage identification card using the code for appropriate insurance entity as listed. Please see appendix B for the specific insurance codes to be used for reporting to MNCM. ***Important Note: Only the primary insurance will be reported.***

The data categories are as follows:

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[5] Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on September 1st, 2008.

Aetna	Medicare Fee-for-Service and supplemental plans[6]
American Family	Metropolitan Health Plan (MHP)
America's PPO	Preferred One
Blue Cross Blue Shield (not MN)	PrimeWest
Blue Cross Blue Shield of Minnesota[7]	Prudential
Cigna	Sanford Health Plan
Comprehensive Care Services	Self-pay[8]
MN Department of Human Services[9]	South Country Health Alliance (SCHA)
FirstPlan Minnesota	State Farm
HealthPartners	Travelers Insurance
Humana	UCare
Indian Health Services	Uninsured[10]
Itasca Medical care	Veterans Administration (VA)
Medica[11]	Wausau [12]
Medicaid (not MN)	Other[13]

MNCM will work with insurance companies to translate this insurance coverage information into one of the following categories:

- Commercial
- Medicare
- Minnesota Health Care Programs (MNCare, GAMC, Medicaid)
- Dual eligible
- Uninsured
- Self-pay

A one page summary of the required data elements is provided in Appendix B.

The Rationale for the Required Data Elements

Determining the minimum set of required data elements was a challenging feat. The EAWG strived to achieve a balance between the need for data distinction with the value gained at any one level of distinction. As each EAWG representative had charted their own course, there was a good breadth of experience upon which to draw. The group's collective experience ultimately informed the determination of the final required data elements. This section provides some of the key highlights from those discussions.

Country of Origin
- The EAWG had lengthy discussions seeking the appropriate balance between:
  - data elements and category selections that would be meaningful to patients
  - data elements that provide segmentation that is meaningful in data analysis, and

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[6] Includes Pyramid Life, Tricare, Unicare, ZMedicare
[7] Includes Aware Gold, Blue Plus, Options Blue, Preferred Gold, Simply Blue
[8] Includes patients who have third party payer/insurance but choose not to use it, or are receiving uncovered, elective services.
[9] Includes Medicaid fee-for-service and GAMC fee-for-service
[10] Includes patients who do not have insurance, or have exceeded a benefit limit and elect to continue receiving services
[11] Includes Patient Choice, Definity Health, Elect, Essential, Insights, LaborCare, Premier, Primary, Select Care, UHC
[12] Does not include Patient Choice
[13] Includes a free form text field for use when the patient's insurance is not on the list

- the limits of IT systems in medical groups

It was concluded that the linking of race/ethnicity to country of origin could achieve the best balance.

- One anticipated challenge with the country of origin list is the updating required by world political events. Several suggestions resulted from this discussion:
  - Include a field for "Other" with a free form comment field so that patients born in countries in transition (proposed states, overthrown states, etc.) can name their country of origin even if it is not on the list.
  - Include known countries in transition, such as the former Yugoslavia and Palestine, in the list.
  - Keep the list to countries with substantive populations, specifically with a population of over 100,000.
  - Review and update the list based on world events, and the data collected in this "Other" field, as needed using www.worldbank.org/countries, www.infoplease.com/countries.html, or http://www.state.gov/www/regions/independent_states.html#note1

- One of the EAWG medical groups provided the following commentary on why country of origin is a relevant data element to collect:
  - Social Determinants of Health: For some refugee arrivals to Minnesota, the political turmoil and displacement they experienced for years could mean exposure to many infectious diseases, mental health issues, lack of preventive services and lack of access to care for chronic diseases.
  - Diseases Endemic to Certain Countries: Some diseases such as tuberculosis, HIV, malaria, parasites, hypertension and diabetes can be correlated with country of origin.

The EAWG also discussed the length of time an immigrant has lived in the United States and how, with integration, they may begin to assimilate unhealthy lifestyle behaviors and the diseases associated with them. In the story of the Center for International Health,[14] reference is made to what doctors call the "healthy immigrant effect," which is the recognition that "it takes about nine years for an immigrant to become 'American' in his body – obese, hypertensive, diabetic, and at risk for strokes and heart attacks."

Race and Ethnicity

- The EAWG had extensive discussion about race and ethnicity data categories. As a social construct, race and ethnicity data categories challenged the EAWG to go beyond the universally accepted categories set by the federal Office of Management and Budget (OMB).
- All the medical groups in the EAWG based race and ethnicity categories in some form on OMB's categories. Some added subcategories to obtain additional detail. Others used OMB categories exactly. One EAWG medical group allows patients to define themselves in their own words which are then rolled up to OMB categories for reporting.
- Definitions will be needed to assist staff and patients in determining appropriate race. The following OMB definitions are recommended:

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[14] My heart it is delicious: setting the course for cross-cultural health care: the story of the Center for International Health by Biloine W. Young, page 92.

- **American Indian or Alaska Native:** A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
- **Asian:** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam.
- **Black or African American:** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- **Hispanic or Latino**: A person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin. The term "Spanish origin" can be used in addition to "Hispanic or Latino."
- **Native Hawaiian or Other Pacific Islander:** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White:** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

- Some medical groups in the EAWG combined OMB's race and ethnicity selections into a single category list, <u>as MNCM is requiring for reporting</u>. Others created two fields and collected the data separately following OMB's recommendation to ask about ethnicity first.
- MNCM, the EAWG medical groups and the OMB recommend allowing the selection of **more than one race along and having patients self-identify their race**, rather than having a catchall "multiracial" or "more than one race" category. Also, having patients self-identify their race reduces the chance of misclassification.

Language
- The EAWG expects that, in compliance with the National Standards for Culturally and Linguistically Appropriate Services (CLAS),[15] many medical groups have established methods for collecting language data to meet patient needs for interpreter services.
- The objective in collecting language data is to evaluate outcomes for those comfortable speaking English and those comfortable speaking a language other than English.

The list provided in the preceding section is from the results of the Minnesota Immigrant Health Task Force. Medical Groups may tailor the list to best meet the languages preferred most by their patients.

Insurance Status
- Insurance status will serve as an indicator for socioeconomic status.
- *Self-pay* is to be used in situations where:
    - A patient actively elects not to use a third party payer
    - A patient receives an elective service for which there is no coverage
- *Uninsured* would include all situations that do not qualify as *Self-pay*, such as when
    - A patient has no insurance coverage
    - A patient reaches a benefit limit and elects to continue receiving services

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[15] National Standards for Culturally and Linguistically Appropriate Services (CLAS). More information can be found at the following weblink: http://www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15

▪ Patients may experience a change in insurance status throughout the reporting period. Medical groups should report the Insurance Status that was **most recently in force** at the time of reporting.

Other Data Elements to Consider

The EAWG considered the value of collecting other data elements beyond those defined as "required" above. While the following data elements will not be required for submission to MNCM, they can contribute to medical group quality improvement initiatives and patient-centered care. They are included here for each medical group to decide whether or not to collect them.

English Proficiency
Assessing a patient's English language proficiency is an important determinant of the need for an interpreter and the patient's ability to understand treatment plans. The HRET Toolkit[16] recommends providers ask the following questions:

▪ How would you rate your ability to speak and understand English? (Options: Excellent, Good, Fair, Poor, None at all, Declined, Unavailable)
▪ Would you like an interpreter?
▪ In which language would you feel most comfortable reading medical or health care instructions? (Provide a list of languages including Other, Do Not Know, Declined, Unavailable)
▪ How satisfied are you with your ability to read English? (Options: Very Satisfied, Somewhat Satisfied, Satisfied, Somewhat Dissatisfied, Very Dissatisfied, Declined, Unavailable)

It is also suggested that medical groups review the Robert Wood Johnson Foundation funded program, Speaking Together,[17] as it contains additional details on improving assessments of English language proficiency.

Health Literacy
In *Endorsing a Framework and Preferred Practices for Measuring and Reporting Culturally Competent Care,* the National Quality Forum (NQF)[18] defines *health literacy* as the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. This publication recommends providers take the following actions to improve communication in situations of low health literacy:
▪ Avoid using medical jargon;
▪ Use audio and/or visual aids;
▪ Include interactive instructions – do, write, say, or show;
▪ Prepare written materials to a 6th grade reading level; and
▪ Pre-test materials for intended outcomes.
Taking steps to improve patient health literacy is a valuable quality improvement initiative.[19]

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[16] Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit.* hretdisparities.org accessed on September 1st, 2008.
[17] Robert Wood Johnson Foundation & George Washington University School of Public Health and Health Services. *Speaking Together: National Language Services Network.* http://www.speakingtogether.org/overview Accessed on November 20th, 2008.
[18] National Quality Forum (2009) *Endorsing a Framework and Preferred Practices for Measuring and Reporting Culturally Competent Care.* http://www.qualityforum.org/projects/ongoing/cultural-comp/. Accessed on May 1st, 2009.
[19] Learn more from Minnesota's Health Literacy Partnership (http://healthlit.themlc.org/home.html)

Religion

Some EAWG medical groups are collecting this data element for the purpose of improving patient-centered care. For example, religion is an important part of conversations regarding family planning. It is also important in managing patients with diabetes who engage in fasting for religious reasons.

A sample list of Religions is provided in Appendix C.

Implementation Considerations

For all the EAWG medical groups, implementing this data collection process was a multi-month, multi-faceted, multi-department project. Through lessons learned from their experience, members of the EAWG identified several critical factors for ensuring the success of the initiative.

Critical Success Factors

- Complete a thorough needs analysis/project definition and get appropriate approvals and needed organizational buy-in before you consult with IT resources. This fosters a more concise conversation with the IT team. Your operational clarity improves their ability to meet your needs.
- Consider other areas of your medical group that may be interested in this type of data. EAWG members found interest among the purchasing and human resources departments and the research foundation that participated in their project teams.
- Engage teams and leaders at the earliest possible stage to gain buy-in and obtain input.
- Have appropriate and visible support from a senior leader.
- Ensure sustainability. Begin with the end in mind. Don't forget to include reports and audits in your specifications.
- Be clear about and frequently communicate the reasons why the medical group is embarking on the project.
- Develop and deliver clear, concise training and provide support for real-time learning.
- Identify measures of success and publicize achievements.
- Establish methods for continuous process management.

Using the EAWG's discussion of lessons learned this section focuses on the following areas that are important to successful implementation:

- Staff Training
- Collecting the Data
- Addressing Common Concerns about Collecting These Data
- IT/System Considerations
- Audit
- Engaging the Community

The insight of the EAWG experience is intended to improve the success of these initiatives in other medical groups.

Staff Training

The EAWG noted that clear, concise training and support for real-time learning is a critical success factor in this project. Several good resources have been developed to help with staff training:

- **Sample Training Presentation:** The HRET Toolkit[20] contains a Sample Training PowerPoint presentation. This presentation provides an excellent base from which to design training for your medical group. Some EAWG members customized this content to their unique training methods and approach. One of the members mentioned working to shorten the session to thirty minutes to reduce staff time away from work during the implementation. The presentation is available on the HRET Toolkit website at http://www.hretdisparities.org. Select Staff Training from the left bar menu.
- **Response Matrix:** Within the Sample Training PowerPoint presentation is a Response Matrix. Though included in the Sample Training PowerPoint, it is a powerful training tool on its own. This matrix helps staff role-play the process and provides a take-away reference document to guide them towards a successful outcome when receiving a difficult response from a patient. The content from the Response Matrix is reproduced in Appendix D for your reference.
- **Key Components Checklist:** An article entitled, "*Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions*" by Baker et al.[21] indicates that the main components of staff training should include:
    - A script that outlines the rationale for collecting the information, describes how to ask the questions, and addresses how the information will and will not be used.
    - Case examples to teach staff how to answer questions from patients who express concerns or who ask why this information is being collected.
    - Instructions for how to record /code the information.
- **Internal Reference Guides:** HealthPartners developed an internal training tool called "How and Why We Ask." It describes the rationale and purpose for the data collection and addresses some of the operational issues that may arise. A copy of this tool is included in Appendix E.

In addition to these tools, the EAWG shared some lessons learned with regard to training:
- Identify and involve your training team early on. This helps trainers gain knowledge of the disparity issue, understand the implementation process, and provides them with time to develop educational materials and procedures.
- Recognize and plan for the learning to take place over time.
- Consider ways to promote the data collection initiative in employee newsletters, break room bulletin boards and around employee workstations.[22]

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[20] Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. hretdisparities.org accessed on September 1st, 2008.

[21] Romana Hasnain-Wynia and David Baker. *Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions.* Health Services Research. Vol. 41:4 August 2006. See additional details in Appendix X: Additional Resources and References.

[22] Robert Wood Johnson Foundation & George Washington University School of Public Health and Health Services. *Speaking Together: National Language Services Network.* http://www.speakingtogether.org/overview accessed on November 20th, 2008. Speaking Together, though grounded specifically in the interpreter initiative, provides great examples of internal promotion and communication.

- Showcase leadership. Demonstrate that top clinic officials are behind the initiative and watching the clinic's performance.
- Communicate the importance of the initiative and the key role that staff members play in its success.
- Communicate the implementation timeline, performance expectations and evaluation methods.
- Reinforce the need for feedback, especially from staff for whom the data collection process is a struggle. Consider an informal survey of staff to solicit feedback; results can inform additional training.
- Don't forget new employee orientation. Instructional materials, training process, and an auditing plan will also be needed when a new employee joins the team.

Role-playing

The EAWG consistently noted that staff comfort and confidence in asking questions related to race/ethnicity and/or country of origin is a barrier that must be overcome and recommended role-playing as a key training method to increase confidence and comfort. By providing specific scripts for roles, trainers can ensure that team members challenge each other sufficiently to build confidence and competence. The HRET Response Matrix (Appendix D) provides a solid start for role-playing exercises.

Collecting the Data

This section details the collection process – asking the questions, question order, scripts, and who answers. Some medical groups collect the data through direct patient interviews. Other medical groups provide patients with forms to complete (either online or on paper). ***The EAWG concluded that the face-to-face interview was the best method because it provides the best opportunity to respond to patient questions about the data collection.*** However, data collection through forms can also be successful, as demonstrated by some EAWG medical groups. The general principles discussed below apply whether collecting in-person or via a form.

Asking the Question

EAWG members differed in their determination of and rationale for which staff members should be responsible for asking questions in face-to-face patient interviews. Each medical group will need to make this determination based on their systems and overall operations. While processes varied among the EAWG, two things were very clear no matter which functional area was responsible for the data collection:

1. You must provide good training and coaching for whichever staff members are responsible for data collection.
2. The more system support you can provide for the completion of the fields the higher the completion rates.

Generally, the EAWG recommended that staff members in any of three roles/functions be charged with asking these questions: Appointment Setting, Registration, and Rooming staff. Here are some of factors to consider in determining who is responsible for gathering the data:

- Who has access to the screens that contain the data fields for this data collection?

- Where does the line of questioning fit? For example, as appointment staff members are likely already asking questions about English proficiency and the need for interpreter services, this may be a good time to ask the other questions.
- Based on patient population and business process, where do you expect to get the most complete and accurate results – the anonymity of a phone call (appointment setting); face-to-face conversation (registration); or face-to-face with the added privacy of the treatment room (rooming staff). This may vary for each question.

The EAWG members emphasized the benefit of system support for data collection in patient interviews. For example, make the data field "required" so the staff person is unable to move to the next screen until the field is completed. Another example is to use a pop up screen that alerts the staff member that the field is not complete and encourages or requires the staff person to complete the field. Both of these methods were successfully employed by the EAWG medical groups.

If data is to be collected via a form, your medical group's administrative process will likely govern your decision about where it best fits. When using forms, recognize that the question order and the descriptions of purpose/data use can influence collection rates. Specific recommendations on question order are provided below. Also, note that completion rates will be highest when medical group staff have a way of identifying patients who did not respond via a form and can thus collect via a patient interview.

Question Order
Some patients may be sensitive about answering these questions, generally because of concerns about discrimination. As a result, researchers have put much effort into developing ways of framing or asking these questions to give patients confidence and comfort when responding. The EAWG members noted that when a staff member is interviewing a patient, discomfort with the questions is often more present in the medical group staff than in the patients. This is why training and practice through role-playing is so important.

The following advice is based on experience and expertise as noted in the footnotes.

- Ask about country of origin (birth country), before race.[23] It is a data element generally easy for patients to answer and often more meaningful to patients than race.
- While MNCM recommends having a single question for both race and ethnicity, if you have separate questions, one for race and one for ethnicity, it is recommended that you ask ethnicity before race. It reduces confusion and increases accuracy.[24]
- Be proactive in asking questions regarding language preference/English proficiency and the need for interpreters throughout the treatment experience.[25]
- Show questions in the system in the order they are to be asked whether it is a guide for an interview or a form, online or paper.[26]
- For form-based collection, include the rationale (script) directly on the form.[27]

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[23] Early Adopter Work Group experience

[24] Office of Management and Budget. *Standards for the Classification of Federal Data on Race and Ethnicity*, 1995. http://www.whitehouse.gov/omb/fedreg/race-ethnicity.html

[25] Robert Wood Johnson Foundation & George Washington University School of Public Health and Health Services. *Speaking Together: National Language Services Network.* http://www.speakingtogether.org/overview Accessed on November 20th, 2008

[26] Early Adopter Work Group experience

[27] Early Adopter Work Group experience

Scripts

Each of the EAWG medical groups developed scripts for use with the data collection. For face-to-face patient interviews, scripts give staff confidence and direction and are an important part of the implementation program. In form-based collection, the additional information can relieve concerns and increase collection rates. MNCM recommends that the question about country of origin be asked first. Listed below are some suggested scripts:

Sample Preamble/Introduction 1

We want to make sure that all our patients get the best care possible. We would like you to tell us your country of origin, racial/ethnic background and preferred language so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care. Your answers will be confidential and will have no effect on the care you receive.

Sample Preamble/Introduction 2

We want to ask you about your country of origin, race/ethnicity and preferred language. Your answer will help us provide the best care to all of our patients. We use this information to help our doctors and nurses give you better care. We will keep your information private and confidential.

Recommended Questions

Country of Origin	*Please tell me in what country were you born?*
Race	*Please tell me the race/ethnicity groups that describe you?*
Language	*In what language can we best serve you?*

Scripts can be used verbally or in writing, depending on the collection method used. One of the EAWG medical groups developed a paper form to support the patient during the interview process. This written form is made available for patient review during the interview. The simple card has been translated into five languages and can assist staff to communicate with patients on this data collection question.

One final note on the importance of scripts: A cross-sectional study conducted in Chicago by the Feinberg School of Medicine assessed patients' comfort with sharing race and ethnicity information. The results demonstrated a significant increase in patient comfort when a patient was informed that race and ethnicity was being collected to monitor the quality of care for all patients. In this study, three other statements about why race and ethnicity data were being collected were found to be less successful at improving patient comfort level. They included: (1) government agencies require it (2) it was needed to gain information to help hire and train staff, and (3) to ensure all patients were treated equally.[28]

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[28] Baker, David; Cameron, Kenzie; Feinglass, Joseph; Georgas, Patricia; Foster, Shawn; Pierce, Deborah; Thompson,Jason; Romana Hasnain-Wynia. *Patients' Attitudes Toward Health Care Providers Collecting Information About Their Race and Ethnicity.* J Gen Intern Med 2005; 20:895–900.

Who Answers?
Who answers the questions may seem obvious but it is important to note. **The answers must be provided by the patient rather than determined by the staff person.** Providing the information remains voluntary. This is why the data categories include options for "declined" or "choose not to answer." Assignment based on staff observation of indicators such as surname, geographic location, or physical appearance, is subjective and can result in inaccuracies that can skew results and conclusions. Take steps to be sure the responses are coming from the patients.

Addressing Common Administrative Concerns about Collecting These Data

The EAWG medical groups encountered several internal barriers that are described here with responses.

The concern that the data is not needed at this medical group.
It can be difficult for health care providers and staff to come to terms with the existence of disparities. Since the publication of Institute of Medicine's (IOM's) 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare,*[29] awareness of the existence of disparities has increased. Accepting that disparities exist is an essential step toward identifying and addressing them. There are several ways to approach this concern, which can arise from a variety of areas in a medical group, from physician to front office staff:

- Highlight the diversity among the medical group's patient population.
    - Seek out data that substantiate that the patient population is diverse.
        - Review the utilization reports from the provider of interpreter services.
        - Review data from the state demographer's office on minority populations in the medical group service area. For medical groups serving the seven county Minneapolis/St. Paul metropolitan area, check out www.tccompass.org for data on the growth of immigrant populations.
- Substantiate that disparity occurs in health care.
    - The article entitled *Physician Performance and Racial Disparities in Diabetes Mellitus Care*[30] provides compelling insight into how individual physician performance for diabetes patients varies between Black and White patients. After studying the performance of 90 physicians who had at least 5 White and 5 Black adult patients with diabetes, Sequist et al. concluded within a physician's panel that Black patients were less likely to control their HbA1c, LDL-C, and blood pressure. A detailed reference for this article can be found in Appendix G.
    - Review IOM's 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare.* Summarize and share the findings with the team.
- Substantiate market demand.
    - Refer to the online article entitled, "*Why Companies are Making Health Disparities Their Business: The Business Case and Practical Strategies.*"[31] It cites a lengthy list

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[29] Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* The National Academies Press. 2003.

[30] Thomas D. Sequist, MD, MPH; Garrett M. Fitzmaurice, ScD; Richard Marshall, MD; Shimon Shaykevich, MS; Dana Gelb Safran, ScD; John Z. Ayanian, MD, MPP. *Physician Performance and Racial Disparities in Diabetes Mellitus Care.* ARCH INTERN MED/VOL 168 (NO. 11), JUNE 9, 2008.

[31] http://www.businessgrouphealth.org/pdfs/business_case_analysis.pdf

of key findings of disparities in health that support the need for businesses to pay attention to this issue.

- Refer to the cross-sectional study of patients in Chicago that found that 79.9 percent of patients somewhat or strongly agreed that hospitals and clinics should collect information on race and ethnicity.[32]
- Engage a high-level medical group leader to sell the business case, champion the cause and lead this effort. Provide this champion with the information and data you obtain about your medical group population.

The concern that asking for race and ethnicity information is illegal.

Matters of race and ethnicity in this country often raise questions about legality because of the events surrounding the passing of the 1964 Civil Rights Act. Title VI of this Act prohibits discrimination on the basis of race or national origin by recipients of federal assistance. This is the law most often referenced in conjunction with this concern.

Much research has been done on this question. Most noteworthy is the 2006 study done by The George Washington University's Department of Health Policy in the School of Public Health and Health Services which analyzed the following question: "Does the collection of patient data by race or ethnicity, as part of a program of quality improvement, violate the law?" The results of this research are published in a Policy Brief entitled, "The Legality of Collecting and Disclosing Patient Race and Ethnicity Data," which was funded by the Robert Wood Johnson Foundation. The authors considered Title VI of the 1964 Civil Rights Act and concluded that "the collection and disclosure of patient data by race and ethnicity in a quality improvement context advances the purpose of Title VI. Such practices would be entirely consistent with the regulations and would operate as evidence of compliance with the law rather than as a violation of it." In addition, they identified other means of establishing the requirements under the Patient Safety Quality Improvement Act and via the powers of the U.S. Department of Health and Human Services. The link to this briefing is provided below.[33]

A follow-up Policy Brief, entitled, "Patient Race and Ethnicity Data and Quality Reporting: A Legal Roadmap to Transparency," goes deeper into the issues regarding use of this data for quality improvement efforts. This analysis concludes that the use and reporting of this data "as part of an effort to measure and report on health care quality is permissible," with cautions against using it for specific discriminatory practices. The link to this briefing is provided below.[34]

The concern that the information is too personal.

With questions regarding legality resolved, personal privacy concerns often arise. Sometimes these arise because of staff discomfort in asking, and sometimes it is genuinely a patient preference for privacy. Overcoming this barrier can take a variety of forms:

- Develop staff thoroughly, including comprehensive training, extensive role playing, easily accessible tools, observation of successful interactions of a mentor/master, and appropriate patient education on how the data will be used.

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[32] Baker, David; Cameron, Kenzie; Feinglass, Joseph; Georgas, Patricia; Foster, Shawn; Pierce, Deborah; Thompson, Jason; Romana Hasnain-Wynia. *Patients' Attitudes Toward Health Care Providers Collecting Information About Their Race and Ethnicity*. J Gen Intern Med 2005; 20:895–900.

[33] http://www.rwjf.org/files/publications/other/RaceEthnicDisparitiesData06222006.pdf

[34] http://www.gwumc.edu/sphhs/departments/healthpolicy/chsrp/downloads/TitleVIandTransparency031708.pdf

- Clarify for the staff that while the data collection is required, the patient response is voluntary. This is why there is a category entitled, "Choose not to disclose/Declined."
- Advise the team that the Minnesota Immigrant Health Task Force recommends race and ethnicity data be collected. This multi-dimensional group, which included representatives from immigrant communities, developed eight recommendations for improving the health of immigrants in Minnesota. The recommendations included support for collection of these data.[35]

The concern that there is not enough time to ask more questions.

It is clear that adding questions to the patient intake process will take additional time, though no early adopter halted the data collection initiative because of time. All EAWG medical groups agreed the value in the data collected is worth the time it takes to collect it. The EAWG agreed that having additional data helped achieve more effective care, and this beneficial outcome outweighs the additional time added from collecting the data.

The concern that the data categories are too broad.

As noted in the section entitled, "The Rationale for the Required Data Elements," the EAWG had substantive discussions about the data details and explored many possibilities in its effort to identify the optimal data set. A consistent reminder regarding the purpose of this data definition was essential – it defines the data required for submission to MNCM.

Some medical groups may identify additional, more detailed data as necessary for quality and care management. MNCM expects medical groups to roll up detailed data categories used for quality and care management into the broad data categories established for reporting.

The EAWG attempted to define data elements that would achieve the optimal balance between keeping the collection process simple and obtaining sufficient data for meaningful analysis.

The concern that patient population totals in our medical group for some categories are too low.

Patient diversity varies greatly among clinics state-wide. In order to achieve consistency in reporting, the data categories must consider patient populations across the whole state. MNCM understands that some medical groups will not have statistically significant representation among some categories and will take this into consideration in data analysis and reporting. Medical groups should also be attentive to sample size when conducting analysis for quality management.

The concern that the IT system cannot accommodate these requirements.

For all EAWG members, information technology (IT) was a big part of the implementation process and the group carefully considered system functionality in defining the data elements. To the degree possible, MNCM solicited feedback from EHR software companies and/or software users on matters of functionality and will continue to foster communication to ensure awareness and alignment regarding implementation. In addition, EAWG members have shared their advice on IT matters in the next subsection.

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[35] Minnesota Immigrant Health Task Force. *Immigrant Health: A Call to Action.* January 2005. The Task Force was sponsored by the Minnesota Department of Health and the Minnesota Department of Human Services. Report available at http://www.health.state.mn.us/divs/idepc/refugee/immigrant/index.html

The concern that we do not have an electronic medical record to track this data.

Medical groups that do not yet have electronic medical records can implement a paper process for data collection. A sample form for use with paper-based systems is included in Appendix F.

IT/System Considerations

A significant part of the project for the EAWG medical groups was the IT/System support. The members shared the following advice:

- Pick lists work better than free form fields
  - It is easier for the staff to select responses, especially when the list narrows based on what they've typed in.
  - Data compilation, analysis and reporting are better.
  - It is helpful to have a free form field available in case the patient's answer is not in the pick list.
- While pick lists are generally preferred over free form fields, some free form is recommended in association with the category "Other," so additional detail can be collected.
- Determine the order in which the questions are to be asked before programming. Have the system reflect the determined order.
- Completion rates will be higher if the system supports completion through required fields or pop-ups.

Audit and Compliance

Evaluating the effectiveness of the system is an important part of the project. EAWG members emphasized the importance of securing the IT and staff resources needed to support evaluation, most notably creating the reports needed for evaluation and audit. Here is a list of key questions the audit/evaluation process and related reports should address:

- What are the collection rates?
  - By data element for all patients
  - By data element for patients seen in the last x months/years
  - By individual staff person
  - By department
- By staff person and department
  - How many patients are coded as other, declined, or unknown, in order to identify system issues or unusual trends in patient responses?
  - Are there any other unusual trends or anomalies by staff person or department?
- How will I ensure that the data collected reflects patient response rather than designation by a staff person?
- Do my data lists need updating? (i.e. "Other" fields for language or country of origin are showing redundant entries)

With regard to auditing activities, the EAWG members also noted that during the initial implementation, auditing will be needed more frequently. Once the system is performing to expectations, audits are recommended no less than once per year. Obviously, when a new staff

person is hired, more frequent auditing is needed until his/her performance is meeting expectations.

Finally, the EAWG recommends that medical groups strive for high collection rates from the beginning. Two years into the data collection initiative, one of the EAWG medical groups introduced a pop-up screen in an effort to improve collection rates. Collection rates went from 80 percent to 95 percent. This success affected their ability to effectively review trends. They discovered that patients "previously uncategorized" had more complex health conditions and once categorized altered the results of categorical queries.

Engaging the Community

MNCM recommends you conduct outreach to communities in your service area and engage community leaders in conversations about why you are collecting the information and how the data will be used. These proactive conversations will enable community leaders to advise community members on the value and purpose of the data collection.

The first step in this process is to identify the communities served by the medical group. With communities identified, seek out community leaders. Advise the leaders on data collection activities and ask the leaders what can be done to help patients feel comfortable responding.

The Minnesota Immigrant Health Task Force suggests working with community health workers. They have experience engaging immigrant populations and are well-positioned to address any fears or reluctance a patient may have with respect to sharing race, ethnicity, or language data.[36] Building relationships with community leaders can also open communications and help address barriers in the community regarding health education. Also, organizations may learn about best practices for dealing with cultural differences between the health care providers and members of the community.

Using the Data

Quality Improvement Purposes

It is the sincere hope of MNCM and the Robert Wood Johnson Foundation, as sponsors of this work, that these data be used for quality improvement purposes. The availability of these data enables wide-ranging analysis and evaluation of disparities in care delivery, outcomes and patient satisfaction. It also shifts the focus from anecdote and hypothesis to data-driven details. In collecting these data, your medical group is taking the first step in identifying and then addressing disparities in health care. Disparity reduction cannot occur without it. Here is an example:

> In 2006, HealthPartners Medical Group began using patient race and language data to drive quality improvement efforts aimed at reducing disparities in care.

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[36] Minnesota Immigrant Health Task Force. *Immigrant Health: A Call to Action.* January 2005. The Task Force was sponsored by the Minnesota Department of Health and the Minnesota Department of Human Services.

- In one clinic HealthPartners identified a gap between White women and African American women who receive mammograms. Further investigations revealed that offering same day screening was a more effective way to increase mammography rates for African-American women. With this change, the gap between the screening rates for White women and African American women decreased from 16 percent to 2 percent.
- HealthPartners also developed customized scripts for talking with African-American patients about the importance of colon cancer screening due to their increased risk of dying from the disease. Due to the success of this effort, HealthPartners plans to increase the amount of educational materials for patients based on their cultural values and health needs.[37]

Public Reporting

Beginning in 2009 medical groups will be asked to develop a system to collect and report in a common format to MNCM the following minimum data set:
- Race/Ethnicity
- Language data
- Country of Origin
- Insurance Coverage (as an indicator for socio-economic status)

The reporting of the above data elements will be voluntary in 2010 (2009 dates of service). Reporting of these data elements will be married with clinical data (diabetes care, ischemic vascular disease, depression) and submitted via the direct data submission method.

The reporting of the above data elements will be required in 2011 (2010 dates of service). Reporting of these data elements will be expected with all subsequently developed Direct Data Submission (DDS) measures.

Customizing Care Based on Racial Risk Factors

Knowing the demographic details of a patient enables providers to customize care based on risk factors. Listed below are some examples taken from the story of the Center for International Health[38]: Knowing race, ethnicity or country of origin, health care providers might:

- Screen a Liberian patient for malaria, even if that person has no symptoms, because malaria is common in Liberia.
- Check an Asian patient for osteoporosis ten years sooner than an American patient because 85 percent of Asians are lactose-intolerant; they avoid dairy products because they cause diarrhea.
- Screen Vietnamese and Korean patients for hepatitis B because of the increased incidence of carriers.

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[37] Smith, Scott. *Confronting Racial Disparities.* Minnesota Medical Association Quality Review. Fall 2008.

[38] Young, Biloine. My heart it is delicious: setting the course for cross-cultural health care: the story of the Center for International. Afton Historical Society Press November 1, 2007.

Determining Workforce Needs and Workforce Satisfaction

One EAWG member re-organized their clinic to better match the culture and life experience of the patients served. Though initially a difficult organizational decision, it has proven positive for patient and employee satisfaction. Here is an overview of their current staffing mix:

- 23 Southeast Asians
- 15 African-born Blacks
- 10 American-born Blacks
- 9 Latinos
- 6 non-European Americans whose primary language is not English
- 2 American Indians

These are just some of the possibilities resulting from consistent collection of these data.

Conclusion

Minnesota Community Measurement is pleased to provide this Handbook on the Collection of Race/Ethnicity/Language Data in Medical Groups. Evaluating and reducing disparities in health care is an important initiative in Minnesota and it cannot be done without the collection of these data. The effort extended in conjunction with this Handbook to define a uniform data set and establish the means of consistent data collection enables Minnesota Community Measurement to provide the reporting needed to achieve disparity reduction. A comprehensive list of References and Resources is provided in Appendix G.

This Handbook would not have been possible without the contributions of the Early Adopters Work Group and all who provided comments during its development. Thank you for your time and input.

Supporting health care providers' implementation efforts is an important part of Minnesota Community Measurement's work. To that end, MNCM will host informational webinars about the data collection and submission and will archive these webinars on its corporate website (www.mncm.org).

Appendix A: Early Adopters Work Group

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Appendix B: Required Data Elements

Country of Origin

Afghanistan	Congo, Republic of	Iran	Nepal	South Korea
Albania	Costa Rica	Iraq	Netherlands	Spain
Algeria	Cote D'Ivoire	Ireland	New Zealand	Sri Lanka
Angola	Croatia	Israel	Nicaragua	Sudan
Argentina	Cuba	Italy	Niger	Suriname
Armenia	Cyprus	Jamaica	Nigeria	Swaziland
Australia	Czech Republic	Japan	North Korea	Sweden
Austria	Denmark	Jordan	Norway	Switzerland
Azerbaijan	Djibouti	Kazakhstan	Oman	Syria
Bahamas	Dominican Republic	Kenya	Pakistan	Taiwan
Bahrain	East Timor	Kuwait	Palestinian State (proposed)	Tajikistan
Bangladesh	Ecuador	Kyrgyzstan	Panama	Tanzania
Barbados	Egypt	Laos	Papua New Guinea	Thailand
Belarus	El Salvador	Latvia	Paraguay	Togo
Belgium	Equatorial Guinea	Lebanon	Peru	Tonga
Belize	Eritrea	Lesotho	Philippines	Trinidad and Tobago
Benin	Estonia	Liberia	Poland	Tunisia
Bhutan	Ethiopia	Libya	Portugal	Turkey
Bolivia	Fiji	Lithuania	Puerto Rico	Turkmenistan
Bosnia Herzegovina	Finland	Luxembourg	Qatar	Uganda
Botswana	France	Macedonia	Romania	Ukraine
Brazil	Gabon	Madagascar	Russia	United Arab Emirates
Brunei	Gambia	Malawi	Rwanda	United Kingdom
Bulgaria	Georgia	Malaysia	Saint Lucia	United States
Burma	Germany	Maldives	Saint Vincent & the Grenadines	Uruguay
Burkina Faso	Ghana	Mali	Samoa	Uzbekistan
Burundi	Greece	Malta	Sao Tome and Principe	Vanuatu
Cambodia	Grenada	Marshall Islands	Saudi Arabia	Venezuela
Cameroon	Guatemala	Mauritania	Senegal	Vietnam
Canada	Guinea	Mauritius	Serbia	Western Sahara
Cape Verde	Guinea-Bissau	Mexico	Sierra Leone	Yemen
Central African Republican	Guyana	Micronesia	Singapore	Yugoslavia (former)
Chad	Haiti	Moldova	Slovakia	Zambia
Chile	Honduras	Mongolia	Slovenia	Zimbabwe
China	Hungary	Montenegro	Solomon Islands	Other (please specify) _____
Colombia	Iceland	Morocco	Somalia	Chose not to answer/Declined
Comoros	India	Mozambique	South Africa	Unknown
Congo, Democratic Republic of	Indonesia	Namibia		

Responses must be provided by the patient rather than determined by the staff person.

Race and Ethnicity

American Indian or Alaska Native	Native Hawaiian/Other Pacific Islander
Asian	White
Black or African American	Choose not to disclose/Declined
Hispanic or Latino	Unknown

Patients <u>must</u> be able to select more than one category to show multi-racial status.

Language

Amharic	English	Karen	Russian	Tibetan
Arabic	French	Korean	Sign Language	Tigrinya
Bosnia	German	Laotian	Somali	Urdu
Burmese	Hearing Impaired	Mandarin	Spanish	Vietnamese
Cambodian	Hindi	Oromo	Swahili	Yoruba
Cantonese	Hmong	Polish	Tagalog	Other _____
Chinese	Japanese	Romanian	Thai	Declined
				Unavailable/Unknown

Insurance Coverage with codes *(use most recent)*

Code	Insurance Name	Code	
18	Aetna	8	Medicare Fee-for-Service and supplemental plans[39]
22	American Family	5	Metropolitan Health Plan (MHP)
27	America's PPO	6	Preferred One
15	Blue Cross Blue Shield (not MN)	10	PrimeWest
1	Blue Cross Blue Shield of Minnesota[40]	25	Prudential
17	Cigna	12	Sanford Health Plan
23	Comprehensive Care Services	16	Self-pay[41]
13	MN Department of Human Services[42]	9	South Country Health Alliance (SCHA)
14	FirstPlan Minnesota	24	State Farm
3	HealthPartners	26	Travelers Insurance
14	Humana	7	UCare
21	Indian Health Services	29	Uninsured[43]
11	Itasca Medical care	19	Veterans Administration (VA)
4	Medica[44]	28	Wausau [45]
20	Medicaid (not MN)	99	Other[46]

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[39] Includes Pyramid Life, Tricare, Unicare, ZMedicare
[40] Includes Aware Gold, Blue Plus, Options Blue, Preferred Gold, Simply Blue
[41] Includes patients who have third party payer/insurance but choose not to use it, or are receiving uncovered, elective services.
[42] Includes Medicaid fee-for-service and GAMC fee-for-service
[43] Includes patients who do not have insurance, or have exceeded a benefit limit and elects to continue receiving services
[44] Includes Patient Choice, Definity Health, Elect, Essential, Insights, LaborCare, Premier, Primary, Select Care, UHC
[45] Does not include Patient Choice
[46] Includes a free form text field for use when the patient's insurance is not on the list

Appendix C: Religion List[47]

African Methodist Episcopal

Assembly of God

Bahai Faith

Baptist

Buddhist

Can Not Answer

Catholic

Christian

Christian Science

Covenant

Division of Science

Druid

Eastern Orthodox

Episcopalian

Evangelical

Greek Orthodox

Hindu

Hmong

Islam

Jehovah Witness

Jewish

Latter Day Saints

Lutheran

Methodist

Mormon

Muslim

Native American

Nazarene

Non-denominational

Orthodox

Pagan

Pentecostal

Presbyterian

Protestant

Quaker

Reformed Latter Day Saints

Russian Orthodox

Salvation Army

Scientology

Seventh Day Adventist

Spiritualist

Unification Church

Unitarian

United Church

Wicca

Declined

None

Other

Unknown

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[47] Compilation of lists used by two of the Work Group medical groups' lists

Appendix D: HRET Toolkit Response Matrix[48]

Patient Response Matrix - Routine

Patient Response	Suggested Response	Hints	Code
I'm American	Would you like to use an additional term, or would you like me to just put American?		American or others if specified
Can't you tell by looking at me?	Well, usually I can. But sometimes I'm wrong, so we think it is better to let people tell us. I don't want to put in the wrong answer. I'm trained not to make any assumptions.		
If using open-ended option: I don't know. What are the responses?	You can say White, Black or African American, Latino or Hispanic, Asian, American Indian or Alaska Native, Pacific Islander or Native Hawaiian, some other race, or any combination of these. You can also use more specific terms like Irish, Jamaican, Mexican.		
I was born in Nigeria, but I've lived here all my life. What should I say?	That is really up to you. You can use any term you like. It is fine to say that you are Nigerian.		

Patients Returning

Patient Response	Suggested Response	Hints	Code
A patient returning for care with "DECLINED" code.	DO NOT ASK AGAIN		
A patient returning for care with the "UNKNOWN" or "Unable to provide information" code.	Proceed to ask for the information per routine		

Tougher Questions (generally indicate DECLINED code)

Patient Response	Suggested Response	Hints	Code
"I'm Human."	Is that your way of saying that you don't want to answer the question? If so, I can just say that you didn't want to answer.	DON'T SAY – I'll just code as declined.	Declined
"It's none of your Business."	I'll just put down that you didn't want to answer, which is fine.	DON'T SAY – I'll just code as declined	Declined
"Why do you care? We're all human beings."	Well, many studies from around the country have shown that a patient's race and ethnicity can influence the treatment you receive. We want to make sure this doesn't happen here, so we use this information to check and make sure that everyone gets the best care possible. If we find a problem, we fix it.	If patient still refuses, DON'T DAY – I'll just code as a declined.	Declined

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[48] Recreated from the HRET Toolkit www.hretdisparities.org

Appendix E: An Example - HealthPartners Internal Training Tool

How and Why We Ask

HealthPartners Clinics began collecting language, race and country of origin data in 2004 to assure that all patients receive high quality health care consistent with the six aims. Language collection is going well, but there is considerable variation in systems and processes for collecting race and country of origin data collection across our system. While we understand staff concerns about lack of time and not wanting to offend patients, data collection is critical for us to provide safe and equitable care for all of our patients.

Q. How can we use this data?
A. Staff members may not be aware of how we can use language, race and country of origin data to improve care. Here are some examples:

- Automated appointment reminder system in patient's native language.
- Epic can alert staff if a patient needs an interpreter or the Language Line.
- Language information will help better allocate resources. For example hiring on-site interpreters at certain sites.
- Maximizing Epic's capabilities. For example, African Americans have a higher incidence of colorectal cancer. African Americans should begin colorectal screening at age 45 rather than 50 years of age and colonoscopy is preferable to sigmoidoscopy due to the location of lesions.
- Tracking health disparities. Minnesota data shows that there are significant differences in diabetes, cancer and heart disease rates based on race. By collecting this data, we can determine the extent of disparities and make plans for closing the gap.

Q. When do we collect the information?
A. Language - Staff should collect the information and enter it in the Epic Registration Demographics screen during appointment scheduling. Race & Country of Origin - Staff should collect this information as part of the rooming process or at the time of check-in. The patient can check his/her responses on a copy of the "Why we want to ask" sheet for entry into Epic Demographics at a later time or the rooming person can enter the data directly into the Clinical Demographics tab in EpicCare. Check to see if we already have the information before asking the patient.

Q: Can we legally ask these questions?
A: Yes. Collecting and reporting race, country of origin and primary language is legal according to Title VI of the federal Civil Rights Act of 1964. At the state level, Minnesota law doesn't prohibit collecting this information either.

Q. How do I ask a patient for this information?
A. Staff members who do a good job of collecting data consistently say that if the person asking for the information is comfortable asking, patients are rarely reluctant to provide it. When patients are uncomfortable responding, reassure them we will use the information to ensure that all patients receive high quality care, regardless of race or ethnic background. Research shows that this response is more successful than other explanations such as "to monitor quality" or "we have to do it."

Other Questions about Race & Country of Origin Information
Q: Why are we collecting race and country of origin information?

A: Research has shown that people of color tend to receive lower quality health care even if they make the same amount of money and have the same insurance as others. We will ask patients about their race and country of origin because we want all patients to receive the same level of high-quality care and service. We will use this information to:

- Supply providers with data that can assist in customizing care based on racial risk factors.

- Assist in determining workforce needs.
- Measure satisfaction and clinical outcomes based on the patient's race.
- For potential research.

This information will be kept strictly confidential. We intend to ask each patient for this information only once. A patient can decline to provide the information.

Q: What's the difference between race and country of origin?

A. Race: In sociology, race defines a group of people who share genetically transmitted physical characteristics. The term has been reshaped and redefined over the years, but still remains a controversial concept because scientifically speaking, there is no such thing as "race." The "race" categories that we will use are: American Indian or Alaska Native; Asian; Black or African-American; Hispanic or Latino; White; Some other race (PLEASE NOTE: this form is from HealthPartners and not the recommended categories from MNCM). The Epic race field will accept multiple values.

Country of origin: This is the country where a person was born.

Q: What if a patient isn't sure which race category to select?

A: Here is some information that may be useful (**Important Note: these definitions do not reflect MNCM's recommendations, please use the definitions listed on page 10-11 of this Handbook).**

American Indian or Alaska Native: A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American: A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

Hispanic or Latino: This may be considered an "ethnic" group but may also be included in "race" categories. A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can also be used in addition to "Hispanic or Latino."

White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Some other race: This category should be used for persons having origins in any of the original people of Hawaii, Guam, Samoa, or other Pacific Islands. It can also be used for people who don't identify with any of the other categories (*Note: this is not a MNCM category*).

Chose not to answer: Patient prefers not to have this information in his/her medical record.

Q: Couldn't this be asked at Appointment Scheduling when the patient is asked about language?

A: No. We believe that patients consider this a more "sensitive" question than language. We prefer to ask this face-to-face during the clinic visit.

Q: Is this a primary care process?

A: No, this is being done in all HPMG medical settings - primary, specialty, urgent care and behavioral

health.

Q: Do providers have a role in this?

A: Yes. Like with other "rooming tasks," if the rooming person does not complete the task, the provider should see that it is completed or personally complete it. Providers will use the language, race and country of origin to provide patient-centered care.

Q: Who should I contact for more information?

A: Your CDS.

Appendix F: Data Collection Form

"We want to make sure that all our patients get the best care possible. We would like you to tell us your country of origin, racial/ethnic background and preferred language so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care. Your answers will be confidential and will have no effect on the care you receive".

Please tell me in what country you were born. *(Circle one or write in the country name beside "Other" if you do not see your country listed.)*

Afghanistan	Congo, Republic of	Iran	Nepal	South Korea
Albania	Costa Rica	Iraq	Netherlands	Spain
Algeria	Cote D'Ivoire	Ireland	New Zealand	Sri Lanka
Angola	Croatia	Israel	Nicaragua	Sudan
Argentina	Cuba	Italy	Niger	Suriname
Armenia	Cyprus	Jamaica	Nigeria	Swaziland
Australia	Czech Republic	Japan	North Korea	Sweden
Austria	Denmark	Jordan	Norway	Switzerland
Azerbaijan	Djibouti	Kazakhstan	Oman	Syria
Bahamas	Dominican Republic	Kenya	Pakistan	Taiwan
Bahrain	East Timor	Kuwait	Palestinian State (proposed)	Tajikistan
Bangladesh	Ecuador	Kyrgyzstan	Panama	Tanzania
Barbados	Egypt	Laos	Papua New Guinea	Thailand
Belarus	El Salvador	Latvia	Paraguay	Togo
Belgium	Equatorial Guinea	Lebanon	Peru	Tonga
Belize	Eritrea	Lesotho	Philippines	Trinidad and Tobago
Benin	Estonia	Liberia	Poland	Tunisia
Bhutan	Ethiopia	Libya	Portugal	Turkey
Bolivia	Fiji	Lithuania	Puerto Rico	Turkmenistan
Bosnia Herzegovina	Finland	Luxembourg	Qatar	Uganda
Botswana	France	Macedonia	Romania	Ukraine
Brazil	Gabon	Madagascar	Russia	United Arab Emirates
Brunei	Gambia	Malawi	Rwanda	United Kingdom
Bulgaria	Georgia	Malaysia	Saint Lucia	United States
Burma	Germany	Maldives	Saint Vincent & the Grenadines	Uruguay
Burkina Faso	Ghana	Mali	Samoa	Uzbekistan
Burundi	Greece	Malta	Sao Tome and Principe	Vanuatu
Cambodia	Grenada	Marshall Islands	Saudi Arabia	Venezuela
Cameroon	Guatemala	Mauritania	Senegal	Vietnam
Canada	Guinea	Mauritius	Serbia	Western Sahara
Cape Verde	Guinea-Bissau	Mexico	Sierra Leone	Yemen
Central African Republican	Guyana	Micronesia	Singapore	Yugoslavia (former)
Chad	Haiti	Moldova	Slovakia	Zambia
Chile	Honduras	Mongolia	Slovenia	Zimbabwe
China	Hungary	Montenegro	Solomon Islands	Other (please specify) _____
Colombia	Iceland	Morocco	Somalia	Chose not to answer/Declined
Comoros	India	Mozambique	South Africa	Unknown
Congo, Democratic Republic of	Indonesia	Namibia		

Please tell me the race/ethnicity groups that best describe you. (*Circle the groups that best describe you. Multiple selections are permitted.*)

American Indian or Alaska Native	Native Hawaiian/Other Pacific Islander
Asian	White
Black or African American	Choose not to disclose/Declined
Hispanic or Latino	Unknown

In what language can we best serve you? *(Circle one language)*

Amharic	English	Karen	Russian	Tibetan
Arabic	French	Korean	Sign Language	Tigrinya
Bosnia	German	Laotian	Somali	Urdu
Burmese	Hearing Impaired	Mandarin	Spanish	Vietnamese
Cambodian	Hindi	Oromo	Swahili	Yoruba
Cantonese	Hmong	Polish	Tagalog	Other _____
Chinese	Japanese	Romanian	Thai	Declined
				Unavailable/Unknown

Appendix G: Additional References and Resources

Articles

Bruce Siegel, Jennifer Bretsch, Vickie Sears, Marsha Regenstein, Marcia Wilson. *Assumed Equity: Early Observations from the First Hospital Disparities Collaborative.* Journal for Healthcare Quality: Vol. 29, No. 5, pp. 11–15. 2007 National Association for Healthcare Quality. "Disparities in healthcare represent a failure in the equity domain of quality. Although disparities have been well documented, little has been written about how organizations might use improved data collection and quality improvement techniques to eliminate disparities. This article describes early findings from the planning phase of the first hospital based disparities collaborative. The authors also discuss the changes in policy and practice that may speed hospitals in placing disparities and equity on their quality agendas." This article is from a hospital perspective, but the observations and lessons learned may be generally implied to health care organizations.

Committee on Health Care Quality in America. *Crossing in the Quality Chasm.* Institute of Medicine. National Academy Press. Washington D.C. 2001. The IOM's six aims for quality care are patient-centeredness, safe, efficient, effective, timely, and equitable. The aim of equity emphasized the importance of eliminating health disparities and regards health care organizations as important stakeholders in the process. Available for free online: http://books.nap.edu/openbook.php?record_id=10027&page=1

David W. Baker, MD, MPH, Kenzie A, Cameron, PhD, Joseph Feinglass, PhD, Jason A, Thompson, BA, Patricia Georgas, BA, Shawn Foster, BA, Deborah Pierce, BA, and Romana Hasnain-Wynia, PhD. *A System for Rapidly and Accurately Collecting Patients' Race and Ethnicity.* American Journal of Public Health. Vol. 96:3 March, 2006. This study tests the possibility of creating a system that allows patients to self-describe their race and compares that system to a system that used the OMB racial categories. The study found that collecting race/ethnicity data using patients' own categories is feasible to capture verbatim responses. It also resulted in lower rates of missing data and unusable data compared to the standard questions.

David R. Nerenz, Kelly A. Hunt and Jose J. Escarce. *Health Care Organizations' Use of Data on Race/Ethnicity to Address Disparities in Health Care.* Health Services Research. Vol. 41:4. August 2006. The is a review of five different articles that provide guidance for health care organizations who wish to identify and help eliminate health disparities.

Health Partners. *Strategies to Identify and Reduce Health Disparities.* 2008. This report summarizes the key findings and strategies that have been useful in identifying and reducing health disparities across HealthPartners clinics, Regions Hospital and HealthPartners health plan. The key findings were: 1) systematic collection of race, ethnicity and language preference data and using it to monitor health care quality and patient satisfaction is the foundation for identifying and reducing health disparities among patient populations. 2) Developing consistent workflows that help caregivers identify and offer needed services to all patients and then customizing those services based on cultural, linguistic, socioeconomic or other differences help reduce health disparities among patient populations. 3) The support of providers, staff, community leaders and community organizations are critical to reducing health disparities (7 pages). http://www.healthpartners.com/files/40901.pdf

Holly Mead, Lara Cartwright-Smith, Karen Jones, Christal Ramos, Kristy Woods, and Bruce Siegel. *Racial and Ethnic Disparities in U.S. Health Care: A Chartbook.* The Commonwealth Fund, March, 2008. This is an extensive chartbook starting with U.S. demographics. The rest of the paper discusses the disparities according to each condition such as diabetes, obesity, and smoking; disparities in insurance status; and, disparities in quality. Lastly, the article discusses clinical strategies for closing the gap in health disparities (140 pages). http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=672908

Joseph J. Sudanoa and David W. Baker. *Explaining US racial/ethnic disparities in health declines and mortality in late middle age: The roles of socioeconomic status, health behaviors, and health insurance.* Social Science & Medicine 62 (2006) 909–922. This was a six-year study that evaluated the independent contributions of SES, health behaviors and insurance in explaining health disparities. It was determined that promoting healthy behaviors and gaining coverage is not sufficient for reducing health disparities.

M. Weinick, Jacquelyn M. Caglia, Elisa Friedman, and Katherine Flaherty. *Measuring Racial and Ethnic Health Care Disparities In Massachusetts; Lessons from implementing a publicly mandated data collection program.* Health Affairs: September-October, 2007. In 2006, policy changes were implemented in Massachusetts to better measure disparities in the quality of health care provided to racial and ethnic minority residents. This article discusses the challenges faced by providers, policymakers, and patients.

Nicole Lurie, Allen Fremont. *Looking Forward: Cross Cutting Issues in the Collection and Use of the Racial/Ethnic Data.* Health Services Research. Vol. 41:4 Part 1. August, 2006. This article discusses the availability of reliable race/ethnicity data. It also addresses the challenges and limitations of using existing data to improve the quality of care.

National Quality Forum. Revised voting draft for *Endorsing a Framework and Preferred Practices for Measuring and Reporting Cultural Competence – Part I.* July 18, 2008. This is NQF's endorsement of the HRET toolkit. A justification for choosing the toolkit and how they came to their conclusions is covered throughout the article.

Roderick K. King, Alexander R. Green, Aswita Tan McGrory, Elizabeth Donahue, Jessie Kimbrough-Sugick, and Joseph Betancourt. *A Plan for Action: Key Perspectives from the Racial/Ethnic Disparities Strategy Forum*. The Milbank Quarterly, Vol. 86, No. 2, 2008 (pp. 241–272) Published by Blackwell Publishing. "The forum's participants concluded that to identify and effectively address racial/ethnic disparities in health care, health care organizations should: (1) collect race and ethnicity data on patients or enrollees in a routine and standardized fashion; (2) implement tools to measure and monitor for disparities in care; (3) develop quality improvement strategies to address disparities; (4) secure the support of leadership; (5) use incentives to address disparities; and (6) create a messaging and communication strategy for these efforts. This article also discusses these recommendations in the context of both current efforts to address racial and ethnic disparities in health care and barriers to progress."

Romana Hasnain-Wynia and David Baker. *Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions.* Health Services Research. Vol. 41:4 August 2006. This paper argues that health care organizations that systematically collect race/ethnicity and language data from patients will enhance their ability to monitor health care processes and outcomes, and target quality initiatives more efficiently and effectively. It also provides information on overcoming obstacles such as addressing staff and patient discomfort with asking and providing race and ethnicity information.
.

Scott Smith. *Confronting Racial Disparities in Minnesota.* Minnesota Medical Association Quality Review. Fall 2008. This edition on the Quality Review provides details about how Children's Hospitals and Clinics of Minnesota are increasing their awareness and commitment to end disparities in their care system by collecting more accurate race, ethnicity, and language data. Also in this publication is a description of Minnesota Community Measurement's efforts on organizing medical groups to agree upon a standardized way to collect race, ethnicity, and language data. Finally, there are some examples of interventions by health care organizations that are committed to reducing and eliminating health disparities. Follow the link below and click on *Confronting Racial Disparities in Minnesota, Fall 2008 Volume 3 Issue 4:* http://www.mmaonline.net/Publications/QualityReview/tabid/1444/Default.aspx

Stephanie L. Taylor, PhD; Rebecca McLaughlin, BA; Eric Peterson, MD, MPH; B. Waine Kong, PhD, JD; T. Bruce Ferguson, Jr, MD. *Racial and Ethnic Disparities in Care: The Perspectives of Cardiologists.* http://circ.ahajournals.org/ "We conducted a Web-based survey of 344 cardiologists to determine their level of awareness of disparities and views of underlying causes. Thirty-four percent of cardiologists agreed that disparities existed in care overall in the US healthcare system, and 33% agreed that disparities existed in cardiovascular care. Only 12% felt disparities existed in their own hospital setting, and even fewer, 5%, thought disparities existed in the care of their own patients." Overall awareness of disparities for cardiologists remains low.

The Brookings Institution, Itasca Project, Living Cities. *Mind the gap: Reducing Disparities to Improve Regional Competitiveness in the Twin Cities.* The Brookings Institution Metropolitan Policy Program, 2005. This article discusses three different disparities in the Twin Cities: race, class, and place. It gives reasons for reducing disparities such as: 1) increases competitive workforce; 2) brings more money to the Twin Cities; 3) makes our region stronger. The last portion of the article discusses a policy framework for reducing disparities (44 pages). http://www.brookings.edu/reports/2005/10cities_sohmer.aspx

Thomas D. Sequist, MD, MPH; Garrett M. Fitzmaurice, ScD; Richard Marshall, MD; Shimon Shaykevich, MS; Dana Gelb Safran, ScD; John Z. Ayanian, MD, MPP. *Physician Performance and Racial Disparities in Diabetes*

Mellitus Care. ARCH INTERN MED/VOL 168 (NO. 11), JUNE 9, 2008. Racial differences in "Diabetes outcomes are primarily related to patients' characteristics and within physician effects, wherein individual physicians achieve less favorable outcomes among their black patients than their white patients. Efforts to eliminate these disparities, including race-stratified performance reports and programs to enhance care for minority patients, should be addressed to all physicians." (7 pages). http://www.ncbi.nlm.nih.gov/pubmed/ (Search: *Physician Performance and Racial Disparities in Diabetes Mellitus Care)*

Initiatives

Harvard Vanguard Medical Associates. Using the Chronic Care Model (CCM) Harvard Vanguard Medical Associates designed a randomized control study to evaluate whether enhancements to the CCM can produce significant improvement in the quality of diabetes care for Black patients.
http://www.solvingdisparities.org/grantees/round1/hvmam

Healthy People 2010. The U.S. Department of Health and Human Services designed a comprehensive set of disease prevention and health promotion objectives for the Nation to achieve over the first decade of the new century. Healthy People 2010 identifies the elimination of health disparities as a critical national goal. www.healthypeople.gov

Minneapolis Somali Health Care Initiative*.* The MN International Health Volunteers received a grant from the Minnesota Department of Health (MDH) to reduce health disparities between the Somali community and the general population of Minnesota. www.mihv.org

National Institutes of Health. The Science of Eliminating Health Disparities, December 2008.
http://www.blsmeetings.net/2008healthdisparitiessummit/

National Health IT Collaborative for the Underserved*.* In collaboration with public and private organizations their aim is to reduce health disparities experienced by medically underserved areas and populations through the use of advances in health IT. http://www.omhrc.gov/npa/templates/browse.aspx?lvl=2&lvlid=23

Third National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health. February, 2009.
The U.S. Office of Minority Health developed the National Partnership for Action to Eliminate Health Disparities (NPA). NPA is hosting a Summit in February 2009. The goals for the Summit are to:
1: Increase Awareness of Health Disparities
2: Strengthen Leadership at All Levels
3: Enhance Patient-Provider Communication
4: Improve Cultural and Linguistic Competency in Delivering Health Services
5: Coordinate and Utilize Research and Outcome Evaluations More Effectively
To view more details about the Summit and registration details visit: http://www.omhrc.gov/npasummit2009/

Agencies

Minnesota Department of Health
Data and Assessment
http://www.health.state.mn.us/divs/idepc/refugee/immigrant/data.html
Relevant Sections:
- Why does better data and assessment matter?
- Data and Assessment: What Can You Do
- Data and Assessment: Programs and Tools
- Data and Assessment: References

Office of Minority and Multicultural Health
The Office of Minority and Multicultural Health, a division of the Minnesota Department of Health, leads the statewide *Eliminating Health Disparities Initiative.* The purpose of this initiative is to provide grant funding Tribal Nations and community organizations for American Indians, Africans/African Americans, Asians, and Latinos. The 8 focus areas for eliminating health disparities are: breast and cervical cancer, cardiovascular disease, diabetes, healthy youth development, immunizations, infant mortality, HIV/AIDS and sexually transmitted infections, and unintentional injury and violence. http://www.health.state.mn.us/ommh/index.html

Minnesota Immigrant Health Task Force
Immigrant Health: *A Call to Action.* : *Recommendations from the Minnesota Immigrant Health Task Force.* January, 2005. This report describes eight important action steps to improve immigrant health in Minnesota. It suggests concrete ways for policy makers, health care administrators, educators, providers, and immigrant advocates to carry out the action steps. For a downloadable copy of this report, as well as a wealth of additional on-line references and resources on how to improve immigrant health in Minnesota, visit the Immigrant Health Task Force website, at www.health.state.mn.us/refugee. Click on "Immigrant Health Task Force Report."

Office of Management and Budget
Standards for the Classification of Federal Data on Race and Ethnicity, 1995
http://www.whitehouse.gov/omb/fedreg/race-ethnicity.html
Relevant Sections:
- Should there be different collection standards for different purposes?
- Should "race/ethnicity" be asked as a single identification or should "race" identification be separate from Hispanic origin or other ethnicities?
- Should self-identification or the perception of an observer guide the methods for collection of racial and ethnic data?

What should the specific data collection and presentation categories be?

Robert Wood Johnson Foundation
http://www.rwjf.org/
RWJF: Disparities Strategies
http://www.rwjf.org/pr/topic.jsp?topicid=1180&p=os
Expecting Success, Excellence in Cardiac Care, September 2007.
http://www.rwjf.org/files/research/esissuebrief092007.pdf

U.S. Department of Health and Human Services: Agency for Healthcare Research and Quality**.** *National Healthcare Disparities Report 2007.* http://www.ahrq.gov/qual/qrdr07.htm

Washington State Department of Health
Guidelines for Working with Race/Ethnic Groups in Data Analysis
http://www.doh.wa.gov/data/guidelines/Raceguide1.htm#minimum
Relevant Sections:
- Data Collection
- Data Presentation
-

Websites/Other

American Medical Student Association.
Information on the definition and current trends in health disparities in the United States.
http://www.amsa.org/disparities/whatis.cfm

Disparities Solutions Center. The DSC is dedicated to the development and implementation of strategies that advance policy and practice to eliminate racial and ethnic disparities in health care.
http://www.massgeneral.org/disparitiessolutions/

California Pan-Ethnic Health Network
Using Race, Ethnicity and Language Data to Eliminate Health Disparities, June 2008.
http://www.cpehn.org/pdfs/CPEHN%20data%20brief%20June2005.pdf
Relevant Sections:
- Solutions for Improving the Collection and Use of Race, Ethnicity and Language Data
- Principles for Improving the Collection and Use of Race and Ethnicity Data
- Recommendations for Improved Data Collection to Address Health Disparities.

Finding Answers: Disparities Research For Change
 A National Program of the Robert Wood Johnson Foundation at the University of Chicago. They award and manage research grants to healthcare organizations implementing interventions aimed at reducing disparities.
http://www.solvingdisparities.org/home

Hennepin County SHAPE study

Survey of the Health of All the Population and the Environment (SHAPE). This survey assessed the health of Hennepin County residents. SHAPE stratified the results of the study by race and ethnicity. The collection of race/ethnicity data was a key element of the study because it identified health disparities in Hennepin County. The survey and results can be found at: http://www.hennepin.us/SHAPE

Health, Research, and Educational Trust (HRET) - Northwestern University
A Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients
Citation: Hasnain-Wynia, R., Pierce, D., Haque, A., Hedges Greising, C., Prince, V., Reiter, J. (2007) *Health Research and Educational Trust Disparities Toolkit*. http://www.hretdisparities.org, accessed on September 8, 2008.
Relevant Sections:
- Who Should Use the Toolkit
- Why Collect Race, Ethnicity, and Primary Language
- Why Collect Data Using a Uniform Network
- Collecting the Data – The Nuts and Bolts
- How to Ask the Questions
- Staff Training
- Informing and Engaging the Community

The HRET toolkit is also a resource for staff training and addressing barriers. Practice questions and training programs can be found in the "Staff Training" section of the toolkit: http://www.hretdisparities.org/Staf-4190.php
(Registration is free)

Institute of Medicine
In March 2002, the Institute of Medicine released *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* The report reviewed numerous studies on health disparities and found that even when racial and ethnic minorities have the same health insurance and conditions as whites, they often receive different health care treatment, receive lower quality health care and suffer worse health outcomes. The entire report is available free online at
http://www.nap.edu/catalog/10260.html

Journal of Public Health Management and Practice
In collaboration with the U.S. Department of Health and Human Services Office of Minority Health, the Journal of Public Health Management published a special "Practice Health Disparity Issue." The issue has various articles related to the availability of health disparity data, challenges in obtaining accurate data, and different ways to measure health disparities. The specific issue is: November 2008, Volume 14**, Issue 6** Supplement. Full contents are free for download: http://www.jphmp.com

Minnesota Department of Health
In 2009, the Minnesota Department of Health launched a voluntary statewide roster of spoken language health care interpreters to address access concerns for Minnesotans, particularly in rural areas. On the MDH website providers can search for interpreters by language and region.
http://www.health.state.mn.us/interpreters

National Center for Minority Health and Health Disparities of the National Institute of Health. This website provides information on the National Institutes of Health programs and initiatives to reduce or eliminate health disparities. Many of the programs provide funding for local or national initiatives that advance health disparity research. http://www.ncmhd.nih.gov/

Stratis Health. Stratis Health is a non-profit organization that leads collaboration and innovation in health care quality and safety, and serves as a trusted expert in facilitating improvement for people and communities. Their website is a great resource for information on delivering culturally competent care in response to Minnesota's changing demographics. The best way to access this information is to go the home page and use their search "Cultural Competency" in the upper right hand corner of the screen. http://www.stratishealth.org/

U.S. Department of Health and Human Services
In 2006, DHHS published *Healthy People 2010 Midcourse Review.* The report lists numerous statistics about racial and ethnic disparities in health and health outcomes, and proposes eliminating these disparities as one of the two overarching goals that the nation should work toward over the next decade. To view the report online, visit
http://www.healthypeople.gov/Publications/

REL Collection Policy: Collecting REL data from individuals under 18
Addendum to Handbook on the Collection of Race/Ethnicity/Language Data

While the collection of race/ethnicity/language (REL) and country of origin data has been explained in detail in the *Handbook for the Collection of Race, Ethnicity, Language Data in Medical Groups*, the issue of collecting this information from children under the age of 18 has not been specifically examined. This addendum seeks to explore the issue of collecting REL data from children under 18, demonstrate current methods for collecting this data as well as present sample questions for collecting this data and FAQs for circumstances that medical groups may experience in the clinical setting.

Background

The scope of research on best practices for collecting REL data from individuals in health care settings has widened and now includes a detailed evidenced based set of instructions for carrying this work out in a clinic setting. While the HRET Toolkit and the MNCM *Handbook on the Collection of Race/Ethnicity/Language Data in Medical Groups* has examined in detail how to ask these questions to adults in clinic settings, literature and research reviews examining the issue of collecting the data from children has yet to yield a set of best practices. However, as medical groups themselves as well as researchers in the field have examined this issue, a set of recommendations has emerged. It includes:

- A parent or legal guardian should provide the information for minors using the same general approach as when an individual over 18 years old self-reports his/her race. It may be necessary to re-word the questions (See "Sample Questions for Collecting REL Data from Parents/Guardians for children or individuals under the age of 18").
- In situations where a teen schedules their own appointment and does not have a guardian present to answer the questions, self identification of REL and country of origin status is acceptable using the same guidelines or sample questions demonstrated in the Handbook.

Sample Questions for Collecting REL Data from Parents/Guardians for children or individuals under the age of 18

Race/Ethnicity
Please tell me the race/ethnicity that describes your child.
Language
In what language can we best serve you and your child?
This field can also be populated based on the "language" or "interpreter needed" selected for the parent.
Country of Origin:
Please tell me in what country was your child born?

Frequently Asked Questions/Scenarios for Collecting REL data from Children

Does country of origin refer to the country the parents were born in or the country the child was born in?
- Country of origin refers to the country the patient was born in. If a clinic would like to collect a more granular level of data, they are free to add an additional question to the intake form to identify the country of origin of the parents, but this should be an additional question and should not replace the country of origin identification for the patient (or child).

If the questions are asked on an intake form instead of in person or over the phone while scheduling an appointment who should fill out the form?
- Parents/Guardians should fill out the form for individuals under the age of 18. If a teen attends an appointment alone, it is appropriate to have them fill out the form.

What if a parent asks not to list one of the country of origin, race, ethnicity, or language categories for their child?

- Choose the "Chose not to Answer" option.

What if a child was born on a US Military Based in another country?

- Choose the "United States" as the country of origin.

**For additional Frequently Asked Questions, see the *Handbook on the Collection of Race/Ethnicity/Language Data in Medical Groups*.

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