

11 - 0219

Collection of Racial/ Ethnic Health Data by the Minnesota Departments of Health and Human Services

Minnesota Department of Health
Minnesota Department of Human
Services

January 2011





Protecting, maintaining and improving the health of all Minnesotans

January 31, 2011

The Honorable David Hann
Chair, Health and Human Services Committee
Minnesota Senate
Room 328, State Capitol
75 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, MN 55155-1606

The Honorable Jim Abeler
Chair, Health and Human Services Finance Committee
Minnesota House of Representatives
479 State Office Building
100 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, MN 55155-1606

The Honorable Steve Gottwalt
Chair, Health and Human Services Reform Committee
Minnesota House of Representatives
485 State Office Building
100 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, MN 55155-1606

To the Honorable Chairs:

Laws of Minnesota 2010, Special Session Chapter 1, directed the Department of Health and the Department of Human Services to conduct an inventory of health-related data collected by each department, to determine the extent to which data on race, ethnicity and language is being collected. The departments were also directed to consult with a variety of stakeholders to determine whether the current data is sufficient for the identification of health disparities for particular communities or if additional types or categories of data are needed, and to make recommendations related to improving data collection efforts in order to ensure the collection of high-quality, reliable data to facilitate policy decisions related to the elimination of health disparities. The attached report represents the fulfillment of that assignment, and I am pleased to transmit it on behalf of MDH and DHS.

The report finds that:

- Only 60 percent of MDH datasets that include data on individuals collect data on race, ethnicity or language. At DHS, information about broad race/ethnicity categories (Black/African American, American Indian, Asian/Pacific Islander, Hispanic/Latino, White) is collected for most enrollees in Minnesota Health Care Programs; for enrollees with refugee status, country/culture of origin and language are also collected.
- The stakeholder workgroup determined that current data collection by MDH and DHS is not sufficient to allow for the identification of health disparities in many areas, and recommended that both agencies should use a standard construct to collect more detailed information on race, ethnicity and language while also improving access to data by community organizations.
- The workgroup also recommended that the standard construct be used by other entities that collect health-related data, including hospitals, clinics, and health plans.

If you would like further information on the report, please contact Diane Rydrych (MDH) at 651-201-3564 or diane.rydrych@state.mn.us or Vicki Kunerth (DHS) at Vicki.kunerth@state.mn.us or 651-431-2618.

Sincerely,

Edward P. Ehlinger, MD, MSPH
Commissioner
P.O. Box 64975
St. Paul, Minnesota 55164-0975

PO Box 64882 • St. Paul, MN 55164-0882
<http://www.health.state.mn.us>
An equal opportunity employer

Report to the Legislature: MDH/DHS race/ethnicity data collection

Introduction

Minnesota is one of the healthiest states in the nation. On a variety of indicators, from insurance status to life expectancy to the overall quality of care available from health providers, Minnesota ranks at or near the top among all states. But Minnesota also has some of the greatest disparities in health status and incidence of chronic disease between Populations of Color/American Indians and whites. Communities of color in Minnesota experience significantly higher rates of many chronic and infectious diseases, illness and premature death than the white population. These inequities in health pose a threat to the health of all Minnesotans, and present moral, ethical, and financial issues for our healthcare system that must be addressed.

The causes of health disparities are complex and can occur throughout the lifespan. They include individual factors as well as factors related to the physical, social and economic environment in which people live (often referred to as 'social determinants of health'). For example, beginning before a child is born, a mother's access to high quality prenatal care, her level of nutrition and the amount of stress that she experiences during pregnancy, her age, income and education level, her relationship with the child's father, and risk factors such as smoking, can contribute to low birthweight and prematurity, which increase a child's risk of lifelong health problems. In infancy, childhood and adulthood, nutrition, physical activity, stress levels, access to immunizations and preventive care, income, education, safe housing, and the physical environment of a neighborhood can all influence health and well-being. Some of these factors are closely related to the healthcare delivery system; others are related to the broader environment in which individuals and families live and work. While health disparities for Populations of Color and American Indians are the focus of this report, many of these issues affect other communities as well; lesbian, gay, bisexual and transgender populations also experience significant health disparities, as do people with disabilities and those in certain rural communities.

One of the challenges related to developing and evaluating programs to address and eliminate health disparities is the relative lack of data on many of these contributing factors/social determinants, and even on health status itself, for many communities. Recognizing these issues, the 2010 Minnesota Legislature directed the commissioners of the Minnesota Department of Health (MDH) and the Minnesota Department of Human Services (DHS) to conduct an inventory of health-related data collected by their two agencies. The 2010 legislation was initiated by a coalition of racial and ethnic communities led by the Alliance for Racial and Cultural Health Equity (ARCHÉ).

The commissioners were also directed to consult with individuals and organizations representing a broad range of stakeholders to assess the thoroughness of racial/ethnic data collection and the usability of the current data for the purposes of identifying and addressing health disparities, and to develop recommendations to improve data collection efforts to ensure that data are sufficient for creating measurable program outcomes and facilitating public policy decisions regarding the elimination of health disparities.

This report provides information about the process used to conduct the data inventory, the results of the inventory for MDH and DHS, the process used to convene the workgroup, participants in the workgroup, and an overview of the discussions and recommendations of the workgroup. The full statutory language is available in **Appendix A** of this report.

While this report focuses primarily on issues related to data collection and analysis, readers should remember that the causes of, and solutions to, health disparities are complex and occur throughout the lifecycle. Improving the infrastructure for health data collection is a necessary and important step for the development and evaluation of programs to eliminate disparities, but it is only the first of many steps that needs to be taken.

In addition, it is important to note that MDH and DHS are not the only sources of relevant data on health disparities. Developing broad-based, effective solutions to health disparities requires addressing the social determinants of health described above, which will require robust data collection and analysis not only by MDH and DHS, but also by other state agencies and organizations that deal with issues such as education, jobs, housing, transportation, environmental contamination, and public safety, among others. It is important for all of these stakeholder organizations to develop and nurture strong relationships with communities of color in order to ensure that their activities are addressing the true causes of disparities. Wherever possible, the recommendations in this report should be applied as broadly as possible to other types of organizations whose work can also have an impact on individual and community-level factors that contribute to disparities.

Finally, this report summarizes the inventory results and workgroup discussions, and presents a series of recommendations for improving Minnesota's health data infrastructure with regards to race/ethnicity/language data. But this report does not discuss any costs associated with expanding data collection mechanisms or modifying databases. In some cases, statutory changes might be required; in others, substantial costs could be involved in making these types of modifications.

MDH data inventory

MDH conducted its data inventory during June and July of 2010. The inventory covered more than 90 datasets, whether or not MDH was the original source of the data. The inventory was conducted using a web-based survey mechanism, and covered the following topics:

- An overview of each dataset, including the purpose and use of the dataset, method of data collection, whether the dataset includes information about individuals' race, ethnicity, and primary language, and (where relevant) the reasons why this information is not collected.
- Details of the race/ethnicity/language data collection, including wording of race and ethnicity categories, option for multi-race selection, source of race/ethnicity data (self report, observation, or administrative records), summary groups used for reporting, and whether additional information related to country of origin, length of time in the U.S., tribal enrollment status, or socioeconomic status is collected;
- Use and availability of the data, including Minnesota Data Practices Act classification, conditions of data availability, size of the dataset, years of data available, level of geographic detail, and completeness/accuracy of the data.

A copy of the data inventory survey is available in **Appendix B** of this report.

Results

Responses to the inventory were received from 91 datasets containing data on individuals. Of those, 55 datasets or 60.4 percent included data on the individual's race and ethnicity. MDH datasets that include data on an individual's race and/or ethnicity include:

- Vital records (birth and death registrations, including historical birth, death and fetal death records)

Report to the Legislature: MDH/DHS race/ethnicity data collection

- Maternal/child health data, including WIC, newborn screening, the Pregnancy Risk Assessment Monitoring system (PRAMS)
- Minnesota Fathers' Adoption Registry
- Woman's Right to Know and induced abortion dataset
- HIV/AIDS surveillance datasets
- Minnesota Cancer Surveillance System (MCSS)
- Traumatic Brain Injury registry and trauma databank
- The Behavioral Risk Factor Surveillance System (BRFSS)
- The middle school asthma survey and Minnesota Student Survey
- Several insurance-related datasets, including Medicare administrative data and the Minnesota Health Care Access Survey
- The Minnesota Immunization Information Connection (MIIC), a registry of immunization data on adults and children, and datasets of school outbreaks, critical illnesses and infectious disease registries, and influenza incidence surveillance
- Certain chronic disease programs that provide direct services, screening or referrals to clients, including the SAGE program for breast and cervical cancer screening and the "I CAN prevent diabetes" program

Among the 36 datasets that do not collect data on an individual's race or ethnicity, the primary reasons for not collecting the data were:

- Not currently required by program or legislation
- Not seen as currently relevant to purpose of dataset – i.e. professional licensing
- Dataset collects only contact information
- Collecting minimal demographic information – current dataset focus is outbreak or health data
- Data obtained from data source that doesn't include race/ethnicity data
- Subset of a larger dataset – can be linked to get race/ethnicity data for these individuals

Race/ethnicity categories

Among the 55 datasets that include data on an individual's race, all include ethnicity as well, and most often collect this information through two separate questions. For race, most use the Office of Management and Budget (OMB) standard classifications with little or no variation; the OMB classifications include White, Black or Black/African American, American Indian or American Indian/Alaskan Native, Asian, and Other.

When datasets include information about ethnicity, most commonly the only category is Hispanic or Latino, although some datasets do include multiple options under the Hispanic/Latino category. One dataset includes "Hmong" and "Somali" as ethnicity categories, and two others include a variety of African and Asian ethnicities in this field.

The standard OMB race/ethnicity categories, while very widely used, are generally considered to be minimum standards for data collection. As Minnesota's population continues to become more diverse, the OMB categories do not allow for an accurate representation of the many subgroups that comprise these broad communities. In response to this concern, some datasets do include more detailed information about an individual's race, including a wider range of options for race, ethnicity, or country of origin. In general, it is in the "Asian" category that the most variation exists. The most extensive list of choices for racial/ethnic self-identification is in the Minnesota

Cancer Surveillance System, which includes more than 20 categories for race. [See Appendix * for details]

Of the 55 datasets that collect information about an individual's race/ethnicity, 10 report the ability to select more than one race or to indicate "multi-race," though only two ask the subject to then choose one race. Including the ability to choose more than one race allows for better representation of the growing number of Minnesotans who are of mixed race or ethnicity; however, some people prefer to then choose a primary race/ethnicity with which they most closely identify.

Other findings

- MDH datasets gave mixed responses when asked whether their race/ethnicity data was collected directly from the individual or their representative (35%), from other sources (31%), or from a combination of sources.
- 13 datasets (14 percent) collect information about primary language, with three more considering or planning to add this information in the future.
- 27 datasets (30 percent) collect information about country of origin, with six more considering or planning to add this information in the future.
- 19 datasets (21 percent) include information about an individual's education, with smaller numbers including information about an individual's income, occupation, other economic status indicators, tribal enrollment status, or length of time in the U.S.
- Most dataset owners felt that the overall quality of their race/ethnicity data was good, but some datasets have had issues with missing data on some records. In cases where race/ethnicity data is obtained from a third-party organization such as a hospital or clinic, MDH dataset managers are constrained in their ability to improve accuracy and completeness of the data.

DHS data inventory

DHS does not collect a wide variety of health care data sets. DHS purchases health care services for over 600,000 enrollees each year. DHS collects eligibility data including demographic information, race, and ethnicity data from all applicants for Minnesota Health care Programs (MHCP). For the large majority of enrollees, DHS uses the Office of Management and Budget (OMB) standard classifications: White, Black or Black/African American, American Indian, or American Indian/Alaskan Native, Asian, and a single ethnicity of Hispanic or Latino.

For enrollees with a refugee status, DHS collects all the culture or nation of origin information, INS categories, and language preferences as declared by the enrollee. See **Appendix C** for the race, ethnicity, and language questions on DHS' applications and the most common groups of culture or nation of origin data provided by refugee enrollees. Surveys and studies conducted by the department use the eligibility data rather than collecting the race and ethnicity data again. Health services data collected on MHCP enrollees include: diagnoses, provider identification, and the services provided by clinics, hospital, labs, pharmacy, nursing homes, and home care providers.

Other Health Care organizations that collect health-related data on individuals

While the inventories described in this report cover only datasets held by MDH and DHS, it is important to note that many other types of organizations collect and use health-related data on

Report to the Legislature: MDH/DHS race/ethnicity data collection

individuals. Notably, hospitals, clinics, and other providers delivering health care services to Minnesotans collect a variety of health care data on individual patients, including demographic data, diagnoses, services received, professional recommendations, service authorizations, referrals, clinical results and health outcomes. But not all providers currently collect race/ethnicity/language data.

Nationally, the Agency for Healthcare Research and Quality sponsors the Healthcare Cost and Utilization Project (HCUP), a collection of state hospital discharge databases. Minnesota is one of 42 HCUP partner states. Of the 42 partner states, 38 receive race and ethnicity data as part of their hospital discharge data sets. Minnesota is one of just four partner states that do not require collection of race and ethnicity data,¹ although a number of individual hospitals do collect this information.

On the clinic side, currently approximately 550 medical clinics report data on the percentage of patients who are receiving optimal care for diabetes and cardiovascular disease to the Minnesota Department of Health through its contractor, Minnesota Community Measurement (MNCM). Other measures related to certain types of cancer, immunization, and other conditions are reported by health plans to MNCM. Under Minnesota's 2008 health reform law [Minnesota Session Laws, Chapter 358], health care providers are required to submit quality data under Minnesota Statutes, § 62U.02. The Department of Health is working with MNCM and health care providers to investigate the feasibility of reporting information about race, ethnicity, primary language and country of origin.

Health care delivery systems, including medical groups and hospitals, may vary in their access to electronic health record systems and therefore vary in their ability to work with population data from these sources. An electronic health record system is needed to systematically collect data to evaluate and communicate about services, patients, and results. Organizations that do not yet have a fully implemented system may find it much more difficult to provide feedback to their own providers, or share information with communities.

Racial/Ethnic health data workgroup

The Commissioners of the State Departments of Health and Human services were directed to consult with a workgroup that included representatives of "culturally based community groups, community health boards, tribal governments, hospitals, and health plan companies" in order to make recommendations on the adequacy of current sources of race/ethnicity data for identifying and addressing health disparities, and whether additional data sources or strategies are needed in order to improve quality and accessibility of the data.

Working closely with the ARChE' and the Center for Cross Cultural Health (CCCH), MDH and DHS identified more than 40 individuals representing community-based organizations, hospitals, health plans, local public health, tribal government, and other stakeholders to participate in the workgroup. A full list of invited workgroup participants is available in **Appendix D** of this report; not all individuals who were invited were able to participate.

¹ Hanlon C and Raetzman S. *State Uses of Hospital Discharge Databases to Reduce Racial and Ethnic Disparities*. Online October 14, 2010. U.S Agency for Healthcare Research and Quality (AHRQ).

The workgroup met three times between September and November to discuss the inventory results and to develop recommendations in response to the questions outlined in statute. At the first meeting, workgroup participants were provided with the results of the MDH and DHS data inventories, along with an overview of types of data collected by these state agencies and by other healthcare stakeholder organizations, such as hospitals, clinics, and health plans. At the subsequent meetings, workgroup participants discussed several specific questions designed to assist in the development of actionable recommendations:

- What questions about their community's health are community organizations trying to answer? What types of data do they need in order to know about their community's health? Which organizations (MDH, DHS, hospitals, health plans, and providers) have the data that communities need?
- In what ways can engagement between state agencies and communities of color about issues related to data collection and analysis improve?
- What are some of the difficulties that communities have in getting the data they need, and what strategies might address those challenges? Can community needs for granular data be met, given existing privacy/data practices considerations related to data on individuals?

Workgroup Questions and Discussion

1. *Are the data currently being collected sufficient to identify and describe health disparities for particular communities? Or is the collection of additional types and categories of data necessary in order to better identify health disparities and to facilitate efforts to reduce these disparities?*

Currently, the data being collected is not sufficient to identify disparities in all communities. This is the case in both state agencies and in the health care delivery system in general.

Workgroup participants agreed that they are looking for information on rates of disease, health care access, and social determinants of health that would help them demonstrate the burden of disease and risk behaviors by a community in such health areas as obesity, diabetes, asthma, tobacco use, cancer, substance abuse, and other chronic conditions. Several participants noted that when seeking information for program development, grant proposals, and gap analyses, adequate data to illustrate the health of a community is often lacking. Often, organizations are forced to try and 'piece something together' using multiple data sources, none of which adequately covers the geographic area or racial/ethnic/language community of concern.

Even more often, organizations do not know where to go to find the data that do exist. Given that MDH, DHS, and health care plans and providers all hold different types of data at different levels of detail and with different restrictions on its release, knowing where to go to find the answer can be a daunting task.

2. *If additional types and categories of data collection is determined necessary, what additional types and categories should be collected and in what areas?*

Participants agreed that it is very important that 'community' be defined as narrowly as possible, in order to capture differences that may exist between populations that share the

Report to the Legislature: MDH/DHS race/ethnicity data collection

same broad racial category; for example, while cancer mortality rates might be lower in the Asian community overall than in the White community, community organizations want to know whether there are different challenges and opportunities facing the Vietnamese, Hmong, Cambodian, or Karen communities in order to design appropriate interventions. As the data inventory showed, most datasets currently only include the OMB race/ethnicity categories, which mean that any differences between subgroups cannot be identified.

The workgroup also discussed the fact that certain types of data collection do not lend themselves to this level of detail. In particular, telephone surveys or other random sample-based data collection systems are not generally able to collect data on enough individuals to allow for a breakdown into race/ethnicity categories more detailed than those in the OMB classification system, even with strong over-sampling of respondents. However, some disease surveillance systems, some administrative databases, and the vital records system at MDH may contain a high enough volume of data to allow for the use of more granular categories, as does DHS's Medicaid database. Workgroup participants also pointed out that some individuals in communities of color may not feel comfortable participating in telephone-survey based research, and discussed the need to move toward a mixed-mode approach to data collection that supplements traditional survey methods with a more participatory process in which researchers partner with communities to collect data.

Workgroup participants agreed that there needs to be a standard construct for collecting race, ethnicity, and language data across MDH, DHS and health care organizations that is used whenever possible. Having a greater degree of consistency in data collection across programs and agencies will lessen confusion for community organizations and stakeholders that are seeking data, and increase the likelihood that data can be compared across programs or agencies. Participants discussed the need for this construct to be applied beyond MDH and DHS, to include health care organizations such as: hospitals, health plans, clinics, other state agencies and others who collect and analyze health data. Participants also agreed that this construct needs to be flexible, in order to respond to changing demographics in the state and capture data on new groups as they become large enough to be distinct communities.

3. *Is there a need to aggregate data to make data in the categories identified above more accessible to community groups, researchers, and to the legislature?*

In some cases, even if datasets include information on detailed race/ethnicity/language categories, data privacy issues will prevent the reporting or release of data. Generally, government data practices rules prevent the release or publication of any data on individuals without aggregating data to the point where an individual cannot be identified. In those cases, even if data are collected using detailed, locally relevant race/ethnicity categories, it will be necessary to aggregate data into broader groups in order to avoid violating the Minnesota government data practices act before reporting or releasing the data. However, the need to aggregate data for some groups should not discourage the collection of granular data by health care organizations.

4. *Are other ways to improve data collection efforts needed in order to ensure the collection of high-quality, reliable data that will ensure accurate research and the ability to create*

Report to the Legislature: MDH/DHS race/ethnicity data collection

measurable program outcomes in order to facilitate public policy decisions regarding the elimination of health disparities?

Participants in the workgroup agreed that the discussions begun during these three meetings should be continued via the establishment of a standing group to consult with MDH and DHS on collection of race, ethnicity, and language data. The group's discussions could include identifying a uniform data "construct" for data collection and identifying strategies for improving access to data.

Recommendations – Data Collection Policy and Communication

- 1. Existing data collection categories for race, ethnicity and language are inadequate for many of the purposes for which community organizations need data. More detailed categories of race and ethnicity data should be used so that the data is more useful in understanding health issues and needs for particular groups of patients.*

Comment: The group strongly felt that all datasets of state agencies and health care organizations that collect data on individuals should include questions on race, ethnicity and language (R/E/L) and that these data elements should be collected using more detailed categories than the standard OMB options. Workgroup participants discussed the fact that certain types of data collection systems, such as disease surveillance registries, vital records systems, medical records, or large-scale administrative datasets, might be more able to collect granular data than small datasets or those that collect data via telephone or mail surveys, and recommended that MDH, DHS and other health care organizations develop a timeline that would allow them to begin collecting more detailed R/E/L data for large, high-priority datasets immediately. The collection of Social Determinants of Health indicators along with R/E/L data needs further discussion to understand where and how the data could be applied in understanding the needs of patients and improving health care delivery.

Resources to expand data collection systems are a serious consideration. Costs could involve programming and software changes to collect data and to maintain the databases for analysis and reporting. The workgroup did not discuss resource needs to expand data collection.

- 2. The state agencies and organizations that collect and use health data should be regularly engaged with diverse communities in order to promote full understanding of how race, ethnicity, language and culture affect health care quality, access, wellness and cost.*

Comment: There are relatively few avenues through which community members and organizations are able to work with state agencies and other health care stakeholder groups to discuss current literature, research, studies, and issues related to data collection strategies, interpretation of results for communities of color, dissemination of results, and development of new research studies in an ongoing and collaborative way. State agencies and other health care stakeholder groups that collect and use health data should look for ways to partner with communities on these issues, and to bring community members into their discussions in an ongoing way.

- 3. Data collected by state agencies and health care organizations should be as accessible to communities as possible. The criteria and process for obtaining access to data should be provided to and discussed with the communities, and agencies should take steps to ensure*

Report to the Legislature: MDH/DHS race/ethnicity data collection

that information about relevant datasets is easily available online. A process should also be established so that communities can identify their priorities for obtaining reports useful to their communities from agencies and health care organizations that are collecting and analyzing data.

Comment: The process for establishing community priorities and developing and implementing strategies for making sure that community organizations, researchers and others can more easily identify and access data about their communities, can be a focus of the ongoing discussions. There are many issues of privacy and resources that would need to be clarified for any specific collaborative projects or reports.

4. This workgroup or a similar group should continue on an ongoing basis so that communities, health care stakeholders and government agencies can partner together to improve data collection policies and practices and, using the data, eliminate health disparities.

Comment: The workgroup strongly feels that the discussions held during its three meetings were important ones that need to continue beyond the point at which these recommendations are submitted to the Legislature. The group further feels that it is important for a similar group to meet during 2011 and possibly beyond, to flesh out the details of these general recommendations and turn them into actionable steps for MDH, DHS, and health care organizations.

During the proceedings, work group members also discussed whether the charge to the continuing group should be expanded to encompass areas beyond data collection practices that affect health disparities. Because the legislative charge of the work group was limited to data collection, this report and recommendation addresses only this issue. However, several members of the work group representing different community organizations indicated they would separately develop recommendations that would be provided to the Governor and Legislature as a companion report from the communities themselves.

The ongoing advisory group could:

- 1) Evaluate existing R/E/L categories and standards that could be adapted for use by MDH, DHS, and other health care organizations;
- 2) Develop a recommended process for revising the standard R/E/L list to encompass new communities as they grow in size;
- 3) Determine resources or legislative authorizations needed to revise data collection systems;
- 4) Develop recommendations and strategies related to data access;
- 5) Work with the Minnesota Hospital Association, Minnesota Community Measurement, Minnesota Medical Association, the Minnesota Council of Health Plans, and other stakeholder groups to ensure more robust collection of race, ethnicity and language data by those organizations using a standard model; and
- 6) Consider collaborative research projects with communities, state agencies and health care provider organizations that would allow for ongoing partnerships on specific issues.

5. A uniform data "construct" should be developed so that all health data collected uses the same categories for race, ethnicity and language. The uniform construct should be used not just by MDH and DHS, but also by licensing boards, other governmental agencies, health plans, hospitals, clinics, nonprofit agencies, quality and performance measurement programs, and others who collect, analyze and report health data so that disease burden,

Report to the Legislature: MDH/DHS race/ethnicity data collection

risk and protective factors, access to care, and quality of care can be measured and communicated for smaller populations within an overall population. The uniform construct should build on existing frameworks for data collection, to eliminate duplication of effort.

Comment: Health data is collected by many different organizations from many different sources in many different ways. Whenever possible, data elements related to race, ethnicity and language should be consistent across programs within organizations. The organizations named above should collaborate to develop a standard, locally relevant list of categories that can be used across organizations.

6. The data construct should be flexible so that the categories can be changed in the future as needed. A process should be developed for assessing changes in racial/ethnic populations in Minnesota and determining when populations are of a sufficient size to be reported as a separate category.

Comment: The standard data construct recommended above should be locally relevant, including race, ethnicity and language categories that accurately represent Minnesota's populations. A process should be developed through which new categories can be added in response to changing demographics, with agreement on the population size that would trigger the addition of a new category or the removal or combination of categories. Organizations that collect health data should also use a standard approach for aggregating responses within each granular category into broader groupings.

7. Programs that rely on survey data should consider oversampling or mixed mode approaches in order to obtain larger numbers for communities of color.

Comment: The workgroup discussed the challenges associated with the use of telephone or mail surveys to collect data from communities of color; given their small size relative to Minnesota's overall population, it can be difficult to identify and contact sufficient numbers of respondents from each group to allow for analysis of the results for subgroups. In addition, some communities may be less likely to respond to this type of survey, when they do not know the person or organization that is calling them, or where language barriers may make completion of the survey more difficult. The workgroup recommended that MDH and DHS consider options to address these challenges through a) the use of oversampling of communities of color in order to increase the number of respondents, and b) the use of mixed approaches that combine traditional surveys with more participatory and/or qualitative approaches to supplement or flesh out responses from communities of color. The practice of both state agencies is to oversample for communities of color when resources are available and program priorities indicate, but in general the results from using this approach for survey data only yield distinctions for the largest communities of color.

Appendix A

Statutory Language on race/ethnicity data collection

Minnesota Session Laws 2010 1st Special Session chapter 1 Article 19 Section 23

Section 1. **DATA COLLECTION ON HEALTH DISPARITIES.**

Subdivision 1. **Inventory.** The commissioners of health and human services shall conduct an inventory on the health-related data collected by each respective department including, but not limited to, health care programs and activities, vital statistics, disease surveillance registries and screenings, and health outcome measurements.

The inventory must review the categories of data that are collected, describe the methods of collecting, organizing, and reporting data relating to race, ethnicity, country of origin, primary language, tribal enrollment status, and socioeconomic status, and specify whether the data being collected in these categories is currently required.

Subd. 2. **Review.** (a) Upon completion of the inventory in subdivision 1, the commissioners of health and human services shall consult with representatives of culturally based community groups, community health boards, tribal governments, hospitals, and health plan companies to review the compiled inventory and make recommendations on:

(1) whether the data currently being collected is sufficient to identify and describe health disparities for particular communities or if the collection of additional types and categories of data is necessary in order to better identify health disparities and to facilitate efforts to reduce these disparities;

(2) if additional types and categories of data collection is determined necessary, what additional types and categories should be collected and in what areas;

(3) whether there is a need to aggregate data to make data in the categories identified in subdivision 1 more accessible to community groups, researchers, and to the legislature; and

(4) other ways to improve data collection efforts in order to ensure the collection of high-quality, reliable data in clauses (1) to (3) that will ensure accurate research and the ability to create measurable program outcomes in order to facilitate public policy decisions regarding the elimination of health disparities.

(b) In making recommendations, the work group shall consider national and state standardized data classification systems, as well as federal or state requirements for collection of certain data based on predetermined classification systems that may impact some data collection efforts.

Subd. 3. **Report.** By January 15, 2011, the commissioners of health and human services shall submit to the chairs and ranking minority members of the legislative committees and divisions with jurisdiction over health and human services the inventory compiled in subdivision 1 and the recommendations developed in subdivision 2.

Appendix B
MDH racial/ethnic health data inventory

Race/Ethnicity Data in Health Datasets Inventory Survey

PLEASE COMPLETE A SEPARATE SURVEY FOR EACH DATASET

For questions about completing this survey, please call Carol Hajicek at the Minnesota Center for Health Statistics at 651-201-5945 or e-mail carol.hajicek@state.mn.us .

Please enter the following information:

Dataset Name , Division , Program , Your Name , Phone # , E-mail address

1. Dataset type:

(select all that apply)

- ☐ Administrative
- ☐ Investigative
- ☐ Program monitoring and evaluation
- ☐ Research
- ☐ Surveillance
- ☐ Survey
- ☐ Other, specify:

2. Describe the purpose and use of the dataset:

3. Does this dataset contain records on individuals?

if No [Goto the END]

4. Describe the method of data collection used in this dataset: (e.g. survey, interview, clinic records, civil registration)

5. Are these data collected... (select one)

- ☐ through sampling of individuals, cases or occurrences
- ☐ for every case or occurrence

6. Is race and/or ethnicity information collected in this dataset?

if not, please explain why not:

If race and/or ethnicity information is not collected, then scroll to the bottom and submit survey.

Report to the Legislature: MDH/DHS race/ethnicity data collection

Race/Ethnicity Data Collection

7. Are data collected on both race and ethnicity?

If both, are race and ethnicity collected as separate items, -and- which is asked first?

8. The Federal Office of Management and Budget (OMB) defines the *minimum* standard for race and ethnicity categories as follows. Please check those that are worded in this dataset exactly as stated here:

Ethnicity:

☐ Hispanic or Latino

List those ethnicity categories used in this dataset that are worded differently than above or any additional categories used (e.g. Hmong, Somali):

Race:

☐ White

☐ Black or African American

☐ American Indian or Alaskan Native

☐ Asian

☐ Native Hawaiian or Pacific Islander

☐ Other

List those race categories used in this dataset that are worded differently than above or any additional categories used:

Please send a printed copy of the page(s) of the data collection instrument where race and ethnicity are collected via inter-office mail to:
Carol Hajicek
Center for Health Statistics
3rd Floor Golden Rule

9. May more than one race and/or ethnicity category be selected for a given individual?

If more than one category may be selected, are subjects also then asked to choose a single race or ethnicity that best describes them?

10. Is a response to race and ethnicity questions optional?

Report to the Legislature: MDH/DHS race/ethnicity data collection

11. What is the source of the race and ethnicity information?

(select all that apply)

- ☐ Self-report by subject
- ☐ 2nd party report, e.g. parent, next of kin, etc.
- ☐ Observation by person collecting the data
- ☐ Obtained from another record within your program
- ☐ Obtained from another MDH program record, please specify
- ☐ Obtained from an outside data source record, please specify
- ☐ Other, specify:

12. Are categories collapsed into summary groups for reporting?

If yes, specify the summary groups and their components:

e.g. Asian: Japanese, Chinese, Vietnamese, Asian Indian and Korean

13. Are any changes anticipated or planned in the collection or reporting of race/ethnicity data?

If yes, please explain and indicate when this will be implemented:

14. Are any of the following currently collected in this dataset or under consideration:

	Currently collect	Definite plans to collect	Considering	No interest at this time	Don't know
Primary language spoken					
Country of origin/birthplace					
Length of time in U.S.					
Tribal enrollment status					
Education level					
Income					
Occupation					
Other socioeconomic indicator					

Use and Availability of Data:

15. What is the Minnesota Data Practices Act classification of this data set?

(select all that apply)

- ☐ Public
- ☐ Private/nonpublic (accessible only to data subject and persons/entities authorized by law)
- ☐ Confidential/protected nonpublic (accessible only to persons/entities authorized by law)
- ☐ Don't Know

If more than one classification, please explain:

16. Is this dataset (including race/ethnicity data) available outside your program area as:

(select all that apply)

- ☐ Not available outside program area
- ☐ Aggregated data
- ☐ Record-level data: available without restriction (public data)
- ☐ Record-level data: available with restriction, please specify

17. In what year were race/ethnicity data first collected in this dataset?

18. How many years of data contain race/ethnicity information?

19. How large is this dataset? (number of records per year):

20. What geographic information is collected in this dataset?

(select all that apply)

- ☐ State
- ☐ County
- ☐ City
- ☐ Street address
- ☐ ZIP code
- ☐ Other, specify:

20a. Are these data geocoded?

21. Are the main data elements in this dataset (e.g. cancer cases, health behaviors, births) reported by race/ethnicity by your program?

If no, why not?

22. List up to five titles of written reports, publications and/or links to web pages that use the race/ethnicity data in this dataset:

Report to the Legislature: MDH/DHS race/ethnicity data collection

23. How complete and accurate do you consider the race/ethnicity data in this dataset to be (missing and unknown data, under-reporting, etc.)? Please explain:

24. What limitations are there to the race/ethnicity data in this dataset?

25. Please tell us anything else about the race/ethnicity data in this dataset that you would consider to be important:

Reminder:

Please send a printed copy of the page(s) of the data collection instrument where race and ethnicity are collected via inter-office mail to:

Carol Hajicek

Center for Health Statistics

3rd Floor Golden Rule

Thank you for completing this survey!

Submit

Powered by Vovici: Conduct your own [online surveys](#)

Report to the Legislature: MDH/DHS race/ethnicity data collection

Appendix C
**DHS Collection of Race/Ethnicity/Language for Access to Minnesota
Health Care Programs**

***All applicants for Minnesota Health Care Programs (MCHP) fill out the following
information on race when applying.***

MHCP Application

RACE (check all that apply)

☐ Asian ☐ Black/African American ☐ American Indian/Native Alaskan
☐ Pacific Islander or Native Hawaiian ☐ White

HISPANIC OR LATINO? ☐ Yes ☐ No

☐ Check this box if you are an American Indian living on a reservation. (Some American Indians have the option to not receive their health care services through a health plan.)

What language do you speak most of the time? _____

Do you need an interpreter? ☐ Yes ☐ No

Refugee Program -

**DHS collects all data reported on Language and
Nationality/Culture/Heritage from Refugee enrollees.**

**The following list of language and Nationality or Heritages are those
most frequently reported.** (March 2010)

Spoken Language

9 "Amharic"	12 "Oromo"
10 "Arabic"	6 "Russian"
8 "ASL"	11 "Serbo-Croatian"
14 "Burmese"	7 "Somalian"
15 "Cantonese"	1 "Spanish"
99 "English"	18 "Swahili"
16 "French"	13 "Tigrinya"
2 "Hmong"	3 "Vietnamese"
4 "Khmer"	19 "Yoruba"
20 "Korean"	97 "Unknown"
5 "Laotian"	21 "Karen"
17 "Mandarin"	98 "Other"

Nationality/Culture/Heritage

AA Ameriasian	AF Afghanistan
EH Ethnic Chinese	BK Bosnia
EL Ethnic Lao	CB Cambodia
HG Hmong	CH China, Mainland
KD Kurd	CU Cuba
SJ Soviet Jew	ES El Salvador
TT Tinh	ER Eritrea

Report to the Legislature: MDH/DHS race/ethnicity data collection

ET Ethiopia
GT Guatemala
HA Haiti
HO Honduras
IR Iran
IZ Iraq
MC Micronesia
MI Marshall Islands
MX Mexico
WA Namibia (SW Africa)

PK Pakistan
RP Philippines
PL Poland
RO Romania
RS Russia
SO Somalia
SF South Africa
TH Thailand
VM Vietnam
OT All Others

Drug and Alcohol Abuse Normative Evaluation Systems (DAANES)

Race:

☐ White ☐ Black ☐ American Indian ☐ Asian/Pacific Islander ☐ Alaskan Native
☐ Mixed ☐ Other

Hispanic ethnicity:

☐ Not of Hispanic origin ☐ Puerto Rican ☐ Mexican ☐ Cuban ☐ Other Hispanic

Tribal affiliation:

☐ Minnesota Chippewa Tribe ☐ Red Lake Band of the Chippewa ☐ Minnesota Sioux Tribe
☐ Other ☐ Not applicable

Background: DAANES collects information on individuals who receive chemical dependency (CD) treatment services in Minnesota. CD treatment providers are required to submit information on each treatment episode at the time of admission and at discharge.

Appendix D

Invited Workgroup Participants

Invited Participants: Race/Ethnicity Health Data Workgroup		
Last Name	First Name	Organization
Adam	Abdisalam	Dar al Hijra Cultural Center
Amla	Paul	Amla International
Baisa	Alamayo	Oromo Community of Minnesota
Banks	Roger	Council on Black Minnesotans
Barry	Anne	MN Department of Human Services
Brust	Janny	MN Council of Health Plans
Cole	Terra	Hennepin County
Davis	Mitchell	Minneapolis Urban League
Eliason	Sandra	Center for Cross Cultural health
Gonzalez	Jose	MN Department of Health
Gutierrez	Rodolfo	HACER
Hayden	Peter	Turning Point, Inc.
Hurtado	Monica	Aqui Para Ti, HCMC
Ibrahim	Abdikadir	Dar al Hijra Cultural Center
Kunerth	Vicki	MN Department of Human Services
LaFromboise	Bonnie	Fond du Lac Min No Aya Win Clinic
Linares	Juan	Eastside Prosperity Campaign
Narayan	Gopalkrishnan	Mpls Dept of Health and Family Support
Nguyagwa	Stephan	African & American Friendship Association for Cooperation and Development
Oo	Mimi	African & American Friendship Association for Cooperation and Development
Peterson	Kevin	University of Minnesota
Pomplun	Nancy	MN Asian American Health Coalition
Poupart	John	American Indian Policy Center
Quevi	Ajar	West African Association
Rydrych	Diane	MN Department of Health
Scandrett	Michael	LPaC Alliance
Schierman	Rebecca	MN Medical Association
Shafi	Hashi	Somali Action Alliance
Smith	Debra	Fond du Lac Band of Lake Superior Chippewa
Smith	Sharon	MN Department of Health
Snowden	Anne	MN Community Measurement
Sonneborn	Mark	MN Hospital Association
Stroud	David	MN Department of Health
Thorson	Diane	Ottertail County Public Health
Vang	Bao	Hmong American Partnership
Vazquez	Gabriela	Health Partners Foundation
Velez	Gwen	African American AIDS Task Force
Wako	Tashite	Neighborhood Development Center
Whitney-West	Stella	Northpoint Clinic
Wilcoxon	Antonia	MN Department of Human Services
Woodrich	Noya	Division of Indian Works