

**Prevention and
Chronic Care
Management
Advisory
Council**

**Data Collection of
Chronic Diseases in
Multicultural Groups of
Racial and Ethnic
Diversity in Iowa**

**In response to House File
2144**

**Iowa Department of Public
Health**

December 2011

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The Issue

A *health disparity* is a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Racial and ethnic minorities still lag behind in many health outcome measures. They are less likely to get the preventative care they need to stay healthy, more likely to suffer from serious illnesses, and when they do get sick, are less likely to have access to quality health care. Disparities are documented in many chronic conditions, including: diabetes, obesity, cancer, hypertension, asthma, congestive heart failure, arthritis, mental illness, hyperlipidemia, HIV/AIDS, neurological/behavioral conditions, coronary artery disease, lower back pain, chronic obstructive pulmonary disease (COPD).ⁱ

These chronic diseases account for seven out of every 10 deaths and affect the quality of life for tens of thousands of Iowans. Identifying populations in Iowa that are highly burdened by chronic diseases is a first step to building awareness and providing education and outreach to these populations. Multicultural groups of racial and ethnic diversity are a population in Iowa that significantly lack this statistically accurate data related to health disparities. This report lays out the barriers of collecting this data and provides recommendations to improve the collection of disparities data.ⁱⁱ

Iowa's Legislative Charge

The 2008 Iowa Legislative Assembly created wellness, promotion, and chronic disease prevention priorities within Iowa's Health Care Reform legislation, House File 2539.ⁱⁱⁱ This legislative language created the Prevention and Chronic Care Management (PCCM) Advisory Council^{iv} to study and develop recommendations for state initiatives that would address health promotion, prevention and chronic care management in Iowa.

House File 2144^v has charged the PCCM Advisory Council to submit recommendations by December 15, 2011 on strategies to collect and provide statistically accurate data concerning chronic disease in multicultural groups of racial and ethnic diversity in the state. Following implementation of the strategies and collection of data, the council shall also make evidence-based recommendations to the director to address and reduce identified disparities.

Impact of Chronic Diseases in Iowa

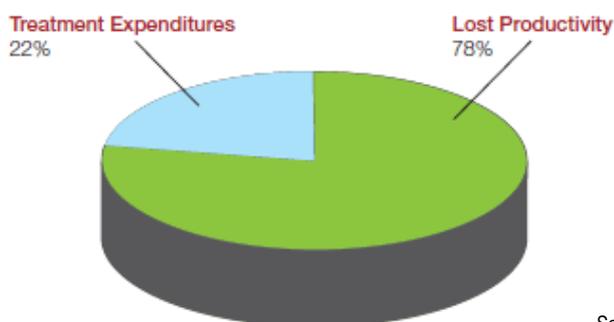
A chronic disease is defined as "an established clinical condition that is expected to last a year or more and that requires ongoing clinical management".^{vi} Chronic diseases are also known to be ongoing physical and mental conditions, such as diabetes, heart disease, cancer, asthma, and mental illness which may limit activities of daily living. They are often preventable and frequently manageable through early detection, improved diet, exercise, and treatment therapy. In 2007, chronic diseases accounted for 68% of all deaths in Iowa.^{vii}

In 2005, 133 million people, or almost half of all Americans, lived with at least one chronic condition. Seventy percent of all annual deaths in the U.S. are due to chronic diseases. The medical care costs of people with chronic diseases account for more than 75 percent of the nation's \$2 trillion spent on health care annually.^{viii} Three out of every four dollars spent on health care is related to chronic diseases. The U.S. spends 15.5 percent of its Gross Domestic Product on health care, more than any other industrialized country.^{ix}

And while the human cost is enormous, the economic cost also is great. The cost of treating chronic conditions — without even taking into consideration the many secondary health problems they cause — totaled \$2.9 billion in 2003. These conditions also reduce productivity at the workplace, as ill employees and their caregivers are often forced either to miss work

days or to show up but not perform well. Figure 1 shows that the impact of lost workdays and lower employee productivity resulted in an annual economic loss in Iowa of \$10.5 billion in 2003.

Figure 1- Economic Impact in Iowa 2003- Annual Costs in Billions



Figures may not sum due to rounding.

Economic Impact in Iowa 2003 (Annual Costs in Billions)

| | |
|-------------------------|---------------|
| Treatment Expenditures: | \$2.9 |
| Lost Productivity: | \$10.5 |
| Total Costs: | \$13.4 |

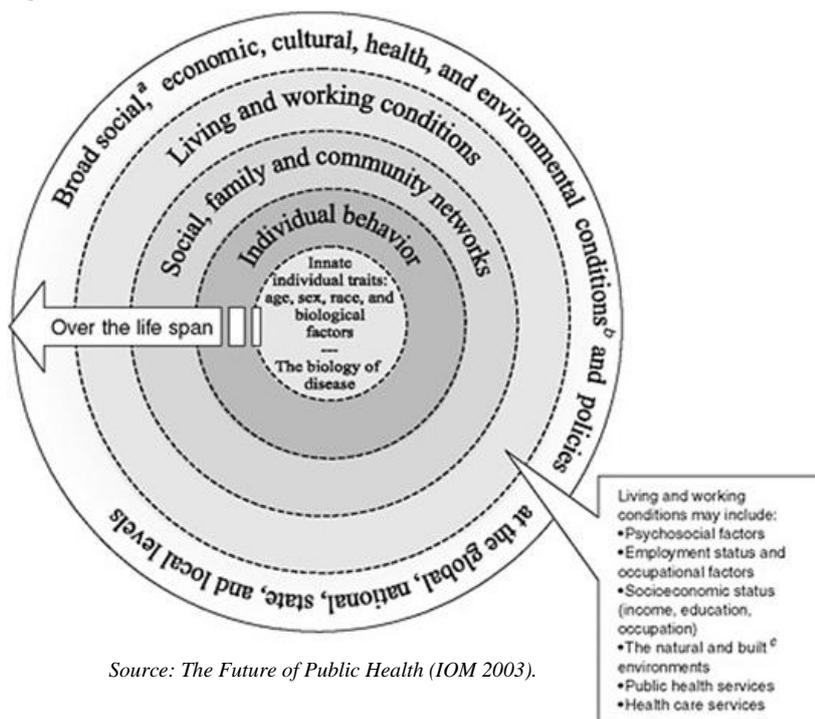
Source: DeVol, Ross, and Armen Bedroussian, *An Unhealthy America: The Economic Burden of Chronic Disease*, Milken Institute, October 2007. www.milkeninstitute.org.

Social Determinants of Health

Some Iowans will die 20 years earlier than others who live just a short distance away because of differences in social determinants such as race, ethnicity, education, income, and where they live. These Iowans die prematurely from preventable health problems and their health is greatly influenced by these powerful social determinants. Iowa must find ways to reverse the negative effects of these determinants and enable more people to lead healthy lives and avoid getting sick in the first place.

The social determinants of health are mostly responsible for **health disparities** – particular types of health differences that are closely linked with social or economic disadvantages. There is growing evidence supporting the impact of these determinants on individual health throughout the lifespan. The Social Determinants of Health Model (Figure 2) lists the major social determinants categorized under the political, global, social, economic, cultural, biological, physical, environmental and behavioral factors that influence health.

Figure 2- Social Determinants of Health Model



Source: *The Future of Public Health* (IOM 2003).

The social determinants of health are the circumstances in which people are born, grow up, live, work, and age, as well as the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics.

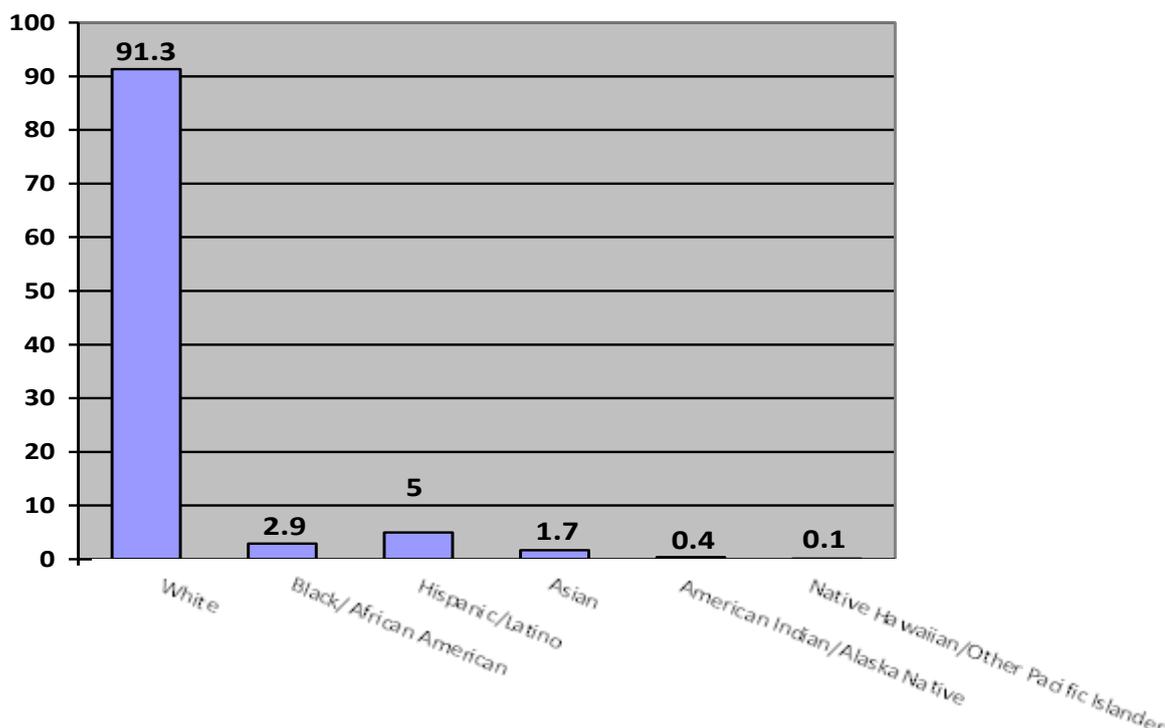
- World Health Organization

This report focuses on data collection centered on **racial** and **ethnic** health disparities in Iowa. The following racial and ethnic categories were used to collect this data:

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander
- White

These are the standards for the classification of federal data on race and ethnicity from the Office of Management and Budget (OMB). See Figure 3 for a breakdown of the percent of Iowans that fall into each category according to the 2010 census.

Figure 3- Percent of Iowans in the OMB Racial and Ethnic Categories



Federal Effort to Reduce Health Disparities in the U.S.

The Federal Affordable Care Act (ACA) offers a number of provisions related to disparities reduction and data collection. It is highly recognized that reducing health disparities and collecting more comprehensive and accurate disparities data is a critical issue that needs to be addressed. The provisions within the ACA offer the potential to address the needs of racial and ethnic minority populations by bringing down health care costs, investing in prevention and wellness, supporting improvements in primary care, and creating linkages between the traditional realms of health and social services

In April 2011, the U.S. Department of Human Services (HHS) released an Action Plan to Reduce Racial and Ethnic Health Disparities^x. The Action Plan outlines goals, strategies and actions HHS will take to reduce health disparities among racial and ethnic minorities. It builds on provisions of the ACA which will help address the needs of racial and ethnic minority populations by bringing down health care costs, investing in prevention and wellness, supporting improvements in primary care, and creating linkages between the traditional realms of health and social services.

Within the framework of the HHS Action Plan, the five overall goals for reducing disparities and associated action steps include:

1. **Transform Health Care:** Action steps include expanding insurance coverage, increasing access to care through development of new service delivery sites and introducing quality initiatives such as increased utilization of medical homes.
2. **Strengthen the Nation's Health and Human Services Workforce:** Action steps include a new pipeline program for recruiting undergraduates from underserved communities for public health and biomedical sciences careers, expanding and improving health care interpreting and translation, and supporting more training of community health workers.
3. **Advance the Health, Safety and Well-Being of the American People:** Action steps include implementing the CDC's Community Transformation Grants, and additional targeted efforts to achieve improvements in cardiovascular disease, childhood obesity, tobacco-related diseases, maternal and child health, flu and asthma.
4. **Advance Scientific Knowledge and Innovation:** Action steps include implementing a new health data collection and analysis strategy authorized by the Affordable Care Act, and increasing patient-centered outcomes research.
5. **Increase the Efficiency, Transparency and Accountability of HHS Programs:** Action steps include ensuring that assessments of policies and programs on health disparities will become part of all HHS decision-making. Evaluations will measure progress toward reducing health disparities.

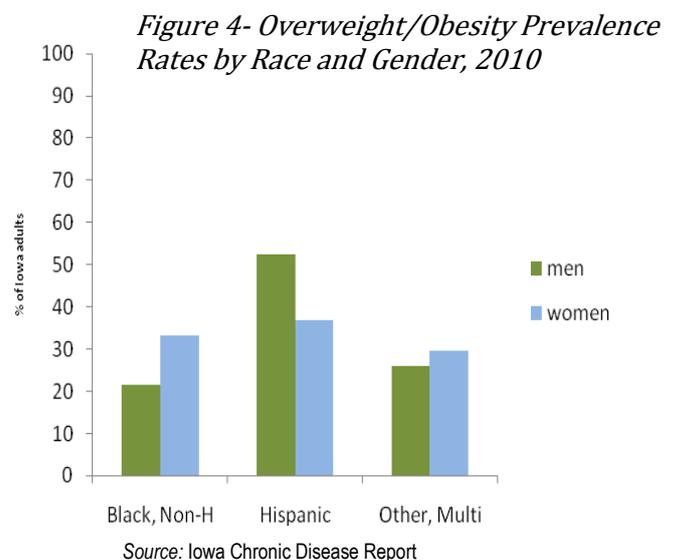
The plan also calls for HHS to set data standards and upgrade collection and analysis of data on race, ethnicity, primary language and other demographic categories in line with new provisions of the ACA

Snapshot of Health Disparities in Iowa

Obesity- Hispanic men at high risk

Overweight/obesity prevalence rates show that both Iowa Hispanic men and women had the highest rates among minority groups. Rates for Hispanic men were double the rates for other/multi-race groups and black non-Hispanic minority groups.

Because Whites comprised the majority of survey respondents, prevalence rates for overweight/ obesity among minority groups were calculated separately (see Figure 4). Among White adults the prevalence rate for overweight/obesity among men was 75% and among women 55.4%.^{xi}

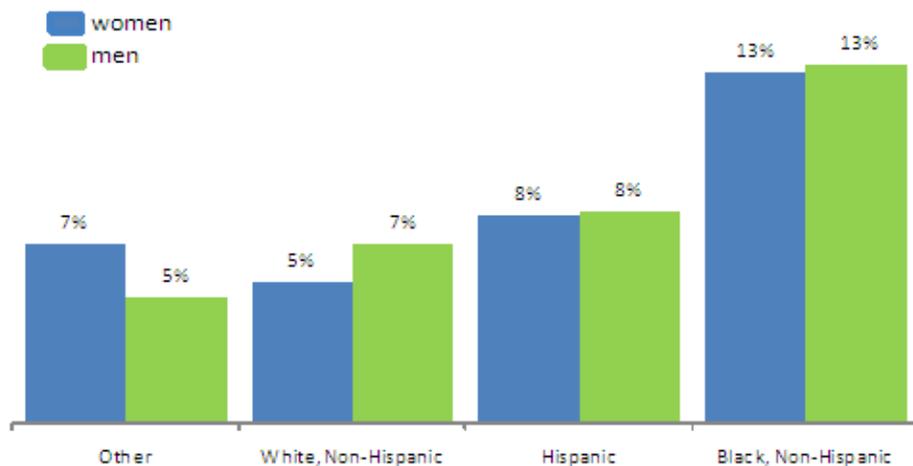


Diabetes- Black/African American adults at high risk

Age-adjusted sex and race-specific diagnosed diabetes prevalence rates show that both African American men and women in Iowa had rates of diabetes double or more those of same-sex White and Other (minority) race men and women. Rates for Hispanic men and women were also high relative to same-sex White and Other race rates.

While White men and women were at lower risk of having diabetes compared to Black/African Americans and Hispanics, White men (76,200) and women (75,300) account for about 95% of all cases of diabetes (151,500 of 161,700 cases of diabetes) in Iowa during 2006-2008.^{xii} See Figure 5 on the next page.

Figure 5- Diabetes Prevalence, by Race and Sex, Iowa



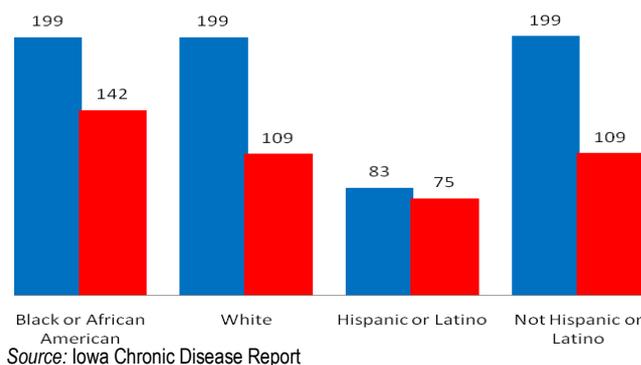
Ten-year average annual age-adjusted diabetes prevalence rate per 100 adults, by race and Hispanic ethnicity, Iowa BRFSS, 1999-2008

Coronary Heart Disease (CHD)- Black/African American and White males (equally) and Black females at high risk

Black/African American and White males showed about the same CHD death rates (2003-2007 combined); however Black females exceeded White females by 33 deaths/100,000: 142.2/100,000 vs. 108.8/100,000 during the same period.

Non-Hispanic males and females had higher CHD deaths than their Hispanic counterparts.^{xiii}

Figure 6- Coronary Heart Disease Age-Adjusted Death Rate by Race, Hispanic Origin and Gender, Iowa 2003-2007



Source: Iowa Chronic Disease Report

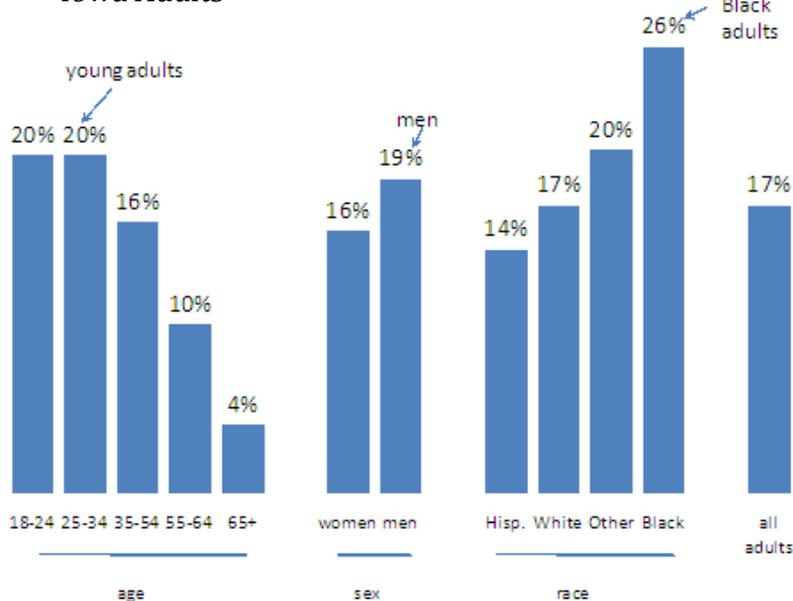
Tobacco Use- Black/African American adults at highest risk

In 2009-10, 20% of the population 18-34 years of age smoked, while only 4% of adults 65 and older smoked. i.e. The rate for young adults was 5 times that of older adults.

The rate for men (19%) was 20% higher than that for women (16%).

Smoking among Black/African Americans was the highest of all racial/ethnic groups—45% higher than that of Whites and 83% higher than that of Hispanics. Figure 6 to the right shows this data.^{xiv}

Figure 7- Smoking Prevalence by Age, Race, Sex- Iowa Adults



Source: Iowa Chronic Disease Report

Tobacco Use (cont.) – Black/African American adults at highest risk

Since 2000-2004, cigarette smoking prevalence rates among Black/African American adults in Iowa have exceeded those of all other racial ethnic groups.

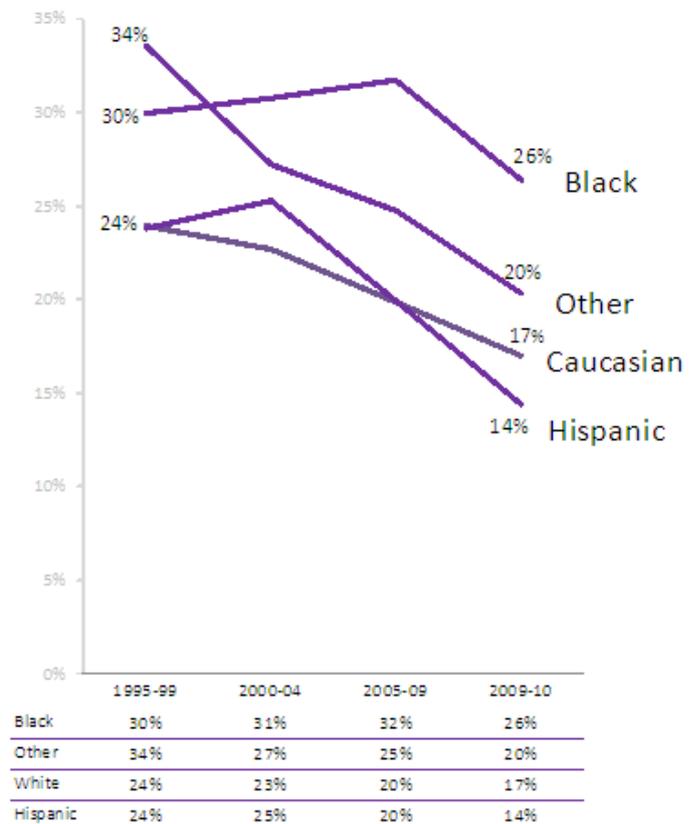
Hispanics now appear to have the lowest smoking prevalence rate among adult racial/ethnic groups in Iowa, but Hispanic rates were close to those of White adults for all years 2005-2010.

For all racial ethnic groups, smoking prevalence rates declined substantially between 1995-1999 and 2009-2010. Rates declined the least for Blacks (down 12%), followed by Whites (down 29%), Hispanics and other races (down 40%).^{xv}

Figure 8- Five-year average annual age-adjusted percent of adults age 18 and older who smoked cigarettes in the past 30 days (current smoking prevalence rate per 100 adults), by race, Iowa, 1995-2010.

Source: Iowa BRFSS, IA Dept. of Public Health

Figure 8- Trends in Smoking Prevalence, by Race- Iowa Adults



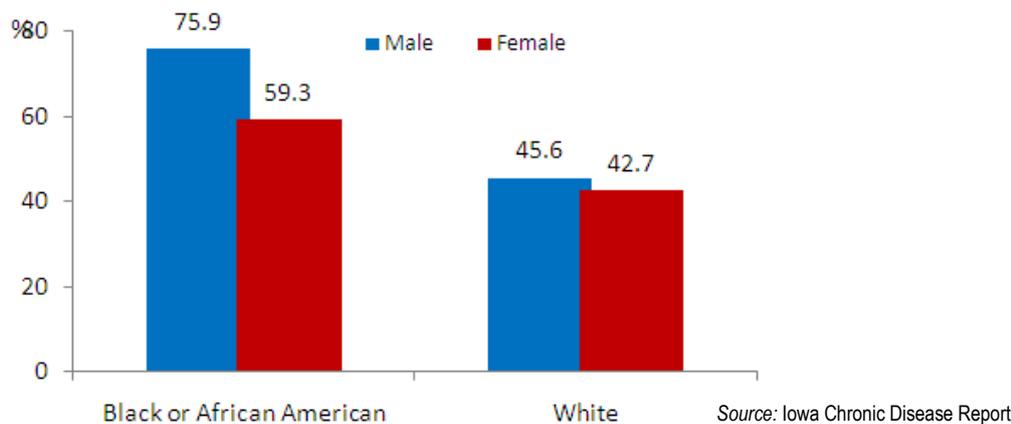
Stroke – Black/African American males adults at high risk

Black/African American men had a 66% higher stroke death rate (76/100,000) than White men (46/100,000) in Iowa.

Black/African American women had 39% higher rate (59/100,000) than the White females (43/100,000) in Iowa.^{xvi}

The Stroke death rate for Iowa Hispanic or Latino Origin was 30.5/100,000 (2003-2007). During these five years, there was a total 49 stroke deaths. There is no difference between genders in this race.

Figure 9- Age-Adjusted Stroke Death Rate by Race and Sex- Iowa, 2005-2007



Cancer – Black/African American males at highest risk

The State Health Registry of Iowa estimates 16,000 new cancer cases will be diagnosed in 2008 and 6,300 Iowans will die from cancer in 2008. Cancer is the second leading cause of death in Iowa. Cancer is not just one disease but many diseases. There are more than 100 different types of cancer. Most cancers are named for the organ or type of cell in which they start. This section of the report refers to statistics for all cancer sites combined.^{xvii}

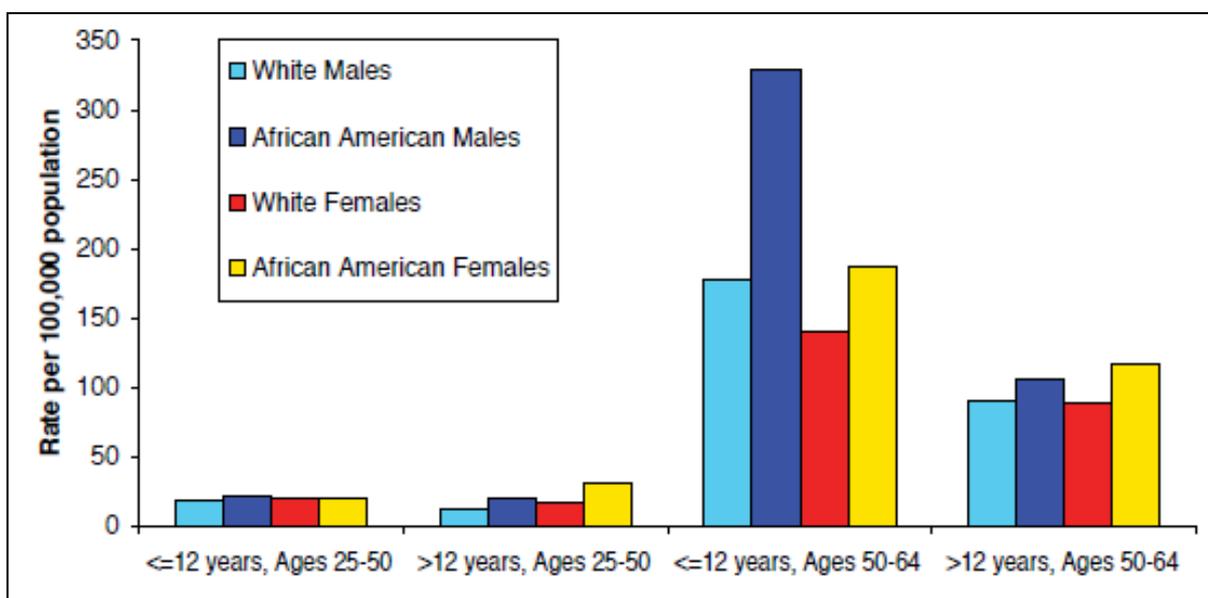
Cancer occurs in all age groups, but it occurs most often among older age groups. Sixty percent of new cancers occur in persons age 65 and older. Of all cancer deaths, over 70% occur in this group. Age is especially important in Iowa where 14.6% of residents are age 65 and older, higher than the national average of 12.4%.^{xviii}

Education level is an important factor in cancer mortality rates. Black/African American men age 50-64 who have less than 12 years of education are dying from cancer at rates over two times that of Black/African American men with more than 12 years of education. Similar results are seen in White males. Educational differences do not play as large a role for Iowa women in determining cancer mortality, but as education increases, cancer mortality rates decrease for both Black/African American and White Iowa women. Higher education levels are also associated with higher levels of cancer screening.^{xix}

Race, like education, is a determining factor in predicting cancer mortality. Black/African American males, regardless of education, have higher mortality rates than their White counterparts.

As shown in Figure 10, Black/African Americans are diagnosed with cancer 10% higher than Whites and die from cancer at rates nearly one and a half times that of White Iowans. Available data show that Black/African Americans die at higher rates than any other racial group in Iowa. American Indians/Alaska Natives have the highest rates of cancer incidence in Iowa, although small numbers in this population make this rate unstable. Low representation of American Indians in Iowa prevents cancer mortality rates from being released.^{xx}

Figure 10- Mortality Rates for All Cancer Sites by Educational Attainment, Race and Sex, Iowa 2001-2005.



Rates are age-adjusted to the 2000 US population
 Source: State Health Registry of Iowa

Iowa Minority Disease/Health Disparities Report

The Iowa Department of Public Health's Office of Minority and Multicultural Health has applied for and received federal funding to develop a Minority Disease/Health Disparities Report. A statewide Advisory Council is guiding the production of this report.

The Office of Minority and Multicultural Health Advisory Council and the PCCM Advisory Council have formed a working relationship with the University of Northern Iowa's Iowa Center on Health Disparities^{xxi} (Iowa Center) to aid in these efforts. The Iowa Center provides statewide academic leadership in addressing and reducing health disparities among minority, immigrant, and medically underserved populations in Iowa. The Iowa Center provides a number of services including applied research, community education and outreach programs with diverse and underserved populations, and trainings and workshops on health disparities and culturally competent health care for educators and providers.

Barriers to Multicultural Health Disparities Data

1. Iowa has very unique demographics including primarily aging Whites, relatively few minorities, and even fewer minorities when broken down by diseases, gender, age, etc.
2. Smaller, rural communities in Iowa have small sample sizes that limit validity of calculations of formulas like incidence (number of **new** cases per population in a given time period) and prevalence (number of **total** cases per population in a given time period) rates.
3. The potential for violations of the Health Insurance Portability and Accountability Act (HIPPA) and confidentiality regulations exist due to small sample sizes, especially by age, gender, disease, etc.
 - o The small sample size creates large confidentiality issues. For example, releasing data that 25 percent of Sudanese living in a small town in Iowa have HIV/AIDS, and only four Sudanese are currently living in that town, it would not be difficult for community members to determine who that person was.
4. A general bias towards quantitative (numerical) research exists, particularly that collected through impersonal but more efficient methods such as telephone interviews, mailed surveys, and internet sites
5. Iowa is experiencing growing "microplurality" (small numbers of immigrants from a wide variety of countries) that leads to greater need for more complex and labor intensive methods to collect data in real time for mobile and hard-to-reach populations.
 - o Immigrants come to Iowa from a variety of countries across the world. According to the Iowa Bureau of Refugee Services, refugees settled in Iowa came from Sudan, Ivory Coast, Somalia and other African nations, Russia and other parts of the former Soviet Union, Vietnam, Cambodia and other parts of Southeast Asia, Iraq, Haiti, Cuba and Bosnia and other places in the Balkans. Between 1975 and 1999, nearly 22,000 refugees were settled in Iowa. Between 1997 and 2002 alone, 7,441 refugees were settled in Iowa with the most (5,383) coming from the former Yugoslavia. Several thousand more refugees came to the state as "secondary migrants" who were initially resettled in other states but then moved to Iowa.^{xxii}
6. The growing number of immigrants from a variety of countries creates language, literacy and cultural barriers.

- Cultural barriers include differences in religion, gender, values, behaviors, relationships, and many more.
7. Transportation, geographical, and regional differences exist in Iowa making data collection and access to information difficult.
 8. Not all Iowans are legal U.S. citizens, causing a barrier to collecting data on chronic disease in multicultural groups of racial and ethnic
 - Illegal immigrants living in Iowa are unlikely to participate in data collection surveys, especially those through phone, internet, or mail.
 9. There is an overall limited awareness of how to define “diversity” and the importance of supporting collection of culturally specific data.

Recommendations to Improve Racial and Ethnic Health Disparities Data

- 1. Identify and educate Iowans on the existence of health disparities in multicultural groups of racial and ethnic diversity in the state.**

Racial and ethnic minorities lag behind in numerous health outcome measures. Identifying populations in Iowa that are highly burdened by chronic diseases is crucial to building awareness and providing education and outreach to these populations. Identifying where this population is currently getting health care and the source of payment would also be valuable knowledge.

- 2. Support alternative means of collecting statistically accurate data concerning chronic diseases in multicultural groups of racial and ethnic diversity in Iowa, including qualitative techniques often practiced by global health organizations working with mobile and difficult-to-reach populations.**

Alternative means of collecting information are needed until critical population masses exist and there is a large enough sample size to report data on. Alternate methods of collecting multicultural data include qualitative research including in-person focus groups, oral interviews, and field research to learn and understand the population’s culture. Qualitative research aims to gather an in-depth understanding of human behavior and the reasons that govern such behavior. The qualitative method investigates the *why* and *how* of decision making, not just *what*, *where*, *when*.

In order to conduct this more extensive qualitative research, a portion of funding must be shifted from standard quantitative (numerical) methods into including more labor-intensive supplemental methods with smaller sample sizes. Some of the minority populations may need to be oversampled to allow for larger pools. Careful judgment will need to be applied to the allocation of scarce resources.

- 3. Reconsider confidentiality regulations in an agency, where possible, to allow access to data to those that need it for programming and policy purposes.**

Gaining access to this information will improve the collection of disparities data and increase awareness of the populations that would benefit from targeted education and outreach programs.

- 4. Utilize a consistent approach to collecting racial and ethnic data by following the Office of Management and Budget (OMB) categories.**

These are the standards for the classification of federal data on race and ethnicity from the Office of Management and Budget (OMB).^{xxiii} The six categories are defined as follows:

- **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, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. 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.

Respondents should be offered the option of selecting one or more racial designations.

Recommended forms for the instruction accompanying the multiple response questions are to "Mark one or more" and "Select one or more."

5. Support increased training and ongoing education targeted at data staff on diversity by language and culture.

The quickly growing demographic changes, expansion of immigrant populations, and increasing health disparities in Iowa increases the need for continuous training and education on diversity to staff members collecting the demographic data.

6. Encourage efforts to collaborate with minority and immigrant populations as partners in gathering information and implementing targeted health programs based upon that data.

Collaborating with minority and immigrant populations as partners in gathering information is a potential method to collect accurate data for the implementation of targeted health programs. A number of community centers offering a variety of services to minorities and immigrants exist throughout Iowa. These centers could take advantage of all opportunities to collect data directly, including at all points of contact, and supplement these with indirect methods. Collecting data through a center or service that this population knows and trusts is a potential solution to collecting more comprehensive and accurate health data.

Conclusion

There is widespread agreement that the collection of valid and reliable data is a fundamental building block for addressing health disparities. The research laid out in this report gives a snapshot of the multicultural data currently being collected in Iowa, the barriers to collecting this data, and recommendations to improve data collection. Accurate collection of this data can increase the understanding of health care disparities can advance the quality of health care provided to all Iowans.

Resources

- ⁱ HHS Action Plan to Reduce Racial and Ethnic Health Disparities
http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf
- ⁱⁱ HHS Action Plan to Reduce Racial and Ethnic Health Disparities
http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf
- ⁱⁱⁱ <http://coolice.legis.state.ia.us/Cool-ICE/default.asp?Category=billinfo&Service=Billbook&menu=false&ga=82&hbill=HF2539>
 accessed January 2009.
- ^{iv} Iowa Department of Public Health, Prevention and Chronic Care Management Advisory Council,
http://www.idph.state.ia.us/hcr_committees/prevention_chronic_care_mgmt.asp
- ^v House File 2144. http://www.idph.state.ia.us/hcr_committees/common/pdf/prevention_chronic_care_mgmt/082710_hf2144.pdf
- ^{vi} <http://coolice.legis.state.ia.us/Cool-ICE/default.asp?Category=billinfo&Service=Billbook&menu=false&ga=82&hbill=HF2539>
 retrieved November 2009.
- ^{vii} Healthy Iowans. Iowa Chronic Disease Report. 2009. Available at
http://www.idph.state.ia.us/apl/common/pdf/health_statistics/chronic_disease_report.pdf
- ^{viii} Centers for Disease Control and Prevention. 2009. Chronic Disease Overview. <http://www.cdc.gov/NCCdphp/overview.htm>
- ^{ix} Partnership to Fight Chronic Diseases. 2009 Almanac of Chronic Disease: Impact of Chronic Disease on U.S. Health and Prosperity: A Collection of Statistics and Commentary. Available at http://www.fightchronicdisease.org/pdfs/2009_PFCDAImanac.pdf
- ^x HHS Action Plan to Reduce Racial and Ethnic Health Disparities
http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf
- ^{xi} Iowa Chronic Disease Report Supplement, 2011.
http://www.idph.state.ia.us/apl/common/pdf/health_statistics/chronic_disease_report.pdf
- ^{xii} Iowa Chronic Disease Report Supplement, 2011.
http://www.idph.state.ia.us/apl/common/pdf/health_statistics/chronic_disease_report.pdf
- ^{xiii} Iowa Chronic Disease Report Supplement, 2011.
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- ^{xiv} Iowa Chronic Disease Report Supplement, 2011.
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- ^{xvi} Iowa Chronic Disease Report Supplement, 2011.
http://www.idph.state.ia.us/apl/common/pdf/health_statistics/chronic_disease_report.pdf
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- ^{xx} Iowa Cancer Health Disparities Report, http://www.idph.state.ia.us/CCC/common/pdf/ia_cancer_health_disparities.pdf
- ^{xxi} Iowa Center on Health Disparities. <http://www.iowahealthdisparities.org/welcome.php>
- ^{xxii} The University of Northern Iowa's New Iowans Program
<http://www.bcs.uni.edu/icili/PDFDocument/new%20iowans%20series%20text.pdf>
- ^{xxiii} OMB Standards for Data on Race and Ethnicity
<http://minorityhealth.hhs.gov/templates/browse.aspx?vl=2&lvID=172>