

# **Assessment of Race, Ethnicity and Language Data Collection in New Hampshire Public Health Data Sets**

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## Introduction

In 2003, The Institute of Medicine (IOM) report *Unequal Treatment* concluded that “race and ethnic disparities in healthcare exist” and that in many cases they were “associated with worse outcomes” in the United States. These disparities were not associated with genetic differences, but instead due to “historic and contemporary social and economic inequality and evidence of persistent racial and ethnic discrimination.”<sup>i</sup>

New Hampshire is the second healthiest state in the nation. However, when looking at race and ethnicity in New Hampshire, not every documented group meets national guidelines for good health.<sup>ii</sup> In order to begin to address this variation in health status, we must ensure that we collect accurate data to measure health status by race, ethnicity, and language in New Hampshire.

If New Hampshire follows national population trends, we can expect that the state population will continue to diversify. Demographers anticipate that the population of the United States will experience a demographic shift to a minority-majority by mid-century. Indeed, recent analysis of Census data and estimates revealed that almost fifty percent of births in the United States last year were to minorities<sup>iii</sup>, signaling that the anticipated demographic shift to a minority-majority population for the nation may be here, early. Further analysis of Census data and estimates revealed that the demographic shift is not only driven by a boom in the Hispanic population but a decline in the number of non-Hispanic white births. With dynamic shifts in the population of racial and ethnic populations, we can expect that the value of understanding racial and ethnic differences in the experience of health and healthcare will become increasingly important.

## **A State Plan to Address Disparities and Promote Health Equity Plan<sup>1</sup>**

The New Hampshire Department of Health and Human Services (DHHS) Office of Minority Health, the New Hampshire Minority Health Coalition, the Endowment for Health, the Foundation for Healthy Communities, and the New Hampshire Institute for Health Policy and Practice at the University of New Hampshire are collaborating to lead the development of a ***State Plan to Reduce Health Disparities and Promote Health Equity in New Hampshire***. This public-private partnership was formed to identify priorities for action to work towards health equity for racial, ethnic and linguistic minorities in New Hampshire (NH). The plan will serve as a basis for collaboration between diverse stakeholders, public and private, to achieve this goal. The scope and implementation of the plan will not be limited by the resources of state government nor by the capacity of a single person, agency or organization.

### **What are Health Disparities?**

Not everyone in the United States enjoys the same health opportunities. Studies show that minority populations experience poorer than average health outcomes – they are much more likely to die as infants, have higher rates of diseases and disabilities, and have shorter life spans. This disproportionate burden of disease and mortality is reflected in health disparities. The 2002 Institute of Medicine Report, *Unequal Treatment*, helped to raise awareness nationally about health disparities. Unfortunately, eight years later disparities still persist. For example:

- Infant mortality rates are twice as high for black babies as they are for white babies, and
- Hispanic women are twice as likely to have cervical cancer as white women.<sup>1</sup>

Unequal access to health care and differences in the quality of care received certainly contribute to health disparities; and culture and language barriers are critical to people's ability to access high quality health care. However, other factors are now recognized as being equally, if not more, important in determining one's health and health status including income and poverty status, education, employment and working conditions, housing quality, and neighborhood features including whether one has access to healthy food choices and walkable streets. This complex array of social, cultural and environmental factors that impact quality of life are called social determinants of health and they contribute significantly to health disparities. It is the combined differential experiences in access to health care, quality of health care, and social determinants that result in inequalities in health for racial, ethnic and linguistic minority populations.

In NH, there is a growing population of racial, ethnic and linguistic minorities, predominated by immigrants and refugees. Between 2000 and 2008, there has been a 23% growth in the State's foreign-born population.<sup>1</sup> Despite our demographic changes, our public health data systems do not yet accurately collect race, ethnicity or language information. This system failure limits the ability of practitioners and researchers to identify evaluate and address health inequities in NH.

### **Why Does NH Need a Plan?**

Every resident in NH is bound by the same concerns for health, housing, education, employment, and the like. Some populations in NH struggle because they do not have a fair chance to be healthy. We succeed as a state when we ensure opportunity for all, including the opportunity for health. By applying our NH ingenuity, we can make better use of our limited resources, progress towards solving health disparities, and develop programs and services fairly distributed and accessible across all communities. Developing a *State Plan to Reduce Health Disparities and Promote Health Equity in New Hampshire* will focus our collective efforts to promote initiatives and policies that can help make our communities healthier places to live, learn, work and play for all.

### What is the Process to Develop a Plan?

A State Plan Advisory Group of key stakeholders has been convened to guide the work of creating a state plan.

#### Phase I Planning Work – Completed August 2010

With funding from the Endowment for Health, the NH Institute for Health Policy and Practice has conducted the *Assessment of Race, Ethnicity and Language Data Collection in New Hampshire Public Health Data Sets*. The assessment included identification of priorities and strategies for financing and implementing recommendations for changes in the NH public data collection systems.

#### Phase II Planning Work – In Process through August 2010

Coordination by Altarum Institute, funded by the NH DHHS Office of Minority Health:

- Conduct a review of various reports related to the health of minority populations in NH.
- Engage minority community members, key health institutions, public and private entities, and minority health experts to expand the NH State Plan Advisory Group.
- Engage stakeholders in the process to collect qualitative data regarding needs, gaps, priorities and strategies for addressing disparities and promoting health equity.
- Use the Phase I planning work, Phase II qualitative data, research review of available minority health reports/disparities data, and input from the Advisory Group to identify priority issues (needs, gaps, priorities, and strategies) to address in a NH Health Equity Plan.
- Develop a summary report/presentation for the NH State Plan Advisory Group and other stakeholders.
- Draft an outline of a state plan to address health disparities and promote health equity for NH using a social determinants framework.
- Identify funding opportunities for finalizing the Plan.

#### The New Hampshire Health and Equity Partnership

Coincident with this process, various individuals, organizations, and coalitions concerned with issues of access, quality, cultural competency, and equity have coalesced around a shared vision. The public-private partnership structure of the State Plan Advisory Group has evolved into an umbrella entity, integrating the Diversity Task Force and the Medical Interpretation Advisory Board, to continue this health equity work collaboratively. The work of the **New Hampshire Health and Equity Partnership** will be guided by the *State Plan to Address Health Disparities and Promote Health Equity in New Hampshire* into the implementation, evaluation, monitoring, and improvement phases, and beyond, to promote a more just and equitable future for all people in New Hampshire.

## Guidelines for the Collection of Race, Ethnicity and Language Data

The Office of Management and Business (OMB) updated guidelines for the collection of race and ethnicity data in 1997<sup>iv</sup>. The new standards were implemented in the Bureau of the Census in the 2000 decennial census, and other Federal programs were directed to adopt the standards by January 1, 2003, for use in household surveys, administrative forms and records, and other data collections. The new guidelines were to be adopted nationally by January 1, 2003. They included a two-question format for the collection of race and ethnicity. Best practices dictate ethnicity to be asked before a person's race. Ethnicity is assessed in a single question to identify Hispanic ethnicity. The second question identifies race, and includes five options for race including the option to select more than one. This is considered the minimum data that should be collected about race and ethnicity.

### OFFICE OF MANAGEMENT AND BUDGET, *Federal Register* Notice, October 30, 1997

#### Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity

**AGENCY:** Executive Office of the President, Office of Management and Budget (OMB), Office of Information and Regulatory Affairs

**SUMMARY:** By this Notice, OMB is announcing its decision concerning the revision of Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting.... The revised standards will have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino." (Source: <http://www.whitehouse.gov/omb/rewrite/fedreg/ombdir15.html>)

In 2009, the Institute of Medicine released a report, *Race, Ethnicity and Language Data: Standardization for Healthcare Quality Improvement*<sup>v</sup>, that added the recommendation that more granular ethnicity be collected. More specifically, granular ethnicities would expand the Hispanic ethnicity question to include a list of locally relevant ethnicities to choose from (such as Cuban, Puerto Rican, Somali and Chinese). They also recommend the collection of language data, specifically the collection of language proficiency and preferred language for a doctor visit.

### Race, Ethnicity and Language Data: Standardization for Healthcare Quality Improvement

**Recommendation 3-1:** An entity collecting data from individuals for purposes related to health and health care should:

- Collect data on granular ethnicity using categories that are applicable to the populations it serves or studies. Categories should be selected from a national standard list (IOM Recommendation 6-1a) on the basis of health and health care quality issues, evidence or likelihood of disparities, or size of subgroups within the population. The selection of categories should also be informed by analysis of relevant data (e.g. Census data) on the service or study population. In addition, an open-ended option of "Other, please specify: \_\_\_" should be provided for persons whose granular ethnicity is not listed as a response option.
- Elicit categorical responses consistent with the current OMB standard race and Hispanic ethnicity categories, with the addition of a response option of "some other race" for persons who do not identify with the OMB race categories.

The United States Department of Health and Human Services Office of Minority Health published a report in 2001, recommending national standards for culturally and linguistically appropriate services (CLAS) in health care. Several CLAS standards are **mandates** -- Federal requirements for all recipients of Federal funds (Standards 4, 5, 6, and 7)<sup>vi</sup>.

#### **National Standards on Culturally and Linguistically Appropriate Services (CLAS)**

- **Standard 4** Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
- **Standard 5** Health care organizations must provide to patients or consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.
- **Standard 6** Health care organizations must assure the competence of language assistance provided to limited English proficient patients or consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
- **Standard 7** Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

CLAS **guidelines** are activities recommended by OMH for adoption as mandates by Federal, State, and national accrediting agencies (Standards 1, 2, 3, 8, 9, 10, 11, 12, and 13). Particularly relevant to public health data collection, standard 10 of CLAS states: “Health care organizations should ensure that data on the individual patient’s/consumer’s race, ethnicity and spoken and written language are collected in health records, integrated into the organization’s management information systems and periodically updated.”<sup>vii</sup> It is worth noting, that to be in compliance with the mandated CLAS Standards, it becomes necessary for organizations to collect patient language data.

Since 2007 Massachusetts has mandated the collection of race and ethnicity through an edict from the Executive Office of Health and Human Services<sup>viii</sup>. In Massachusetts, HHS uses a list of 33 granular ethnicity choices based on an assessment of their population. They also collect language data which is used to assess the need for interpreters and other services for patients.

There have been recent studies that assess the collection of race, ethnicity, and language by hospitals in New Hampshire, but nothing that provides a comprehensive assessment of how these data are collected in the state’s public health data sets. For this reason, the Endowment for Health funded, as the first phase of the development of the State Health Equity Plan, an assessment of data collection practices for public health data sets in New Hampshire. This report is a summary of that assessment.

## Methods

In order to determine how closely New Hampshire public health data sets align with the guidelines established by the OMB and recommendations issued by the IOM's *Race, Ethnicity and Language Data*, a survey<sup>ix</sup> of the data stewards of the New Hampshire public health data sets was conducted in the spring of 2010. The survey assessed data collection practices in three main areas: race and ethnicity, language, and other related information. Each section contained questions that evaluated the specific values for each of the areas of race, ethnicity and language. The survey also contained questions related to how the data is collected, who collects it, how those who collect the data are trained, and what quality control measures are in place to ensure that the data collection practices are implemented.

The public health data sets that were evaluated in this survey were:

1. Population Estimates
2. Childhood Lead Program
3. Early Hearing Detection and Intervention
4. Family Planning
5. Perinatal Client Data Form
6. Newborn Screening Program
7. NH Birth Conditions
8. Hospital Discharge
9. Medicaid
10. Cancer Registry
11. Behavioral Risk Factor Surveillance System (BRFSS)
12. Bureau of Behavioral Health
13. Communicable Disease
14. Youth Tobacco Survey (YTS)
15. Youth Risk Behavioral Survey (YRBS)
16. Women, Infants, and Children (WIC) Program, Centers for Disease and Control (CDC) Pediatric and Pregnancy Nutrition Surveillance System
17. Automated Hospital Emergency Department Data Project (AHEDD)
18. Healthy Smiles, Healthy Growth
19. Vital Records: Birth Certificate, Fetal Death, Death Certificate, Marriage and Civil Unions, Divorce

The survey was sent to the State Health Equity Plan Advisory Group and other stakeholders to be reviewed. Feedback was incorporated into the final form of the survey.

Data stewards for each of the data sets listed above were contacted by email and phone to complete the survey on-line or through an interview format.

In addition to the survey of public health data stewards, state and federal legislation and guidelines were reviewed in order to understand the mechanism for establishing and updating the various public health data collection systems in the state.



## Results

Four data stewards completed the survey by phone, fourteen completed it on-line, and one completed a printed version of the survey and mailed it back. Those who completed it over the phone had the chance to ask questions additional information about their data collection practices. Those who took the survey on-line were constrained to multiple choice responses by the format of the survey. Twelve of the nineteen data stewards collect data from organizations that provide state wide services (see Figure 1).

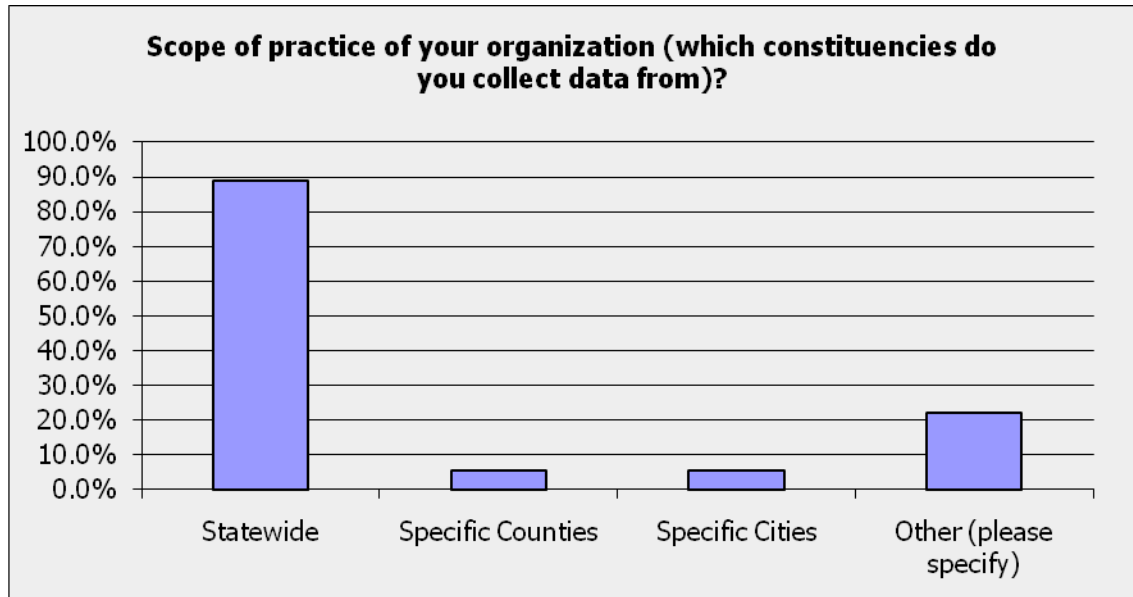


Figure 1. Scope of Public Health Data Collection

## Collection of Race and Ethnicity Data:

Fifteen of the nineteen public health data stewards indicated that they collect race and ethnicity data (Table 1). Those who do not are AHEDD, Healthy Smiles/Healthy Growth, and Newborn Screening. Those who do not collect this data at this time indicated that there are no plans to start collecting it any time soon. Of the sixteen that are collecting race/ethnicity data, the data stewards are collecting race and ethnicity from every person (except clients that refused to provide that information).

Question	Yes	No	N/A
Collect Race/Ethnicity Data?	16	3	
Required by Federal or by State to Collect R/E Data?	7	7	5
Separate Question for Hispanic Ethnicity?	13	2	4

**Table 1. Collection of Race and Ethnicity Data**

## Race:

For data stewards that collect race, almost all follow the OMB guidelines. The Cancer Registry, Perinatal Client Form, Vital Records, Population Estimate, and Birth Conditions collect more races than those required by the OMB guidelines (Table 2). Most of the data sets that collect race allow for more than one to be chosen.

Question	Number of respondents that collect R/E data
<b>Of the 15 data stewards that collect race data, what are the options for race?</b>	
A) Black/African American	16
B) White	16
C) Asian	16
D) American Indian/Alaskan Native	16
E) Native Hawaiian/Other Pacific Islander	16
F) Not Available/Refused	6
G) Other	4
H) Unknown	5
I) Chinese	3
J) Vietnamese	3
K) Samoan	3
L) Filipino	2
M) Japanese	3
N) Korean	3
O) Guamanian or Chamorro	3
P) Asian Indian	3
Can more than one race be chosen	14
Is there a place where a race can be filled in	9

**Table 2. Collection of race data in NH public health data sets**

## Ethnicity:

For the public health data sets that capture ethnicity, almost all follow OMB guidelines. Medicaid was an exception; some options for race in the Medicaid data sets are defined as “ethnicities”. The Cancer Registry, Population Estimates, Newborn Hearing Screening, Vital Records and Perinatal Client Data follow the IOM guidelines by offering granular ethnicities. The other data sets follow the minimum OMB guidelines and offer two options, Hispanic or Non-Hispanic. The Cancer Registry, Population Estimates, Medicaid and Perinatal Client Data allow for the selection of more than one ethnicity. A few data sets including the Cancer Registry, Medicaid, Population Estimates, Childhood Lead, and WIC allow the option to “fill in” an ethnicity (Table 3).

Question	Number of respondents that indicated that they collect
<b>Of the 15 data stewards that collect ethnicity data, what are the options for ethnicity?</b>	
Hispanic	11
Non-Hispanic	12
Chicano	1
Cuban	1
Mexican/Mexican American	1
Puerto Rican	1
Other	2
American Indian/Alaskan Native	1
Asian	1
Black/African American	1
Native Hawaiian/Pacific Islander	1
White	1
Can more than one ethnicity be chosen	3
There is a place where an ethnicity can be filled in	6

**Table 3. Collection of ethnicity data in NH public health data sets**

**Note: Cancer Registry collects more ethnicity categories than those listed here.**

## NH Public Health Use of Race and Ethnicity Data:

There is extensive variability in how the collected race and ethnicity data are used. The most common reasons are to describe the population served and for an assessment of health disparities (Table 4). BRFSS and Newborn Hearing Screening are the only data sets that do not regularly analyze the race and ethnicity data collected. In the case of BRFSS data, the sample size is too small to analyze data for race and ethnicity for a single year. The BRFSS data steward also indicated that while race and ethnicity are including in the survey, they are not required elements, and survey respondents often refuse to report their race or ethnicity. The data stewards representing the Population Estimates and BRFSS mentioned that the number of non-whites is so small in New Hampshire that this information is hard to assess; this was echoed in similar sentiments by other data stewards. WIC, Medicaid, Vital Records and Family Planning use or report the race and ethnicity information primarily in response to funding requirements. For the most part, these data are made available to state and federal agencies. Many of the state public health data sets are part of larger federal data sets that have reporting requirements for all states.

Question	Number of respondents
<b>Of the 15 data stewards that collect race/ethnicity data, how are the race/ethnicity data currently used?</b>	
To describe the population you serve	9
For an assessment of health disparities	5
In compliance with funding requirements	4
Not currently used	2
For quality of care improvements	1
Public health surveillance	1
To report to federal government	1
New so still trying to figure out how to use it	1
Transmitted to CDC to be analyzed	1
For grant proposals	1
Numbers are too small to be used	1
Hope to use the information to describe the population	1
Access health disparities and improve care in the future	1

**Table 4. Purpose of Collection of Race and Ethnicity Data**

## Method of Collection of Race and Ethnicity Data:

There was little consistency in how race and ethnicity data are collected. Many public health data stewards rely on data that is self-reported, either written or verbally reported (Table 5). Some data stewards indicated that they use multiple methods to collect data within a single data set. IOM recommends that race and ethnicity data be collected directly via self-report, either through a written form or verbally asking, instead of observing, or identifying by surname.

Question	Number of respondents
<b>How is race/ethnicity data collected?</b>	
Self-report (written form)	5
Self-report (interview form)	4
Documented by an observer	3
Determine ethnicity by looking at name	1
Use the chart	5
Combination (from Vital Records, Cancer Registry, hospitalization data, BRFSS, and insurance claims)	2

**Table 5. Method of collection of race and ethnicity data**

## Collection and Analysis of Race and Ethnicity Data:

There is little standardization in terms of collection or analysis of race and ethnicity data among the public health data stewards (Table 6).

Data Set	Person who Collects	% Collected
Cancer Registry	Cancer Registry Operator	Greater than 97%
WIC	WIC local agency staff	None
Hospital Discharge Data	Different for each hospital	Just started collecting, currently unknown
Vital Records (Birth Certificate, Death Certificate, Fetal Death, Marriage Certificate, Civil Union, Divorce)	Birth Registrar (Birth Certificate)	Greater than 90%
Bureau of Behavioral Health	Different for each mental health center	Race 94%, Ethnicity 60%
AHEDD	N/A	N/A
Perinatal Client Data Form	Varies by agency (intake coordinator, clinician social worker)	80%
BRFSS	CATI Interviewer	About 99%
Communicable Disease	Medical provider on chart	Varies by disease, lowest for race is 72% and highest is 92%; for ethnicity, 72% to 89%
Healthy Smiles/Healthy Growth	N/A	N/A
Newborn Screening Program	N/A	N/A
YRBS	Education Consultant and Survey Coordinator	99.98%
Birth Conditions	Birth Registrar	Greater than 90%
Childhood Lead Program	Lab or health care provider	Unknown
Population Estimates	Variable per data set used	90%
Newborn Hearing Screening	Unknown	Unknown
YTS	N/A	N/A
Family Planning	Agency Staff	Unknown
Medicaid	Family Service Specialist	Unknown

**Table 6. Collection and Analysis of Race and Ethnicity Data**

## State and Federal Requirements for Data Collection:

There is very little standardization in the methods for how race and ethnicity data are collected in NH (Table 7). Many of the public health data stewards collect their information from a hospital through the medical or patient record. When collecting race and ethnicity data, only five data stewards indicated that they use a standard script; and of these five, four of them use a script that is compliant with the OMB guidelines (outlined in *Guidelines* section above). For example, the Perinatal Client Data Form has an in-depth standardized script instructing the collectors to: 1) collect information during first visit, 2) ask the mother if she is Spanish/Hispanic /Latino, 3) if yes, ask for specific nationalities, and 4) indicate more than one ethnicity.

Question	Yes	No
Is there a standard way that race/ethnicity data are collected in the public health data set (verbally, written form)?	5	10
Are there federal/state guidelines that require you to collect race/ethnicity data in a specific format:	10	4
<b>Of those data stewards that have guidelines, what are those requirements?</b>		
CDC (CDC/NCHS requirements, CDC/Behavioral Surveillance Branch, CDC/National YRBS questions, CDC/National Birth Certificate)	5	
Federal Cancer Registry Guidelines that say where the data needs to be listed and coded	1	
USDA Categories for race and ethnicity	1	
Federal Behavioral Health Department Requirements	1	
Title V Block Grants have specific required categories that answers need to aggregate to	1	

**Table 7. Data collection standards**

## Quality Control of Race/Ethnicity Data:

Most of the data stewards store race and ethnicity data electronically. Many of the data stewards have some form of quality control to ensure that race and ethnicity data is collected for each record (e.g. client) (Table 8). Most of the data sets, except Behavioral Health, use a computer program that will not allow data to be input unless race and ethnicity data is included. This form of quality control ensures the information has been collected; it does not account for the accuracy or completeness of what was collected.

Question	Yes	No
<b>Of the 13 data stewards that have implemented quality control measures to ensure complete collection of data:</b>		
Software that ensures that record includes race/ethnicity data	6	7
Variable based on each agency	1	12
Review how each agency is collecting data and if an agency is doing a bad job connect them with one doing better	1	12
Checked by submitter before sent to public health data stewards	1	12

**Table 8. Quality Control of Data Collection**

## Language:

Four NH public health data sets collect and report language data: WIC, Family Planning, Medicaid, and Hospital Discharge (Table 9). The data is collected for every person in the WIC and Family Planning data set. For Hospital Discharge Data, collection is dependent on the hospital that is collecting the information. OMB guidelines do not specify collection of language, but the IOM report recommends that English competency and spoken language preferred for health care information are collected. There are no plans for the NH public health data sets that are not collecting language data to add that information at this time.

Question	Yes	No
<b>Do you currently collect language information in the data set?</b>	4	15
Required by federal or by state to collect language data	1	3
Language data collected for every person?	2	2

**Table 9. Language Data Collection**



## Types of Language:

There is not a consistent state-wide policy for what languages have to be captured in public health data systems. Although hospitals collect information about patient language, the number and coding of specific languages collected by each hospital varies and is not consistent among the hospitals (Table 10). Medicaid collects data about clients for six languages. WIC uses a typology that includes eighteen languages. Family Planning has codes for seventeen languages, which are all federally defined.

Question	Number of respondents that indicated that they collect
<b>Of the 4 data stewards that collect language data, what languages are collected in your data set? (respondents were asked to provide the list of languages that are captured in their data set)</b>	
American Sign	1
Arabic	1
Asian	1
Bosnian	1
Cape Verdean Creole	1
Chinese	1
English	2
French	2
Greek	1
Haitian Creole	1
Hmong	1
Khmer	1
Lao	1
Polish	1
Portuguese	1
Russian	1
Somali	1
Spanish	2
Vietnamese	1
Other	1
Option to Fill-in	4

**Table 10: Language Options.**

**Note: WIC has 18 choices for language; not all are listed here.**

## NH Public Health Collection and Use of Language Data:

WIC and Family Planning collect information on the level of English competency of the service recipient. WIC and Hospital Discharge collect information on what language is preferred during health care. WIC, Medicaid, and Family Planning all collect language spoken at home. Language data can be collected in various ways: observation, asked directly, self-report on forms, self report fill-in. Medicaid allows the service recipient to self-report through a written form or phone interview. Hospital Discharge collects data from NH hospitals so the public health data is based on each of the 24 hospitals data systems, which at the time of this writing, is not a state-based universal coding practice of language for all NH hospitals. Family Planning uses a written form for the service recipient to self-report their language.

For WIC, language data is collected through observer reporting, so they do not directly ask the service recipient about language. For Family Planning and Medicaid, the data is self-reported in a written form. There are various uses for this language data for WIC, Medicaid, Family Planning and Hospital Discharge Data (Table 11).

Question	Number of respondents
<b>Of the 4 data stewards that collect language data, how is the language currently used?</b>	
A) Public Health Surveillance	1
B) In compliance with funding requirements	1
C) To describe the population you serve	1
D) For quality of care improvements	0
E) For an assessment of health disparities	1
F) To request interpreters	1
G) Not currently used	1
<b>Who is this language data made available to?</b>	
A) State Public Health Departments	2
B) Federal Public Health Departments	1
C) University or other research bodies	0
D) Payers	0

**Table 11. Uses and Users of Language Data**

## Standardization, Training, and Quality Control for Language Data:

Medicaid is the only public health data steward that has a standard way of collecting language data, but they are not sure how well it is followed.

WIC trains people at the local office to collect language data. For Hospital Discharge, the level of training is dependent on the hospital training its staff. For Family Planning it is unknown if they are trained. For Medicaid, mandatory training focuses on how to conduct the interview.

There are no reported quality controls that exist for the collection of language data from WIC, Medicaid, Family Planning or Hospital Discharge. Completeness of client language data in the public health data set is unknown for Medicaid, Family Planning and Hospital Discharge. All of WIC clients have language data.

## Other Data:

In the spirit of understanding other social determinants of health, the survey also evaluated how data collection systems are capturing information about socio-economic factors beyond race, ethnicity, and language.

### ***Data Collected for Children:***

Most of the data stewards collect some information about children. The Cancer Registry, WIC, Hospital Discharge, Behavioral Health, YRBS, Childhood Lead Program, Birth Conditions, Medicaid, Population Estimates, and Communicable Disease all collect race, ethnicity and language data about children (Table 12). WIC contains information about parent’s race and ethnicity. Birth Conditions and Population Estimates collect information about the mother’s race. Medicaid collects information about parent’s race and ethnicity, education, and language. Childhood Lead collects information about the parent’s language.

<b>Question</b>	<b>Number of respondents that indicated that they collect</b>
<b>Is Race/Ethnicity/Language data collected about children?</b>	12
<b>What information is collected about children/parents?</b>	
Child’s language	2
Child’s race/ethnicity	10
Parent’s education	2
Parent’s language	2
Parent’s race/ethnicity	3
Parent’s emergency contact info	1
Mother’s race/ethnicity	2

**Table 12. Data Collection about Children**

***Highest Level of Education:***

Four NH Public health data sets capture data about highest level of education: Cancer Registry, Medicaid, Population Estimates, WIC and BRFSS, and Vital Records. The Cancer Registry collects higher education information that is available in the patient medical record. Because education data is not consistently collected in the patient medical record, there is little consistency in how the collection of this data is captured in the cancer registry. WIC and Vital Records allow for an individual to select from a number of categories: less than high school, high school degree, some college and college degree. Vital Records and Medicaid also allow for an individual to fill-in if they have a graduate/professional school degree. Population Estimates use data captured in the census.

***Country of Origin:***

The Cancer Registry, Medicaid, and Population Estimates collect data about country of origin. Cancer Registry uses a large code set that is programmed in the Cancer Registry data system. Other data sets use a free text field to capture the information.

***Improving the Collection of Race, Ethnicity and Language Data:***

Data stewards were also asked what would be needed to improve the collection of race, ethnicity and language data. In order to consistently collect race, ethnicity, and language data, many of the public health data stewards indicated various resources would be required (Table 13). Many data stewards indicated that they need help getting those who actually collect the data to consistently collect it. Similarly, YRBS and Childhood Lead need training for staff.

Question	Number of respondents
<b>In order to consistently collect race, ethnicity and language data, what additional resources does your organization need?</b>	
Increased Staff	6
Technology	5
Training	5
National/State Standards	4
Funding	3
None	3
Making sure hospitals collect the data at the source	2

**Table 13. Resources needed to consistently collect R/E/L data**

**Challenges:**

During the course of the interviews with the NH public health data stewards, each of them speculated about the challenges that they might face if they had to implement new methods to collect race, ethnicity, and language data (Table 14). AHEDD anticipates that it would be difficult to collect additional information from the hospitals because the MOUs with the hospitals specify a limited number of data elements for the AHEDD data feed. Behavioral Health, YRBS, Childhood Lead and Perinatal Client Data indicated that they anticipate resistance from clients to collection of race, ethnicity, and language data. The data steward from YRBS indicated that 92.9% of all NH middle and high school students are white, so there may be little support for the collection of race and ethnicity.

Population Estimates added that there would be not only resistance, but also difficulty in collecting accurate numbers with the non-white population being such a small proportion of the population. Behavioral Health anticipates staff resistance, lack of appropriate technology, decrease in time dedicated to other activities, and inadequate training to implement data collection.

Perinatal Client Data and Medicaid expressed concern about not having enough staff resources for collection of the data. Birth Conditions anticipates problems being able to collect this data without any changes to the Birth Certificate or changes in the medical charts; new state and federal requirements need to be in place. Family Planning fears they will not have the appropriate technology or training and that it will pull them away from other important activities.

## Conclusions:

Title VI of the Office of Civil Rights “prohibits discrimination on the basis of race, color or national origin in all programs or activities that receive federal financial assistance.”<sup>x</sup> An effective way to monitor discrimination is through the collection of race, ethnicity, and language data.

As evidenced in the survey about public health data collection, most of the public health data stewards in New Hampshire reported that they have implemented the OMB guidelines for the collection of race and ethnicity data. Unfortunately, OMB represents a minimum requirement, and many public health data sets do not go beyond this to capture data about specific ethnicities and language in the populations that they serve.

While code sets exist for ethnicity and language, the national or international codification may be too cumbersome for implementation at the state or local level. For example, International Standards Organization has a code set of 564 language codes in the standard language code set, 639-2<sup>xi</sup>. However, many of the NH public health data stewards indicated that they would like guidance on the implementation of a standard code set for the collection of ethnicities and languages.

In Massachusetts, the Executive Office of Health and Human Services has proscribed the collection of granular ethnicities for its public health agencies. There are over 30 ethnicity codes for the ethnicity field for each of its public health data sets.

Only 20% (4 out of 19) of the NH public health data stewards surveyed collect language data. Without information about the languages of the population, the public health systems will not only find it increasingly difficult to serve the needs of the population, but also provide public health materials in appropriate languages. In addition, language may play a contributing role in health disparities and/or equity. There is the potential to connect the data collection efforts with DHHS’s Communication Access Plan.

There may be some procedural challenges to changing the way race, ethnicity and language data is currently collected in the public health data sets. For example, some data sets require change of administrative rules or legislation in order to change the procedure for data collection. See Appendix B for a complete list of challenges for each of the data sets and description of process and/or contact for how to make a change.

Surveys face particular challenges when it comes to the collection of race, ethnicity, and language data in that, by design, the survey is intended to capture information about a *sample* of the population. In the case of NH, approximately 6,000 surveys are typically completed each year. If by extension, 10% of those surveyed were non-white, 600 of the surveys would represent non-white NH residents. But “non-white”, in terms of understanding racial or ethnic disparities, is not descriptive enough. Each race and ethnicity, if described, further splits the sample.

Attempts to capture information about subgroups of the population by survey have included oversampling of select populations. That is, sampling regions with higher proportion of a non-white population in hopes of capturing data for a larger part of the non-white population.

However, oversampling requires additional funding. In the case of the BRFSS, which is very expensive to conduct every year, oversampling in ethnically-rich geographic areas could add to the cost. Another potential issue with oversampling is having a limited population to draw from

and, essentially, potentially being unable to draw a survey sample with sufficient numbers to run analysis for the different race and ethnic subgroups of interest.

In addition to assessing *what* is collected, the data stewards provided information about *how* it is collected. Some of the public health data sets collect information from patient charts, some from other public health data sets (e.g., the Birth Certificate), and some from other sources. Many of the stewards indicated variation in the process for data collection at the source. The variability affects the completeness and quality of the data in the public health data sets. Consistent guidelines should be implemented in not only the public health data sets, but also in parallel with data sources that supply the public health data sets (e.g. hospital data systems).

Data stewards indicated that there should be more consistency in the training of those who collect the data. Many public health organizations do not provide training, and those who do have only a small section that addresses issues related to race and ethnicity. As indicated in some of the survey responses, there is some confusion about the definitions of race and ethnicity, and relevant choices for race and ethnicity. Consistent training might provide definitions for race and ethnicity, as well as education about the distinction between the two constructs. Education may help data collectors feel more comfortable asking questions about an individual's race, ethnicity or language, as well as address patient/client concerns, thereby improving the quality of the data collected.

New Hampshire data stewards also expressed concerns about the ability to collect data and explain the importance of collection of the data to the clients and patients. The country of Scotland<sup>xii</sup>, recognizing the need for consistent training, established a country wide training program for the collection of race and ethnicity data. In the United States, HRET Disparities Toolkit: A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients<sup>xiii</sup> is widely used and recommended for training purposes. It may be possible to adapt either training program or toolkit for public health data collection in New Hampshire.

From a data systems perspective, more consistent recording of race, ethnicity and language data could be facilitated through automated quality control processes in the electronic storage of the data. Many of the public health data systems use electronic tools for quality assurance and edits of the data. This is a way to ensure that the data that is submitted is complete because some electronic submissions won't allow the data to be submitted without it. With the American Recovery and Reinvestment Act's (ARRA) focus on electronic medical records, there may be the potential to invest in the creation of electronic tools that could facilitate the collection of race, ethnicity, and language data at the source, as well as in the public health data system.

Though country of origin and higher education are not prioritized by IOM, these data may be useful in describing the community of people being served and the type of services they may need. If the state were to create new guidelines for collection of race, ethnicity, or language data it may be an opportunity to explore collecting other socio-demographic data as well.

## ***Recommendations:***

Given that the collection of race, ethnicity and language data not only describes the population that is served in the state, and thus the health and health care needs of the populations served, but also is often required in order to receive federal funding, we recommend that the data collection of race, ethnicity and language be standardized in a timely but locally sensitive manner.

**RECOMMENDATION 1: The State Health Equity Plan Advisory Group should collaborate with stakeholders to define a discrete list of relevant ethnicities and languages for the state.** The State should then delineate and adopt a code set for ethnicities and languages that could be implemented universally across the NH public health data sets. Specifically, NH could use the 2010 census and other sources to assess the racial and ethnic groups that most commonly live in New Hampshire. A system to periodically update the discrete lists to reflect changing demographics should be determined as well.

**RECOMMENDATION 2: Prepare collectors of the data.** Establish NH DHHS guidelines (based on lists developed in Recommendation 1), and advocate for federal guidelines that follow the IOM recommendations, ensuring the collection of granular ethnicity, expanded race options, and language data by the NH public health data sets. These guidelines will assist the public health data stewards in their data collection processes (e.g. form and database development)

**RECOMMENDATION 3: Prepare submitters of the data.** Establish NH DHHS guidelines for the collection of race, ethnicity, and language data for hospitals and other sources that collect data for the public health agencies.

**RECOMMENDATION 4: Develop data collection and use strategy.** Provide a forum for providers and data stewards to communicate and understand importance of race, ethnicity and language data collection, and agree on how to implement the collection guidelines (listed above in Recommendation 2 and 3) and promote effective use of the data that is collected.

**RECOMMENDATION 5: Identify funding for training for public health data agencies** to ensure they can effectively collect race, ethnicity and language data (as defined in guidelines produced in Recommendation 2).

**RECOMMENDATION 6: Identify funding opportunities (e.g. American Recovery and Reinvestment Act funding) for resources to develop electronic methods for the quality assurance** of the collection of race, ethnicity, and language data. Ensure that collection includes options for “unavailable” and “declined” to monitor quality control and refusal rates.

**RECOMMENDATION 7: Consider adding level of education, literacy level, country of origin, and data about parent race, ethnicity, and language (of children) to guidelines.** Given the SDOH framework, it would be useful to do a similar assessment for other public data sets – education, labor, and criminal or juvenile justice for example and promote a consistent set of standards across all of these public data sets so that research into the SDOH that underlie many disparities can be conducted.

**RECOMMENDATION 8: Provide clear and consistent education material to the public and service recipients (at point of service) about the collection of race, ethnicity and language data.** The educational material should include information about how the data collected may help address health disparities and health equity in the state.



## ***Appendix A***

Summary of Data Stewards' Responses to Survey Questions is available upon request.

## Appendix B

Review of applicable legislation and process for making changes to data sets:

Data Set	Challenges of Data Set	Who to Contact to Change
Population Estimates from Office of Energy and Planning (OEP)	Law 78-A:25 just requires that they estimate the population numbers, also number is an estimate from other data sources (school enrollment and building permits). Instead of collecting race, ethnicity or language data themselves they just compile info from the US census, the Cancer Registry, the Perinatal Client Data Form, Vital Records, Hospital Discharge, and BRFS	US census sets the basic guidelines that need to be followed to collect the data, OEP sets specific guidelines for what is collected and how in NH. OEP reported using Birth Certificate, BRFS, insurance records, Cancer Registry and Hospital Discharge so it would help if these data sets started collecting this information. Could also change 78-A:25 to require increased collection of granular ethnicity and race data.
Birth Certificates	Follows OMB guidelines for Mother and Father, doesn't have info regarding language or granular ethnicity for them and doesn't have any info for the baby	Department of Health and Human Services and Secretary of State. Need to include: (a) A description of the data set (b) A business plan for how it will be used (c) resources to pay for any expenditures induced (d) can't negatively affect any contracts HHS currently has
Death Certificates	National standard has OMB classification, doesn't contain information on language or granular ethnicity. New Hampshire follows the national standard.	Same as Birth Certificate
Divorce, Fetal Death, Marriage, Civil Unions		Same as Birth Certificate
Maternal and Child Health (MCH) data		
Childhood Lead Program	Don't report any race, ethnicity or language data in their annual reports and don't mention it anywhere else, don't list if they have to follow any guidelines for collection of data	Childhood Lead Poisoning Prevention Program
NH Birth Conditions	Federal report of NH UDS data includes information following OMB guidelines, plus allowing one to chose a more than one race and unreported/refused to report, also lists if the patient is best served in a language better than English, doesn't list granular ethnicity. NH didn't report the REL data in their summary report.	Overall data collected by the Health Resources and Service Administration of the Federal Government, NH MCH does a report of this data, so need to change it at a federal level
Early Hearing Detection and Intervention	Through the link to the Birth Certificate, improvements to the BC would be reflected in EHDI.	

Newborn Screening Program	Nationally list race for birth and metabolic screening, but not listed in NH reports	Nationally listed on the National Newborn Screening Information System and through New Hampshire run by Maternal and Child Health
Perinatal Client Data Form	Through the link to the Birth Certificate, improvements to the BC would be reflected in EHDl.	
Cancer Registry	Survey performed in 2003 showed only 3 out of 22 hospitals reported race and ethnicity data and 21 out of 22 identified race instead of having patients self-report, current form has Hispanic ethnicity and race (have to choose one). One of the better data sets with granular ethnicity and a large group of race options.	Based on Title X 141: B-7, the state of New Hampshire follows the standard set in the North American Association of Central Cancer Registries; Department of HHS makes the final decision
Hospital Discharge	Inpatient discharge data collection only has Race listed, not ethnicity or language	Department of Health and Human Services is in charge of this data set
Automated Hospital Emergency Department Data (AHEDD)	Currently they are unable to collect this data because their MOU restricts the form of data they can collect to the bare minimum from hospitals.	Division of Public Health Services, AHEDD Project Manager. Also, talking to hospitals about changing the MOUs
Communicable Disease	Differences for each disease that they collect based on those who collect the disease.	Per Title X Section 141-C:8 the Public Health Department Commissioner is responsible for what is on the forms used for Communicable Disease reporting, only thing that can't be listed is mental health status
Medicaid claims and Comprehensive Health Care Information System (CHIS)	According to Chapter 4000 Uniform Reporting System for Health Care Claims Data Set, Section 02: General Requirements for Data Submission, they have listed that health care claims shall have listed race (with the option to put in a second race), Hispanic ethnicity, and granular ethnicity (with option to put in a second granular ethnicity)	Title XXXVII, RSA-A:15 and RSA 420-G:14, gives the insurance commissioner the power to determine what data is collected for CHIS
Behavioral Risk Factor Surveillance System (BRFSS)	The survey is only conducted in English. The person needs to have a phone to be able to be contacted.	Overall this is run by the CDC Behavioral Science Branch, the racial and ethnic demographic data is set by the CDC but the state can add specific questions for their state, which is decided by the department of Health and Human Services (and contingent on approval from CDC Behavioral Science Branch)
Youth Risk Behavior Surveillance System (YRBS)	Only .6% of those who took it were African American and only 2.8% were Hispanic/Latino	Nationally the CDC sets the guidelines for this, but it is administered by the NH Department of Education

Behavior Health	Their sheet to document sentinel events did not include any information on race, ethnicity or language	Bureau of Behavioral Health, part of HHS (Division of Community Based Care Services is responsible for the sentinel event form), the information is collected from Behavioral Health Centers, so need them to start collecting it as well
Youth Tobacco Survey		Tobacco Prevention and Control program on New Hampshire
Healthy Smiles, Health Growth	Don't report any REL data on the data they have on-line	Dept of HHS, Obesity Prevention Program
WIC Program	National Requires a minimum of the OMB guidelines for Ethnicity and Race for the participants (mom and child), state has the option of how to input race, allowing for more than one or just one reported. Also, includes education level.	Reported on the Health and Human Services Website, doesn't indicate it is associated with another org
Family Planning Program	Nothing listed	Part of Maternal and Child Health

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- <sup>viii</sup> Weinick, R.M., J.M. Caglia, E. Friedman, and K. Flaherty. (2007). "Measuring Racial and Ethnic Health Care Disparities in Massachusetts: Lessons from Implementing a Publicly Mandated Data Collection Program." *Health Affairs*, vol. 26, no. 5, pp. 1293-1302.
- <sup>ix</sup> A copy of the survey is available upon request.
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