CHAPTER 3:

Collect Diversity Data

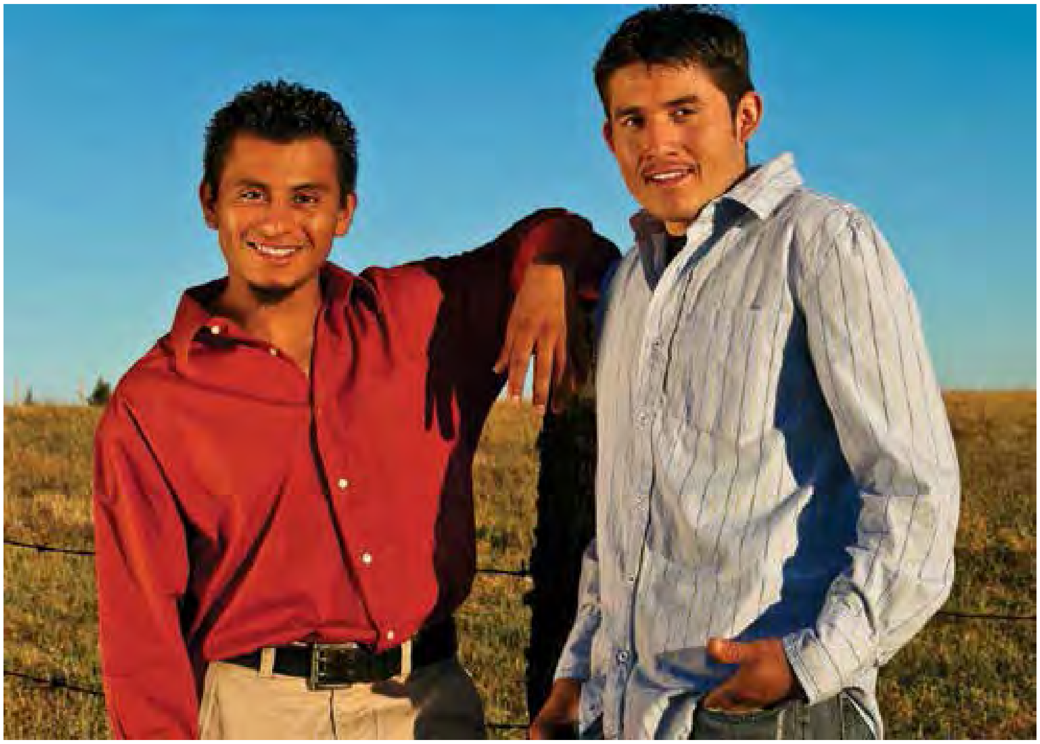
Introduction

Gathering data about the diversity in our communities is essential. In fact, data collection is where the cultural competence cycle begins and ends. Data begins the cycle by helping providers better understand and serve clients. It closes the cycle by providing a reflection of progress and areas for improvement.

Collecting data on race, ethnicity and language, as well as other markers of diversity like disability or socioeconomic status and sexual orientation, not only allows agencies to meet federal or state requirements, but can also help programs identify and prioritize needs, such as cultural competence skills.

Data are essential to understanding client needs, planning health services, identifying disparities and benchmarking.

Chapter 3 presents tools to assist agencies in the process of collecting diversity data. It begins with an overview of benefits and requirements. Then, it presents a sample process and tools to help agencies collect data, update systems and identify affordable resources.



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CLAS Standards Covered

Standard 11: Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery.

Standard 12: Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.

Why Collect Race, Ethnicity and Language Data?

Meet State and Federal Reporting Requirements

State and federal policies support race, ethnicity and language data collection. In fact, new federal policies encourage more detailed data collection. In Massachusetts, for example, all acute care hospitals are required to collect and report detailed race and ethnicity demographic information.[i]

Set the Foundation for Cultural Competence

Understanding clients and their needs is the starting point for cultural competence. Having REL data is often a prerequisite for meeting other CLAS requirements, like offering interpreter services, budgeting, planning and self-assessments.

Prevent and Eliminate Health Disparities

Regularly reviewing updated demographic data is key to identifying, preventing and eliminating health disparities. A 2002 study by the Institute of Medicine notes that certain biases and stereotypes are "…invisible to institutions and providers unless they constantly gather and analyze data about treatments according to the race and ethnicity of the clients."[1] Reviewing data about populations served can help providers "see" invisible biases, identify patterns of discrimination and correct them.

Become More Responsive to Cultural Preferences

Staying attentive to data can help agencies become more aware and responsive to cultural preferences and demographic changes. For example, understanding what language clients prefer to be addressed in can help improve communication.

Tailor Services to Diverse Needs

As providers gain insight into cultural issues related to care-seeking and use of services, they can better plan for new services and policies, and target efforts. Data can also help identify translation and interpretation needs.

Use Resources Cost Effectively

Having the right data facilitates planning budgets according to real needs and preventing waste.

Become More Competitive

Collecting race, ethnicity and language data can help agencies become more competitive in two ways. First, it enables them to attract more clients through services that meet client needs. Second, having updated demographic data is documented proof of efforts to meet CLAS for state Requests for Responses (RFRs) and contracts.

Data collected by Massachusetts health institutions are used to:

- Identify differences in health use and outcomes for clients of different races and ethnicities
- Develop programs to address health disparities
- Target programs and services to those in need
- Develop health care policy
- Assist with public health studies
- Identify illnesses that are more prevalent in some ethnic groups and improve treatment protocols for them

Source: Massachusetts Hospital Association (2006)[2]

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[i] *See state regulation 114.1 CMR 17.00, adopted July 2006 and updated September 2006.*

Step 1. Identify Diverse Populations

Consult a Variety of Sources

When collecting demographic data, U.S. Census or official state numbers are good sources to start with. But with a constantly changing population, these data alone may not be enough to give a full picture.

Often, gaining a detailed picture requires combining data from a variety of sources.

Work with Community Partners

Looking to the community can add dimension to data. At the community level, you can find information to make numbers come to life. Knowing, for example, how many African immigrants are in your service area is important. Knowing about their health beliefs and traditions adds a new level of depth.

The best sources of community data are often members of the community itself. Working with key members of the community can help anticipate trends. Key partners can serve as ***cultural brokers*** (see Glossary), who can help your agency gain important cultural insights. Local churches can also be good places to get the pulse of minority populations. For example, one provider sought out expertise on Mayan-Quiche women by visiting a local church that attracted many of her clients.

> *"Schools will regularly survey students to find out what languages they speak. Looking at these surveys has given us a good sense of what languages the families in our neighborhoods are speaking at home, and what countries they come from."*
>
> ***– A Boston public health professional***

TOOLS

Demographic Data Sources

Consider using a variety of sources, including:

- Community sources Massachusetts Mutual Assistance Associations, faith-based organizations, professional organizations
- Local hospital utilization data of primary/preferred language of clients
- Office of Refugee and Immigrant Health **http://www.mass.gov/refugee**
- Massachusetts Immigrant Refugee Advocacy Coalition (MIRA) **http://www.miracoalition.org**
- Massachusetts Department of Education and First Language Is Not English (FLNE) and Limited English Proficiency (LEP) surveys (analyzed by MDPH) **http:/www.profiles.doe.mass.edu**
- Municipal Boards of Health
- Massachusetts Division of Medical Assistance data
- Massachusetts Community Health Information Profile (MassCHIP) **http://mass.gov/dph/masschip**
- U.S. Census data of your service area **http://www.census.gov**

TOOLS

Tool 3.4: Data Sources

Chapter 2: Build Community Partnerships

Step 2. Develop a Standard Process

While data collection may vary from one public health agency to another, the purpose of collecting the information is the same: to identify disparities and barriers to access, monitor services, identify and prevent discrimination, and improve client care.

Define an Overall Approach

There is no one-size-fits-all way to collect data. There are, however, principles that can make for a smoother process. This chapter compiles helpful information from the Massachusetts Department of Public Health, the Massachusetts Hospital Association, the Cambridge Health Alliance and the Health Research and Evaluation Trust.[3]

This information can help you develop an approach that meets the needs of your agency, that uses consistent processes, and incorporates REL data collection into your daily operations. This will ensure you have information available when you need it, for example, when you are submitting paperwork for a contract, planning budgets, or developing new programs.

Develop a Standard Process

A consistent, step-by-step approach will allow you to gather correct information, organize it and analyze it according to your needs. The goal is to develop a process simple enough that everyone involved can consistently carry out.

As you plan for data collection, ask: When will you collect the data? Who will collect the data? What will you tell clients? How will you address confidentiality? How will you collect the data? What information will you collect? What tools will you use to collect and store information? And, how will you train staff?

GUIDE

A Process for Collecting REL Data

When?	Ask for data on race, ethnicity, preferred language, disability status, income, gender and sexual orientation early on, ideally during admission or client registration.
Who?	Admissions or reception staff should collect data.
What will you tell clients?	Address concerns up front and clearly. Develop a script to tell clients: ■ This information is important (explain why). ■ We will use it to improve care and services and to prevent discrimination. ■ Your information will be kept confidential.
How?	Clients self-report—select their own race, ethnicity preferred language, disability status, income, gender and sexual orientation.
What information will you collect?	Start with the MDPH categories (see Tool 3.2), and add your own according to needs.
Tools to collect and store data	Use standard collection instruments. Store data in a standard electronic format.
Training	Provide ongoing data training and evaluation to staff.

Adapted from the Health Research and Evaluation Trust Health Disparities Toolkit [3]

When should you ask for client data? The goal is to get the information early in your encounter with a client. Ideally, ask prior to an appointment or during phone registration. If you can't get the information at that point, try to do it as soon as possible after an appointment.

Who will collect client information? This will depend on the size and needs of your organization. Because they are the first to see clients, it helps to have front line staff (like receptionists) collect the information.

What will you tell clients? Many clients, especially those of different backgrounds, may be concerned when you ask questions about their race, disability status or sexual orientation. Be sensitive to concerns and explain why you are collecting data and how you will use it.

Research shows that once they understand the purpose of questions, most clients are happy to cooperate. Massachusetts' surveys show that most patients believe it is important for hospitals and clinics to collect information from patients about their racial and ethnic backgrounds.[6]

Before you ask for any information, tell clients:

- Data will NOT be used to discriminate against clients.
- Data WILL be used to identify inconsistencies in service.
- Data WILL be used to ensure that all clients receive the highest quality care and services.
- Information WILL be kept confidential and participation is voluntary.

How will you address confidentiality?

Specific guidelines[ii] regulate the collection of data on race, ethnicity, language and disability status. Federal civil rights (Title VI) law and malpractice liability laws favor the collection and analysis of race and ethnicity data as a way to[4]:

- Improve the quality of health programs and services
- Analyze how well health providers meet the needs of diverse populations
- Take affirmative steps to overcome and prevent discrimination
- Demonstrate how organizations prevent and remedy discrimination

The Health Insurance Portability and Accountability Act (HIPAA) is concerned primarily with disclosure—what happens with client information once it has been collected. Having information about clients' racial and ethnic background requires sensitive and responsible handling. Agencies must ensure that information is kept confidential and is never used to discriminate.

How will you collect information?

The Massachusetts Department of Public Health recommends using the "self-report" data collection method. Self-report means each client has the opportunity to choose from several categories. Because it reflects how clients describe themselves, self-reporting is the most consistent and valid source of information. Other methods, like data collection by proxy or observation are more prone to errors and often involve guesswork.

Use an introductory statement explaining why you are collecting information and how it will be used. Offer clients a minimum of five race categories plus the Hispanic/Latino ethnicity category. Clients should be able to choose more than one category. They should also have the option not to answer if they so choose ("declined/unavailable" option).

LAWS

Massachusetts Information Collection Requirements

The Massachusetts Department of Public Health and its contracted agencies have authorization to collect data for public health surveillance, planning, research, program development and evaluation, setting strategic priorities, evaluating the impact of outreach and messages on different populations, evaluating the efficacy of programs, and addressing health disparities.

Massachusetts' guidelines[ii] require agencies to ensure that client data will be kept confidential and that it will not be used to discriminate.

If agencies are to collect data, including race, cultural origin and ethnicity, for purposes other than those authorized for MDPH, agencies must obtain permission from proper state authorities and must offer proof that such information will be used in good faith and for a proper purpose. Agencies must detail the purposes for additional use of the data.

[ii] *Massachusetts Executive Order 478: Order Regarding Non-Discrimination, Diversity, Equal Opportunity and Affirmative Action, Section 6*

LAWS

See **Appendix B: Overview of Laws**

TOOLS

See **Tool 3.1: Explaining the Data Collection Process**

What information will you collect? Data categories, simply put, are the kinds of information asked for. Age, race, gender and income are examples of data categories. Being consistent in the kinds of data collected makes it easier to compare and analyze those data in the future.

It helps to put questions in a standard script, such as the one found in Tool 3.1.

Begin by selecting data categories required and recommended by the U.S. Department of Health and Human Services (HHS) and the Massachusetts Department of Public Health (MDPH) (see Tool 3.2). While HHS guidelines require only the collection of five categories, recommended optional data fields include religion, mobility needs, sexual orientation, gender identity, and socioeconomic measures like education, income, occupation, family size and relationships.

Collecting data by these categories can help to quantify and identify disparities across diverse groups. See the chart on the next page for category ideas.

> *"Gathering data about our clients' ethnic backgrounds has been really important for us. We have a lot of clients from African countries that are of the same race but have very different ethnicities. If you only ask for race and don't ask for ethnicity, you don't get the full picture."*
>
> ***– A Worcester public health professional***

LAWS

Federal Data Collection Guidelines

The HHS Office of Minority Health and Section 4302 of the Affordable Care Act require that all national data collection efforts include information on:

- Race
- Ethnicity
- Sex
- Primary language
- Disability status

HHS-recommended optional data fields include:

- Religion
- Mobility needs
- Sexual orientation
- Gender identity and expression
- Education
- Income
- Occupation
- Family size and relationships

Sources: U.S. Department of Health & Human Services, 2011; Affordable Care Act, 2010; The National Committee on Vital Health Statistics, 2012; The Joint Commission, 2010.

LAWS

Massachusetts Department of Public Health Data Collection Standards[9]

- Encourage clients to self-report in the registration process.
- Allow for the selection of multiple race categories.
- Collect information on detailed ethnicity groups as well as broad race categories.
- Maintain consistency with Federal Office of Management and Budget (OMB) standards: **http://www.hhs.gov/ocr/civilrights/resources/specialtopics/lep**

Race, Ethnicity and Language

Race, ethnicity and language are key categories when collecting client data. Race refers to physical characteristics, while ethnicity gives further explanation on heritage and nationality. A client's primary language informs you of how he or she prefers to communicate and when to offer interpreter services, forms and materials in a language other than English.

Disability, Sexual Orientation and Socioeconomic Status Data

Section 4302 of the 2010 Affordable Care Act includes, in addition to race, ethnicity and language, the collection of data on disability status.[10] Since 2011, HHS has collected sexual orientation data in its population surveys and has recommended that questions on sexual orientation and gender identity be incorporated into the National Health Interview Survey and other federal data collection efforts.[11]

In 2012, the National Committee on Vital Health Statistics recommended that data on socioeconomic status be collected across all racial and ethnic populations and socioeconomic groups.

***Race** is defined as the groups that you identify with as having similar physical characteristics or similar social and geographic origins.*

***Ethnicity** refers to your background, heritage, culture, ancestry, or sometimes the country where you or your family were born.*

Sample categories for data collection:

Client Data
- Race
- Ethnicity
- Nationality
- Preferred spoken / written language
- Age
- Literacy needs
- Disability status
- Gender or gender identity
- Sexual orientation
- Income
- Education
- Occupation
- Family size and relationships
- Informed of / use of interpreter services
- Treatment and medical history
- Outcome data
- Client satisfaction

Staff Data
- Race
- Ethnicity
- Nationality
- Primary/preferred language
- Gender or gender identity
- Sexual orientation
- Records of cultural competency training participation and evaluations

Sources: HHS Office of Minority Health, Boston Public Health Commission Hospital Working Group Report, Technical Assistance Partnership for Child and Mental Health [7]

TOOLS

See:

Tool 3.2: MDPH Detailed Ethnicity Categories

Tool 3.3: MDPH Preferred Data Collection Instrument

What tools and systems will you use to collect and store data?

To ensure the accuracy of data collection, it helps to use instruments (client forms, surveys, etc.) and information systems that conform to new guidelines.

In its HRET Disparities Toolkit[8], the Health Research Education Trust suggests that data collection instruments should include:

- A rationale for why the client is being asked to provide race, ethnicity and language information
- A script for staff to use each time so that they ask questions in a uniform way
- A method allowing clients to self-identify their race, ethnicity and language
- A standardized approach to "fit" your categories with OMB categories for analytical and reporting purposes
- Assurances that the data will be held confidential and that a limited number of people will have access to the data, and a mechanism to guarantee this claim

How will you train staff?

Asking for information about race, disability status or sexual orientation in an institutional setting can be uncomfortable. Staff must be trained to ask these sensitive questions. Using a standard process, and practice, can help ease the discomfort of asking these questions.

After pilot testing its data collection programs, the Massachusetts Department of Public Health reported that "training data collectors makes them much more comfortable asking these sensitive questions since they understand the importance of the information, how it will be used, how to respond to questions, and how to overcome uncertainty and resistance."[9]

Use formal opportunities (such as new employee training, staff meetings and evaluations) as well as informal opportunities to train staff on client data collection. The Massachusetts Department of Public Health, the City of Boston and Massachusetts General Hospital offer training materials specifically for race, ethnicity and language data collection in health care settings.

> *"Updating our data collection systems was a major undertaking. We had to update our data entry system, records and forms, translate forms into different languages, and train employees on how to use the new forms and systems. It was a big project. But it helps tremendously. Now we can print and compare data on a moment's notice. It gives us a reflection of where we really are."*
>
> ***– A Worcester public health professional***

TOOLS

See:

Tool 3.5: Low Cost Data Collection Tools

Tool 3.6: Data Resources

Step 3: Integrate Client Data Collection into Frameworks

Making data collection a part of daily operations is the best way to make sure it is collected consistently. The goal is to collect client data as a standard part of client registration. If staff have to go out of their way to collect the information, they are less likely to do it.

Incorporate REL into Existing Forms, Processes and Systems

Think of ways to make race, ethnicity and language data collection part of day-to-day operations. For example, instead of creating a new form specifically for REL data, consider incorporating new categories into existing forms. Also, ask clients to report their race, ethnicity and language preferences as part of the standard registration process. As employees become familiar with new systems, use reminders, like flags or check boxes in forms.

Ensure Records "Fit" with MDPH and Other Reporting Systems

If you are adding REL categories and updating your data collection systems, keep in mind how these will appear in reports and how they will integrate with other reporting systems.

Step 4: Assess Needs and Areas for Improvement

Out of context, data have no value. For the purposes of cultural competence, REL data should be used to offer a clear sense of who your clients are and how well your agency meets their diverse needs. How you collect data is important. Even more important is how you use data once you have it.

How you collect data is important. How you use data once you have it is even more important.

Evaluate Client Satisfaction Levels

In addition to collecting demographic data, CLAS guidelines recommend evaluating client satisfaction. This can be done through surveys, focus groups and reports from staff working directly with diverse populations (e.g. interpreters, reception staff).

Benchmark

Once you begin collecting data on a regular basis, CLAS guidelines encourage using those data for evaluations, annual reports and benchmarking. Use concrete data to evaluate performance and identify areas to improve. Make plans accordingly. ***See Chapter 4 for more information on benchmarking.***

FIELD LESSONS

Field Lessons: Tracking Client Progress and Language in a Single Form

To streamline language data collection, a public health agency in Central Massachusetts tracks client progress and use of interpreter services in a single form. The client progress note has a box where providers can check off "Were interpreter services used? Interpreter used or refused?"

Compare Client Health Across Race, Ethnicity and Language

Comparing health outcomes by race, ethnicity, disability status, sexual orientation and socioeconomic status can help providers identify areas of particular health concerns as well as areas for improvement.

Identify and Prevent Health Disparities and Discrimination Trends

Adequate data on key populations can help agencies identify health disparities and potential areas of discrimination.

Budget and Plan for Programs and Services According to Needs

Developing new programs takes much time and planning. Updated, correct data can help programs allocate funds based on key client needs.

Plan for Language Services

Having information ahead of time can help providers avoid scrambling to find an interpreter. Anticipating needs with accurate data can help accurately plan for language needs.

Hire Staff that Are Reflective of Clients

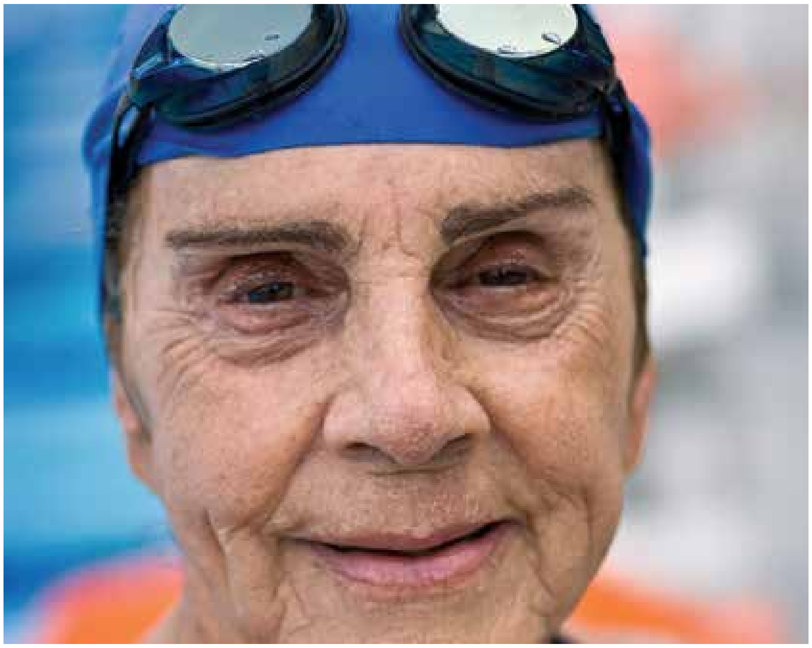
Knowing whom you serve can help you identify cultural competence skills needed in employees. Updated data can help you determine how well staff diversity and skills match the diversity of clients.

Step 5: Share CLAS-related Data

As part of a collaborative effort to end health disparities and share successes, the CLAS standards recommend sharing CLAS-related progress. You can accomplish this through social marketing, newsletters, client information materials, meetings, reports, brochures, presentations and informal exchanges with community partners. For more details on this topic, see Chapter 2.

While sharing information can have a positive impact, it is crucial to maintain client confidentiality at all times. Data shared with the community and other agencies should contain no personally identifiable information. Reports should reflect overall trends and patterns, and should never contain any information that can be linked to individuals.

As part of a collaborative effort to tend health disparities, the CLAS standards recommend sharing data on CLAS-related progress.



TOOLS

See:

Chapter 2: Build Community Partnerships

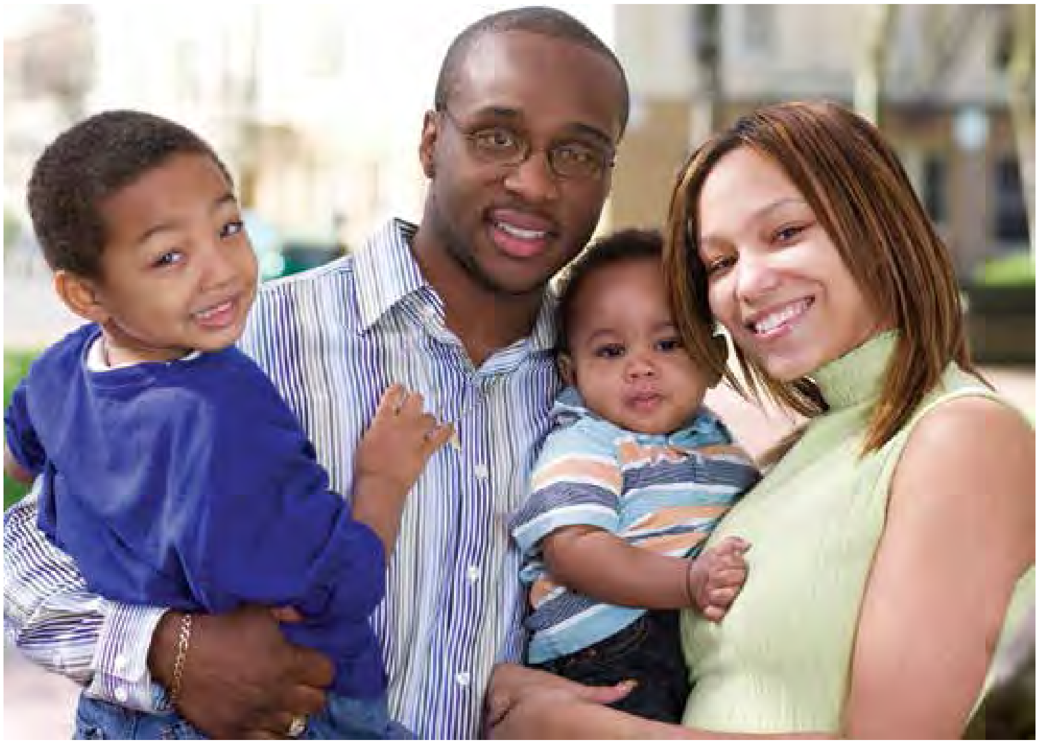
Conclusion

Following state and federal data collection guidelines requires dedicated efforts and investment. But the benefits far outweigh the costs. If your program is committed to cultural competence, data can be your ally. Gathering information about your clients' race, ethnicity, language, disability status, gender, sexual orientation and socioeconomic status should be the starting point for offering client-centered care.

Benefits of Demographic Data Collection

Having updated client data can help your program:

- Understand clients' racial, cultural and socioeconomic background
- Determine how well your staff diversity "matches" client diversity
- Compare health outcomes across race, ethnicity, language, disability status, gender, sexual orientation and socioeconomic status
- Identify health disparities and discrimination trends
- Adapt services to health- and culturally related needs
- Incorporate valuable information into staff training and evaluations
- Identify areas to improve and develop strategies to improve
- Determine what language, ASL interpretation, and adaptive communication services are needed
- Plan for programs and services according to reported needs
- Distribute funds according to needs
- Meet RFR and contract requirements



CASE STUDIES

Case Study 3: Using Data to Develop Relevant Programming

The Agency: Cambridge Prevention Coalition

Services: Community prevention activities, education, training and technical assistance services, substance abuse community forums

Client Population: White (48%), Hispanic (30%), Cape Verdean (10%), Portuguese (6%), African-American (< 4%), Asian (< 1%)

Background

The Cambridge Prevention Coalition (the Coalition) is a community-based coalition linking substance abuse prevention to a range of health promotion initiatives. The Coalition seeks to promote community health and wellness through the reduction and prevention of substance abuse. The core of the Coalition's effort is based on coordinating and promoting collaborative community prevention efforts.

Challenge

Upon receiving the Mass Call 2 Grant—a grant awarded to programs throughout Massachusetts with the purpose of reducing opiate overdoses in the community—the Coalition was given the challenge to assess services to better serve and understand their target population: opiate users in the city of Cambridge.

Approach

Finding Clues in Existing Data Sources

Gisela Rots, Director of the Coalition, and her team began the process by consulting a variety of data sources, including: MassCHIP; Drug Awareness Warning Network (DAWN) member hospital data; Pro-Ambulance data; Cambridge Police Department drug arrest and drug incident data; and Cambridge Cares About AIDS (Cambridge Cares) data collected as part of their needle exchange program.

Collecting their Own Data

Looking at existing data was only the beginning for the Coalition. The team continued their research by collecting qualitative data with interviews, surveys, and focus groups with treatment providers, opiate users and their families.

Interviews
The Coalition conducted one-on-one interviews with providers, homeless service programs, emergency room doctors, addiction specialists and treatment providers in the city of Cambridge.

Surveys
Rots and her team worked closely with Cambridge Cares, providers and community partners to develop, test, and distribute a survey for opiate users.

Focus Groups
To complete the picture, the Coalition spoke with families of users, both in focus groups and one-on-one interviews. This offered family members an opportunity to tell their stories and discuss factors contributing to opiate use. It also provided a forum to share ideas and suggestions for improvements.

> *"It's important to look at cultural competence with a wide lens. The usual demographic data is important, but I think we need to go beyond that. Collecting data is broader than just gathering racial and linguistic information—it's about getting to the true culture and motivations of the people."*
>
> *– Gisela Rots, Director, Cambridge Prevention Coalition*

Case Study 3: Using Data to Develop Relevant Programming (cont.)

Going Beyond Demographics

The Coalition's research explored key issues around opiate overdose, prevention and contributing factors. One very interesting point, according to Rots, was asking opiate users what helped prevent future opiate overdoses. "Most of the respondents gave very similar responses. In fact, their suggestions alluded to a program that was already being funded. This was very positive because it confirmed that our money was going into a program that mattered to our clients," Rots said.

Identifying Targets

As the Coalition grouped and organized data from different sources, they were able to confirm their target population for the opiate prevention program.

Using Data to Focus on the Right Population

According to Rots, "having updated data about our target population has offered us clear benefits. The information we have collected gives us a focus—it allows us to confidently focus on a population and **know that we are reaching out to the right population.** It has also added legitimacy to our program in the eyes of the community."

Bringing Clients to the Table to Stay Informed

Gathering data in the community has offered a number of unexpected benefits for the Coalition. In particular, connections were made with opiate users' family members, who have since become involved as advisory members. "It's so much more interesting to have them at the table," Rots says. "Besides getting buy-in from clients and their families, it just makes the work so much more interesting."

> *"It's so important to understand your target population. Without data, you won't be able to provide services that are accepted by your population—or you may provide the wrong services. Without data, you may be spending your funds to create programs that are irrelevant.*
>
> ***– Gisela Rots, Director, Cambridge Prevention Coalition***

Chapter 3 Checklist: Collect Diversity Data

This checklist includes suggested ways for programs to improve cultural competence. See *Appendix A: CLAS Self-Assessment Tool* for measures used by MDPH in contract monitoring and RFRs. See also: *DPH REL Data Collection Standards*, http://www.mass.gov/eohhs/docs/dph/health-equity/race-ethnicity-language-data.pdf

Step 1. Identify Populations Served

- ○ Updated demographic data are collected regularly from a variety of state and federal sources, community-based organizations, refugee assistance services, FLNE surveys, MassCHIP, etc.

Step 2. Develop a Standard Process

- ○ A standardized process exists for data collection, specifying who collects data, when data are collected, what categories are used, where data are stored, how client concerns are addressed, and how staff are trained.
- ○ Forms explain the purpose and intended use of data, assure that data will be kept confidential and allow clients to self-identify REL, disability status, gender, sexual orientation, income and other categories.
- ○ A data collection script exists detailing how staff can ask questions about race, ethnicity, language, disability status, gender, sexual orientation and income in a uniform way.
- ○ Data categories and indicators are consistent with federal (HHS, Affordable Care Act of 2010) standards and MDPH-preferred categories.
- ○ Staff receive training on REL data collection and use of electronic systems.

Step 3. Integrate Data Collection into Frameworks

- ○ Data on REL, disability status, gender, sexual orientation and income is collected as part of regular client procedures (e.g., intake).
- ○ Electronic client records contain REL, disability status, gender, sexual orientation and socioeconomic status data categories.
- ○ Client forms include questions on REL, interpreter services, disability status, gender, sexual orientation and socioeconomic status.

Step 4. Assess Needs and Areas for Improvement

- ○ Client satisfaction surveys and focus groups are conducted.
- ○ Annual reviews and reports incorporate REL, disability status, gender, sexual orientation, and socioeconomic status data.
- ○ Data are compared across categories to identify disparities or discrimination.
- ○ A plan exists to track progress in decreasing disparities identified by clinical indicators, client satisfaction and quality improvement activities.

Step 5. Share CLAS-related Data

- ○ Reports of relevant data are shared at staff, board, planning and evaluation meetings.
- ○ Appropriate data are shared with other health agencies, community organizations and the public through printed materials, e-mail, social marketing initiatives, presentations, meetings, staff meetings, and other dissemination methods.
- ○ Notices of available information are made to the public.

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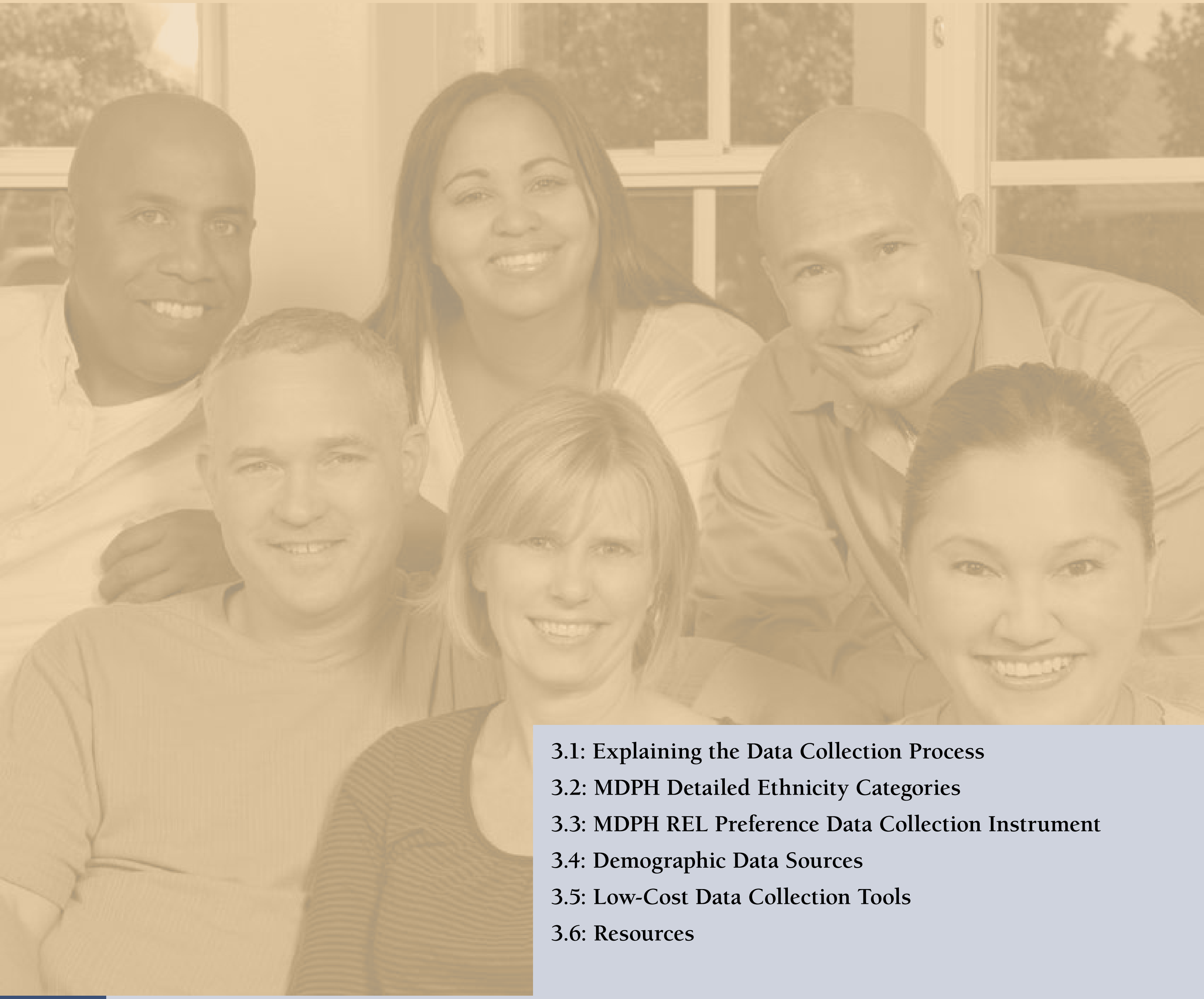
12. U.S. Department of Health and Human Services: National Committee on Vital and Health Statistics. 2012. Development of standards for the collection of socioeconomic status in health surveys conducted by the Department of Health and Human Services. National Committee on Vital Health Statistics. http://ncvhs.hhs.gov/120622lt.pdf

CHAPTER 3: Collect Diversity Data

Tools



3.1: Explaining the Data Collection Process
3.2: MDPH Detailed Ethnicity Categories
3.3: MDPH REL Preference Data Collection Instrument
3.4: Demographic Data Sources
3.5: Low-Cost Data Collection Tools
3.6: Resources

TOOLS

Tool 3.1: Explaining the Data Collection Process to Clients

Asking clients for information about race, disability status and sexual orientation requires skill and sensitivity. It is critical that staff receive training on appropriate protocols for collecting data. The following script can serve as a model.

Before asking for any information, tell clients:

- We are collecting data on race, ethnicity, disability, socioeconomic status, gender and sexual orientation for all clients.
- We need this information to improve the care we offer all clients.
- This information will be kept private and only be used to meet the needs of all clients we serve.
- We will NOT use this information to discriminate against clients.

A sample introductory statement could look like the following:

"We want to make sure that all our clients get the best care we can offer regardless of their racial, cultural background, income level, gender, sexual orientation or disability status. We are collecting this information so we can review the services all clients receive and make sure everyone gets the highest quality of care. The collection of this information is confidential and voluntary. It will never be used to discriminate or affect the way we provide services."

If a client asks, "Why?" Explain:

- We are collecting this information from all clients. This will help us to see differences in health among different populations.
- We can reduce those differences by making sure that all clients receive the same quality of care.
- Collecting this information is legal according to federal and state laws. The Affordable Care Act of 2010 and Massachusetts state regulations require health service providers to collect this information. We have obtained permission from state officials to collect this information.
- This information will only be used to meet the needs of clients.
- We will not share this information with Immigration Services.

If a client asks about privacy, tell him or her:

- Your privacy is protected.
- Would you like a copy of our privacy statement?

Tool 3.1: Explaining the Data Collection Process to Clients (cont.)

If a client asks, “What is ethnicity?” Use the following definition.

Ethnicity refers to your background, heritage, culture, ancestry or sometimes the country where you were born. You can tell me more than one.

If a client responds, “I’m multiethnic,” explain:

We can record as many categories as you need to describe yourself. Please tell me all of your ethnicities.

If the client cannot describe his or her ethnicity, give more detail.

For ethnicity, please let us know if you are Haitian, Vietnamese, Brazilian, etc. You can tell me in your own words and I will record your response.

If a client asks, “What is meant by Hispanic, Latino or Spanish?”

Explain: A person is Hispanic, Latino or Spanish if they or their family originally come from a country in Latin America or another Spanish-speaking country.

If a client asks, “What is race?” Use the following definition:

Race is the group or groups that you identify with as having similar physical characteristics or similar social and geographic origins. You can tell me more than one.

If the client cannot describe his or her race, give examples.

For race, please let us know if you are Asian, black, white, etc.
You can tell me in your own words and I will record your response.

If the client responds, “I’m multiracial,” say:

We can record as many categories as you need to describe yourself. Please tell me all of your races.

Use the following questions to ask about primary language:

- What is the primary language spoken in your home?
- In what language do you prefer to discuss health-related concerns?
- In what language do you prefer to read health-related materials?
- Have you requested an interpreter if one is needed?

Tool 3.1: Explaining the Data Collection Process to Clients (cont.)

If the client thinks the answers are obvious, explain:

I understand that you may think that the answers are obvious. I have to ask every patient. It is really important that we record your response.

If the client refuses, reassure him or her and explain confidentiality and purpose:

I understand that these questions may be sensitive. We are required to ask all clients. This information will be kept private and will only be used to improve the care we provide to all clients.

If the client still refuses...

That is okay. You have the right to not answer these questions.

If the clients gets upset, say:

I will call my manager.

If the client wants more information:

Here is a pamphlet explaining more about why we are collecting this information and how it can be used to better meet the needs of communities we serve.

From: *"Reporting Race, Ethnicity and Language: A Guide to Helping Patients," developed by Massachusetts hospital communities through the Massachusetts Hospital Association.*

Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006)

Ethnicity Categories	**Subcategories and Supplemental Code Set**
Cuban 2182-4	
Dominican 2184-0	
Mexican, Mexican American, Chicano 2148-5	Mexican American 2149-3, Mexicano 2150-1, Chicano 2151 – 9 , La Raza 2152-7, Mexican American Indian 2153-5
Puerto Rican 2180-8	
Salvadoran 2161-8	
Central American (Other) 2155-0	Costa Rican 2156-8, Nicaraguan 2159-2, Panamanian 2160-0, Central American Indian 2162-6, Belize
South American (Other) 2165-9	Argentinean 2166-7, Bolivian 2167-5, Chilean 2168-3 Ecuadorian 2170-9, Paraguayan 2171-7, Peruvian 2172-5, Uruguayan 2173-3, Venezuelan 2174-1, South American Indian 2175-8, Criollo 2176-6, Guyana

Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006) (cont.)

African 2060-2	Botswanan 2061-0, Ethiopian 2062-8, Liberia 2063-6, Namibian 2064-4, Nigerian 2065-1, Zairean 2066-9 African also includes: Angola, Benin, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Djibouti, Egypt, Equatorial Guinea, Eritrea, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Libya, Madagascar, Malawi, Mali, Mauritania, Mauritius, Morocco, Mozambique, Niger, Reunion, Rwanda, Sao Tome & Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Tunisia, Uganda, Western Sahara, Zambia, and Zimbabwe
African American 2058-6	
American AMERCN	
Asian 2028-9	Bangladeshi 2030-5, Bhutanese 2031-3, Burmese 2032-1, Hmong 2037-0, Iwo Jiman 2048-7, Indonesian 2038-8 Madagascar 2052-9, Malaysian 2042-0, Maldivian 2049-5, Nepalese 2050-3, Okinawan 2043-8, Pakistani 2044-6, Singaporean 2051-1, Sri Lankan 2045-3, Taiwanese 2035-4, Thai 2046-1
Asian Indian 2029-7	
Brazilian BRAZIL	
Cambodian 2033-9	
Cape Verdean CVERDN	
Caribbean Island CARIB	Barbadian 2068-5, Dominica Islander 2070-1, Jamaican 2072-7, Trinidadian 2074-3, Tobagoan 2073-5, West Indian 2075-0
Chinese 2034-7	
Columbian 2169-1	

Tool 3.2: MDPH Detailed Ethnicity Categories and Supplemental Code Set (December 2006) (cont.)

European 2108-9	English 2110-5, French 2111-3, German 2112-1, Irish 2113-9, Italian 2114-7, Scottish 2116-2, Greek GRK, Spanish SPAN, Armenian 2109-7, Polish 2115-4 Albanian ALBA, Azerbijan AZER, Belarus BELA, Bosnia and Herzegovina BOSHER, Bulgaria BULG, Croatia CRO, Czech Republic CZECH, Estonia EST, Georgia GEOR, Hungary HUNG, Latvia LAT, Lithuania LITH, Moldova MOLD, Macedonia MACD, Montenegro MONT, Romania ROM, Serbia SERB, Slovakia SLOVK, Slovenia SLOVE, and Ukraine UKR
Filipino 2036-2	
Guatemalan 2157-6	
Haitian 2071-9	
Honduran 2158-4	
Japanese 2039-6	
Korean 2040-4	
Laotian 2041-2	
Middle Eastern or North African 2118-8	Assyian 2119-6, Egyptian 2120-4, Iranian 2121-2, Iraqi 2122-0, Lebanese 2123-8, Palestinian 2124-6, Syrian 2125-3, Afghanistani 2126-1, Israeli 2127-9 Middle Eastern also includes: Algerian, Jordan, Kuwait, Oman, Qatar, Saudi Arabia, Sudanese, United Arab Emirates, and Yemen
Portuguese PORTUG	Azorean, Canarian 2145-1
Russian RUSSIA	
Vietnamese 2047-9	
Other OTHER	
Unknown/ not specified UNKNOW	

Tool 3.3: MDPH Race, Ethnicity and Language Preference Data Collection Instrument

Introduction

In order to guarantee that all clients receive the highest quality of care and to ensure the best services possible, we are collecting data on race and ethnicity. Could you please select the category or categories that best describes your background?

1. What is your ethnicity? (You can specify one or more)

○ African (specify_______________)
○ African-American
○ American
○ Asian Indian
○ Brazilian
○ Cambodian
○ Cape Verdean
○ Caribbean Islander (specify_________)
○ Chinese
○ Colombian
○ Cuban
○ Dominican
○ European
○ Filipino
○ Guatemalan
○ Haitian
○ Honduran
○ Japanese
○ Korean
○ Laotian
○ Mexican, Mexican-American, Chicano
○ Middle Eastern (specify_________)
○ Portuguese
○ Puerto Rican
○ Russian
○ Salvadoran
○ Vietnamese
○ Other (specify_________________)
○ Unknown/not specified

2. What is your race? (You can specify one or more)

○ American Indian/Alaska Native (specify tribal nation______________________)
○ Asian
○ Black
○ Hispanic/Latino/Black
○ Hispanic/Latino/White
○ Hispanic/Latino/other
○ Native Hawaiian or other Pacific Islander (specify_________________________)
○ White
○ Other (specify_________________________)
○ Unknown/not specified

3. What language do you prefer to speak with us about health?

○ English
○ Spanish
○ Portuguese
○ Cape Verdean Creole
○ Haitian Creole
○ Khmer
○ Vietnamese
○ Somali
○ Arabic
○ Albanian
○ Chinese (specify dialect____________)
○ Russian
○ Other (specify_____________)

4. What language do you prefer to read health-related materials?

____

For updates, and an alternative form, visit ***http://www.mass.gov/eohhs/docs/dphhealth-equity/race-ethnicity-language-data.pdf***

TOOLS

Tool 3.4: Demographic Data Sources

Massachusetts Sources for REL Data

- **Local hospital utilization data** of the primary/preferred languages of patients using the hospital.
- **Community input:** Input from a community advisory board, consultants and key informants from community-based organizations and/or community meetings.
- **Massachusetts Mutual Assistance Associations,** self-help agencies for newcomer communities, can provide useful information on the most recently arrived populations. A PDF directory of Massachusetts MAAs is available from **http://www.mass.gov/eohhs/consumer/specific-populations/refugees-asylees/maa.html**
- General information from the **Massachusetts Immigrant and Refugee Advocacy Coalition (MIRA),** a statewide coalition of grassroots immigrant organizations. **http://www.miracoalition.org**
- **"First Language is Not English" (FLNE) and Limited English Proficiency (LEP) surveys** of the public school system analyzed by the Department of Education and compiled by the MDPH Office for Refugee and Immigrant Health. **http://profiles.doe.mass.edu**
- Information collected by municipal **Boards of Health.**
- **Massachusetts Division of Medical Assistance** data on self-reported, preferred, spoken and written language preferences of MassHealth Benefit Request/Children's Medical Security Plan applicants.
- **Massachusetts Community Health Information Profile (MassCHIP)** and a broader array of publications which include ethnic/racial group data and special reports on specific ethnic/racial groups. **http://www.mass.gov/dph/masschip**
- **MDPH's Divison of Research and Epidemiology** offers links to Massachusetts population health statistics including birth data, death data, Healthy People 2010 Leading Health Indicators, population information, race and ethnicity reports, Regional Health Status Indicators Reports, Smoking Reports and Women's Health. **http://www.mass.gov/dph/repi**
- **U.S. Census data** of your service area. **http://quickfacts.census.gov/qfd/states/25000.html**

Tool 3.4: Demographic Data Sources (cont.)

Sources of Disability, LGBT, Literacy, REL and Socioeconomic Status Data

Centers for Disease Control and Prevention (CDC)
http://www.cdc.gov

Disability and Health Data System (DHDS)
http://www.cdc.gov/ncbddd/disabilityandhealth/dhds.html

HHS Health Resources and Services Administration Bureau of Primary Health Care
http://datawarehouse.hrsa.gov

LGBT Data
http://www.lgbtdata.com
A no-cost, open access clearinghouse for the collection of sexual orientation and gender identity data and measures.

Migration Information Source
http://www.migrationinformation.org
Global and U.S. data on migration, country and population profiles.

Modern Language Association (MLA) Language Map
http://www.mla.org
Displays the locations and numbers of speakers of the thirty languages most commonly spoken in the U.S.

National Assessment of Adult Health Literacy (NAAL)
http://www.nces.ed.gov/naal

National Institutes of Health (NIH)
http://www.nih.gov

Occupational Safety and Health Administration of DOL (OSHA):
http://www.osha.gov

U.S. Department of Education (DOE)
http://www.ed.gov

U.S. Department of Health and Human Services (HHS)
http://www.hhs.gov

U.S. Department of Housing and Urban Development (HUD)
http://www.hud.gov

U.S. Department of Labor (DOL)
http://www.dol.gov

The U.S. Environmental Protection Agency (EPA)
http://www.epa.gov

Tool 3.5: Low-Cost Data Collection Tools

Chronic Disease Electronic Management User Network (CDEMS)

CDEMS is a software application developed by the Washington State Diabetes Prevention and Control Program in 2002. This Microsoft Access database application is designed to help medical providers and managers in tracking the care of patients with chronic health conditions. The application allows users to define tracking measures for any chronic health condition. The CDEMS resource offers links to resources including a data entry guide, a reports guide and an electronic lab interface guide.

Epi Info

http://www.cdc.gov/epiinfo

With Epi Info and a personal computer, public health and medical professionals can rapidly develop a questionnaire or form, customize the data entry process, and enter and analyze data. Epidemiologic statistics, tables, graphs and maps are produced with simple commands such as READ, FREQ, LIST, TABLES, GRAPH and MAP.

Massachusetts Hospital Association Training Resources

http://www.mhalink.org/Content/NavigationMenu/MyMHA/Resources/RaceEthnicityData

The Massachusetts Hospital Association offers a number of adaptable resources to streamline race, ethnicity and language data collection, including Frequently Asked Questions, scripts, and strategies for updating data collection systems. *Available to subscribers and members only.*

Patient Electronic Care System (PECS)

Bureau of Primary Health Care

http://www.aristos.com/pecsys_guidelines.shtml

The PECs is a software program specifically aimed at supporting the adoption of the Care Model in the care of patients with diabetes, cardiovascular disease, asthma, depression, cancer and preventive service needs. The program was designed as an easy-to-use, simple tool for information entry, retrieval and review.

Survey Monkey

http://www.surveymonkey.com

Survey Monkey is an online survey software designed to enable users to create professional online surveys quickly and easily. The software includes some free features for surveys with up to 100 responses and is also available for a monthly or annual fee.

Tool 3.6: Resources

Data Collection Guidelines and Standards

Improving Data for the LGBT Community, HHS
http://www.minorityhealth.hss.gov/templates/content.aspx?lvl=2&lvlid=209&id=9004

Standards for the Collection of Socioeconomic Status Data
National Committee on Vital Health Statistics
http://www.ncvhs.hhs.gov/120622lt.pdf
Standards for the collection of socioeconomic status in health surveys conducted by the Department of Health and Human Services.

Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status, U.S. Department of Health and Human Services
http://www.minorityhealth.hhs.gov/section4302
Standards for collection of race, ethnicity, primary language, sex and disability status required by Section 4302 of the Affordable Care Act of 2010.

Toolkits and Resources

The Current State of Health Care for People with Disabilities
National Council on Disability
http://www.ncd.gov/publications/2009/Sept302009
Includes data on health coverage and benefits, health and health disparities of persons with disabilities, as well as data collection recommendations.

Disparities Solutions Center
Massachusetts General Hospital
http://www.massgeneral.org/disparitiessolutions
The Disparities Solutions Center at Massachusetts General Hospital site offers a number of data collection resources, including:

- *Getting Started: Building a Foundation to Address Disparities through Data Collection.* A Web seminar about practical aspects of data collection.
- *Getting it Right: Navigating the Complexities of Collecting Race/Ethnicity Data.* A panel of experts answers questions about moving forward with data and related obstacles, including legal concerns and geocoding.
- *Creating Equity Reports: A Guide for Hospitals.* A how-to guide with practical information on collecting and using data to develop an equity report.

HRET Disparities Toolkit: A Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients
The Health Research and Educational Trust
http://www.hretdisparities.org
Web-based tool that provides resources for data collection. Free access with registration.

Tool 3.6: Resources for More Information (cont.)

Ethnic and Language Data Resources

Ethnologue: Languages of the World
http://www.ethnologue.com
Encyclopedic reference work cataloging the world's 6,912 known living languages; the Web edition contains all the content of the print version. Offers searches by language or country.

Ethnomed
http://www.ethnomed.org
Medical and cultural information on immigrant and refugee groups includes print, audio and video materials for providers and patients. Ethnic/cultural groups included are Amharic, Cambodian, Chinese, Eritrean, Hispanic, Oromo, Somali, Tigrean, and Vietnamese.

Hablamos Juntos
http://www.hablamosjuntos.org
A project that seeks to address language barriers in health care.

Hmong Health Education Network
http://www.hmonghealth.org
Bilingual Hmong-English site that offers information on specific health topics, traditional approaches to health and wellness, and an annotated health dictionary.

Native Web
http://www.nativeweb.org
An international, non-profit, educational organization dedicated to using telecommunications, including computer technology and the Internet, to disseminate information from and about indigenous nations, peoples and organizations around the world.