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**Pilot Study of County Data Resources
Improving the Health
of Minority Populations:
Final Report**

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Final Report: "Pilot Study of County Data Resources Improving the Health of Populations"

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EXECUTIVE SUMMARY

Description of the Project

This report summarizes the results of the Pilot Study of County Data Resources, commissioned by the New Jersey Office of Minority and Multicultural Health. The study's goal is the creation of a baseline sketch of the collection and use of race and ethnicity related data within Middlesex County at the local level of health care service provision. It assesses patterns of data collection and data tracking generated by a sample of the health care facilities that care for this county's residents. Project findings suggest a number of data collection system improvements and interventions that can lead to enhanced data quality, augmented analytic capacity and more effective program interventions for the reduction of health disparities in Middlesex County.

Summary of Methods

Before beginning the interview process in Middlesex County itself, the research team ran a small pilot test in three geographically distinct areas of the state: the Camden-Burlington County area and the cities of Newark and Jersey City. Within Middlesex County, the team conducted a total of 37 key informant interviews averaging approximately forty-five minutes in length. Interviews took place in 4 local clinics, 3 local hospitals and 3 local health departments. At least one administrator and one intake worker from each facility were invited to take part in the research process. The resulting interviews (36 in-person, 1 by phone) generated information on the codified procedures and institutionalized data collection practices represented by study participants.

The research team collected hard copies of all relevant data collection forms encountered in each health care setting. Team members assessed providers' ability to



provide verbal and written translations when asking clients for race and ethnicity related information. Issues of cultural competency and the presence of multicultural and multiracial front line staff were explored; interviewers also assessed worker and institutional awareness of racial disparities in health. Finally, six observations were conducted, two in each facility type (health department, clinic, and hospital), in order to observe procedural nuances.

Major Findings

Health Departments

Local health departments within Middlesex County have been able to turn the challenge of operating with a small staff and smaller budget into an advantage: they have been forced to turn to their home communities in order to recruit health ambassadors and clinic volunteers. These volunteers function as translators, key informants and cultural brokers, assisting the departments in identifying and meeting the needs of minority populations.

Health departments are also accustomed to providing each other with mutual aid; they emphasize collective action in problem solving, both among themselves and in conjunction with a range of different health organizations. In the absence of resources and guidance, these agencies collaborate with a range of institutions, import useful strategies and successes into multiple arenas and maintain multiple annual training sessions for their staff. They were the only providers observed to offer a consistent and frequent schedule of training activities related to cultural competency data collection and reducing disparities.

Clinics

All clinics included in the study prioritize cultural competency and continually move towards improving the provision of health care delivery for the largest segments of their minority patient populations. Like health departments, they address many of their problems by turning to community members, even hiring front line workers who share important characteristics with their patient populations. Clinics have utilized the strategy of hiring Spanish speaking staff members and individuals of Puerto Rican descent in particular.

This choice has had positive and negative results. Local Hispanics are able to provide translation services and culturally competent care as long as they are not overburdened. Problems emerge when intake workers find themselves understaffed and overwhelmed by the sheer volume of the patients seeking care. Importantly, these workers lack consistent training and cannot turn to a standardized process to guide data collection. Most importantly, for culturally specific reasons there is a strong trend for local Hispanic intake workers to feel a deep discomfort with the task of assigning clients of Hispanic background to categories of race. Thus, efforts to produce a caring, culturally sensitive staff at the local level have resulted in challenges to the collection of accurate race and ethnicity related data.

The intermittent lack of race and ethnic categorical assignment by Hispanic intake workers is virtually undetectable and could lead to serious undercounting and misclassification. To combat this, staff must be trained to follow explicit data collection procedures in a culturally sensitive manner that acknowledges the existence of their inherent discomfort, but explains and validates the data collection process. Training will make explicit the link between accurate data collection and the potential reduction of the racial disparities that staff encounter in their communities every day.

Hospitals

The combination of data collection requirements, frequently isolated data collection encounters and the absence of specific collection guidelines has created a heightened level of frustration for hospital staff. Supervisors and intake workers share this frustration and it is unclear to them why the data must be collected; they perceive that this very challenging activity is largely useless.

This environment creates the opportunity for misclassification and undercounting. The isolation of each registration worker, the frequency and brevity of the intake encounter and the opportunity to determine each individual's race and ethnicity based on each worker's prior cultural experience and personal theory of race constitute a formidable challenge for preserving data collection accuracy.



Recommended Next Steps

1. Training should be provided for all intake and supervisory staff across provider types. Modules should include a detailed explanation of why and how data is to be collected on race and ethnicity. Information provided should help clarify the relationships among and differences between race, ethnicity, country of origin and nationality. Information on OMB Directive 15 should also be provided, outlining why country of origin is utilized in clarifying Hispanic ethnicity and why this data element cannot be used to assign race. Finally, the preference for self-identification over any form or visual assessment should be explained.
2. Enhanced data collection activities are required at the local level. More coordination at the regulatory level is essential in order to ensure data accuracy and allow longitudinal measurement across provider type.
3. Upon seeking health services, each prospective patient should be provided with a detailed explanation of the policies and procedures adopted by that facility, as well as information about the questions and data requests that are required as part of the intake process within the health care facility. This information should be made available in the preferred language of the patient.
4. For low literacy populations, facilities should provide a short, continuously playing video about why race and ethnicity related data are being collected and explaining the importance of accurate documentation throughout this process. This vehicle for educating the patient population should make explicit the link between data collection and the campaign to reduce racial and ethnic disparities in health.

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Introduction

In August 2001, the New Jersey State legislature promulgated an act in an effort to address wide and persistent health disparities in the state of New Jersey. This act renamed the existing Office of Minority Health within the State Department of Health and Senior Services—now the New Jersey Office of Minority and Multicultural Health (OMMH)—and assigned the agency division additional duties. These duties include functioning as an advocate for the identification, adoption and implementation of effective measures to improve the health of racial and ethnic populations within the State and serving as a resource center for minority health information and health related data. The OMMH now assumes responsibility for the development of a clearinghouse dedicated to the organization of data on a county-by-county basis and provides grants to community-based organizations for research on the reduction of health disparities in at-risk minority populations. Finally, the office will seek to improve existing data systems by ensuring the collection of race and ethnicity-specific identifiers. These tasks are increasingly important as New Jersey, like its sister states, documents the existence of wide disparities in health between minority and non-minority groups particularly in the incidence of heart disease, stroke, cancer, diabetes, HIV/AIDS, asthma, infant mortality, mental health, substance abuse and childhood immunization rates.

Previous studies (Martin, 2001) have noted that the reporting of race and ethnicity at the local level is inadequate, leaving unanswered questions about the causes of health disparities. Given this information gap, it is difficult to track minority groups adequately, document levels of possible undercounting and develop targeted interventions for improving minority health status. In an effort to gather information on the contributory causes of health disparities in minority populations, the OMMH funded a pilot study, the purpose of which was to assess those sources of health data collected by local providers and determine the range of local data collection practices and utilization. Documentation of the formal and informal processes of routine racial and ethnic data collection can provide useful insights for improving data quality through the identification of a



standardized data format for the collection and development of uniform practices across providers. It can also inform the creation of standardized policies and practices and promote progress towards the use of consistent definitions when classifying patients. At a time when the federal government has begun to focus on the identification of the root causes of growing disparities across minority populations and the development of innovative interventions to narrow the gap, this small project is indeed timely (HHS award announcement - 11/01/02).

This study will present a sample of findings from a series of interviews with a representative group of local providers within an urban county. Investigation focused on the data collection practices of these providers and on their perceptions of the minority patients served. This collective sketch of race and ethnicity related data collection will serve as a baseline by which to guide recommendations for future interventions designed to enhance data quality. In addition, it will set the stage for future system improvements. Finally, findings from this study should orient future program efforts as well as promote effective interventions targeted to reduce racial and ethnic disparities among the minority population within the State.

Background

It is known that a complex variety of factors influence health and healthcare disparities. This complexity, coupled with the fact that disparities in care or in health outcomes are not always readily apparent to either patients or providers, increases the need for data to better understand both their extent and the circumstances under which they are likely to occur (Smedley et. al. 2002:169). Increasingly, U.S. social and political scientists and policymakers have moved towards the position that the collection of data related to race and ethnicity is necessary for the elimination of health disparities. "The collection of race and ethnic information is a critical component of any public health surveillance system used to address differences in health status among population groups." (Hahn and Stroup 1994:1). This perspective stresses that the collection of such data would allow researchers to better isolate factors that generate disparities, identify discriminatory practices, contribute to civil rights enforcement, allow for the evaluation of interventions, ensure the accountability of insurers and providers and improve service delivery (Smedley et. al. 2002:169).

Racial and Ethnic Disparities in Health Care

The health status of African-Americans, Native Americans, Hispanic Americans and other minority groups currently is and has always been unequal to that of White Americans within the United States. Despite major medical advances and numerous enhancements to the public health system in the United States that have helped to improve the health status of most Americans, African-Americans and many other minority groups continue to suffer an unequal burden of death and disease. (Silva, Whitman, Margellos et al 2001; Levine, Foster, Fullilove, et al. 2001; Cooper, Kennelly, Durazo-Arividu et al. 2001; Guest, Almgren, and Hussey. Feb 1998). Excess morbidity and lower life expectancy continues to plague minorities much more than non-minorities and this appears to be highly resistant to change. According to the literature, health care disparities within minority populations appear to reflect differences in SES, health-related risk factors and poor housing environments as well as unequal treatment and/or discrimination that creates access barriers (Mayberry 2000, Williams, 1997, LaViest 2000). The social construct of race, in combination with socioeconomic status, seems to explain some of the differences in treatment and outcome experienced by minorities as they access the health care system. However, in order to conclusively identify the factors to which these differences may be attributed, adequate data on race, ethnicity and primary language are essential.

Racial Classification

The federal government and private groups have been engaged over several years in an intensive study regarding those categories of healthcare data that should be collected and the ways in which this information should be analyzed and reported (U.S. DHHS, 1999; National Quality Forum, 2001; Perot and Youdelman, 2001). Through the commencement of activities to develop methods for ensuring reliable data collection, the U.S. government has taken the position that the collection of race and ethnicity related data is critical in efforts to measure and address observable disparities among populations (Smedley et. al. 2002:170). The evolution of the modern federal position begins in the late 1970s; until then the White-Non-white contrast was the central feature of race differentiation in the federal data collection system (Williams et. al 1994:7; Evinger, S. 1995:7). New guidelines were issued in October 1997 under the title "Standards for Maintaining, Collecting, and Presenting Federal Data on Race and

Ethnicity". This policy required agencies to offer respondents the option of choosing one or more of the following five racial categories:

- a. **American Indian or Alaskan Native**—having origins in any original peoples of North and South America and maintains tribal affiliation.
- b. **Asian**—having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent.
- c. **Black or African American**—having origins in any of the black racial groups of Africa.
- d. **Native Hawaiian or Other Pacific Islander**—having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- e. **White**—having origins in any of the original peoples of Europe, the Middle East, or North Africa.

The standards also provided for the separate collection of data on whether or not a person is of "Hispanic or Latino" origin. That category is defined as "a person of Cuban, Mexican, Puerto Rican, South and Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino." The guidelines allow a single respondent to select multiple racial categories as well as indicating "Hispanic or Latino," but they do not permit a response that asserts an ethnic heritage that is both "Hispanic or Latino" and "Not Hispanic or Latino".

The relatively recent emergence of standardized federal data collection categories and practices, if adopted by states, can create the opportunity for truly comparable data collection. In addition, their use could promote improved standards and data collection practices at the local level.

Addressing Disparities from the Federal Level

The issue of race and ethnicity related health disparities has gained a great deal of visibility and momentum at the federal level in the last three years. One outgrowth of this increase in federal focus has been the funding of new demonstrations at both the federal and state level creating specifically targeted interventions to improve health outcomes for minority groups. Another has been a recent study conducted by the Institute of Medicine (IOM) focused on the volume and type of disparities experienced by minority versus non-minority populations. The conclusion of this report suggests that more research be

conducted in the area of social categorization in order to determine its effect on clinical decision making and institutional practices.

State Level Data Collection and Disparity Reduction

At a local level, states have also been engaged in various activities focused on the reduction of racial and ethnic disparities. Data collection practices are key in assuring the adequate assessment of services provided to minority populations over time, determining minority health status and devising interventions that effectively address health gaps. Thus, many states seek to ensure the use of uniform data collection and reporting practices across health care facilities. A recent review was conducted across several states in order to identify legislation and those regulations put in place to facilitate the collection of race related data throughout hospitals, health departments and clinics. This investigation also assessed official guidelines governing the details of data collection and it examined to whom racial and ethnicity related data was routinely released. It should be noted that all states will be updating these guidelines to include new provisions established under the Health Insurance Portability and Accountability Act (HIPAA). The following is a brief synopsis of the various data collection and reporting practices established within the New York tri-state area.

New York

New York has created a centralized, state-wide healthcare system that unites the data collection and reporting practices of a wide range of medical facilities. Under this system, race and ethnicity related data is gathered and reported according to a uniform set of procedures. The system utilizes a taxonomy based on the minimum race and ethnicity categories defined by the Office of Management and Budget (OMB) and a more detailed set of race and ethnicity categories maintained by the Bureau of Census (BC). The Department of Health in New York has established two distinct divisions: one administering the Medicaid program and the other overseeing a variety of health facilities including hospitals. The latter requires that health care providers report racial and ethnic information for births, deaths, adoptions and lead poisoning and who collects these data.

Pennsylvania

Pennsylvania has developed a standardized system for gathering and reporting patient-related administrative and medical data. It is based on the uniform billing form, a standard data set and format used nationally by the institutional health care community to assemble and deliver charge and claim information to all third-party payers (National Uniform Billing Committee web site p.1). The Department of Health requires health care providers to report racial and ethnic data for the following diseases or conditions: cancer, births, hospital discharge data, and abortions. It is responsible for collecting this data. In addition, DOH collects and reports race and Hispanic origin information on birthing mothers and birth-related deaths.

Connecticut

Connecticut has a standardized system, instituted through the Office of Health Care Access (OHCA), that authorizes this agency to collect inpatient discharge and outpatient encounter data from health care and other non-profit facilities (excluding health care educational facilities and those operated by the Christian Science organization). Currently, OHCA collects discharge data from only short-term acute care general hospitals and children's hospitals and both groups are required to follow race and ethnicity coding practices for all patients in accordance with state-defined categories for racial and ethnic groups (O. Armah at OHCA, personal communication, October 4, 2002). The Department of Public Health requires health care providers to report racial and ethnic information for the following conditions: lead poisoning, tumors, infectious diseases, long term care, Healthy Start, children with special health care needs, and hospital discharge data. It is responsible for collecting this data. In addition, DPH maintains race as a category within the vital record system (births, deaths, adoptions and marriages).

New Jersey

The Department of Health and Senior Services (DHSS) is responsible for licensure and monitoring of health facilities within the state, including hospitals, home health agencies, nursing homes, cardiac facilities and ambulatory care facilities. The conditions and diseases for which DHSS collects racial and ethnic data include: HIV and AIDS,

coronary heart disease (e.g., encounter data for cardiac surgery centers), and communicable diseases reported by hospitals. Also collected are performance reports on organ transplantation, and home health agency records. In addition, race and Hispanic origin information is collected regarding births and deaths.

Recent efforts in the state of New Jersey have focused on coverage and targeted improvements to local health delivery systems. The Office of Minority and Multicultural Health is working towards improving local data systems through better collection of racial and ethnic identifiers, promoting standard data collection practices and training local intake workers. In order to institute these improvements, it is necessary to understand the differences in current data collection procedures that occur among providers at the local level. It is also necessary to understand the role of institutional or individual provider bias in access to care and health service delivery. Equally essential to this equation are the establishment of norms in the provision of language interpretation services, and in the promotion of cultural awareness and knowledge of the patient population. This study will attempt to provide a baseline assessment of local practices upon which additional program interventions can be founded.

Methods

Research Strategy

A total of 37 key informant interviews were conducted among a group of health care professionals who oversee and collect race and ethnicity related data in three types of local health care facilities. Two individuals from each facility (an administrator and an intake worker) were identified; these individuals were asked to take part in the research process. The resulting interviews generated information on the codified procedures and institutionalized data collection practices represented by study participants. In addition, the research team explored intake workers' insights and opinions about these processes and began to trace their impact on local health and social service organizations within Middlesex County (e.g., internal county interviews). Specifically, study participants were asked to describe the formal and informal collection and reporting strategies utilized by their institutions to identify, categorize and transmit patient race and ethnicity related information, immigration status and other culturally sensitive data. In-person interviews (averaging approximately forty-five minutes in length) were conducted with clinic supervisors, clinic intake staff, emergency room administrators, emergency room

registration staff, and health department workers employed in Middlesex County health care facilities. A single interview was conducted over the phone. (See Appendix A for specific data.)

The research team collected hard copies of all relevant data collection forms encountered in each health care setting. Team members assessed providers' ability to provide verbal and written translations when asking clients for race and ethnicity related information. Issues of cultural competency and the presence of multicultural and multiracial front line staff were explored; interviewers also assessed worker and institutional awareness of racial disparities in health. Researchers also probed each participating informant about the underlying rationale for data collection, and through participant observation, assessed existing procedures and processes and identified recommendations for possible system improvements.

In order to study real time data collection activities in each of the three provider types as well as observe procedural nuances difficult to capture through the interview process, six observations were conducted. These observations—two in each health department, clinic, and hospital—occurred at two distinctly different periods: one moderately busy and one very busy period. The underlying rationale for the use of this technique was to independently verify interview information and other anecdotal data about procedure, data collection practice, patient population origin, and degree of cultural competency among staff and organizations.

Research Design

The County Racial and Ethnic Disparities Data Project was designed to examine the collection and deployment of race and ethnicity related data within Middlesex County. It assessed patterns of data collection and data tracking generated by a sample of the health care facilities that care for this county's residents. A two-stage interview technique was assembled to assess varying perceptions concerning race and discover whether race and ethnicity related data was being collected consistently at the local level. This approach allowed the interview team to identify where this was being done and for what purpose.

A three-pronged approach was adopted based on recommendations from the New Jersey Department of Health and Senior Services Office of Minority and Multicultural Health (OMMH). A purposeful sample of hospitals, clinics and health departments serving large numbers of minority populations were all targeted for inclusion. This

approach ensured that representatives from each of the major health care providers within Middlesex County would be included in the sample.

Before beginning the interview process in Middlesex County itself, the research team ran a small pilot test in three geographically distinct areas of the state: the Camden-Burlington County area and the cities of Newark and Jersey City (geographically external to Middlesex county). All three areas were selected because they included hospitals, health department clinics and Federally Qualified Health Centers (FQHCs) that served substantial minority populations (African-American, Hispanic and Asian), and because taken together, they provided some representation of several different regions within the state. A total of five external phone interviews were completed as part of the field test.

Interview Guide

The semi-structured interview guide for this study evolved through a number of drafts (See Appendix B). The original questionnaire was modified according to the recommendations of OMMH representatives and members of the OMMH Health Advisory Commission, the results of pilot testing and the recommendations of the Center for State Health Policy's director and staff. Field testing proved especially important to the revision process. Through field testing, it was discovered that language barriers were a central concern of emergency room personnel, and the guide was expanded to include a section on coping with non-English speaking patients. This was later confirmed to be an area of substantial importance during the internal interview process and subsequent analysis.

Field testing also revealed a key procedural difference between clinic data collection and emergency room data collection. Clinic patients were expected to self-identify as they filled out their own forms, and the primary role of clinic personnel in this process was to remind each client to fill in all the sections of the intake form. ER patients, however, were not expected to self-identify. Instead, registration workers sitting across from the patient filled in the race and ethnicity sections of the form based primarily on their observations of the patient and, at times, based on consultation with other staff members. The implications of this discovery for data collection were serious, and thus the revised interview guide included an expanded section designed to elicit the exact procedure(s) used for race and ethnicity related data collection in each facility.

External field testing confirmed the results of the preliminary literature search: there is no consistent methodology for the collection of race and ethnicity related data

within the state of New Jersey. As noted above, health care facilities may depend on patient self-report, intake staff observation or the assessment of attending health care professionals in the process of recording this type of data.

Each method may yield different demographic data and affect the count of minority patients served at a facility. Because of this, careful attention was paid to the range of data collection methods used across the county and factors potentially affecting the accuracy of the data collection process were carefully noted, particularly in cases of potential miscounting and undercounting. Team members particularly sought to identify those categories of information that were not being collected and pinpoint areas in which undercounting is a concern.

Internal Interviews

Thirty-six in-person interviews and one telephone interview were conducted at health care facilities located in three distinct geographic regions of the county: New Brunswick, Perth Amboy and Edison. Each facility is located in a densely populated area that serves a large number of minority clients.

The research team conducted key informant interviews with administrative and intake personnel in each hospital, health department and clinic targeted for inclusion. Prospective interviewees were identified through knowledgeable clinicians and administrators affiliated with both the Center for State Health Policy and major health care facilities in Middlesex County. Printed materials (including guidelines, forms, written policies, procedural guides and manuals) were collected, reviewed, and analyzed prior to individual site interviews whenever possible. Each interview was transcribed and entered into a software data analysis program (NVIVO) for qualitative data. Documents were then coded and scanned for key themes and patterns.

Findings

Synopsis of External Findings

The most striking finding was the clear division between the data collection practices and central concerns of hospital emergency room staff and those of clinic staff. In terms of standard collection procedure and categories used, all three hospital emergency rooms followed a nearly identical pattern that stood in sharp contrast to the

practices of the two clinics. Likewise, all three hospital supervisors voiced identical primary concerns, each focusing on the availability of translators and translation services.

Clinics, Hospitals and Health Departments: General Trends

Over the past five to seven years, much of the population of Middlesex County has changed as more and more individuals speak a language other than English at home. Anecdotal perceptions that Hispanics make up a greater percentage of the county's population today than was the case seven years ago are supported by data from a recent survey of Middlesex County residents. That study revealed that over 16% of the population speaks Spanish at home (Eagleton Institute on Politics, 1996). Given observable shifts in the population, the promotion of effective communication through the provision of translation and interpretation services is more important than ever. All health professionals interviewed emphasized the significance of this issue and noted that it was essential to the provision of quality care.

In assessing data collection activity of race and ethnicity terms, all three types of facilities showed signs of intense struggle around issues of classification. In the absence of detailed policies to guide the data collection process, each individual staff person was left to interpret her or his facility's coding scheme based on personal definitions of "race" and "ethnicity". Further, this had to be accomplished while managing both worker and client anxieties about these topics during the intake encounter. Staff members at all facilities were keenly aware that their questions would offend some clients, and many nurses and intake workers were moderately to seriously uncomfortable asking race and ethnicity related questions in the first place.

The most common solutions to these problems involved the adoption of a modified form of visual assessment to determine a patient's race or ethnicity when possible and the substitution of the word "nationality" for the word "race." A third popular strategy was the decision not to designate a race category for Hispanics at all, even if the difference between race and ethnicity was clearly understood by the worker and the facility's forms distinctly asked for this data element. To confound the situation even further, a substantial proportion of both staff members and clients interviewed across all three facilities confused the concepts of race and ethnicity, and several intake workers reported that their clients were not familiar with the term "ethnicity" at all.

Clinics

Core Issue I: Cultural Competence and Concordance

In total, 21 clinic personnel working in four different facilities were interviewed. Ten individuals worked as supervisors and eleven were primarily responsible for client intake services. Most of the supervisors were White, with the exception of two individuals: one was of African descent and one was of Hispanic descent. Ten of the eleven intake workers were Hispanic, and nine of these were of Puerto Rican descent. Only one intake worker identified as African American.

In all four clinics surveyed, Hispanics made up the vast majority of the patient population. When asked to describe the population that used their services, clinic staff noted that from 50 to 90% of their patient population was Hispanic (the range varied depending on particular clinic). Perhaps because of this, clinics were among the most proactive facilities in meeting their core constituency's demands for cultural competence. In each clinic surveyed, special care had been taken to seek out Hispanic intake workers, most of whom were native speakers of Spanish and either first- or second-generation immigrants themselves. Since all four clinics served a primarily Hispanic population, this minimized language barriers and enhanced the ability of the clinics to provide culturally sensitive care. Additionally, a number of the Non-Hispanic supervisors had some command of Spanish, and a few had prior experience working in Latin American countries.

Both supervisors and intake workers stressed the importance of culturally competent care throughout their interviews and asserted the importance of delivering their services in a manner most acceptable to both their Hispanic and Non-Hispanic clients.

Two related problems emerged as impediments to interviewed workers ability to provide good service: serious work overloads and challenges associated with the changing demographics of the local community surrounding the clinic. It seems that the challenges of meeting the needs of a rapidly changing population make it difficult to ensure both adequate coverage and that Hispanic and African American patients can benefit from concordance with intake staff.

Core Issue II: Classification and Concordance

Despite their substantial successes in delivering culturally competent care, clinic staff members struggled in the attempt to accurately fulfill the demands of their facility's classification requirements. Although federal guidelines, as designated in OMB Directive 15, strongly reinforce the notion that individual self-identification is important, clinic intake workers generally did not adopt this approach. They rejected it based on a complex set of reasons, including a deep concern about the possibility of offending clients and a culturally derived discomfort around assigning categories of race to those of Hispanic descent.

Eight individuals reported the use of occasional or frequent modified visual assessment, employing appearance, last name and use of language in order to determine race or ethnicity. As in other facilities, clinic intake workers (N=11) were more likely to use categories of race and nationality interchangeably. Five individuals confused categories of "nationality" and "race," particularly in reference to Hispanic patients. Of the 11 intake workers interviewed, 10 were themselves Hispanic and 8 of these were Puerto Rican. None of these Hispanic workers was comfortable applying categories of race to individuals of Hispanic descent. Instead, they struggled to meet the categorization requirements of a data collection system that did not reflect their own understandings of race. Several intake workers reported frustration over having to choose White Hispanic or Black Hispanic when documenting client race and ethnicity.

However, not all of these workers were forced to choose a race option while collecting data about their Hispanic clients. Those who did not have to enter the data into a computerized system that forced users to select a race option for Hispanics were free to respond in other ways such as noting all Hispanic individuals regardless of color as "Hispanic".

Many intake workers (6) were vocal in their assertions that the race categories offered by their data collection systems did not work for the classification of Hispanics, but they were much less likely to articulate this by pointing out the lack of good options for biracial individuals. Unlike a number of hospital workers, Hispanic clinic staff did not argue for the creation of a multiracial category. Instead, they argued for the abandonment of racial categories for Hispanics in particular. However, the single African American clinic intake worker interviewed did point out that biracial individuals could not be accurately represented by the clinic's data collection system.

The majority position held by clinic intake workers, that the category Hispanic should not be subdivided by race, was reinforced by the absence of race and ethnicity related data collection guidelines, policies or standards. However, across all 11 facilities surveyed, only 1 facility—a hospital—was able to produce a data collection policy that prescribed a procedure for the collection of race and ethnicity related information. Thus the lack of clear guidelines was in no way specific to clinics, but cut across all categories.

In the case of those clinics surveyed, the predominantly Hispanic group of intake workers developed the following strategies. They preferred to avoid assigning race to Hispanic clients when possible. Intake workers sometimes automatically designated clients Hispanic when they were approached in Spanish (3) and they sometimes automatically designated light-skinned persons White if they were spoken to in English (2). Staff members worked hard to collect accurate data while avoiding insensitivity and any appearance of racism. However, this proved to be very difficult and was more successful in some cases than in others.

Although it is probable that many or most individuals making up the current Hispanic population of Middlesex County can be identified by modified visual assessment only, some level of undercounting is inevitable with this method. In those cases that workers identify as especially resistant to modified visual assessment, some even employ a group decision making process, gathering together all the available intake staff in an attempt to make the most accurate race and ethnicity assessments possible (4). However, despite these good faith efforts, their discomfort with the data collection process and their culturally inflected understanding of race and ethnicity made accurate data collection difficult when combined with an absence of clear guidelines and detailed standards. Staff members, both intake and supervisory, were aware that the data collection process was far from ideal, and that there was no consistency of data reporting even within the same clinic.

Both clinic intake workers and clinic supervisors noted several other challenges to data collection accuracy. Five individuals mentioned that clients sometimes gave out false data in order to hide their status as illegal immigrants. They explained that cautious individuals sometimes gave staff false names; they also sometimes reported a false date of birth and a false country of origin in an attempt to appear as if they were legal immigrants. Four individuals reported problems in assigning race categories to former residents of Middle Eastern countries and three felt that the category "Asian" was too inclusive. In one case, a staff member felt that it was inappropriate to include Chinese,

Vietnamese and Korean clients in the same category while 2 other staff members would have preferred to assign separate categories to Asian Indians and non-Indian Asians.

Finally, 6 clinic intake workers asserted that the race and ethnicity data collected by their facilities was not used for any specific purpose. All six seemed anxious to establish that this data was kept completely confidential and was not released to anyone outside of the clinic. The remaining intake workers had no specific knowledge about how the data was used, but surmised that it was utilized in some fashion by clinic administrators. Like the intake staff, half of the clinic supervisors had specific knowledge about some internal use of the information and half did not. However, when discussing the reasons behind the collection of race and ethnicity data, an interesting split could be observed between intake workers and supervisors.

Differing Perceptions of the Collection of Race and Ethnicity Related Data

Intake workers, in general, did not know why the information was collected but were not frustrated by the requirement that they collect it unless they were attempting to assign race to their Hispanic clients. Although intake workers were very uncomfortable about assigning race to their Hispanic clients, many had no reservations about probing for ethnicity, asking about country of origin or recording preferred language data. These workers did not object to asking clients about their nationality or the length of time that they had been in the United States. Most tellingly, all the intake workers interviewed pointed out that over time, as their clients returned as they came to trust the clinic and its staff. Workers felt that they were very successful in responding to patient discomfort and they did not express anger or frustration at their inability to tell their clients exactly how the race and ethnicity related data was used when they were asked questions about it.

Clinic supervisors, however, expressed their own doubts about the guiding principles underlying the data collection process. Essentially, supervisors were more concerned about the principles guiding data collection efforts and more critical about the process itself than were intake workers. Aside from assigning race to Hispanic clients, intake workers were relatively unconcerned about the data collection process.

Hospitals

Core Issue I: Cultural Competency

A total of nine interviews were completed among the staff of three different hospitals (4 supervisors, 4 intake workers and one supervisor/intake worker). Two of the supervisors were of mixed race, one was Hispanic and one white. The intake workers were equally split with two of Hispanic descent and two of African-American descent. In providing services to a diverse population, hospital staff articulated the existence of numerous problems related to patient literacy. Many patients were unable to read or write, a fact that often emerged once questions were posed to them during the registration process by intake staff. When asked for information, they were unable to answer, answered inappropriately or indicated when asked that they did not speak English. Faced with this obstacle, workers usually then tried to work through the completion of the necessary forms by pointing to spaces on the document, attempting to verbally illustrate what they were referring to and articulating certain key words or phrases in Spanish.

The process of completing registration forms has made hospital intake staff aware of the cultural sensitivities that can be triggered when particular questions are asked of minority group members. Patients took offense to some questions due to the belief that the very nature of these questions was discriminatory when asked of minority group members. Hospital staff asserted that there were certain questions that one could ask of a White individual without incident, but that the same questions posed to a Hispanic client could yield explosive results.

The general observation was that white patients would answer questions like these with few reservations whereas Hispanic and Black individuals would be more sensitive to this line of questioning. One minority worker eloquently explained that there was an art to approaching a Non-White individual and sidestepping sensitive issues and areas.

Issues of concordance were raised by various hospital staff members and most asserted the belief that concordance between worker and patient did make a difference in a variety of circumstances. It was seen as important when asking sensitive registration questions, interpreting or translating for clients, and noted as especially crucial for clinical providers who might be better able to understand any cultural issues affecting the particular individual seeking care.

Training in cultural competency was not a regular part of the hospital worker's experience. Across the board, both supervisors and intake workers encountered training as a one time activity. It was often provided as part of a general orientation, encapsulated in cultural celebrations or ethnic day activities, or in response to the attacks of September 11th. Common among all staff interviewed was the notion that this training was open to all staff members within the facility and that attendance at these sessions was not mandatory. Variance from this pattern was observed in only one facility where every staff person received a three-hour training session on cultural diversity immediately when hired. However, follow-up training was provided only to nursing staff, since clerical staff were not thought to deal with patients directly.

One facility recently founded a committee on cultural diversity that met once a month. The focus of the committee was to increase the number of available translators and develop more brochures that would be well accepted by the diverse population that they served. The goal of this facility was to insure that all hospital materials were ultimately translated. However, a timetable for the completion of this project had not yet been set. Another facility used a "cheat sheet" for registration purposes. The document was provided to staff to ensure the collection of particular demographic and financial information. It was created by the New Jersey Hospital Association some years ago to assist hospitals in the data collection process in recognition that some of the questions asked during registration could be interpreted as being very sensitive. In yet another facility, ethnic sensitivity classes were held for staff in order to teach them how to be culturally sensitive and behave appropriately.

On the whole, more intake workers than supervisors in this sample articulated concerns about the need to acquire a better understanding of different cultures and key cultural issues.

Core Issue II: Classification and Frustration

Even more than clinic staff, hospital staff battled frustration while attempting to collect race and ethnicity related data. Hospital intake workers mentioned the challenge of fending off annoyed or curious clients much more often than clinic workers did. All four of the four hospital intake staff recounted stories of clients who had no idea why they were being asked about their origins and resented the questions. All four noted that they themselves did not know exactly why the data was being collected. Two hospital supervisors as well articulated no knowledge about their facility's use of race and

ethnicity data collected. Additionally, they worried that the information was collected but indeed not used in any constructive manner. This shared concern between intake workers and supervisors contrasts with the split in attitude found in the clinics.

In the context of the chasm between the collection of race and ethnicity data and its unknown (and doubtful) utility, both hospital intake workers and supervisors are particularly concerned about minimizing the discomfort of each encounter for both staff person and patient. Substituting the category "nationality" for that of "race" is one way to soften the impact of the race question immediately. Four of the interviewees (2 intake workers and 2 supervisors) explained that they sometimes or regularly ask clients for their nationalities rather than asking them to designate a race. In three cases, (2 workers, 1 supervisor) these individuals appeared to confuse the meanings of the two categories, but all four interviewees clearly understood that they were less likely to offend patients if they posed their questions by asking for the patient's "nationality". And as was often the case in the clinics, race was then determined through the application of the formula "country of origin + modified visual assessment," as workers tried to find answers to the race question without actually using the word "race." Like clinic workers, Hispanic hospital staff were particularly resistant to coding Hispanic patients as Black or White. Study data confirm that Hispanic health care workers across multiple facilities are particularly offended when asked to categorize Hispanic clients according to race for data collection purposes.

Puerto Ricans and others of Latin American descent may have internalized the racial hierarchies that characterize their original homelands, thus special care must be taken to avoid eruptions around this emotionally charged issue when addressing Hispanic clients. The implications of this finding for clinics, hospitals, health departments and medical facilities of all kinds are serious. Both Hispanic clients and Hispanic intake workers are likely to superimpose their own strongly felt perceptions about race upon data collection procedures that mandate the separate collection of race and ethnicity identifiers (as recommended by federal guidelines), resulting in possible misclassifications and undercounts.

Despite the heightened levels of frustration experienced by hospital staff in particular, they faced many of the same kinds of problems as the clinic workers and they adopted the same kinds of strategies in response. Like clinic workers, hospital workers often used categories of race and nationality interchangeably and depended on modified visual assessment in order to assign clients to categories. Like clinic workers, they

sometimes encountered clients intent on passing along false data. Two hospital staff members reported that clients sometimes gave false names and a false country of origin in order to pose as legal immigrants; one supervisor recounted the story of a recent emergency room client who had attempted to pose as her sister in order to hide her immigration status. Finally, hospital workers, like their clinic counterparts, understood that there was no consistency in coding even within the same facility.

Hospital staff even reported a repertoire of strategies similar to those of clinic workers for coding race. These included always coding Hispanics as white (1), always coding second generation Hispanics as White Non-Hispanic (1), designating country of origin through language style and accent (1), automatically coding Spanish speakers as Hispanic (3) and automatically coding light-skinned English speakers as White (1). In one small way, however, hospital workers differed from their clinic counterparts. Three of the hospital workers brought up the difficulty of assigning accurate categories to multiracial individuals. All three had encountered biracial individuals and/or were themselves biracial, and these staff members were concerned about the lack of fit between their facility's data collection systems and the lived experience of their multiracial patients. Interestingly, two of these individuals identified primarily as African American and only one identified as Hispanic. Since this topic surfaced so rarely and fleetingly during the clinic interviews (a brief mention by one White clinic supervisor and a single discussion by the lone African American intake worker) it stands out as an interesting difference.

Health Departments

Complications: Limited Resource and Additional Challenges

Seven interviews with health department personnel were conducted in total, three with supervisors who doubled as intake workers, two with special program personnel (one health educator and one health ambassador) and one with a secretary who doubled as an intake worker. Health departments differed in many ways from the clinics and hospitals surveyed. Unlike both clinics and hospitals, most relied on a comparably tiny staff, composed of perhaps six individuals (with the exception of the county health department, which was considerably larger than the other small local health departments). Operating on tiny budgets with very limited resources, they faced the challenge of implementing a wide and disparate range of public health programs and

coordinating all of the requirements and forms for each one. The health departments surveyed participated in health fairs, ran childhood immunization and Child Health Conference clinics, offered screening services for female cancers and hypertension, implemented lead poisoning and tuberculosis detection and control programs, ran STD and HIV clinics and offered high risk pregnancy management programs. They also offered a number of smaller, periodic programs like smoking cessation groups and babysitter training workshops.

Each program that the health departments offered came complete with its own set of forms to be filled out for each patient and sometimes for the patient's family. Some of the forms remained on file at the health department's headquarters and some were forwarded to the state. All of them had different race and ethnicity data collection requirements. As an additional complication, many of the forms inherited by the health department staff interviewed were very old. Two health department supervisors reported revising several of the forms they were given in order to improve the quality of the race and ethnicity data collected.

Their most immediate challenges included the necessity of providing interpreters and culturally sensitive care to their clients without a budget, managing the collection of data across numerous programs and forms with vastly inconsistent data collection requirements and soothing the anxieties of clients who feared discrimination and investigations by immigration services.

A Different Emphasis: Targeting the Uninsured

Because health departments were often in close contact with many of the underemployed and under-or uninsured members of their local communities, they maintained strong bonds with a percentage of the members of those groups most heavily represented in their particular areas. Health department personnel confirmed that services were most often rendered to uninsured minority group members of their communities in need of basic health services (such as well baby checkups and immunization services) and health screenings (for conditions such as female cancers and hypertension).

Partly because of this focus on providing basic services to the uninsured, minorities were well represented among those served by health department programs. In addition, periodic health fairs and local community activity days created opportunities for

health department staff to reach out to these smaller, ethnic communities nestled within larger municipalities.

Core Issue I: Partnering with the Community to Enhance Cultural Competency and Provide Interpretation Services

Through the innovative use of volunteers and a creative, need-driven search for solutions, these facilities have discovered a powerful strategy for addressing disparities and delivering culturally competent care. Health departments were the only providers noted that offered mandatory inservice sessions, including workshops on cultural competence a minimum of four times a year in an attempt to educate staff about the health care barriers experienced by their clients. Not surprisingly, most health department staff were quite articulate about health care barriers and very concerned about possible remedies for these deep-seated problems. Health departments have clearly done an exceptional job of reaching out to their minority clients, engaging community-level resources for interpretation and enhancing cultural competence through the use of health ambassadors and even high school students. They exhibit a strong commitment to both reach and understand the populations they serve under challenging conditions of scarcity.

Core Issue II: Classification Among A Multitude of Programs and Requirements

Managing data collection across so many forms without any kind of consistent race and ethnicity requirements created its own challenges. As in the case of the clinics and the hospitals, nurse/intake workers had to deal with both their own anxieties and those of their clients with each exchange. When the intake encounter is characterized by constraints and anxieties on both sides of the exchange, data collection becomes exceedingly complicated, and accuracy is difficult to achieve.

Many of the intake staff interviewed attempt to circumvent their discomfort and avoid alarming their patients by dropping questions about ethnicity and race. In all, 3 of the 7 interviewees reported the use of this tactic either occasionally or frequently. Health department workers appeared similar to hospital workers in reporting elevated anxiety about the process of asking race and ethnicity related questions. In 2 interviews, staff substituted nationality for race, asking about "nationality" or "country of origin" in place

of asking for "race". Racial classification of Hispanics was also a problem here, and 2 supervisor/intake workers reported this, stating that they were aware that it was a challenging issue. In one case, some workers refused to assign race to Hispanic clients and in another, the data collection policy itself treated the category "Hispanic" as if it were a race. For the most part, when asked to collect race and ethnicity data, this data is lumped together into the category "Hispanic" and treated as if it referred to race. Classification of a multi-racial individual presents lack-of-fit problems under the existing system.

Because none of the health department interviewees were themselves Hispanic, it was not possible to investigate whether or not Hispanic staff members working in health departments were more uncomfortable about assigning race to Hispanic clients than were non-Hispanic staff, as found in other types of facilities. However, as occurred in both the clinics and the hospitals, one worker did confuse the category of race and with the category of ethnicity. Despite this, the majority of health department staff interviewed displayed a sophisticated understanding of the nuances underlying race and ethnicity related data collection. Perhaps because they had been trained as nurses and were also accustomed to operating simultaneously as supervisors and intake workers, all four of the health department supervisors interviewed had a good grasp of both the challenges of the intake process and recent thinking about race-related data collection issues.

There is much client dissatisfaction with the race categories offered to them. Four of the seven interviewees reported encountering clients who wanted race options that better reflected their primary identification. And as previously noted, 2 of those 4 individuals responded to this perception of bad fit by revising some of their forms. In general, this reflected the interdependent quality of the relationships observed between health departments and the ethnic communities they served.

When health department personnel were asked about the internal and external uses of the race and ethnicity related data they collected, two individuals reported that it was used internally by the nurses on staff. They explained that they referred to it informally on a case-by-case, day-to-day basis in order to plan their activities and guide service delivery. But they also noted that except in the case of reporting to funders of specific grants, it was not reported or used externally for any particular purpose. All four supervisors interviewed agreed that the data was not being used externally for any particular purpose.

Conclusions

Health Departments

As local health departments within Middlesex County function with an unbelievably miniscule annual budget and have little ability to generate additional operational resources, one would expect, under the circumstances, that these agencies would be the most crippled of service providers. On the contrary, these departments have turned challenges into advantages because they have been forced to go into communities they serve and rally assistance in the form of health ambassadors and clinic volunteers. As a result of their short-staffed existence, these agencies have reaped additional advantages from the nursing staff who, due to the circumstances, have become jacks-of-all trades, providing intake services as well as conducting community outreach activities. These experienced nursing personnel are duly armed with the familiarity and knowledge that only multifaceted exposures can bring.

An additional advantage emerging from both their small resource base and this consolidation of experience is a tendency towards mutual aid across different health departments and an inclination towards collective action. In the absence of resources and guidance, these agencies collaborate with each other, import strategies and successes into other settings and maintain annual training for staff. They were the only providers observed in this study to offer a consistent schedule of training activity to their staff. They were also the providers with the most frequent number of annual trainings for staff per year.

Clinics

All facilities have made significant progress in enhancing cultural competency and continue to move towards improving the provision of health care delivery for the largest segments of their patient populations. However, study findings show that clinic workers lack consistent training and cannot turn to a standardized process to guide data collection. In addition, they frequently experience patient resistance when requesting information about race and ethnicity.

In this setting, there is a strong trend for local Hispanic intake workers to feel a deep discomfort with the task of assigning clients of Hispanic background to categories

of race for culturally specific reasons. Thus, efforts to produce a caring, culturally sensitive staff at the local level have resulted in challenges to the collection of accurate race and ethnicity related data. This unexpected and knotty outgrowth of a beneficial strategy has lain hidden, only to emerge in the context of in-person ethnographic interviews.

This quandary could lead to serious undercounting and misclassification and is virtually undetectable. The answer to the dilemma lies in carefully training staff to follow explicit data collection procedures in a culturally sensitive manner that acknowledges the existence of their inherent discomfort but still validates the process under which they are asked to operate. Training should invite them to air their concerns while at the same time carefully explaining the benefits of the data collection process; it should make explicit the link between accurate data collection and the potential reduction of the racial disparities that they encounter in their communities every day.

Hospitals

The requirements of data collection and the multitude of brief encounters without opportunity for follow-up, together with the absence of data collection guidelines, have created a heightened level of frustration for hospital staff. Supervisors and intake workers share this frustration and it is unclear to them why this data must be collected; thus a challenging activity appears to them to be a useless endeavor. Without a sense of support or any reference to the actual dimensions of the issue (its connection to the gap in health experienced by minority patients), workers struggle to offer possible solutions. One worker recommended that English as a second language be provided to prospective emergency room patients and another suggested the simplification of a data collection form. In a sense, it is easy to fall back on the practice that one intake worker defined as "individual racial profiling".

This environment creates the opportunity for misclassification and undercounting. The isolation of each registration worker, the frequency and brevity of the intake encounter and the opportunity to determine each individual's race and ethnicity based on prior cultural experience and personal theories of race constitute a formidable challenge for preserving data collection accuracy.

Recommendations

Findings from this study suggest that the State should provide local providers with detailed guidance in the form of activities designed to generate standard practices and policies for data collection centered around culturally sensitive issues. Specific recommendations are:

1. Training should be provided for all intake and supervisory staff across provider types. Modules should include a detailed explanation of why and how data is to be collected on race and ethnicity. Information provided should help clarify the relationships among and differences between race, ethnicity, country of origin and nationality. Information on OMB directive 15 should also be provided, outlining why country of origin is utilized in clarifying Hispanic ethnicity and why this data element cannot be used to assign race. Finally, the preference for self-identification over any form or visual assessment should be explained.
2. Enhanced data collection activities are required at the local level. More coordination at the regulatory level is essential in order to ensure data accuracy and allow longitudinal measurement across provider type. In addition, collective coordination across local health agencies regarding the collection of required data elements can assist in influencing policy change to more directly address the disparities issues. (Examples of legislative influence can be seen in California and Massachusetts).
3. Upon seeking health services, each prospective patient should be provided with a detailed explanation of the policies and procedures adopted by that facility, as well as information about the questions and data requests that are required as part of the intake process within the health care facility. This information should be made available in the preferred language of the patient.
4. For low literacy populations, facilities should provide a short, continuously playing video about why race and ethnicity related data is being collected and explaining the importance of accurate documentation throughout the process. This vehicle for educating the patient population should make explicit the link between data collection and the campaign to reduce racial and ethnic disparities in health.

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Appendix A

Internal Interviews Sorted by Facility and Primary Role

Health Department Key Informants

Health Department A	2 interviewees: 2 supervisor/intake workers
Health Department B	2 interviewees: 1 supervisor/intake worker, 1 health educator
Health Department C	3 interviewees: 1 supervisor/intake worker, 1 secretary/intake worker, 1 health ambassador
Health Department D	Declined
Total Completed Health Department Interviews:	7

Clinic Key Informants

Clinic A	6 interviewees: 5 supervisors, 1 intake worker
Clinic B	6 interviewees: 2 supervisors, 4 intake workers
Clinic C	3 interviewees: 1 supervisor, 2 intake workers
Clinic D	6 interviewees: 2 supervisors, 4 intake workers
Total Completed Clinic Interviews:	21

Hospital Key Informants:

Hospital A	3 interviewees: 1 administrator, 1 supervisor/intake worker, 1 intake worker
Hospital B	4 interviewees: 2 supervisors, 2 intake workers,
Hospital C	2 interviewees: 1 supervisor, 1 intake worker
Hospital D	did not agree to participate
Total Completed Hospital Interviews:	9
TOTAL INTERVIEWEES:	37

Appendix B

Interview Guide

1. Where exactly do you work? What is your job title? How long have you worked there?
2. Do you fill out any forms that collect information about the race, ethnicity or preferred language of your clients/patients? Which ones? What is each one for? What department or individual is this information that you collect reported to?
- 3a. Can you describe exactly how each form asks these questions?
If we do not have the forms in advance: What do they look like?
If we do have the forms in advance: Formulate specific questions in order to clarify the forms.

If we do not have the forms in advance:

- 3b. Can you fax me copies of those forms?

Ask everyone:

4. Which, if any, of these forms does the client/patient always fill out himself?

If no:

5. Does a staff person ever fill out a form that asks for race and ethnicity related data for the client/patient? If so, when does that happen? Why does it usually happen?
6. Does a staff member ask the person about his/her race and write the answer down? Does the staff person ever ask someone else in the office about what to write down? Does the staff member simply determine what the client's race is and write it down?

Ask everyone:

7. If someone identifies himself as Hispanic or has a Hispanic last name, is he also asked to classify himself by race?
8. Which non-English languages are spoken by patients at your location? Please give those languages that would appear with 3 or more different patients in a year.

Spanish
Russian
Hungarian
Portuguese
Vietnamese
Chinese (specify: Mandarin, Cantonese, etc.)
Hindi
Urdu
Creole
Others: _____



9. In which of the languages you mentioned earlier do you have written health education materials?

10. How do you handle situations in which a client/patient doesn't speak English? What usually happens when non-English speaking patients arrive at your facility for care? **(When they mention translators: What kind of training do your translators receive?)**

11. Do you think that the race/ethnicity of the staff member helping patients/clients ever affects the way in which patients/clients answer questions about race and ethnicity? How?

12. Would you tell me the racial distribution of your non-clinical intake staff? Please note all that apply:

White	_____
Black or African American	_____
Asian	_____
American Indian or Alaska Native	_____
Native Hawaiian or Other Pacific Islander	_____

13. How many of these individuals are of Hispanic origin? Which ones? How do they affiliate themselves? Do they identify as Puerto Rican, Cuban, Mexican or by another cultural designation?

Ask everyone:

14. If a patient/client identifies as black, are they ever asked if they are native born, recently immigrated, or second generation?

15. Has anyone expressed dissatisfaction with the options they are offered to describe their ethnicity or race? How often has this happened? What did they prefer?

16. Is the procedure you've described to me in your (clinic, ER, health department) part of a formal policy there?

IF yes:

17. Can you provide me with a copy of this section of your policies and procedures manual?

Ask everyone:

18. Is this information collected to fulfill any state or federal requirements for funding or for any other reason? Is it collected as part of a grant requirement? **Probe:** Can you tell me more about that?

If yes:

19. Can you provide me with a copy of the report or form that your organization generates to fulfill its reporting requirement?

Ask everyone:

20. How is this information used? Does your organization ever use it for any reason? Does anyone outside of your organization ever use it? How?
21. Do you think the procedures used here allow you to capture patient race/ethnicity accurately? All of the time? Most of the time?
22. How do you think collecting this information will impact patient's confidentiality concerns?
Do you think that patients/clients take offense to race and ethnicity questions?
23. Are there any changes you would like to make to your facility's data collection process in order better target the populations that you serve? Which ones and why?
24. Have you heard much about racial or ethnic disparities in health? Have you encountered them among your patients/clients?
25. Does your facility hold special training sessions or cultural diversity days? When was your last one?
What kind of training was it? Who attended?
26. What are your thoughts about improving New Jersey's racial and ethnic disparities in health care?
How could the collection of race and ethnicity-related data affect this process?

Appendix C

Categories of Data Collection Format by Provider Type

	Hospital	Clinics	Health Department
Registration Form	Paper System Standardized Computer Input	Paper Form Computerized Input from Paper Direct Computer Input	Paper Form Confidential Health History Child Health Record
Assessment Form	History Form	Paper Form (History & Health Behaviors)	Child Health Record
Specialty Program Information	Consent Forms	Medical Assistance Referral Form Specialty Care Case Management Forms	Consent Forms for Examination & Treatment STD Clinic Medical Record Specialty Clinic Program Forms HIV/STD Testing Form* Immunization Form* Lead Screening Form* Cancer Screening Form Hypertension Screening Form TB Testing Record*
County/State Funder Requirement	NJ Family Care Form Certification of Presumptive Eligibility Consent Forms for Insurance	Special Reports to Funding Agency United Way Forms Grant Reporting Requirement New Proposals	Health Survey Form

* State information program requirement.



Appendix D

Providers That Formally Collect Race/Ethnicity Data on Some Format

Collection of Race, Ethnicity and /or
Language Data Elements

	Hospital	Clinic	Health Department
Registration Form	3	4	0 (N/A)
Assessment Form	1	1	0 (N/A)
Specialty Form	0	3	3
State and other Funding Requirements	1	4	2
Total	3	4	4

Appendix E

Primary Languages/ Country of Origin

Hospitals

<i>Hospital A</i>	<i>Hospital B</i>	<i>Hospital C</i>
Primary Language Spoken: Spanish (approx. 30-40%)	Primary Language Spoken: Spanish (approx. 80-85%)	Primary Language Spoken: Spanish
Other Languages: Russian, Hungarian, Portuguese, Vietnamese, Chinese (maybe Mandarin), Hindu/Urdu, Creole, unknown African dialects, and Arabic/Middle Eastern languages Very Common Language(s): Hindi/Urdu	Other Languages: Russian, Hungarian, Portuguese, Vietnamese, Chinese, Creole, and Polish Very Common Language(s): Hindi/Urdu	Other Languages: Russian, Hungarian, Portuguese, Vietnamese, Japanese, Chinese, Hindi/Urdu, Creole, Polish, and Middle Eastern languages

Clinics

<i>Clinic A</i>	<i>Clinic B</i>	<i>Clinic C</i>	<i>Clinic D</i>
Primary Language Spoken: Spanish (approx. 95%)	Primary Language Spoken: Spanish (approx. 80%)	Primary Language Spoken: Spanish	Primary Language Spoken: Spanish (approx. 95%)
Other Languages: Russian, Hungarian, Vietnamese, Chinese (Mandarin), Hindi/Urdu, Hungarian, Portuguese, German, Egyptian/Middle Eastern languages, and African languages	Other Languages: Russian, Hungarian, Vietnamese, Chinese, Korean, Hindi/Urdu, Hungarian, Egyptian/Middle Eastern languages, Creole, and African Languages	Other Languages: Russian, Hungarian Portuguese, Hindi/Urdu, Arabic/Middle Eastern languages, Creole, and African Languages	Other Languages: Russian, Polish, Hungarian, Portuguese, Vietnamese, Chinese/other Asian, Hindi/Urdu, Hungarian, and Egyptian/Middle Eastern languages

Health Departments

<i>Health Dept. A</i>	<i>Health Dept. B</i>	<i>Health Dept. C</i>
<p>Primary Language Spoken: Spanish</p>	<p>Primary Language(s) Spoken: Asian Indian, Chinese, Filipino, Korean</p>	<p>Primary Language Spoken: Asian Indian (e.g. Kudrathi, Punjabi, Hindi), Chinese</p>
<p>Other Languages: Russian, Hungarian, Portuguese, Vietnamese, Chinese (e.g. Mandarin, Cantonese), Hindi/Urdu, Hungarian, Polish, Creole, and African languages</p>	<p>Other Languages: Spanish, Vietnamese (maybe), Chinese (e.g. Mandarin, Cantonese), Hindi/Urdu, Creole, Gujarati, Punjabi,</p>	<p>Other Languages: Spanish, Korean, Urdu and Middle Eastern languages Very Common Language(s): Arabic</p>