Improving Race and Ethnicity Data Collection: An Intake Worker Training Tool

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Executive Summary

In the fall of 2002, the OMMH commissioned the Rutgers Center for State Health Policy (CSHP) to evaluate current sources of racial and ethnic data collected and utilized by providers within the health care system. The first phase of this project produced a report entitled the “Pilot Study of County Data Resources: Improving the Health of Populations,” which provided a baseline account of the collection and utilization of racial and ethnic data within the Middlesex County health care system. This pilot study was the first stage in understanding local level practices concerning the collection of racial and ethnic data in health. The initial report that emerged from the pilot study yielded a series of key recommendations that set the framework for the project’s second phase. These recommendations focused on four major issue areas and included the following:

Recommended Actions for Phase Two

- Training of Intake and Supervisory Staff
  - Provide detailed explanations of proper racial and ethnic data collection; information on OMB 15; clarification of the concept of the ‘Hispanic’ ethnicity; and explanation of using patient self-identification rather than visual assessment.

- Enhancement of local and regulatory-level data collection practices
  - Improve accuracy of data collection by the introduction of newly designed intervention tools for use by intake / registration workers within a health care setting. Further, the introduction and use of such tools is expected to force a subsequent change in facility-related policies and procedures, allowing for longitudinal measurement.
• **Providing Explanations of Facility Procedures and Policies**
  - Provide detailed explanations of health care facility procedures and policies to prospective patients, including information explaining the rationale of questions asked during the intake process; information to be available in multiple languages.

• **Providing a Comprehensive Rationale for Racial and Ethnic Data Collection**
  - Accommodate the needs of low literate persons within the health care facility through the use of short, continuously playing videos explaining the rationale or through the use of an introductory informational process consisting of written documentation for prospective patients.

In order to fulfill these objectives, the second phase of the project consisted of an extensive literature review of current data collection practices and issues related to this effort, followed by the development, testing, and evaluation of an interventional training tool. This tool consists of a set of strategic materials to be used in the training of hospital intake workers, enabling them to collect race and ethnicity related data efficiently while also being conscious of cultural competency issues and the needs of low English proficient (LEP) populations (Campanelli, 2003; IOM, 2002; GAO, 2003; Perot & Youdelman, 2001; Alliance for Health Reform, 2003; HHS, 2001; NAHDO, 2002; Bhopal & Donaldson, 1998; Bierman, Lurie, Scott Collins & Eisenberg, 2002; Mays, Ponce, Washington, & Cochran, 2003; Friedman, Cohen, Averbach, & Norton, 2000; Nerenz & Courier, 2002).

The elimination of disparities will require that system-level improvements occur specifically in the quality and reliability of racial and ethnic data currently collected and reported by health care providers. This will necessitate enhanced data collection practices that result in the correct identification of high-risk populations, the use of standardized data practices within as well as across health care facilities, and the proper evaluation of the effectiveness of new health care system interventions in targeting minority groups. To this end, the central focus of the second phase of this project was to create the flexible intervention tool described above.

Draft one of this multi-level intervention tool was developed and shared among various clusters of English-speaking, Spanish-speaking and bilingual intake workers as well as one group of Spanish-speaking patients through a series of focus groups. Group participants provided the
research team with their opinions about the content of the intervention components, suggestions for improvements to these components, recommendations for the optimal application of the intervention tool within existing systems, and the expected overall impact resulting from the use of this intervention.

This project’s findings suggest that these tools can lead to improved dissemination practices at the facility level that clarify the importance of the collection of race/ethnicity data. They can also improve communication between patients and intake / registration staff during the intake encounter and provide patients with a basic level of familiarity with facility informational requirements (e.g., policies and procedures), as well as the reasons for data collection. Focus group study participants confirmed that the use of this tool will lead to improved patient/intake worker interaction, enhanced data quality and better patient-level estimates as designated by race /ethnicity. Additionally, utilization of this tool will lay the foundation for more targeted and effective program interventions to improve the health of vulnerable populations.

**Recommended Actions**

Based on the focus group results, we recommend several initial courses of action regarding the organization and use of the intervention tool as well as a series of next steps for further research and implementation.

**Revision and Use of the Intervention Tool**

- All components of the intervention tool should be translated into Spanish as well as English and distributed in both languages.

- The Patient Information Sheet should be translated into the most often utilized four languages for each facility in which it will be used.

- Large versions of the Patient Information Sheet should be produced and posted prominently in facility waiting areas.

- The OMB 15 Guidelines should be produced in two versions: an expanded version for training intake workers and a shortened version for possible distribution to patients who have questions about the appropriate use of racial and ethnic categories. Both
sheets should include an expanded section explaining the use and utility of the categories “White Hispanic” and “Black Hispanic”.

- Charts showing the most common 5 illnesses broken down by race and ethnicity should be made available in the most often used languages at each facility and distributed to triage nurses and nurses/physicians for use in educating patients. They should also be made available to local health departments and the sponsors of health fairs so that they can be distributed among interested minority communities.

- The Cultural Competence information sheet should be made available to hospitals and clinics; it should be produced in a hospital-specific version and a clinic-specific version.

- The Glossary should be included primarily as an intake worker training tool, but it should be made available to intake workers and translators in Spanish and English in order to assist them in answering patient questions regarding race and ethnicity data collection with the appropriate terminology and definitions.

Focus Group Results

Findings regarding the intervention components are noted as follows: the patient Information Sheet should continue to be produced in both Spanish and English using the double-sided format. It should include a short section or several sentences noting which state regulations require the collection of hospital and ER data. Hospitals may benefit from a version that is written as if it originates not from any one particular facility, but from a broader institutional perspective. This information sheet may be appropriate for inclusion with a patient information packet that can be distributed at admission, at discharge or mailed out with the hospital survey.

The Cultural Competency Information Sheet should be revised and reworded in order to create a better fit for use in the hospital environment. The current version may be more appropriate for clinic use than for ER use. In a hospital environment, a revised version can be used to train intake workers and staff and perhaps be distributed for patients. The OMB 15 Guideline Sheets are appropriate for the training of hospital and intake workers and supervisory staff. In clinics, the short version may be posted and distributed to patients who ask for more
detailed information about the race and ethnicity categories in use or the reasons for data collection. In hospitals, a much shorter version may be appropriate for inclusion with a patient information packet that can be distributed at admission, at discharge or mailed out with the hospital survey.

The Glossary is primarily appropriate for the training of both hospital and clinic intake workers although it could be offered to patients, particularly in a clinic setting. The intake mock script is useful for both hospital and intake patients and could, together with the list of OMB 15 categories used for race and ethnicity, form the core of a laminated “cheat sheet” to be posted at each workers’ desk for easy access. Both the Data Charts and the Self Assessment Tool are useful in intake worker training, although the Self-Assessment may be modified to reflect those data elements collected at each particular facility. The Data Charts have a useful, additional clinic application: they can be shown to patients by the triage nurse during regular clinic visits in order to review the most important causes of mortality and morbidity in specific minority communities. As a health education tool, they may prove as useful to patients, in this context, as they are to intake workers.

Video dissemination of the intervention information was enthusiastically received by clinic intake workers, although ER workers expressed concern that patients and families in the waiting room might object to the loss of regular TV programming during their long waits. Alternatively, they suggest the use of an electronic ticker-tape device to disseminate information in that setting. Finally, ER supervisors suggested the creation of a flip chart containing all of the intervention components to be distributed throughout the hospital as well as posted in the waiting room. In this way, the information could be readily accessible to all clinical and non-clinical staff.

Both clinic and hospital intake workers agreed that large versions of the Patient Information Sheet should be posted in waiting rooms. Some clinic staff also suggested posting the short version of the OMB 15 Guideliners Sheet. Because of disagreement among participants, this option should be further reviewed before implementation. For a summary of the findings regarding the major components of the intervention tool, please see Table 2 below.
Tool Components

List of Tool Components

1. Mortality and morbidity data charts
2. Intake Worker Self-Assessment Tool
3. Interactive Cultural Competency/Visual Assessment Exercise
4. Kaiser Permanente Film Vignette & Discussion
5. ‘What Is Cultural Competence? Why Is It Important?’
6. Glossary of Key Terms
8. Patient Information Sheet
9. Mock Script for Intake/Registration Workers

Components

Each component will be introduced by a short description.

[1] Mortality and Morbidity Data Charts

The Mortality and Morbidity Charts were created using data from the National Vital Statistics Reports and the New Jersey State Health Assessment. The charts depict the leading causes of death among the following groups: White Americans, Black Americans, Asian/Pacific Islanders and Hispanic Americans. Four different charts are included in the document; they break down the data for the United States as a whole and for New Jersey, and Middlesex County. These visual representations of disparities in health among several racial and ethnic groups provide a basic informational backdrop against which the intervention itself can be deployed.
Top Leading Causes of Death in the United States by Race & Hispanic Origin - 2000

WHITE
1. Heart Disease
2. Cancer
3. Stroke
4. Respiratory Diseases
5. Accidents
6. Influenza & Pneumonia
7. Diabetes
8. Alzheimer's Disease
9. Kidney-Related Diseases
10. Suicide

BLACK
1. Heart Disease
2. Cancer
3. Stroke
4. Accidents
5. Diabetes
6. Homicide
7. HIV
8. Respiratory Diseases
9. Kidney-Related Diseases
10. Influenza & Pneumonia

ASIAN/PACIFIC ISLANDER
1. Cancer
2. Heart Disease
3. Stroke
4. Accidents
5. Respiratory Diseases
6. Influenza & Pneumonia
7. Diabetes
8. Suicide
9. Kidney-Related Diseases
10. Perinatal Complications

HISPANIC
1. Heart Disease
2. Cancer
3. Accidents
4. Stroke
5. Diabetes
6. Chronic Liver Disease & Cirrhosis
7. Homicide
8. Respiratory Diseases
9. Influenza & Pneumonia
10. Perinatal Complications

Number of Deaths for Top Leading Causes of Mortality by Race & Hispanic Origin: United States - 2000

Source: National Vital Statistics

Rutgers Center for State Health Policy
Rates of Leading Causes of Death in New Jersey & Middlesex County - 2000

**WHITE**

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<th>Stroke</th>
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<tr>
<td>Middlesex</td>
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**BLACK**

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<th>Diabetes</th>
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**OTHERS** *

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</tr>
<tr>
<td>Middlesex</td>
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</table>

* Others: includes Asian/Pacific Islander race and persons of Hispanic ethnicity

Note: "Others" data for Stroke & Diabetes in Middlesex County not available

Source: New Jersey State Health Assessment Data
The Intake Worker Self-Assessment Tool was designed to mirror the list of questions intake workers routinely ask incoming ER patients (e.g., race, country of origin, primary language, religion, marital status, employer, and insurance status, among others). This component is meant to reverse the usual roles of intake workers and patients, allowing the worker to reconsider many of the questions that they ask everyday. The goal of the tool is to provoke him/her into asking whether or not the questions can be confusing and whether or not they can be offensive or seem discriminatory.
Intake Worker Self-Assessment Tool

1. Which of the following terms best describes you? (Please check as many as apply)
   - White/Caucasian
   - African American/Black
   - Latino/Hispanic – Cuban, Puerto Rican, Mexican, Dominican, Colombian, Nicaraguan, Costa Rican, Salvadoran, Honduran….
   - Asian American/Chinese, Japanese, Phillipino, Vietnamese, Cambodian, Korean…
   - Alaskan Native
   - American Indian
   - Asian Indian - Pakistani,
   - Middle Eastern
   - Other

2. Were you born in the United States?

3. How many years (months) have you lived in the United States?

4. If not, what is your country of origin?

5. Is English your primary language?

6. If not, what is your primary language?

7. What language do you most often use at home?

8. In what language do you read?

9. How many years of schooling have you completed?

10. What is your religion?

11. Who is your employer?

12. Please complete the following sentence by describing the race/ethnicity of the majority of the population where you live.
   In my neighborhood, the population is mostly______________

13. Who is your primary health insurer?
Intake Worker Self-Assessment Tool (Spanish)

1. ¿Cuál de los siguientes términos lo describe mejor a usted?
   - Blanco/Caucásico
   - Afro Americano /Negro
   - Latino/Hispano – Cubano, Puertorriqueño, Mejicano, Dominicano, Colombiano, Nicaraguense, Costaricense, Salvadoreño, Hondureño,…
   - Asiático Americano/Chino, Japonés, Filipinos, Vietnamita, Camboyano, Coreano,…
   - Nativo de Alaska
   - Amerindio
   - Indio - Paquistaní
   - Del Medio Oriente
   - Otro

2. ¿Nació Ud. En los Estados Unidos?

3. ¿Hace cuanto tiempo que vive Ud. en los Estados Unidos?

4. Si no nació en los Estados Unidos, ¿Cuál es su país de origen?

5. ¿Inglés es su idioma principal?

6. Si no, ¿Cuál es su idioma principal?

7. ¿Qué idioma utiliza Ud. con más frecuencia en casa?

8. ¿En qué idioma lee Ud.?

9. ¿Cuántos años de escuela ha cumplido Ud.?

10. ¿Cual es su religión?

11. ¿Dónde trabaja Ud.?

12. Por favor rellene la siguiente frase para describir la raza/etnicidad de la mayoría de la población donde vive Ud. En mi barrio, la mayoría de gente es _________________

13. ¿Con qué empresa tiene su seguro médico?
The Interactive Cultural Competency/Visual Assessment Exercise is a brief timed exercise in which participants are presented with an individual who offers them only his or her first and last name. Participants are then given approximately sixty seconds in which to write down their answers to a series of short questions about the subject’s race, ethnicity, preferred languages, cultural background, and probable ethnic and racial self-identification. The exercise simulates the experience of intake worker who utilize the technique of modified visual assessment to categorize incoming hospital ER patients. Often, the worker has only moments in which to collect race and ethnicity related information and chooses to work on his/her assumptions, based on the patient’s visual appearance and surname. The subjects of this exercise are intentionally selected for their ambiguous or hidden racial and ethnic group membership (i.e. a dark-skinned person with a non-Hispanic surname who appears to be African-American but is actually Black Hispanic; a light skinned person with a non-Hispanic surname who appears to be White but is actually White Hispanic). The goals of this exercise are to demonstrate the hidden pitfalls of modified visual assessment and highlight the likelihood of mistakes in classification when utilizing physical appearance and/or name.
Interactive Cultural Competency/Visual Assessment Quick Exercise

Trainer puts subject #1 at head of group and asks them to look closely at her/him. Trainer then asks each person to write down their answers to the following questions. Repeat with subject #2.

1. What is the subject’s race?

2. What is his/her ethnicity?

3. What languages do believe he/she speaks and/or is fluent in?

4. How would you describe this individual’s cultural background?

5. How do you believe this person identifies him/herself (e.g., race and ethnicity)?

After all have responded, trainer brings each subject to the head of the group and asks them to answer these questions themselves. Highlight the following: the ease with which Hispanic ethnicity and Spanish as a primary language can go unnoticed among White Hispanics; the ease with which Black Hispanics can appear to be purely African American.

Discuss the ramifications of the exercise for accurate identification and undercounting of Hispanics.
Kaiser Permanente has produced a video that incorporates a series of vignettes showing illuminating the importance of cultural competency and linguistic sensitivity in health care settings. The vignette selected for use in this intervention portrays two different versions of the same clinical encounter. The first version depicts the struggles of a physician untrained in cultural competence who attempts to provide appropriate care to a non-English speaking patient. The second vignette depicts the same situation as managed by a physician trained in cultural competence who is working with a certified medical translator.

Together, the vignettes highlight the impact of language-related barriers, the importance of identifying and working with cultural standards and beliefs and the potentially dangerous outcomes of failing to address these issues adequately. Although the video targets physicians, it provides an excellent example of how cultural sensitivity can ameliorate potential problems and eliminate or reduce anxiety and hostility in staff/patient encounters. The goal of this tool is to introduce participants to culturally sensitive communication techniques, pinpoint the critical importance of cultural issues in the health care delivery process and serve as a basis for discussion of communication during the intake encounter.

The cultural competence information sheet (entitled What Is Cultural Competence? Why Is It Important?) provides a basic, comprehensible definition of cultural competence. It defines “racial and ethnic health care disparities” and discusses the connections between cultural competence, race and ethnicity data collection and better health outcomes for all patients. It provides examples of particular areas in which data collection has the potential to impact health outcomes in a positive way and outlines the importance of preserving quality of care across all population groups through data collection and other methods. The goal of the tool is to provide the reader with basic, highly accessible information about racial and ethnic disparities in health care, cultural competence, preserving/enhancing quality of care, data collection and the interconnections among these areas of concern.
Cultural Competence is a set of knowledge, skills, attitudes, policies and practices that enable health care providers and programs to work well with culturally diverse consumers, families and communities.¹

Racial and Ethnic Healthcare Disparities are differences in the quality of health care that cannot be explained by the patient’s ability to afford care, the kind of illness or injury the patient has, the patient’s preferences, or the kind of treatment that’s usually considered best for the patient’s problem.

It has always been important to strive for racial and ethnic fairness in health care. Because we expect that minority groups will make up a bigger proportion of our country’s population in the near future, it will soon be even more challenging and urgent to reach the goal of racial and ethnic fairness. We need to overhaul the system now, instead of waiting for disaster to strike.

It is important to the improvement of quality and access to care to document health care provided across population groups. The collection of race, ethnicity, country of origin, and language preferences begins to shape the description of different population groups served by facilities, their individual preferences, the types and levels of illness most common for any given group, and their experience with the system (patient outcome). Even though our data collection process needs a lot of improvement, we can already tell that members of minority groups get worse care than members of the majority for conditions such as: cardiac procedures, pneumonia, pain management, renal transplantation, immunizations and mammograms.

We only know about these disparities because of the data we’ve been able to collect so far. Your help in making our data collection even better is crucial, if we’re going to improve the health care system thoroughly. There are probably other treatment disparities we don’t know anything about yet.

In order to get rid of racial and ethnic disparities in health care and improve patient access, changes at the system level as well as provider level are needed. Whole hospitals and bureaucracies and training programs will have to adjust what they’re doing, not just the individual people in them. Such a system is culturally sensitive, responsive, effective, and respectful of all cultures and individual religious and unique health beliefs. A culturally competent healthcare system is one that acknowledges and incorporates, at all levels: the importance of culture, understanding of cross-cultural relations, the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs.²

² Betancourt et al. 2003
CAPACIDAD CULTURAL

¿QUE ES?
¿POR QUE ES IMPORTANTE?

Capacidad cultural es un conjunto de conocimientos, habilidades, actitudes, tácticas y normas que permiten a las personas que proporcionan asistencia médica y programas de salud a trabajar mejor con los consumidores de diversas culturas, familias y comunidades.¹

Disparidades Raciales y Étnicas en el sistema de Asistencia Médica son diferencias en la calidad de asistencia médica que no se pueden explicar por medio de la capacidad de un paciente de pagar por su cuidado, la clase de enfermedad o herida que el paciente tiene, las preferencias de el paciente, o la clase de tratamiento que usualmente es considerado mejor para el problema de ese paciente.

Siempre ha sido importante procurar ser racial y étnicamente justos en un centro de salud. Porque esperamos que las minorías sean una proporción más grande de la población en nuestro país en un futuro próximo, muy pronto va a ser más desafiante y urgente alcanzar la meta de ser justos racial y étnicamente. Necesitamos revisar y modificar el sistema ahora en lugar de esperar a que venga un desastre.

Es importante, para poder mejorar la calidad y el acceso de asistencia médica, documentar el cuidado de salud proveido a los diferentes grupos de la población. La colección de datos de raza, etnicidad, país de origen, y preferencias de idioma, empiezan a formar la descripción de diferentes grupos servidos por instalaciones, sus preferencias individuales, los tipos y niveles de enfermedad más comunes en cada grupo, y su experiencia con el sistema (resultado de el paciente). Aunque nuestra recopilación de datos necesita mejorar, ya podemos decir que miembros de minorías reciben peor cuidado de salud que miembros de mayorías en las siguientes condiciones: procedimiento cardiaco, neumonia, manejo de dolor, transplante renal, inmunizaciones y mamografías.

Solo sabemos de estas disparidades por los datos que hemos podido colectar hasta ahora. Si queremos mejorar el sistema completamente, su ayuda para mejorar la recopilación de datos es crucial. Probablemente hay otras disparidades de tratamiento de las cuales nosotros todavía no estamos enterados.

Para poder librarnos de las disparidades raciales y étnicas en el sistema de asistencia médica y mejorar el acceso de el paciente, necesitamos cambios en el sistema y también en quién lo suministra. Hospitales en general, la burocracia y los programas de instrucción deberán hacer ajustes en lo que hacen, no solo los individuos en ellos. Tal sistema es culturalmente sensible, susceptible, efectivo, y respeta todas las culturas y religiones individuales y creencias de salud. Un sistema de asistencia médica culturalmente competente, es uno que reconoce e incorpora en todos los niveles: la importancia de cada cultura, entiende la relación a través de todas las culturas, las dinámicas que resultan de las diferencias culturales, reconoce el desarrollo del conocimiento cultural y adapta sus servicios para poder satisfacer las necesidades únicas de cada cultura.²

² Betancourt et al. 2003
Glossary of Key Terms

The Glossary defines a series of key terms related to race and ethnicity, including definitions of the OMB 15 race and ethnicity categories and terms such as culture, bilingualism, disparities, nationality, identity and cultural sensitivity as well as others. It is meant primarily as a training tool for intake workers who need to understand the data element categories that they will be working with and the most important terms that may be used throughout the training process. The Glossary was adapted from a selection of more detailed glossaries, including the glossary included as part of Kaiser Permanente’s Culturally Competent Care Toolkit. The goal of this tool is to provide intake workers, supervisors, trainers and other facility staff with definitions of the most frequently used terms they encounter, and in particular, to clarify ambiguous or erroneously interchanged words such as, “nationality” and “ethnicity.”
KEY TERMS / GLOSSARY

African-American: The term “African-American” refers to U.S. Americans who are descendants of peoples from the continent of Africa. The majority of African Americans are descendants of persons brought from Africa to the Americas between the 17th and 19th century.

Asian: The term “Asian” refers to the various subgroups that originate from the continent of Asia and the Pacific Islands and represent the fastest growing group in the United States. Asian refers to very diverse and heterogeneous groups with unique cultural values and health behaviors and beliefs.

Bilingual: Equal proficiency in two spoken languages.

Biracial/Multiracial: Biracial indicates a relation to or identification with, two races whereas multiracial indicates a relation to or identification with multiple races.

Birthplace (also Country of Origin): Place of birth or origin. The country or nation in which one is born.

Cultural Competence: A set of integrated attitudes, knowledge and skills that enable a health care professional or organization to care effectively for patients from diverse cultures, groups and communities.

Cultural Sensitivity: Having awareness and insight to the various nuances of one’s own culture as well as other cultures.

Culture: An integrated pattern of learned core values, beliefs, norms, behaviors and customs that are shared and transmitted by a specific group of people. Some aspects of culture, such as food, clothing, modes of production and behaviors, are visible. Major aspects of culture, such as values, gender role definitions health beliefs and worldview, are not visible.

Discrimination: Denying people equal opportunity by acting on prejudice.

Diversity: Diversity is a way of life created when we all recognize that the whole is better because of its unique parts. In a diverse environment an individual’s uniqueness is celebrated, valued, and used to further the mission of the organization. Diversity enriches us all, and takes nothing from anyone.

Ethnicity: A cultural group’s sense of identification associated with the group’s common social and cultural heritage.

Health Care Disparities: Health care disparities refer to the disproportionate burden of morbidity, and disability between groups.

Identity: Individuals have multiple aspects to their persons, and these aspects may be referred to as identities. The salience of identity changes in different contexts. For example, in one setting, a person’s identity as a woman may be more salient than her identity as an American.

Interpreter: An individual who has been specifically trained to translate speech (including medical information) from one language to another in a complete and accurate manner. Translator is a specially trained individual who can translate written information from one document to another.

Latino: The term “Latino” is used to aggregate several distinct populations from Central and South American countries and cultures.

Multicultural: Identifying with many cultural groups.

Nationality: Membership in a particular nation. A group of people having a common origin, tradition, and language who frequently identify themselves as members of a particular country and/or nation.

Race: A group of people with similar physical characteristics who are considered to belong to the same type, or the fact of belonging to such a group. Race is sometimes used to mean a group of people who share the same language, history, characteristics, culture, traditions, etc.

Racism: Racism is the belief, conscious or otherwise, that one race is superior or more valuable than others.

South Asian: The term “South Asian” is used to aggregate several distinct populations from South and Southeast Asia. (E.g. India, Pakistan, Bangladesh, Vietnam)

Stereotype: The notion that all people of a given group are the same, that there is no within group variation.

Adapted from “Culturally Competent Care Toolkit” Kaiser Permanente, Institute for Culturally Competent Care, National Diversity Department, 2003.
Palabras claves/glosario

**Americano africano:** El término “African American” se refiere a los estadounidenses quienes son descendientes de la gente del continente de África. La mayoría de los “African Americans” son descendientes de la gente traída de África a las Américas entre los siglos 17 y 19.

** Asiático:** El término “Asian” se refiere a los varios subgrupos que vinieron del continente de Asia y las Islas Pacíficas. “Asian” se refiere a los grupos diversos y heterogéneos con valores culturales únicos y comportamiento y creencias de salud peculiares de ellos.

**Bilingual:** Competencia para poder hablar 2 idiomas al mismo nivel.

**Biracial/Multiracial:** El término “biracial” indica una relación a, o identificación entre 2 razas. El término “multiracial” indica una relación con, o identificación con razas múltiples.

**Lugar de nacimiento (País de origen):** El país o la nación donde una persona nace.

**Aptitud cultural:** Una serie de actitudes, conocimientos y habilidades que permiten a los profesionales de salud, o a una organización eficazmente atender bien a los pacientes de diversas culturas, grupos y comunidades.

**Comprensión cultural:** Tener conciencia y perspicacia a varios matices de su propia cultura además de las otras culturas.

**Cultura:** Una estructura integrada con valores, creencias, normas, conductas y costumbres aprendidos que están compartidos y transmitidos por un grupo específico de gente. Aspectos importantes de una cultura como valores, nitidez del papel del género, creencias de salud y perspectiva del mundo no son visibles.

**Desminización:** Negar oportunidades iguales a gente por medio de actos de prejuicios.

**Diversidad:** Diversidad es la manera de vida creada cuando reconocemos que todo es mejor por sus diversas partes. En un ambiente diverso, lo único de una persona está celebrado, valorado, y usado para fomentar la misión de la organización. Diversidad enriquece a todos nosotros, y no quita nada a nadie.

**Etnicidad:** El sentido de identificación de un grupo cultural asociado con la herencia social y cultural del grupo que tiene en común.

**Disparidades del cuidado de salud:** El término “health care disparities” se refiere a la carga desproporcionada de mortalidad, la pena y la minusvalía entre grupos.

Adapted from “Culturally Competent Care Toolkit” Kaiser Permanente, Institute for Culturally Competent Care, National Diversity Department, 2003.
The explanation of the OMB 15 Guidelines describes the federal government’s commitment to the elimination of health disparities through the collection of race and ethnicity related data. Most critically, this document provides fully detailed definitions of each category of race and ethnicity utilized in the OMB system. The guidelines note that the federal government requires all federal agencies to collect race and ethnicity data according to this set of standards and explains that most health care facilities seeking to follow the gold standard set by the government also follow some form of these OMB regulations. Additionally, it explains the requirement to collect race and ethnicity data elements separately and the importance of asking for patient self-identification. The goal of these tools are to identify the federal government as the source of the data collection system currently in use and explain that the health care facility is seeking to act responsibly by collecting race and ethnicity related data in the particular manner that they do. The first tool is designed for intake workers, while the second, shorter tool is designed to be given to patients. The third tool, in Spanish, is a longer version comparable to the first intake worker version in English.
What are the “OMB 15 Guidelines”?

The U.S. government understands that the collection of race and ethnicity related information is a very important part of any plan to eliminate inequalities in health among different groups of people. Because of this, many Federal agencies collect and use racial and ethnic information in agreement with guidelines referred to as the OMB 15 regulations.

What is important about the OMB 15 guidelines, and why are they used?

- Many agencies and organizations have adopted some version of this system.
- It allows people to have a say in deciding how they will be counted.
- Any organizations that use this system can easily compare information together

Why do we have to ask race and ethnicity questions at all?

- In order for researchers to distinctly see any health disparities based upon race, ethnicity, national origin or preferred language, so that they can see how to make the health care system fairer.
- Since race and ethnicity data help identify problems and show us whether particular solutions are working, this information gives us one of the most basic and important tools we have to help get rid of racial disparities in health and to fight racism in the healthcare system.

Race: A group of people with similar physical characteristics who are considered to belong to the same type, or the fact of belonging to such a group. Race is sometimes used to mean a group of people who share the same language, history, characteristics, culture, traditions, etc.

a. American Indian or Alaskan Native – A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

b. Asian – A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

c. Black or African American – A person having origins in any of the black racial groups of Africa. The term “Negro” can be used in addition to “Black or African American.”

d. Native Hawaiian or Other Pacific Islander – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

e. White – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Ethnicity: A cultural group’s sense of shared identity associated with the group’s common social and cultural heritage.

f. Hispanic/Latino – A person of Spanish origin or having origin in South America, Central America and the Caribbean.
   - “Black Hispanic” – A person of Hispanic ethnicity and Black racial identification
   - “White Hispanic” – A person of Hispanic ethnicity and White racial identification
What are the “OMB 15 Guidelines”? 

The U.S. government understands that the collection of race and ethnicity related information is a very important part of any plan to eliminate inequalities in health among different groups of people. The OMB 15 regulations require all government institutions to offer people the option of choosing one or more of the following five racial categories when they are asked about their race:

**Race**: A group of people with similar physical characteristics who are considered to belong to the same type, or the fact of belonging to such a group. Race is sometimes used to mean a group of people who share the same language, history, characteristics, culture, traditions, etc.

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaskan Native</td>
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</tr>
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</tr>
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<td>White</td>
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**Ethnicity**: A cultural group’s sense of shared identity associated with the group’s common social and cultural heritage.

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</tr>
</tbody>
</table>
¿Qué son las Directrices OMB 15?

Según el gobierno de Estados Unidos, la colección de información con relación a la raza y etnicidad es una parte muy importante de cualquier plan para eliminar las desigualdades de salud entre diferentes grupos de personas. A causa de esto, muchas agencias Federales reúnen y utilizan información racial y étnica de acuerdo con directrices denominadas regulaciones OMB 15. Publicado en 1997, las directrices tratan de demostrar la creciente diversidad de nuestro país, debido a las cifras más altas de casamientos interraciales y casamientos entre diferentes grupos e inmigración creciente. Las regulaciones OMB 15 requieren a todas las instituciones del gobierno que ofrezcan al individuo la opción de escoger una, o más de una de las siguientes cinco categorías raciales cuando se les pague que de raza son:

A. Nativo Indio Americano, o de Alaska – Una persona que es de origen del Norte o Sudamérica (inclusive América Central), y que pertenece a una tribu o mantiene conexión con la comunidad de la tribu.
B. Asiático – Una persona que es de origen del lejano Oriente, Asia del sudeste, o el subcontinente índico incluyendo, por ejemplo, Camboya, la China, la India, Japón, Corea, Malasia, Pakistán, las Islas filipinas, Tailandia, y Vietnam.
C. Americano Negro o Africano – Una persona que es de origen de cualquiera de los grupos de raza negra de Africa. Los términos tales como “Haitiano” o “Negro” pueden ser utilizados además de “Americano Negro o africano.”
D. Nativo Hawaiano u Otro Isleño Pacífico – Una persona que es de origen de Hawaii, de Guam, de Samoa, o de otras Islas Pacificas.
E. Blanco – Una persona que es de origen de Europa, el Medio Oriente o Africa del Norte.

Estas regulaciones requieren también que se les pregunte a las personas su etnicidad aparte de su raza. Además de preguntarles su raza se les va a preguntar si ellos son “hispanos o latinos” de origen (eso es “una persona cubana, mejicana, pueortorriqueña, Dominicana o de origen de Sur America o de Centro America, u otra cultura o de origen Español, a pesar de su raza”). El término “de origen Español,” puede ser utilizado también en vez de, o además de “hispano o latino.”

¿Por qué debemos preguntar etnia aparte de raza?

La información acerca de la raza de una persona y su etnicidad se recopila por separado para permitir al individuo la opción de escoger una, o más de una de las categorías raciales o de etnicidad, de acuerdo a su criterio.

- Dejar a cada persona definir su raza y etnicidad de acuerdo a su criterio, es más preciso que permitir a otras personas definir o adivinar esta información. - Este sistema no siempre trabaja efectivamente ya que muchos latinos no piensan en sí mismos pertenecer a una raza totalmente aparte de su etnicidad.

- Una nota importante: las directrices OMB 15 no permiten que una persona escoja una herencia étnica que sea ambas “hispana o latina” ni “no hispano o latina” aunque muchas personas tienen un padre hispano o latino y un padre ni hispano ni latino.

¿Por qué las directrices OMB 15 requieren auto identificación?

Las directrices del gobierno requieren que se le pida a cada persona definir su propia raza y etnia, porque:
se considera el derecho de cada persona en los EE.UU. el definir quién ellos son – la gente debe tener el derecho de decidir lo que ellos piensan es la descripción más exacta de su raza y origen.
· Esto no es siempre fácil, ya que mucha gente tiene tantas maneras diferentes de definir raza y etnia.
· Las directrices procuran crear un sistema que le de a cada persona una gran variedad de opciones para escoger, mientras se mantiene la lista suficientemente corta y fácil de utilizar.

¿Qué es la importancia de las directrices OMB 15 y por qué se utilizan?

· Muchas agencias que no son del gobierno federal y organizaciones han adoptado alguna versión de este sistema
· Ofrece la oportunidad al público de decidir como deben ser considerados.
· Cualquier organización que utiliza este sistema puede comparar fácilmente información con otra organización.

¿Por qué necesitamos hacer preguntas acerca de su raza y etnia?

· Para qué los investigadores puedan ver claramente disparidades de la salud debido a la raza, etnia, origen nacional o el idioma preferido, y así ellos puedan asegurarse que el sistema de asistencia médica sea más justo.
· Sin ningún sistema de recopilación de información de raza, etnia, o de datos, es imposible mejorar la salud de cualquier grupo de personas en una manera claramente evidente, exitosa y mensurable.
· Ya que los datos de raza y etnia ayudan a identificar los problemas y nos muestran si las soluciones están trabajando, esta información nos da uno de los instrumentos más básicos e importantes que nosotros tenemos para ayudar a eliminar las disparidades de salud racial y para combatir el racismo en el sistema de asistencia médica.
Patient Information Sheet

The Patient Information Sheet (entitled Welcome to the Hospital) is a resource for prospective hospital ER patients. This component succinctly explains the rationale behind the collection of race and ethnicity related data and places it in the context of the other required questions that the intake workers will ask. The document attempts to set patients more at ease with the unfamiliar hospital setting, informing them in advance about hospital data collection processes, explaining why race and ethnicity related questions are asked and telling them how the information they provide will be used to improve the quality of care for all hospital patients. The goal of this tool is to soothe patient fears about the sensitive questions that they will be asked in advance of the intake encounter itself. It is expected that this strategy will benefit intake workers as well as patients by lowering the levels of anxiety and suspicion experienced by patients when they engage with intake staff.
Welcome to the hospital.

We at the hospital are committed to offering all our patients the best possible care. We are constantly looking for ways to improve the care we give and the ways we give it.

You may be wondering.... Why do we ask so many questions?

We’re striving for a future in which all of our patients get equal access to health care so that everybody we work with can live longer, better lives. We ask everyone the same questions, and we keep track of how we treat all our patients.

We know from national reports and from history that not everyone has always received good quality care. We want to make sure that doesn’t happen at our hospital. For example, we ask everyone about their race and ethnic background so that we can keep track of how well we’re doing with everyone who comes to the hospital. Only by tracking how we treat all our patients and looking at how we treat people of all racial and ethnic groups can we learn to serve all our patients more fairly.

We want to get to know you and make sure that you get the highest quality care possible. Our questions allow us to do just that. When you visit us, we will ask you the following commonly asked questions.

- Where do you live?
- What is your marital status?
- What is your religion?
- Where were you born?
- When were you born?
- Do you work? If so, where?
- What do you do?
- Who do you want us to contact in case of emergency?
- Do you have insurance?
- What is your insurance information?
- What is your race?
- What is your ethnicity?

Your answers to all these questions help us in our effort to make the whole health care system work better for everybody. THANK YOU!
Bienvenidos al Hospital

En este hospital creemos firmemente en ofrecer la mejor atención médica a todos nuestros pacientes. Buscamos constantemente la manera de mejorar la atención médica que ofrecemos y el modo en que la damos.

Usted se preguntará...
¿Por qué hacemos tantas preguntas?

Nos estamos esforzando para un futuro en el cual todos nuestros pacientes tengan la misma facilidad para adquirir asistencia médica y que puedan vivir vidas mas largas y mejores. Nosotros le hacemos las mismas preguntas a todos, y guardamos los datos de como tratamos a todos nuestros pacientes.

Sabemos a través de reportes nacionales y por medio de la historia que no todos nuestros pacientes han recibido asistencia médica de calidad. Queremos asegurarnos que eso no pase en nuestro hospital. Por ejemplo, le preguntamos a todos su raza y grupo étnico para poder mantener datos de que tan bien estamos atendiendo a todos los que vienen al hospital. Solo manteniendo datos de cómo tratamos a todos nuestros pacientes y estudiando cómo tratamos a la gente de todas las razas y grupos étnicos podemos aprender a servir a nuestros pacientes justamente.

Queremos conocerlo y asegurarnos que usted obtenga asistencia médica de la más alta calidad posible. Nuestras preguntas nos permiten llevar esto a cabo. Cuando usted nos visite, le vamos a hacer las siguientes preguntas.

| ¿Dónde vive usted? |
| ¿Cuál es su estado civil? |
| ¿Cuál es su religión? |
| ¿Dónde nació? |
| ¿Fecha de nacimiento? |
| ¿Trabaja? Si trabaja, ¿dónde trabaja? |
| ¿De qué trabaja? |
| ¿Con quién nos podemos comunicar en caso de emergencia? |
| ¿Tiene seguro médico? |
| ¿Cuál es la información de su seguro? |
| ¿Cuál es su raza? |
| ¿Cuál es su pertenencia étnica? |

Sus respuestas a todas estas preguntas nos ayudan en nuestro esfuerzo a que el sistema de asistencia médica trabaje mejor para todos. ¡Gracias!
Mock Script for Intake/Registration Workers

This resource was designed for intake staff on the who are responsible for the direct collection of race and ethnicity related data. The script lists those questions typically asked of patients during the intake encounter in ER settings and supplies workers with a series of answers to commonly asked questions such as “Why do you need to know this?” This tool is designed to assist intake staff to respond in a productive way to patients who do not understand what is being asked of them, do not understand why such sensitive questions are being asked, are afraid to answer, are offended or do not feel that the information is necessary or relevant to their hospital records. The goals of the tool is to lessen the burden of data collection on intake staff, improve the accuracy of the data collected, and help standardize to the data collection process.
Mock Script for Intake / Registration Workers

The State of New Jersey requires hospitals to collect the following information from all patients served by their facility, either through the emergency room or through direct admission to the hospital. The following questions are asked of all patients regardless of their race, ethnicity, sexual orientation or religious affiliation. Please be assured that by law, all information collected is confidential and no individual’s personal information is ever shared or made available for public use.

The collection of this information helps the State of New Jersey improve its services and programs to meet the needs of the state’s population. It also allows the state to measure health care status by group and view population trends over time.

Thank you for your time and cooperation in this important process.

1. What is (your/patient’s) full name?
2. What is (your/patient’s) full address (including street, city, state and zip code)?
3. What is (your/patient’s) date of birth?
4. What is (your/patient’s) sex?
5. In what country were you born? Please circle country from list below. (If not listed below, please fill in country of origin in the response area provided.

<table>
<thead>
<tr>
<th>a. United States</th>
<th>b. Puerto Rico</th>
<th>Outlying Area of the U.S (e.g., Guam, Virgin Islands, other U.S. territories).</th>
<th>c. Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>d. Cambodia</td>
<td>e. China</td>
<td>f. Columbia</td>
<td>g. Cuba</td>
</tr>
<tr>
<td>h. Dominican Republic</td>
<td>i. El Salvador</td>
<td>j. Guatemala</td>
<td>k. Guyana</td>
</tr>
<tr>
<td>l. Haiti</td>
<td>m. India</td>
<td>n. Jamaica</td>
<td>o. Mexico</td>
</tr>
<tr>
<td>p. Nicaragua</td>
<td>q. Costa Rica</td>
<td>r. Ghana</td>
<td>s. Panama</td>
</tr>
<tr>
<td>t. Sierra Leon</td>
<td>u. Venezuela</td>
<td>v. Honduras</td>
<td>w. Nigeria</td>
</tr>
</tbody>
</table>

OTHER COUNTRY OF ORIGIN ____________________________

6. How many years (months) have you lived in the United States? _________
7. What is (your/patient’s) race? {Black, White, American Indian / Native American/ Eskimo, Aleutian, Asian/ Pacific Islander, Other}
8. What is (your/patient’s) ethnicity? { Mexican, Puerto Rico, Cuban, Central or South America, Other Unknown Hispanic, Unknown or not classifiable, Non-Hispanic}

FOR HELP CLARIFYING RACE AND ETHNICITY CATEGORIES, PLEASE REFER TO THE “OMB 15 Guidelines” AND/OR THE “Patient Information Sheet”

If you are asked, “Why do you need to know my race?”
…you can answer: “We want to keep track of how well we are treating people of all racial and ethnic groups so that we can be sure that we are serving all of our patients fairly. Telling us your race and ethnicity will help us to do that.”

If they say, “That’s none of your business,”

…you can answer: “By collecting information on the race and ethnicity of all of our patients and tracking how we treat them, we can make sure that everyone who comes to this hospital is getting the best quality care. But if we don’t know who is coming to see us, we can’t keep track of how well we are doing.”

If they say, “Isn’t that obvious?” or “Can’t you tell?”

…you can answer, “Not really. Many people come from mix of different ethnic backgrounds and races. It’s not always easy to tell just from looking. And we want to know what you consider your race to be---no one else has the right to make that decision for you.”

If they say, “That’s discrimination,”

…you can say, “We ask this question so that we can track how we treat everyone that comes into our facility. By keeping track of how well all of our patients are doing, we make sure that we are not discriminating.

If they say, “What do you mean by ethnicity?” or if they seem unsure about what you are asking,

…you can say “This question is asking whether or not you consider yourself to be either Hispanic or Latino.”

9. Is English your primary language?
10. If not, what is your primary language?
11. What is (your/ patient’s) marital status?
12. What is your religion?
13. Who is (your/patient’s) current employer? {Government agency, private for profit company, non-profit organization, self-employed, other} __________
14. Who is your primary health insurer? _______________________________
PLEASE IDENTIFY FROM FOLLOWING LIST OF HEALTH INSURERS

| a. Private employer sponsored health insurance | b. Private health insurance - purchased | c. Private health insurance – state or local program |
| d. Medicare | e. Medicaid | f. Military health care - VA |
| g. CHAMPUS | h. State sponsored health program (e.g. Family Care, SCHIP) | i. Other government program |
| J. Uninsured |

ALL FIELDS BELOW ARE TO BE COMPLETED BY HOSPITAL STAFF

15. What is today’s date?
16. Type of Admission (DO NOT COMPLETE - This Field Completed by Hospital)
17. Source of Admission (DO NOT COMPLETE - This Field Completed by Hospital)
18. Primary Insured’s Id Number
19. Primary Insured’s Employment Status Code
21. Principal Diagnosis Code
22. Other Diagnosis Code(s)
23. Principal Procedure Code
24. Principal Procedure Date
25. Other Procedure Code(s)
Table 1: Applicability of Intervention Tool Components on the Intake Worker and Patient Levels

<table>
<thead>
<tr>
<th>INTERVENTION COMPONENT</th>
<th>INTAKE WORKER</th>
<th>PATIENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality/Morbidity Data Charts</td>
<td>serves to engage worker in data collection task; without R/E data, such statistics could not be developed</td>
<td>gives patient idea of their R/E standings; statistics could be explained by health care provider</td>
</tr>
<tr>
<td>Intake Worker Self-Assessment Tool</td>
<td>reverses perspective of data collection; helps worker understand own background</td>
<td>n/a</td>
</tr>
<tr>
<td>Cultural Competency/Visual Assessment</td>
<td>effective simulation exemplifying occurrence of erroneous visual assessment of patient by worker</td>
<td>potential use with patients -- to understand awkward task intake workers faced with daily</td>
</tr>
<tr>
<td>Film Vignettes &amp; Discussion</td>
<td>portrays appropriate and inappropriate approaches to culturally &amp; linguistically competent care</td>
<td>provides example of ideal provider-patient interaction, especially amongst LEP individual</td>
</tr>
<tr>
<td>What is Cultural Competency?</td>
<td>basic introduction to concept; highlights importance of understanding &amp; working with people of other cultures</td>
<td>reassures patients they will be treated equally, and that cultural competence improves quality of care</td>
</tr>
<tr>
<td>Glossary</td>
<td>clarifies ambiguities of commonly used terms; effectively defines race groups; facilitates collection</td>
<td>assists in defining unknown unclear terms; assists in self-identification process</td>
</tr>
<tr>
<td>OMB 15 Guidelines Explanation</td>
<td>provides explanation of federal data collection guidelines; improves ability to collect accurate data</td>
<td>explains rights in obtaining equal health care; assuages fears of discrimination</td>
</tr>
<tr>
<td>Patient Information Sheet</td>
<td>facilitates data collection process; explains to patients need for data with assurance of non-discrimination</td>
<td>rationale behind need for data collection, emphasizing usage of data for non-discriminatory purposes</td>
</tr>
<tr>
<td>Mock Script</td>
<td>provides range of communication strategies to elicit disclosure of data from patients</td>
<td>presents list of questions that will be asked of them; full list of questions reviewed in Patient Information Sheet</td>
</tr>
</tbody>
</table>

* R/E = race/ethnicity
<table>
<thead>
<tr>
<th>Table 2: Intervention Tool Components/ Expected Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>**Patient Information Sheet</td>
</tr>
<tr>
<td><strong>Improve Communication</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Provide Reasons for Data Collection</strong></td>
</tr>
<tr>
<td><strong>Lays the Foundation for more Targeted, Effective Program Interventions</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Sums up how the collection of this information leads to better health care outcomes</strong></td>
</tr>
</tbody>
</table>
Next Steps

Focus group participants suggested that a number of additional steps be taken to promote the optimal use of the above components. These include:

- A self-study booklet incorporating the tool should be produced to enhance intake worker training in busy hospital environments.

- A short video version of the Patient Information Sheet should be produced in English and Spanish for periodic screening in clinic waiting rooms; an audio version may also be appropriate.

- A short, laminated “cheat sheet” with the answers to commonly asked patient questions regarding race and ethnicity data collection should be produced and distributed to intake staff. The sheet should include a list of the OMB 15 race and ethnicity related categories used and their definitions as well as possible answers to the most commonly asked patient questions.

- A further, expanded demonstration of the utility of the intervention should be implemented in two to four local hospitals and two to four local clinics.
Literature Cited


National Association of Health Data Organizations. (2002). Developing a Uniform
