Collecting Data on Patient's Race, Ethnicity and Primary Language:

Education Campaign to Improve Hospital Collection of Data on Patient Race, Ethnicity and Primary Language

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Health Research
and Educational Trust of New Jersey

Nonprofit arm of the
New Jersey Hospital Association

Mission:

Engage in research and educational activities that will support and enhance the ability of healthcare providers to provide accessible, affordable and quality care, and promote wellness in their communities.

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Background

- **HRET serves as a data reporter for most NJ Hospitals**

  - **Responsible for applying quality control measures and performing many data quality improvement strategies.**

  - **Routinely reviews data and ensures all data reported by hospitals and submitted to the DHSS are accurate and reliable.**

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Background, *cont.*

- **Identifies issues/gaps**

- **Provides feedback to hospitals on their reporting data practices**

- **Recommends strategies to improve the quality of hospital data**

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Hospital Uniform Billing (UB – 92) Inpatient Discharge Data Set

- **NJ Discharge Data Collection System (NJDDCS)**

  - **Three major components**
    - ▸ **Patient Demographic Module**
    - ▸ **Clinical information Module**
    - ▸ **Financial/Billing Module**

  - **Patient race and ethnicity collected as part of demographic module - the major source of data for the racial and ethnic background of patients**

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Data Quality

- **State, research organizations and hospitals rely on these data to:**

    - Track illnesses by age, gender, race and ethnicity.

    - Determine patient risks for developing certain conditions for more effective prevention or treatment.

    - Assess disparities in healthcare services and outcomes.

    - Develop targeted programs and services that are responsive to individual needs of patients and help reduce/eliminate disparities, following CLAS standards.

    - Ensure the quality of our services for all patients so EVERYONE gets the highest quality care regardless of their racial or ethnic background.

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Data Quality, *cont.*

■ **Critical that these data fields accurately and reliably reflect the populations hospitals serve**

- ● **Rapid growth of the state's minority and immigrant populations and its increasing racial and ethnic diversity.**

- ● **Documented disparities in healthcare access, service utilization and health outcomes of minority populations at both state and national levels.**

- ● **Concerns over accuracy and reliability of the data.**
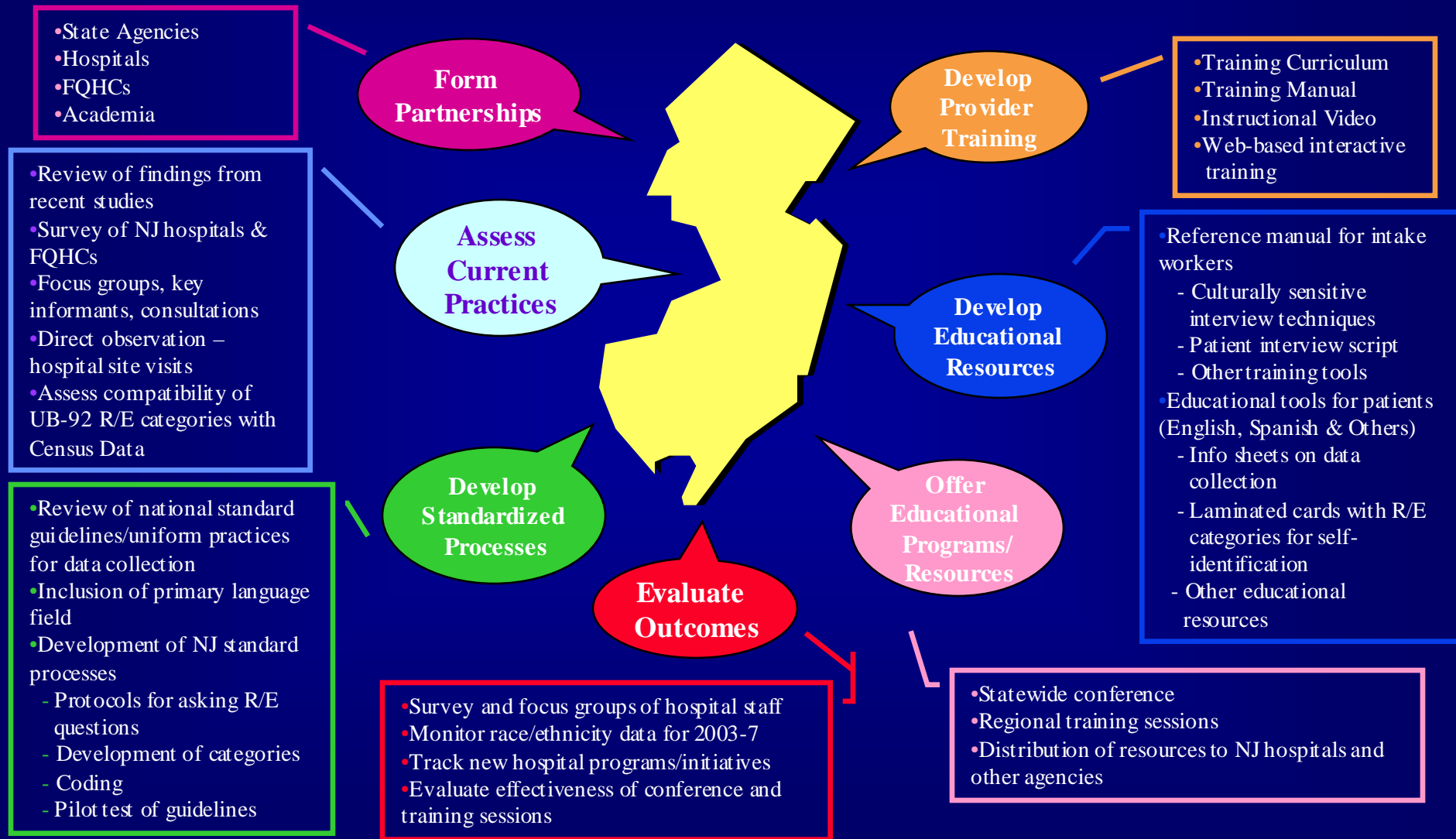
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Previous Studies

- **HRET study and educational interventions - 1996**

- **HRET study of quality issues in NJDDCS - 2004**
  - **Incompatibility of NJDDCS and Census RE Categories**
  - **Hospital reporting of patient RE, 1995-2003**
  - **Comparison with NJ population by county**

- **Other Studies (Rutgers CSHP; AHA/HRET; etc.)**

Previous Study Findings

- **Wide variations in hospital reporting practices**

- **Persistent inconsistency in many hospital collection/coding practices - undercounting and misclassification of certain racial/ethnic categories**

- **Staff barriers in collecting these data**

- **Patient concerns/barriers to provide this data**

- **Consistent need for a standardized data collection and reporting process and routine training of hospital staff**

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting
Funded by a Grant from the Robert Wood Johnson Foundation

State Agencies / Hospitals / FQHCs / Academia

- State Agencies
- Hospitals
- FQHCs
- Academia

Form Partnerships

Develop Provider Training

- Training Curriculum
- Training Manual
- Instructional Video
- Web-based interactive training

- Review of findings from recent studies
- Survey of NJ hospitals & FQHCs
- Focus groups, key informants, consultations
- Direct observation – hospital site visits
- Assess compatibility of UB-92 R/E categories with Census Data

Assess Current Practices

Develop Educational Resources

- Reference manual for intake workers
  - Culturally sensitive interview techniques
  - Patient interview script
  - Other training tools
- Educational tools for patients (English, Spanish & Others)
  - Info sheets on data collection
  - Laminated cards with R/E categories for self-identification
  - Other educational resources

- Review of national standard guidelines/uniform practices for data collection
- Inclusion of primary language field
- Development of NJ standard processes
  - Protocols for asking R/E questions
  - Development of categories
  - Coding
  - Pilot test of guidelines

Develop Standardized Processes

Offer Educational Programs/ Resources

Evaluate Outcomes

- Survey and focus groups of hospital staff
- Monitor race/ethnicity data for 2003-7
- Track new hospital programs/initiatives
- Evaluate effectiveness of conference and training sessions

- Statewide conference
- Regional training sessions
- Distribution of resources to NJ hospitals and other agencies

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Major Areas of Focus

- State Agencies
- Hospitals
- FQHCs
- Academia

Form Partnerships

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Project's Advisory Panel

- **Formed a committee of experts to oversee and steer the project's implementation and provide input on the development of resources and other deliverables.**

- **Panel members were experts in data collection and data quality issues, interviewing techniques, cultural sensitivity or competency, minority health and healthcare disparities.**

- **Members included:**
  - **Healthcare providers**
  - **Hospitals**
  - **State agencies**
  - **The Healthcare Financial Managers Association (HFMA)**
  - **Academia and community organizations in healthcare data quality control, improving race and ethnicity data and/or reducing healthcare disparities.**

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Major Areas of Focus

- Review of findings from recent studies

- **Survey of NJ hospitals & FQHCs**

- Focus groups, key informants, consultations

- Direct observation – hospital site visits

- Assess compatibility of UB-92 R/E categories with Census Data
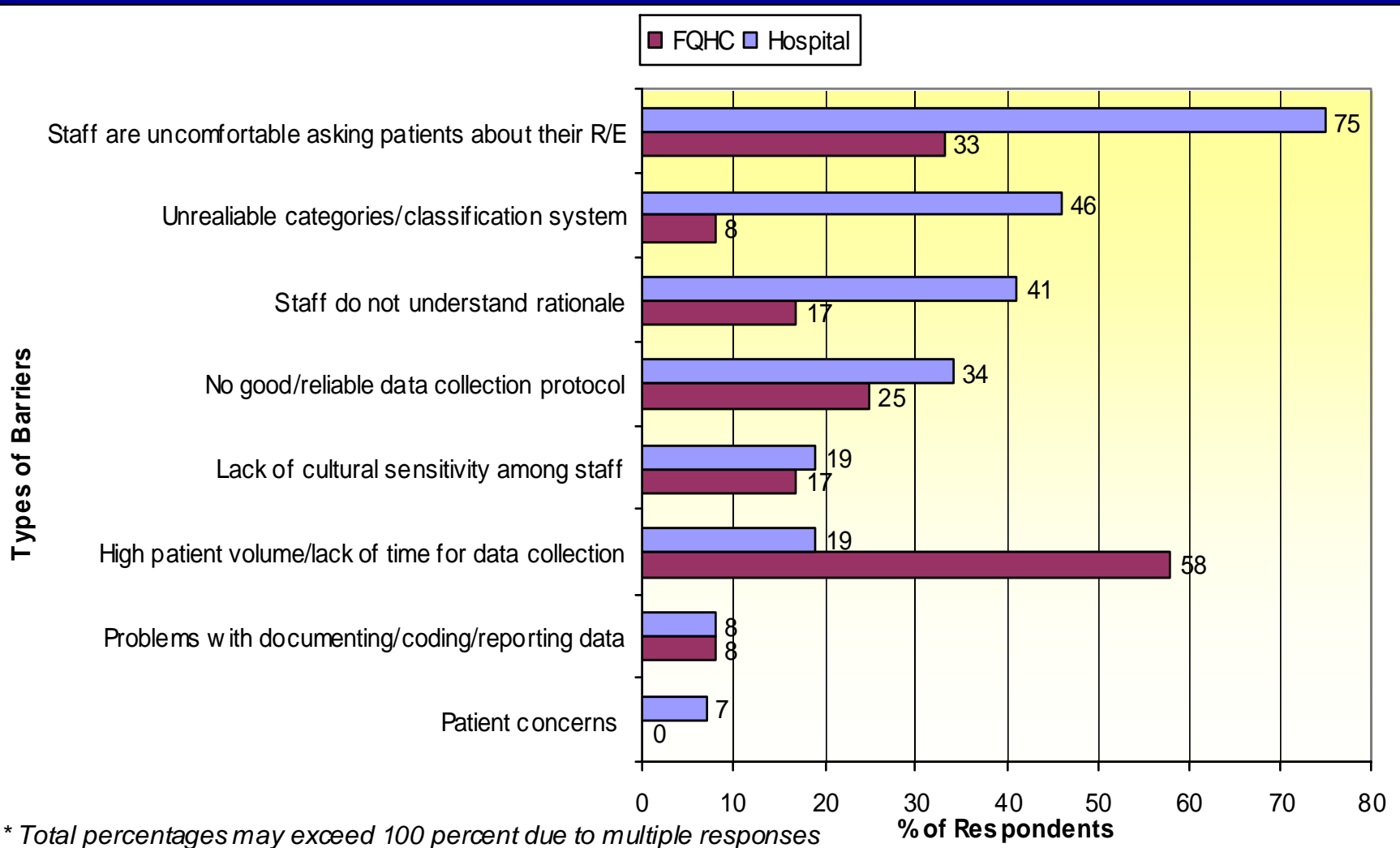
Assess Current Practices

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Hospital Survey Findings

■ **Current Practices**

- **Most hospitals have policies and protocols to ask patients questions about race and ethnicity - only about one third follow OMB guidelines.**

- **About half of the time, admission staff or patient access representatives provide patient race and ethnicity data without directly asking patients - based on observation of patient's appearance.**

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Hospital Survey Findings, *cont.*
Data Collection- Barriers

Legend: ■ FQHC ■ Hospital

Chart — Types of Barriers (Y-axis) vs % of Respondents (X-axis):

- Staff are uncomfortable asking patients about their R/E: Hospital 75, FQHC 33
- Unrealiable categories/classification system: Hospital 46, FQHC 8
- Staff do not understand rationale: Hospital 41, FQHC 17
- No good/reliable data collection protocol: Hospital 34, FQHC 25
- Lack of cultural sensitivity among staff: Hospital 19, FQHC 17
- High patient volume/lack of time for data collection: Hospital 19, FQHC 58
- Problems with documenting/coding/reporting data: Hospital 8, FQHC 8
- Patient concerns: Hospital 7, FQHC 0

X-axis: % of Respondents (0 10 20 30 40 50 60 70 80)

* Total percentages may exceed 100 percent due to multiple responses

Hospital Survey Findings, *cont.*

- **Most frequently reported needs:**
  - **About 75% of responding hospitals do not have resources or training available to staff;**
  - **Only a few hospitals provide information cards to their patients with race and ethnicity categories or reasons for this data collection and their use;**
  - **Most frequently noted needs for training and educational resources:**
    - Info on the best ways of asking questions about patient race and ethnicity.
    - Info on the best ways to choose a category.
    - Handling patients with multiple racial/ethnic backgrounds.
    - Resources and tools for staff orientation and routine in-service training.

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Hospital Survey Findings, *cont.*

- **Primary Language Data Collection**

  - **More than 70 percent of hospitals currently collect this data.**

    - ‣ **No uniform system for asking questions and collecting data on patient primary language.**

- **Only 32% of hospitals have the capacity to link race and ethnicity data and/or primary language data to the medical record and/or quality data.**

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Major Areas of Focus

- Review of national standard guidelines/uniform practices for data collection

- Inclusion of primary language field

- Development of NJ standard processes
  - Protocols for asking R/E questions
  - Development of categories
  - Coding
  - Pilot test of guidelines

Develop Standardized Processes

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Review of National and State Standard Guidelines for Data Collection

- **Current national guidelines**
  - Office of Management and Budget (OMB)
  - American Hospital Association/Health Research and Educational Trust (AHA/HRET)
  - Expecting Success - Montefiore Hospital

- **Review of state initiatives**
  - Rutgers Center for State Health Policy
  - Massachusetts State Plan

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Training Curriculum

- **Builds upon existing resources - the American Hospital Association's HRET tools**

- **Standard protocols for systematic collection of data on patient race, ethnicity and primary language**

- **Information on recommended policies and procedures**

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Recommended Protocols

- **Interviewers should always introduce themselves first and provide a general statement about collecting the patient's personal information;**

- **Race and ethnicity information should be collected directly from the patient or from a designated representative (e.g. parent, guardian or proxy);**

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Recommended Protocols, *cont.*

- **Questions should be asked using two separate questions during the patient interview: Question on Hispanic origin precedes question on race;**

- **Questions should be asked in an open-ended format;**

- **Race and ethnicity information should be collected only once at registration, stored in an electronic format and collected once again during future visits to verify and update as needed.**

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Training Curriculum, *cont.*

- **Builds upon existing resources - the American Hospital Association's HRET tools**

- **Standard protocols for systematic collection of data on patient race, ethnicity and primary language**

- **Information on recommended policies and procedures**

- **Recommended race and ethnicity categories and their definitions**

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Improved Race and Ethnicity Categories

- **Review of current UB categories and gaps**

- **Identify appropriate race and ethnicity categories for New Jersey**
  - **Detailed categories following Census**
  - **Additional categories**
  - **Capacity to aggregate this collected data under broad OMB categories for reporting purposes**

- **State partnership**

- **New race and ethnicity categories - effective January 1, 2007**

- **Primary language data collection – effective January 2008**

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Hispanic Origin Categories

Codes   **Categories**

0   No, not Spanish/ Hispanic/ Latino

1   Yes, Mexican, Mexican American, Chicano

2   Puerto Rican

3   Cuban

4   Central or South American

5   Other Spanish/ Hispanic/ Latino

9   Unknown/Unavailable

A   Declined to Answer

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Race Categories

Codes	**Categories**
1	**White**
2	**Black or African American**
3	**American Indian or Alaska Native**
A	**Asian Indian**
4	**Chinese**
7	**Filipino**
5	**Japanese**
B	**Korean**
D	**Vietnamese**
8	**Other Asian**
6	**Native Hawaiian**
E	**Guamanian or Chamorro**
C	**Samoan**
F	**Other Pacific Islander**
I	**Multiracial: White and Black or African American**
J	**Multiracial: White and American Indian or Alaskan Native**
K	**Multiracial: White and Asian**
0	**Multiracial: Black or African American and American Indian or Alaskan Native**
H	**Other Race**
9	**Unknown/Unavailable**
G	**Declines to Answer**

Asian Categories

Native Hawaiian and Other Pacific Islander Categories

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Training Curriculum, *cont.*

- Builds upon existing resources - the American Hospital Association's HRET tools

- Standard protocols for systematic collection of data on patient race, ethnicity and primary language

- Information on recommended policies and procedures

- Recommended race and ethnicity categories and their definitions

- **Steps to follow during patient interview**

- **Q/A to address concerns of patients about the rationale for collecting these data and their use**

- **Q/A to address concerns of front-line staff about complex situations and how to handle them**

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Training Curriculum, *cont.*

Sample patient responses:

Can't you tell by looking at me?

Why do you need to know my race and ethnicity?

I'm American

Will you treat me differently if I say I'm not white or not a U.S. citizen?

Who looks at this?

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Major Areas of Focus

- Educational tools and resources for registrars
  - Culturally sensitive interview techniques.
  - Patient interview script.
- Reference tools for patients
  - Information sheets on data collection
  - Laminated cards with R/E categories.
- Primary language collection tools and resources.

Develop Reference Tools& Resources

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Reference Toolkit –
Quick Reference for Hospital Registration Staff

Includes all patient and hospital staff resources:

- Patient resources for collection of patient race and ethnicity data (available in 14 languages) include:
  - Fact Sheet for Patients
  - Hispanic origin and race categories

- Patient resource for collection of patient primary language data include:
  - "I Speak…" language identification guide, includes "I Speak…" phrases in 47 different languages.
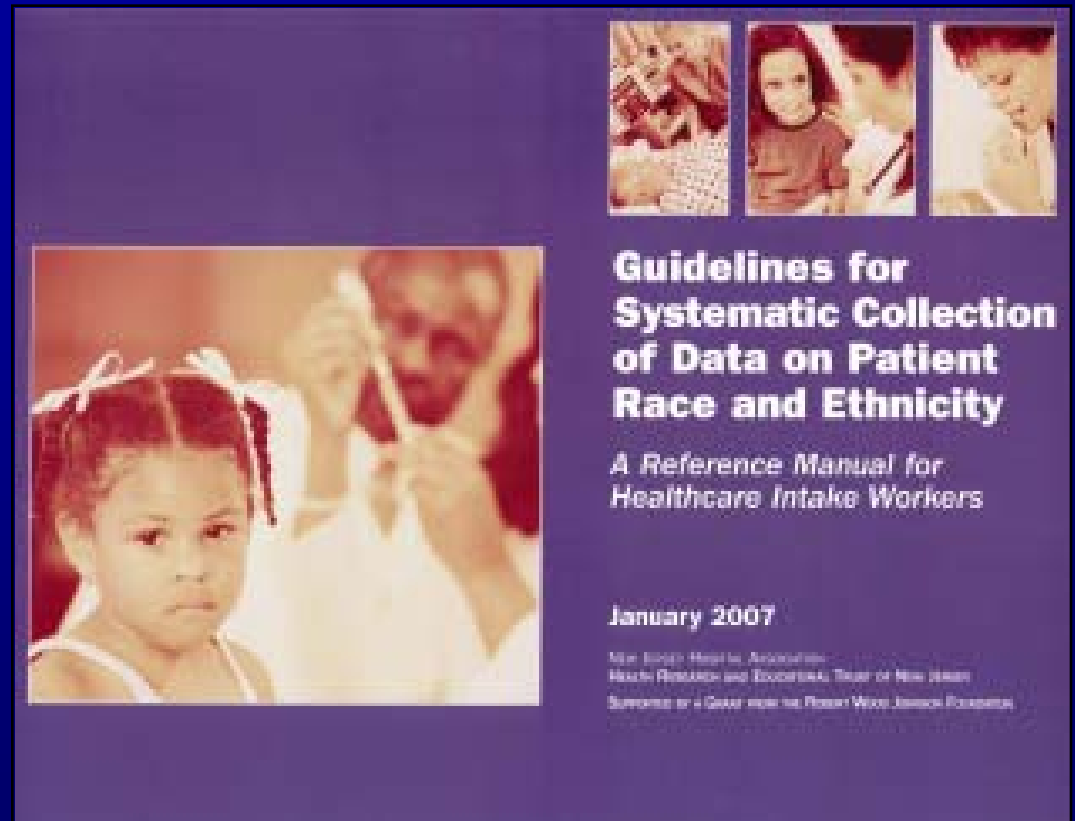
Guidelines for Systematic Collection of Data on Patient Race and Ethnicity

A Reference Manual for Healthcare Intake Workers

January 2007

New Jersey Hospital Association
Health Research and Educational Trust of New Jersey
Supported by a Grant from the Robert Wood Johnson Foundation

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Reference Toolkit –
Quick Reference for Hospital Registration Staff, cont.

- **Hospital Staff resources include:**
  - Interview script for collecting patient race and ethnicity data

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Interview Script for Collection of Patient Race and Ethnicity Data

- **Provides step-by-step directions about how to collect race and ethnicity information during the patient interview process. It includes:**

    - How to ask race and ethnicity questions.

    - How to assist patients in identifying their preferred race and ethnicity category.

    - How and when to use the reference tools and resources during a patient interview.

    - How to effectively answer patient questions about the rationale for collecting patient race and ethnicity data.

    - How to address patient concerns about confidentiality.

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Reference Toolkit – Quick Reference for Hospital Registration Staff, cont.

- **Hospital Staff resources include:**
  - Interview script for collecting patient race and ethnicity data

  - Definitions of Hispanic origin and race categories

  - Quick Reference Tool: Hispanic Origin/Race Categories, Definitions and Sample Responses

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The Quick Reference Tool:
Additional Hispanic Origin Responses

Lists additional Hispanic origin responses not included in the recommended list and their appropriate categories.

(Code: 0) Not Spanish/Hispanic/Latino

(Code: 1) Mexican, Mexican American, Chicano

(Code; 2) Puerto Rican

(Code: 3) Cuban

(Code: 4) Central or South American - Examples may include people who indicate their Hispanic origin as:

- Argentinean
- Bolivian
- Chilean
- Colombian
- Costa Rican
- Dominican
- Ecuadorian
- Guatemalan

- Honduran
- Nicaragua
- Panamanian
- Paraguayan
- Peruvian
- Salvadoran
- Uruguayan
- Venezuela

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The Quick Reference Tool: Additional Race Responses

Includes a list of additional race responses not included in the recommended list and their appropriate categories.

(Code: 1) White – A person having origins in any of the original people of:
- Europe
- Middle East
- North Africa

Examples may include people who indicate their race as:
- Arab
- German
- Irish
- Italian
- Lebanese
- Near Easterner
- Polish
- White

(Code: 2) Black or African American– A person having origins in any of the Black racial groups of:
- Africa

Examples may include people who indicate their race as:
- African American
- Afro-American
- Black
- Haitian
- Kenyan
- Nigerian

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Reference Toolkit –
Quick Reference for Hospital Registration Staff, cont.

- **Hospital Staff resources include:**
  - Interview script for collecting patient race and ethnicity data
  - Definitions of Hispanic origin and race categories
  - Quick Reference Tool: Hispanic Origin/Race Categories, Definitions and Sample Responses
  - Frequently asked questions
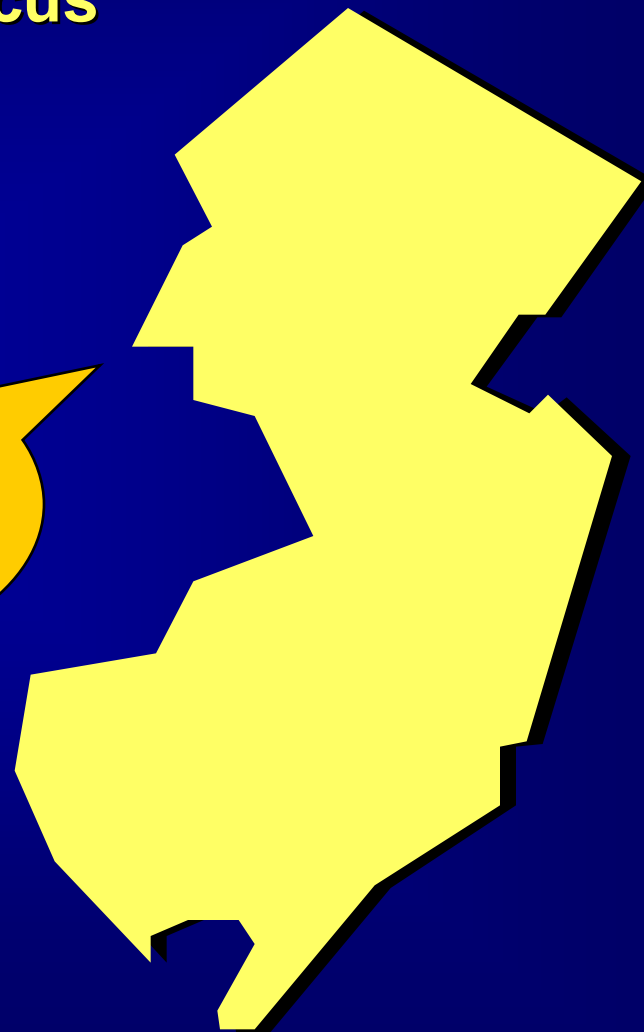 - Interview Script for collecting patient primary language data

- **Resources are laminated for durability and multiple use.**

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Major Areas of Focus

- Training Toolkit
- Instructional Video
- Web-based interactive training course

Develop Provider Training

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Training Toolkit – For Hospital Education Units and Access Managers

- ■ **Provides tools, knowledge and skills to guide intake staff in properly collecting data.**

- ■ **This toolkit is developed for use as a train-the-trainer resource for hospital education units and access managers.**

Guidelines for Systematic Collection of Data on Patient Race and Ethnicity
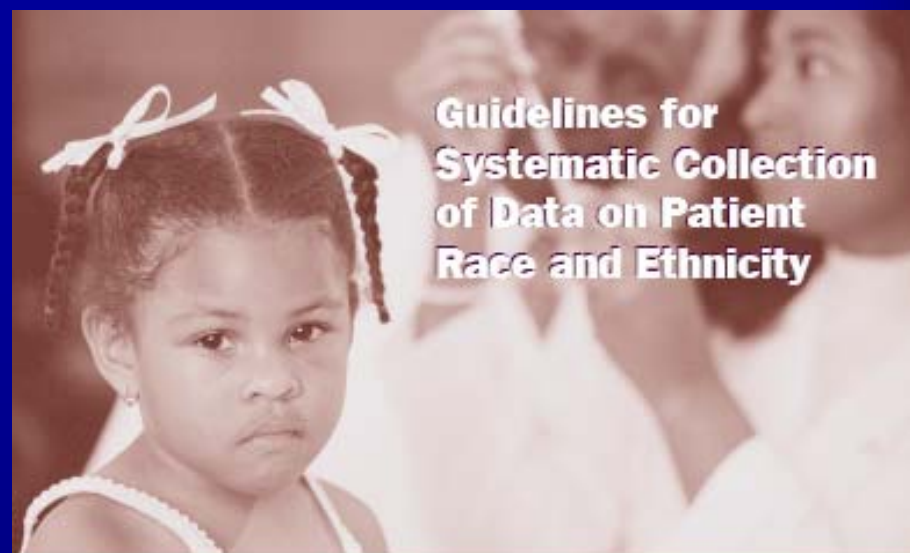
A Manual for Training Healthcare Intake Workers

January 2007

NEW JERSEY HOSPITAL ASSOCIATION
HEALTH RESEARCH AND EDUCATIONAL TRUST OF NEW JERSEY
SUPPORTED BY A GRANT FROM THE ROBERT WOOD JOHNSON FOUNDATION

Improving Patient Race and Ethnicity Data Collection

A Guide for Healthcare Registrars

March 2007

NEW JERSEY HOSPITAL ASSOCIATION
HEALTH RESEARCH AND EDUCATIONAL TRUST OF NEW JERSEY
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Training Toolkit – For Hospital Education Units and Access Managers, cont.

■ **The toolkit includes:**

- The training curriculum;

- Educational tools and materials to guide front-line staff during the interview process and help patients self-identify their race and ethnicity;

- Exercises and Q/As regarding complex situations and how to handle them; and,

- Reference Manual.

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Instructional Video

- **Provides a short (15 min.) training course for hospital staff.**

- **Includes mock interviews of different patient groups and commonly encountered patient concerns.**

- **Addresses training issues due to high staff turnover.**

- **Included as part of the new staff orientation and the current staff routine in-service training.**

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# *Web-Based Interactive Training Course*

- **Provides the entire curriculum in 6 learning modules.**

- **Includes short review assessments after each module and a final assessment at the end of the course to test the course effectiveness.**

- **Expected to go live February 2008.**

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Major Areas of Focus

- Statewide Conference

- Regional Train-the-Trainer sessions

- On-site technical assistance-consultations

- Distribution of resources to NJ hospitals and other agencies

Offer Educational Programs

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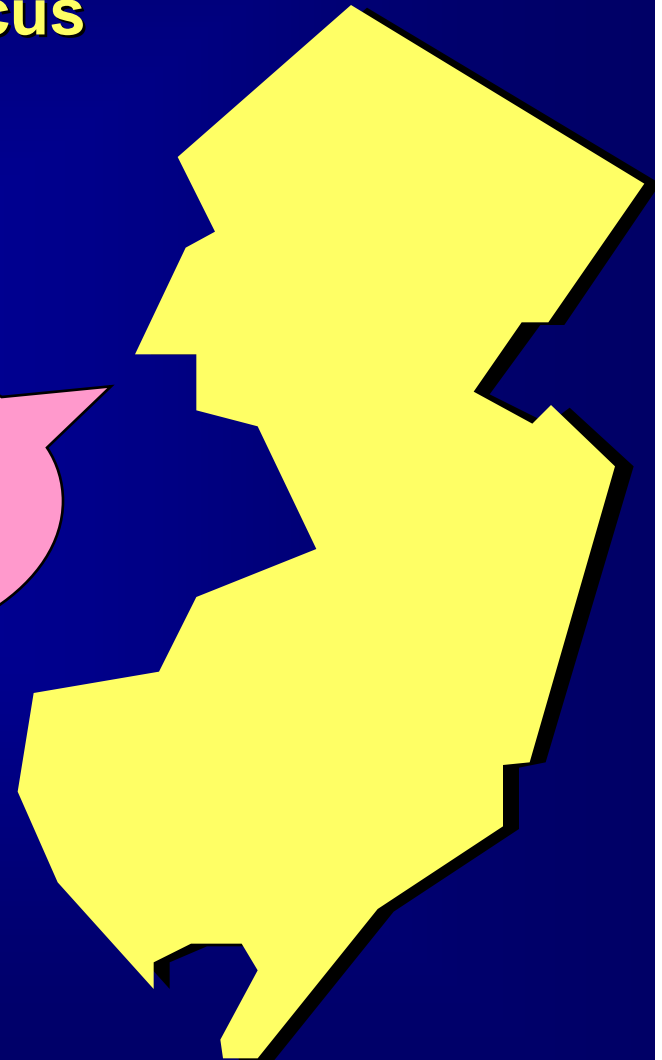
Recommendations / Tips for Hospitals

- **Employ all guidelines and protocols in your routine collection of patient race and ethnicity data.**

- **Use recommended guidelines across all registration encounters.**

- **Provide on-going training for your registration staff.**

- **Collect routine feedback from your staff about their concerns/barriers.**

- **Address staff concerns regularly and improve data collection process as needed.**

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Conclusion - Next Steps

■ **Evaluate outcomes**

- **Evaluate effectiveness of conference, training sessions, training tools and educational resources**

- **Survey and focus groups of hospital staff**

- **Track new hospital programs/initiatives**

- **Monitor race/ethnicity data for 2003-2007**

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Patient Race and Ethnicity: Education Campaign to Improve Hospital Data Collection and Reporting

Our sincere thanks to the:

- ● **Robert Wood Johnson Foundation**

- ● **New Jersey State Department of Health and Senior Services**

- ● **Project's Advisory Panel**

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