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ABSTRACT
The Hospital Association of Rhode Island, in conjunction with the Rhode Island Cancer Registry, received funding for a special project to improve the validity and reliability of race and ethnicity data in hospital inpatient records. In the past year, five hospitals participated in a pilot to improve race/ethnicity data collection. This paper provides an overview of the design and initial implementation of the pilot, and reports on early feedback. Given that the Affordable Care Act strengthens federal data collection efforts, with a new standard issued which adds granularity, these policies can renew efforts to record more accurate and detailed race and ethnicity data. Improved race and ethnicity data will increase our understanding of the health needs of different racial and ethnic groups and health disparities between groups. Better data improves understanding, increases the likelihood of effective actions to address and monitor disparities, and ensure that every American has the opportunity to live the healthiest life possible.

KEYWORDS: Race/ethnicity, data collection

INTRODUCTION
In its landmark 2003 report, the Institute of Medicine noted the high prevalence of racial and ethnic disparities in health care. One of the report’s recommendations, as corroborated by other studies, was that “standardized data collection is critically important in the effort to understand and eliminate racial and ethnic disparities.” In a survey of how hospitals collect race and ethnicity data, 51% reported that admitting clerks determined race and ethnicity based solely on observation. While there are many potential benefits to collecting accurate and complete data on race and ethnicity, the foremost is to improve patient care. Hasnain-Wynia and colleagues (2004) point out “by linking clinical information with information about patients’ race, ethnicity, and primary language, [organizations] will [...] develop interventions [...] to improve the care process for various population groups.”

In response to these data quality concerns, in 2010 the Hospital Association of Rhode Island (HARI) secured funding for a special project, the Data Improvement Project on Patient Ethnicity and Race (DIPPER). The goal is to improve the accuracy and completeness of patient race and ethnicity data for 11 acute care hospitals, the central cancer registry, and health care databases in which Rhode Island participates. Piloting a standardized approach was initiated at five hospitals in the second quarter of 2012. The project has three phases: 1/evaluating current practice, 2/piloting a new approach and 3/developing a voluntary statewide standard for 2013. Pilot hospitals differed in patient demographics, in patient registration software, and in the time and resources they were able to commit to the venture.

This report provides an overview of the design of the pilot, discusses the exploration and adoption of a data collection standard, and summarizes early feedback from pilot implementation. Recommendations for future efforts are also provided.

APPROACH
The initiative began in 2011, by bringing hospital stakeholders together to generate interest, plan, and mobilize support and consensus. The advisory group consists of hospital staff from patient registration, hospital cancer registration, health information management [HIM], hospital administration, Hospital Association staff, partners in cancer control, and staff from the Rhode Island Department of Health. Developed in conjunction with the project’s advisory group, a draft of the proposed voluntary standard was completed in October.

In reviewing the literature on race and ethnicity data collection, a new term emerged. In response to those that identified a need for more detailed ethnic subgroup data in health care research, the term “granular ethnicity” has appeared. Collecting granular ethnicity refers to obtaining more fine-
grained levels of ethnic categorization than has been done previously. This concept is what the Census Bureau defines as ancestry, or “a person's ethnic origin or descent, ‘roots,’ or heritage, or the place of birth of the person or the person’s parents or ancestors before their arrival in the United States.” Ancestry is not the same as the place of birth. The Institute of Medicine subcommittee on data collection adopted the term to describe groups in more detail than the broad Office of Management and Budget (OMB) categories.

Several approaches to race and ethnicity data collection were reviewed. First, the national proposed standard created by the U.S. Department of Health and Human Services, that identifies subpopulations for Hispanics (Mexican, Puerto Rican, Cuban or other), Asians (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese or other Asian), and Native Hawaiians or other Pacific Islanders (Native Hawaiian, Guamanian or Chamorro, Samoan and other Pacific Islander) was considered. Unlike the Census Bureau approach, ‘some other race’ was not a possible response in the federal standard. This increases the likelihood that Hispanics will not find a category for race that they believe accurately describes them. Bhalla et al. (2012) reported “a large proportion of patients of Hispanic/Latino ethnicity declined to identify with standardized race categories.” Other research suggests that not all patients will identify with current categories.

The open-ended approach reported by Baker et al. (2006) was considered, which asks patients to describe their race/ethnicity “with any terms they wanted to use” (and more than 30% preferred using their own words to following the OMB categories). The pros and cons of the state-mandated approaches of Massachusetts and New Jersey, and the voluntary approach of Oregon were also weighed. Recommendations from the Institute of Medicine subcommittee on standardized collection of race/ethnicity data were also considered, and the following limitations and goals were formulated:

1. Given the reporting requirements, which cannot differ between hospitals (i.e., different requirements for pilot and non-pilot hospitals), adherence to the existing two-question format was necessary.

2. Identify subpopulations and granular ethnicities, which are important to Rhode Island. A population-based approach to this question, utilizing data from the 2010 Census, was used.

3. Change ‘unknown’ so that one can distinguish between patients that ‘refused/declined’ to answer from those that are ‘unavailable’ and can be asked at another time.

4. Include instructions so that the data could be reported by OMB categories.

Proposed Patient Interview Standard

The approach that emerged has been modified only slightly from the initial draft, and can be viewed in Figure 1. This served as the basis for modifications to patient registration software and to the approach taken by patient registrars.
Initial Implementation

Before implementation with the new approach, the pilot hospitals modified patient registration systems to accommodate the proposed standard. Software systems varied in flexibility. Only some systems allowed the addition of new variables [e.g., ‘self-identified,’ ‘yes’ or ‘no’]. Text fields were difficult to add. While most hospitals kept race to a single variable, some hospitals created more than one race field to more easily capture biracial patients. All hospitals were able to separate unknown into either ‘unavailable’ or ‘declined/refused’ and changed drop-down menus for existing questions.

Following changes to registration systems, staff training was provided. Training manuals, workstation resources, such as cue cards (and translations), and suggested responses to common patient questions were tailored to Rhode Island. Electronic versions of brochures were also provided to hospitals. DIPPER received permission to use the “We Ask Because We Care” posters, which, along with the brochures, provided tangible support to staff when responding to patient concerns.

At some sites, staff requested a written form. Some patient registrars would have preferred a written questionnaire to be completed by patients. Although this approach has pros and cons, several stakeholders believed the negatives outweighed the positives. Some advisory group members expressed concern this method might not yield accurate and complete information. Primarily, objections stemmed from concerns about literacy and comprehension.

Initial Feedback

The evaluation included a form to record observations about the patient-staff interaction. Observations were made in several areas where registration takes place, including emergency departments, admitting, preregistration, labs and clinics. Most patients had no difficulty or objection to answering the questions. While staff could recall patients that asked questions or declined, no refusals were directly observed.

In cases where patients expressed noteworthy reactions to the way questions were asked, these responses can be sorted into three groups, as shown in Table 1. The first is a visual assumption reaction, such as “Do I look it?” The second is an exclusion reaction, where one either believes the identification of one group is of higher priority than another, or believes s/he is excluded from the possible response options. It is possible that a form with a relatively short list of granular ethnicities is more likely to elicit a feeling of being excluded than a blank line would. This led to the addition of more commonly encountered ancestry terms to the standard and cue cards.

The last noteworthy reactions were those delighted that their cultural background was listed on the cue card. This is a relief reaction, and the example listed in Table 1 came from a Cape Verdean patient. Feedback from staff was generally positive, although non-normative patient feedback was a concern. Some staff reported it was going better than they had anticipated. Many believed adding granular ethnicities was a welcome change, and made their job easier. Resistance to carry out this data collection was greatest where staff believed patient privacy was compromised and waiting time is already of concern. There was also resistance in outpatient laboratories, where it conflicted with staff expectations of efficiency and the rationale for data collection seemed far removed from present tasks and concerns.

Data analysis from the second quarter is not yet available, but preliminary feedback from IT/IS staff has been requested.

DISCUSSION

A group of key stakeholders developed a draft standard for collecting patient race and ethnicity. The redesign was intended to improve the identification of granular ethnicities that are most frequently encountered. DIPPER standardized the racial and ethnic categories used in Rhode Island, who would provide this information (patients or their family member or caregiver), how hospitals should report it (including instructions for OMB categories), and responses to a number of frequently encountered patient responses. After initial observations, the proposed standard was revised in response to feedback. An abbreviated version of the introduction and additional ancestry terms were added to the draft standard. The terms on the cue cards now encompass 75% of the state’s population, and ‘other’ with a blank line is also a choice.

Preliminary results suggest most patients are answering the questions. Feedback from patients and staff is generally positive. Outpatient laboratories, where patient data is often collected for the first time in a hospital system, are sites where staff members tend to be the most surprised that they should ask about patient’s race and ethnicity. Data from hospitals will be examined once available.

Table 1. Examples of non-normative patient feedback at pilot sites

<table>
<thead>
<tr>
<th>Visual assumption reaction</th>
<th>Exclusion reaction</th>
<th>Relief reaction</th>
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<tbody>
<tr>
<td>Staff: “Do you consider yourself Hispanic or Latino?” and “Which race best describes you?”</td>
<td>Patient: “Why don’t you ask about Italian or Irish?”</td>
<td>Patient looking at cue card: “I’m on here! Take my picture!”</td>
</tr>
<tr>
<td>Patient: “Do I look it?”</td>
<td>Patient: “Please don’t cater to _________.”</td>
<td></td>
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In health care entities that own several hospitals, computer software changes often must occur simultaneously at multiple sites. Depending on staff availability for coaching and consulting, this can result in too many sites needing assistance at the same time. Early weeks are critical if staff members are encouraged to ask race and ethnicity only once, because once that information is “in the system” it will not be asked again. Future efforts should ensure that support materials such as posters and brochures are printed and available prior to the launch date. These provide critical support to staff, and are important features of initial implementation. Future efforts should also allow flexibility to change which granular ethnicities are most important to identify over time. Including the most frequently encountered ancestry terms may ensure that no patient feels isolated or excluded. Ideally, fully standardizing when and where the data are collected should be done prior to initial implementation. While DIPPER aimed its effort at inpatients, because of changes to the patient registration system which affected multiple areas and clinics within a system, the scope of the project was sometimes larger than initially intended. Two sources of unknown data that should also receive special attention are ‘specimen only’ or ‘lab/path reports’ and ‘newborns’, which frequently increase the proportion of unknown race and ethnicity data.

Given that race and ethnicity are required items in Section 4302 of the Patient Protection and Affordable Care Act, it is expected organizations will do more in the future to ensure that race and ethnicity data collection is accurate and complete. In the coming year, DIPPER will strive to have all acute care hospitals in Rhode Island adopt the voluntary statewide standard for race and ethnicity data collection. This would involve changes to patient registration systems and staff training at the hospitals that were not initially part of our pilot project.

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