

DiversityRx – Your Voice

Webinar #1:

Race, Ethnicity, and Language Data to Improve Health Care Quality: An overview of the new Institute of Medicine report and perspectives from the field

Monday, September 21, 2009

Questions Log

Section I: Responses to Questions Prepared by Presenters After the Webinar

Q: For Ms. Hasnain-Wynia: In the end, this may reduce health care cost by the reduction of medical errors and other potential health care complications when patients are more involved in their care (language barriers are reduced). Is this standardization of data collection mandated to every health care organization across the nation or is this something that is just highly recommended?

Response: The recommendations discussed during the Webinar are based on the recent report by the Institute of Medicine, which makes recommendations, but does not issue mandates. The IOM subcommittee calls on all health care entities to systematically collect race, detailed ethnicity, and language need data in accordance with the recommendations of the report so that they can be used to identify and address disparities in care. Health care entities have indicated that they have been reluctant to make changes to their systems until there is a standardized categorization approach for race, ethnicity, and language need. This report addresses that barrier. An earlier report by the National Research Council, *Eliminating Disparities: Measurement and Data Needs*, also stresses HHS’s critical role in implementing change.

The federal government’s authority to mandate the nature of data collection is limited, except in large federal health care delivery systems, through the purchasing power of programs such as Medicare, or for recipients of other federal funding mechanisms. HHS administers programs supporting the health care delivery system to provide care to persons at risk of receiving suboptimal care, and these programs present opportunities to influence the quality of care delivered to millions of Americans. For example, at least a 100 million of the 300 million people in the country are served by just three programs administered by HHS—Medicare, Medicaid, and community health centers. That said, there a number of states that mandate data collection by health plans and providers (e.g. Massachusetts, California) The full IOM report also lists the full set of legislation cited in the report.

Q: With collection of granular and other ethnicity data, how will safeguards against discriminatory use of the data be ensured?

Response: The purposes of data collection are for health care quality improvement. Race, ethnicity and language data collection has been mandated previously to ensure that there is compliance **with the laws for nondiscrimination**. Across all entities, these data must be collected, stored, and used responsibly with adequate attention to stewardship of the data.

The legal basis for the collection of race and ethnicity data is well documented, and at least 80 program-specific statutes require reporting and collecting race, ethnicity, and/or language data (including the Title VI of the Civil Rights Act; 2008 MIPPA law regarding Medicare fee-for-service, Medicare Advantage private plans, and Part D prescription drug plans; and the American Recovery and Reinvestment Act of 2009 (ARRA) expectations for electronic health records). A handful of states prohibit collection of race and ethnicity data at the time of enrollment for insurance/health plans, but do not prohibit its collection after enrollment. HIPAA does not restrict the collection of demographic data for quality improvement purposes.

Q: One problem is that the race/ethnicity data don't seem to "follow" the patient across providers. For example, we as a home health care agency, often can't get this info from the hospital who is discharging the patient to us, or from the health plan. What efforts are being made to encourage that this information is considered "essential" in "following" the patient? That would avoid asking the patient numerous times

Response: The subcommittee recognized the importance of reducing redundancies and addressed the need to build an information infrastructure to ideally enable integrated exchange within and among organizations to avoid repeated collection of these data.

Q: We have staff members who are very resistant to asking the race/ethnicity question, feeling it's disrespectful and intrusive. Some patients also question our interest in these answers, feeling that their care will somehow be impacted. No matter what we say to them, they have "no response." Ideas on dealing with this?

Q: Question for Romana: How does the IOM or other experts recommend that hospitals deal with the reluctance of patients to divulge race/ethnicity data as well as staff who may not feel comfortable pressing for this information? Can you talk about existing resources out there for training hospital staff?

Response: Training, Training, Training—It makes a big difference. Engaging staff early in the process, providing an educational session about why these data are important and how they will be used is critical to creating a partnership with staff. From my experience, they will ask a lot of questions and will also fully understand why this information is important, even if they were reluctant at first. Training and education is critical because it also changes the dynamic

about how staff interact with patients about these issues, how they address concern, and pushback. Staff that come in with a knowledge base about data collection and its use before implementation of systematic data collection within their organizations (versus just a directive to collect this information) are empowered to do it effectively and respectfully. Tools that go into detail about training include the HRET Toolkit.

Q: Will you please explain what OMB stands for again?

Response: The Office of Management and Budget, which is the Federal government agency tasked with overseeing Federal statistics.

Q: What does the acronym HEDIS stand for?

Response: The Healthcare Effectiveness Data and Information Set (HEDIS) is a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service. Performance on HEDIS measures is a critical component to achieving accreditation status for health plans. Many health plans offer performance incentives to contracted medical groups and physicians for meeting these quality measures, as well.

Q: How do you define a "hot spot"?

Response: At WellPoint, the term "hot spot" is loosely defined as a geographic location where there is high health disparities in the measure being studied, as well as high population density of racial/ethnic minorities.

Q: Are there laws or regulations that require the collection of race or ethnicity data?

Q: What is the legality of a medical practice asking for race/ethnicity?

Response: In general, there are no prohibitions on the collection of race or ethnicity data at the Federal level. Title VI of the Civil Rights Act of 1964, Title VII of the Civil Rights Act of 1964, and Health Insurance Portability and Accountability Act of 1996 (HIPAA) do not restrict collection of REL data for quality improvement purposes. The Medicare Improvements for Patients and Providers Act of 2008 directs Secretary of Health and Human Services to evaluate, report on, and implement approaches for collection on race, ethnicity, and gender data.

On a state-specific level, six states (CA, MD, NH, NJ, NY, and PA) restrict collection of R/E data for health plans, but generally only application forms to gain insurance coverage. The regulations generally allows collection of REL data outside the application process (e.g., for disease management and language assistance programs).

Q: What methodologies are recommended for data collection; do staff speak specific

languages/dialects of a certain race/ethnic group; are forms in their languages?

Response: If you are in a direct care providing setting, i.e., doctor's office or a hospital, one option may be to use a modified version of the U.S. Census Language Identification Flashcard: http://2010.census.gov/partners/pdf/langfiles/LAG_flashcard.pdf

Q: Also, as these populations increase what assessment tool is recommended to ensure that members of these groups are not stereotyped into a "cookie cutter" mode of healthcare provision. Their personal views of western dominant cultural may merge with their ancestral traditions...we will need to discern these variables to provide patient centered care? Thank you.

Response: Collection of REL data is only the starting point to gain a deeper understanding of health disparities trends and linguistic and other staffing support needs. However, equally important for health care organizations is staff training on effective cross-cultural communication and health literacy issues.

Note – this may be a separate DiversityRx Your Voice Webinar topic.

Q: What are some ideas to engage top administrators in collecting this data?

Response: Many organizations have found that being able to demonstrate that health disparities exist within its own patient/member population using even imperfect R/E data available (third party data from State Medicaid programs, Medicare, indirect estimation models), is a critical first step in engaging senior executives in the discussion. The business case is definitely available. A recent study released in September 2009 wherein researchers at Johns Hopkins and the University of Maryland found that over 30 percent of direct medical expenditures for members of racially/ethnically diverse populations were excess costs linked to health inequalities. Further, these researchers state that eliminating these inequalities would have saved the U.S. economy a grand total of \$1.24 trillion dollars.

Q: While I think everyone feels like this data is important to collect, it seems like individuals are very reluctant to provide this information, fearing discrimination. While standardization may help, can you please comment on strategies to decrease this perception and how to increase the volume of individuals that respond to race, ethnicity, and linguistic questions.

Response: When Aetna first started actively collect REL data directly from its members, it conducted focus groups on the best way to collect this data. The results indicated that once they understood HOW the data is to be used (for quality improvement, to develop language programs) and that the data would be handled securely, they were much more willing to provide REL data. They did not care to hear a laundry list of how the data will not be used (for underwriting, for making claims decisions, etc.)

Q: Many people of mixed race and mixed ethnicity need a way to indicate multiple race or ethnicity. How to handle this?

Response: For patients who are bi-racial or of mixed ethnicity, some organizations build additional data fields into their IT system to accommodate for an additional/secondary R/E code.

Q: What consideration was given to the potential problems incurred by aggregating African Immigrant data with African Americans when using the category "Black" in collecting data?

Response: Yes, the health care and linguistic needs may be very different. This is why collecting ethnicity/country of original data is very helpful in determining whether or not there are differences in the disparities trends observed.

Q: If a patient is 50% Japanese and 50% Caucasian, are both collected or should the patient choose the ethnicity/race they identify with most strongly? Does quantum matter?

Response: Some organizations collect both and will build additional fields into the IT system, but otherwise, encourage the patients to choose the ethnicity/race with which they share the most affinity.

Q: You speak about accuracy of race data - since race is not an objectively definable concept, what is the definition of accurate. If the person's own assessment is the final authority, how can indirect methods ever attain any level of accuracy.

Response: By accuracy, we mean when estimated REL data derived through indirect methodologies are compared with a known set of member's self reported REL data, which is indeed considered the gold standard.

The sensitivity, specificity and positive predictive value validation tests serve as a fair measure of the effectiveness and reliability of the logistic model of indirect race/ ethnicity data methodology as a diagnostic tool. Internal testing of WellPoint's current methodology has yielded excellent results to date. Model development and testing utilized a dataset from WellPoint's California and Connecticut State Sponsored business that contains race/ethnicity data on approximately 1.3 million members. Prior to running the regressions, 192,096 member records were extracted from the model development database and set aside to be used for validation testing. The resulting model predicted within 0.1% of the actual aggregate demographics for the validation sample. This is a marked improvement over the more traditional marketing approaches of using surname lists or census data separately.

Q: Can you clarify what the methods of indirect classification are available, relative strengths/weaknesses?

Response: There are two major categories of indirect data:

- (1) REL data obtained from a third-party – state or federal program eligibility data, other industry stakeholders in the care delivery chain (physician’s offices, hospitals), or from employer groups.. Pros – data may be self-reported by the patient; any granular ethnicity details collect may be more accurate. Cons – data may also be “estimated based on data intake personnel’s perception of the person’s race, ethnicity or language needs; data is likely still not available for entire patient population; data congruency and mapping may pose technical barriers.

- (2) Estimated REL data derived through predictive modeling and statistical analyses using geocoded data from the U.S. Census and surname analyses. Pros – process is relatively inexpensive to implement compared to direct collection or third-party data; in theory, able to estimate data for the majority of the patient population; estimated data at the aggregate level can be highly accurate; estimated data at the individual level may be fairly accurate, if taken above a high confidence level/threshold. Cons – data is an estimation; use of such data for direct, individual outreach may be construed as racial profiling or cause patient abrasion.

For the reasons above, primary source (patient self-identified) data should always be the gold standard. However, in the partial or complete absence of such data, the indirect data sources still offer health care organizations a starting point and the means to study health disparities trends and to initiate quality improvement activities.

Q: Grace spoke to Indirect collection. Would like to know more about this. Methods, etc.

Response: WellPoint’s indirect predictive model for REL data is proprietary, but the Rand Corporation offers consulting services that could guide health care organizations in implementing an indirect data strategy. WellPoint’s indirect REL predictive model is similar to that offered by the RAND Corporation, but there are some differences. However, these differences point to the flexibility of the predictive model in arriving at the best model that fits your business. The contact at the RAND Corporation for indirect methodology is Dr. Allen Fremont: fremont@rand.org.

Section II: FULL LOG OF QUESTIONS FROM THE WEBINAR

Definitions

Q: Will you please explain what OMB stands for again?

Q: What does the acronym HEDIS stand for?

Q: How do you define a "hot spot"?

Operationalizing Data Collection:

Formulating the Questions

Q: To clarify, OMB race, OMB ethnicity, and granular ethnicity are all intended to be separate questions? If so, can you clarify how the granular ethnicity question would be operationalized as a separate question from OMB ethnicity, or would it be acceptable to combine the ethnicity questions?

Legal/Regulatory Issues

Q: Are there laws or regulations that require the collection of race or ethnicity data?

Q: What is the legality of a medical practice asking for race/ethnicity?

Q: For Ms. Hasnain-Wynia: In the end, this may reduce health care cost by the reduction of medical errors and other potential health care complications when patients are more involved in their care (language barriers are reduced). Is this standardization of data collection mandated to every health care organization across the nation or is this something that is just highly recommended?

Q: Can Dr. Hasnaian-Wynia expounded the ARRA requirement related to this subject?

Safeguarding the Data

Q: With collection of granular and other ethnicity data, how will safeguards against discriminatory use of the data be ensured?]

Payment Incentives

Q: Are payment incentives designed to help defray the costs of this data collection for geographic areas that have a great deal of diversity?

Q: Romana-What type of payment incentives are offered to patients for collecting data? I didn't quite understand, can you explain?

Continuity of care:

Q: One problem is that the race/ethnicity data don't seem to "follow" the patient across providers. For example, we as a home health care agency, often can't get this info from the hospital who is discharging the patient to us, or from the health plan. What efforts are being made to encourage that this information is considered "essential" in "following" the patient? That would avoid asking the patient numerous times.

Q: Do the current health reform bills working their way through Congress address data collection for eliminating disparities?

Training Staff/ Engaging Leadership

Q: My question is about strategies for motivating agencies to collect race/ethnicity data, and how to motivate them to train personnel in how to ASK the client to identify their own race / ethnicity. We have found resistance to doing it period, as well as machismo about thinking the provider can just silently identify these themselves without asking any questions. Thank you.

Q: What methodologies are recommended for data collection; do staff speak specific languages/dialects of a certain race/thnic group; are forms in their languages?

Q: Also, as these populations increase what assessment tool is recommended to ensure that members of these groups are not stereotyped into a "cookie cutter" mode of healthcare provision. Their personal views of western dominant cultural may merge with their ancestral traditions...we will need to discern these variable to provide patient centered care? Thank you.

Q: What are some ideas to engage top administrators in collecting this data?

Patient & Staff Resistance to Providing Data:

Q: In dealing with state health departments, a continuous issue that they face in obtaining vital information is the refusal of participants to provide demographic information. Can we develop specific training to help health care workers explain the need for this information with the understanding that their participation will help target funds and services where needed most?

Q: While i think everyone feels like this data is important to collect, it seems like individuals are very reluctant to provide this information, fearing discrimination. While standardization may help, can you please comment on strategies to decrease this perception and how to increase the volume of individuals that respond to race, ethnicity, and linguistic questions.[]

Q: What about the vast majority of our patients, who insist they are "American." Should that be a choice? They are very upset when that is not a choice.

Q: What are the recommendations for addressing discrimination and trust issues?

Q: We have staff members who are very resistant to asking the race/ethnicity question, feeling it's disrespectful and intrusive. Some patients also question our interest in these answers, feeling that their care will somehow be impacted. No matter what we say to them, they have "no response." Ideas on dealing with this?

Q: Question for Romana: How does the IOM or other experts recommend that hospitals deal with the reluctance of patients to divulge race/ethnicity data as well as staff who may not feel comfortable pressing for this information? Can you talk about existing resources out there for training hospital staff?

Classification Issues:

Q: Race/ethnicity is an American construction that has been imposed to those that immigrate to the States. Most of the time race/ethnicity is not a concern in the country that those patients come from, so there is the first problem in problem in collecting quality data collection. Thanks.

Q: I have noticed that many immigrants just don't understand the context or meaning of the question and why we ask it. Can you address this?

Q: Why do we have african american, and not also asian american, european american, oceania american etc. in racial classification?

Q: The OMB data sets include several Middle Eastern ethnicities under White. How does the

IOM report address this?

Q: Also, many Hispanics are European-origin individuals... that is white population

Q: Many people of mixed race and mixed ethnicity need a way to indicate multiple race or ethnicity. How to handle this?

Q: Can you discuss the potential differences between granular ethnicity (as identified by ancestry), and self-reported ethnic identity? Are they the same? Perhaps, but perhaps not...ancestry and self-reported salient ethnic identity may be different.

Q: What consideration was given to the potential problems incurred by aggregating African Immigrant data with African Americans when using the category "Black" in collecting data?

Q: What about patients who say they are "a mongrel, ha ha" or they don't know who their ancestors are, or that they are such a combination they can't specify just one ethnicity.

Q: I assume that a group like Garifuna of Central America would have to be "other". But what about over distinctions say between AmerIndian and Mexican indigenous or Central American Indian?

Q: How were mixed ethnicities dealt with?

Q: If a patient is 50% Japanese and 50% Caucasian, are both collected or should the patient choose the ethnicity/race they identify with most strongly? Does quantum matter?

Q: The OMB category for Hispanic/Latino is incorrect as it links to language. "Hispanic" actually means someone of Iberian genetic origins, but the OMB leaves out Brazilians due to language alone. The present Hispanic term is utilized often by those who are culturally Latino by means of country of origin and/or language, but who genetically are of western & northern European descent. This also affects ability of Brazilian-ethnicity students to be able to access professional education & training programs aimed at ending health inequalities. In addition, in states like MA and CA, there are many immigrants not only from Brazil, but also from other Portuguese-speaking countries, incl. in Africa.

Q: And furthermore, the OMB categories need to be updated to help us address inequities in growing field of genomics.

Q: When does an immigrant from the Caribbean, whose family has lived here for generations become an "African American" or "Black"

Q: How separate biology from geography/culture when considering one's granular ethnicity?

Indirect Classification

Q: You speak about accuracy of race data - since race is not an objectively definable concept, what is the definition of accurate. If the person's own assessment is the final authority, how can indirect methods ever attain any level of accuracy.

Q: Can you clarify what the methods of indirect classification are available, relative strengths/weaknesses?

Q: Question for Romana. You speak about using indirect estimation of ethnicity. However, this interjects a large amount of bias as you are relying on someone else's perception of what the individual patient's ethnicity is. How would you prevent this type of error?

Q: Standards discussed regarding direct collections methods, but none mentioned regarding indirect methods. We receive data that includes a large amount of indirect information that is poorly collected, but no one at this time is willing to spend additional money to do it right, since it's only require to have information, not correct information.

Also, re-above, can never get all information directly as not everyone will self-disclose, so will always need to get some indirect data.

Q: Grace spoke to Indirect collection. Would like to know more about this. Methods, etc.

Electronic Medical Records:

Q: It takes a long time for the "recommendations" to actually get to the level of software we can use in our electronic medical record.

Q: For Romana- on language data- does the HIPAA transaction code set on enrollment transactions include standard language data?

Q: A big challenge is that none of the major software suppliers e.g. Cerner are developing software for this conversion and therefore hospitals are left to make the expensive conversions themselves.

Other Data:

Q: Is there any thought around collecting what generation people are (Immigrant, first, second, etc. generation) or how people arrive to the country (immigrant, refugee, adopted). i believe both have an impact on health outcomes, perhaps more so than race/granular ethnicity.

Q: are there any attempts to use mitoDNA, RNA, SNP, or other types of genotypic race/ethnicity to define racial origin? While REL may be a reasonable surrogate for health care delivery, it is hardly adequate to define biological/medical relationships.

Q: Why even continue to collect racial data when considering LEP ; would it be more accurate to collect/ focus on language and cultural group? Some examples: "white" doesn't necessary refer to a privileged or non-minority group; rather it may cover many groups who have culture / language gaps, eg from former Soviet Union or Yugoslavia, etc., and "Black" may cover individuals who are born/raised in US as well as individuals who recently arrived from a multitude of African countries, in many cases with huge culture and language gaps (Somalia, Sudan, etc.)

Model Programs

Q: What is the best way to obtain the most accurate race/ethnicity/language information from a pediatric population.

Q: If I wanted to use the Wellpoint Model what would I need to do?

Q: what strategies are health care providers employing to collect accurate and complete REL information?

Q: In a state such as North Dakota or Minnesota where many differences in race or ethnicity are not as visually apparent as in other parts of the country, how do we convince the senior administration in our organization of the need for this, and where do we begin? If we are already using an electronic medical record such as EPIC, can this be easily incorporated into the registration process?

Q: for Grace, are you aware of all the potential initiatives actively in WellPoint that are available for the REL data collection?

Q: I am from a Medicaid Plan. The State does not collect the ethnicity. What ways are there to collect this information in a quality manner, understanding the population changes frequently (sometimes daily).

Resources

Q: Where is toolkit - is it online?

Q: the focus group feedback was very important has that been published?

Q: Where can we get samples of training tools for staff?

Examples of Ongoing Efforts

Q: We, Japan Association of Medical Interpreters, JAMI, established this year needs information to nurture non-professional interpreters, so called "Volunteers" to be able to work in medical setting under imminent situation that the society needs language staff in medical setting not only for H1N1 problem but also for serving a huge number of unserved foreign residents in our nation.