Needed: National Standardization of Race/Ethnicity Data to Address Health Disparities

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There is increased understanding of the role of data in eliminating disparities

- Whether disparities exist
- Whether efforts to address them are working
- Benchmarking
- Accountability
- Advocacy
Despite agreement on the role of data in health care system, collecting it is challenging

• Until recently, few systematic efforts

• Government and private sector efforts out of synch
  – CMS
  – State Medicaid programs
  – Health plans
  – Hospitals
  – Providers
  – Public health
  – Employers
National Health Plan Collaborative (NHPC)

- Public-private partnership to improve quality of care and reduce disparities
- 11 plans, > 87 million members
- Technical support initially from RAND and CHCS
- Sponsored by AHRQ and RWJF; now hosted by AHIP
NHPC Members
90+ million enrollees

• Aetna
• BMC HealthNet
• Cigna
• Harvard Pilgrim
• HealthPartners
• Highmark
• Humana
• Kaiser Permanente
• Molina Health Care
• United Health
• Wellpoint
Challenges in Data Collection

- Use of administrative data (e.g. Medicare, Medicaid)

- ‘Direct’ data collection
  - Gold standard
  - Takes years (despite trying, hard to get >30%)
  - ‘Selection bias’ in who reports
  - Supports intervention and direct to person outreach

- ‘Indirect’ data
  - Fast
  - Supports population-level work
  - Can serve as bridge to direct collection
What have plans done with disparities data?

- Recognized there are disparities amongst their enrollees and their employees

- Pilot interventions
  - Direct-to-member (need directly collected data)
  - Practice level
  - Geographic areas
  - Disease management
  - Other system pilots
The environment is changing

- More diverse America
- More sophisticated consumers
  - Increasing requirements to collect and report on disparities by employers, state/local governments
- More sophisticated view of r/e classification
  - Need to account for ‘missing’ groups
  - Increasing ‘other’ category
  - More appreciation of the roles of ethnicity, culture, language
- Increased role for HIT in making r/e data available
- Focus on equity in Obama administration
Current state

- Health plans and others want to address disparities.

- Many are prepared to invest, but face significant constraints if infrastructure needs to be repeatedly modified to address ‘unwarranted’ variations.

- Plans need uniformity:
  - From state to state
  - For apples to apples comparisons between plans, and across delivery system.
Standardized use of R/E categories is needed

• Need to balance burden and granularity
  – Value proposition varies by stakeholder

• Feasibility of implementation
  – Basic vs Full

• Transferrable and consistent across data sets
  – Employers, providers
  – HIPAA transaction standards
NHPC plans felt they couldn’t/shouldn’t make recommendations themselves

- Lack expertise
- Conflicts of interest
- Don’t represent all plans, or the rest of the delivery system
Plans requested help from authoritative third party

- IOM is neutral, credible and authoritative, and has long track record of working on this issue

- Plans feel a sense of urgency, given state and local mandates, and pace of HIT
  - Would like recommendations by July, 2009
The Equity Case for National Standardization of Race and Ethnicity Data Collection

In its seminal report, *Crossing the Quality Chasm*, the Institute of Medicine (IOM) articulated six domains that define quality of care, including 'equity'. An important dimension of equity is ensuring that people from different racial and ethnic groups do not receive different quality of care. A group of eleven plans working together in the National Health Plan Collaborative (NHPC) has been using a variety of data collection and analytic methods (direct and indirect) to identify and reduce disparities in care. Through this work, the lack of standardization of data collection has emerged as a critical issue that must be addressed if significant progress is to be achieved.

A number of states and localities are now beginning to require the collection and reporting of such data, but their approaches differ substantially. Without strong national leadership, this may result in a series of potentially conflicting requirements across the country. Standardization of data elements to be collected is needed to ensure comparability of information across plans, organizations and sites; facilitate its collection from members, providers, employers and other sources, and facilitate incorporation of data on disparities into ongoing improvement efforts by plans, providers, and others. While NHPC plans are prepared to commit to a common set of practices for race/ethnicity data collection, the process of defining standards in this arena requires a larger group of stakeholders than health plans on their own. A broader, more inclusive group of stakeholders (public, private and philanthropic) is needed in order to address the challenges associated with reaching a consensus on how to standardize the collection of race/ethnicity data and guide the industry in its efforts to meet the equity challenge raised by the IOM.

In order to help its member plans and others to achieve their equity goals, the NHPC requests that the Agency for Health Care Research and Quality, and the Office of Minority Health, perhaps with other key public and private sector stakeholders, ask the Institute of Medicine to lead an effort to define a standard set of data collection methods (direct and indirect) as well as race/ethnicity and language categories to serve as a standard for those entities wishing to assess and report on quality of care across these categories.