Collecting the Data: First Steps in Achieving Health Equity

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Evaluations

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Thank you!

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Disclosure Statements

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- NYS Department of Health
### Why Disparities in Health Care are Important

<table>
<thead>
<tr>
<th>The scale of the problem is large, dramatic and persistent</th>
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<tr>
<td>• pervasive inequality in morbidity and mortality</td>
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<tr>
<td>• disparities continue to exist</td>
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<td>• high cost to society</td>
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### How Quality Data Contributes to Solutions

| • Transparency and self-analysis are critical |
| • Ongoing data collection at the community or institutional level is essential for: |
| ✓ understanding and accurately assessing problems |
| ✓ documenting change |
| ✓ monitoring progress, and |
| ✓ demonstrating maintenance of improvement |

### How Quality Data Contributes to Solutions

<table>
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<tr>
<th>Enables identification of population level patterns</th>
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<tr>
<td>• problems cannot be detected through the experiences of individual patients or groups of individuals</td>
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### Business Case

| • better data leads to increased understanding |
| • increased understanding leads to increased efficiency, improved care, and better health outcomes |
| • translates to lower costs and increased return on investment |

### Topics Covered

| • Background-why disparities in health care matter |
| • Quality/disparities intersection |
| • Race/ethnicity and language data collection |
| • Interventions and a road map forward |

### Health Care Should Be

| • Safe |
| • Effective |
| • Patient-Centered |
| • Timely |
| • Efficient |
| • Equitable |
Definitions

- **Health Disparities**: Differences in the:
  - Incidence,
  - Prevalence,
  - Mortality, and
  - Burden
  of diseases and other adverse health conditions that exist among specific population groups in the United States (NIH Definition)

Definitions

- **Health Care Disparities**: Differences in the quality of health care not due to access-related factors or clinical needs, preferences or appropriateness.
- Difference in treatment provided to members of different racial (or ethnic) groups that is not justified by the underlying health conditions or treatment preferences of patients.
  - (Institute of Medicine definition)

Definitions

- Although disparities in health and health care can be inextricably tied to one another, distinguishing between them increases our understanding of the complexity of the problem.

Major Reports on Health Care Disparities

- The Institute of Medicine (IOM) report, Unequal Treatment identified 600+ studies
- The IOM identified many areas of concern:
  - Cardiovascular treatments and cerebrovascular disease
  - HIV disease (HAART and PCP prophylaxis)
  - Diabetes
  - ESRD/Kidney failure
  - Maternal and child health
  - Cancer care
  - Many surgical procedures

Medical and Policy Literature Provide Extensive Data on Inequities in Care

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Racial and Ethnic Disparities in Health Care

- In patients with insurance, disparities exist for:
  - Primary Care
  - Mammography (Gornick et al.)
  - Influenza vaccination (Gornick et al.)
  - Heart disease
  - Cardiac catheterization & angioplasty (Mason et al., Ayanian et al.)
  - Coronary artery bypass graft (Peterson et al.)
  - Treatment of chest pain (Mason et al., Schulman et al.)
  - Referral to cardiology specialist (Peterson et al.)
  - Lung Ca Surgery (Bach et al.)
  - Renal Transplantation (Ayanian et al.)
  - Pain management (Todd et al.)
  - Amputations (Gornick et al.)
The “Usual” Explanations

- **Patient Level:** Patient “preferences”
  - Treatment refusal
  - Clinical presentation of symptoms
  - Mistrust
  - Communication barriers
- **Provider Level:** Beliefs/Stereotypes re. patient health and behavior
  - Inadequate communication
  - Bias/prejudice
- **Organizational Level**
  - Structural and resource differences in where different groups receive care

Reducing Disparities Within the Health Care System

**Detecting**
- Define health disparities
- Define vulnerable populations
- Measure disparities in vulnerable populations
- Consider selection effects and confounding factors

**Understanding**
- Identifying determinants of health disparities at the following levels:
  - Patient
  - Provider
  - Clinical encounter
  - Health care system

**Reducing**
- Intervene
- Evaluate
- Translate and disseminate
- Change policy

In order to make change, we need complete & accurate data.


Detecting and Understanding

- Quality improvement requires high-quality data.
  - Help hospitals gather data on race, ethnicity, primary language
  - Data provides complete/accurate information
- Hospital leaders need to be willing to discuss the possibility of disparities.
  - Physicians/leaders committed to doing right thing
  - Reluctance to consider gaps in care by demographics
  - Must gather data, examine evidence to provide quality, equitable care

Source: Robert Wood Johnson Foundation, Expecting Success: Excellence in Cardiac Care Program

Why Detecting/Understanding is Important

- **B. Siegel et al. Journal of Health Care Quality (2007)**
  - Hospital and Health Care Leaders—“NIMBH”
  - Did not believe that disparities existed in healthcare delivered to different populations
  - Perceived disparities as a function of social and economic factors beyond their control
  - Participating in a collaborative to reduce disparities would be considered an admission of inequitable care

  - 34% Cardiologists:
    - 34% agree disparities exist overall
    - 12% believe disparities exist in own hospital
    - 5% believe disparities exist in own practice

  - 208 Cardiovascular Surgeons:
    - 13% believe disparities occur often or very often
    - 3% believe disparities occur often or very often in own practice

  - 189 Primary Care Clinicians
    - 88% acknowledged that disparities in diabetes care existed in U.S.
    - 40% acknowledged disparities in own practice
Discrepancy in Perceptions


Quality of Care Framework

Health care disparities should be brought into the mainstream of quality assurance and continuous quality improvement discussions


Barriers to Collecting Data

- Legal concerns
- Privacy concerns
- Patients' perceptions/culture
- System-level barriers
- Staff discomfort in explicitly asking patients to provide this information
- Validity, reliability, and utility of data
- Appropriate categories

Successful Data Collection and Quality Improvement Relies Upon Standardized Measures

HOSPITALS

- 82% collect race/ethnicity data nationally but....
- Categories vary within and across hospitals
- Staff mostly collect through observation
- Staff at some hospitals had been trained to "not ask."
- The vast majority do not use data for quality improvement
The Case for Standardization

Standardized race, ethnicity and language data:
• Support comparisons across organizations and regions and over time
• Support combination of data across organizations or regions to create pooled data sets (especially important for getting beyond small sample concerns)
• Support reporting of, and replication of, successful disparity-reduction initiatives

Institute of Medicine, 2009

Data Standards

• Must be for self-reported measures
  — Or for parents to report for children and guardians to report for legally incapacitated adults
• Must comply with the Office of Management and Budget (OMB) standards
  — The law states current OMB standards for race and ethnicity must be used at a minimum

Existing Guidance

• OMB Directive – 1997
  — Hispanic/Latino Ethnicity
  — 5 Race Categories
• Progress has been made in incorporating the OMB categories into many data collection activities – not all are aligned
• The OMB categories are insufficient to illuminate many disparities and to target QI efforts efficiently

Institute of Medicine Recommendations

• Health Care organizations must have data on the race, ethnicity, and language of those they serve in order to identify disparities and to provide high quality care.
• Detailed “granular ethnicity” and “language need” data, in addition to the OMB categories, can inform point of care services and resources and assist in improving overall quality and reducing disparities.

The Affordable Care Act: Section 4302

Race and Ethnicity
— Guided by OMB standards for race and ethnicity
— Consultations with OMB, Dept of Labor, Bureau of Census and other federal partners
— Informed by recent IOM reports on data granularity

The Affordable Care Act: Section 4302

Section 4302 has great potential to improve data collection by
— Requiring the DHHS Secretary to establish data collection standards
— Calling for the use of the standards in federal data collection
— Instructing that the data be used for analyses and that the results be reported
— Articulating some important language about funding
The Affordable Care Act: Section 4302

- Data Collection and Analysis
- Focuses on federal national data collection efforts such as:
  - National Health Interview Survey (NHIS)
  - Current Population Survey (CPS)
  - American Community Survey and the analysis and reporting of these data

Mandated Standards for Race and Ethnicity Reporting in SPARCS

- Race and ethnicity categories per granular CDC categories, which can be “rolled up” to the OMB categories
- Up to a combined ten granular race and ethnicity variables

A Road Forward

Understand Data Collection and Reporting

Improve Race/Ethnicity Data

1. Standardize RE categories

Improve Race/Ethnicity Data

1. Standardize RE categories
2. Optimize self-report of RE
   - Materials
   - Training
   - Dissemination
   - Other improvements
**Improve Race/Ethnicity Data**

1. Standardize RE categories
2. Optimize self-report of RE
3. Improve feedback to hospitals
   - Identification and use of standards
   - Improve current data audits
   - Identify potential gold standards
   - Send Hospital Assessment Reports to each hospital

4. Identify supplemental sources of self-report RE

**What is Aligning Forces for Quality?**

- The Robert Wood Johnson Foundation’s signature effort to lift the overall quality of health care in 16 targeted communities across America.

**Targeted Regions Will Improve and Sustain High-Quality, Patient-Centered, Equitable Care by 2015**

www.forces4quality.org
AF4Q communities

- 16 communities
- 14 states
- 37 million people
- 271 counties
- 12% (>590) of U.S. hospitals
- More than 31,000 primary care physicians

AF4Q and Disparities

- AF4Q communities are working on disparities in the hospital and ambulatory settings
  - Initiatives across communities and within individual communities
- Hospital efforts based on Expecting Success
  - 10-hospital collaborative to address disparities in cardiac care (2005-2008)
  - Funded by the Robert Wood Johnson Foundation

Addressing Disparities Requires Commitment

- Senior leadership must engage
  - Determine organizational priorities
  - Allocate resources
  - Remove barriers
- Provider-level data create ownership
  - Prevents ‘assumed equity’
  - Allows for critical discussions
  - Facilitates action

Addressing Disparities: Three steps

- Collection of standardized race and ethnicity data
  - Categories are standardized
  - Patient self-reports
- Stratification and analysis of performance measures
  - Compare patients within an organization
  - Consolidate data to identify community-level trends
- Use of stratified data to identify disparities and develop QI interventions targeted to specific patient populations

Top Eight Challenges

- Standardized data collection
  1. Staff anxiety
  2. Standardized categories
  3. Changes to information technology (IT) systems
- Data stratification and analysis
  4. Data collection vs. reporting vs. analysis
  5. Purpose of data collection
Top Eight Challenges

- Identifying and addressing disparities
  6. Identified a disparity - what now?
  7. Developing interventions
  8. Moving beyond the four walls into the community

Staff Anxiety

- Biggest challenge = concern about patient reactions
- Solutions:
  - Training, training, training
  - Health Research and Educational Trust toolkit
  - Reasons for collecting data
  - Feedback on findings
  - Monitoring quality of data collected

Closing the Gap

Percent of HF Patients Receiving Discharge Instructions by Ethnicity

A New York Example

- P² Collaborative of Western New York
  - Working with safety net clinics
  - Focused on patients with diabetes or cardiac conditions
- AF4Q Equity Improvement Initiative – 3 clinics
  - Developing interventions to address disparities
  - Developing a culture of equity within the organization

Power of the Data

28 Day Same Cause Readmission Rate of Each Discharge

The Case for Addressing Disparities

- Fulfilling your mission
- Meeting a ‘mandate’
  - NY DOH/SPARCS, JCAHO, meaningful use
- Improving quality
- Changing reimbursement methods
  - Readmissions, ACOs
Additional Information

http://www.improvepatientdatanys.org

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