



EXCEPTIONAL CARE. WITHOUT EXCEPTION.



Boston University School of Medicine

# Development of Quality Indicators for Children with Sickle Cell Disease

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# Today's Agenda

- **Assessment of Technical Quality of Care**
- **Development of Quality Indicators for Children with SCD Using the RAND/UCLA Modified Delphi Method**

# Defining Technical Quality

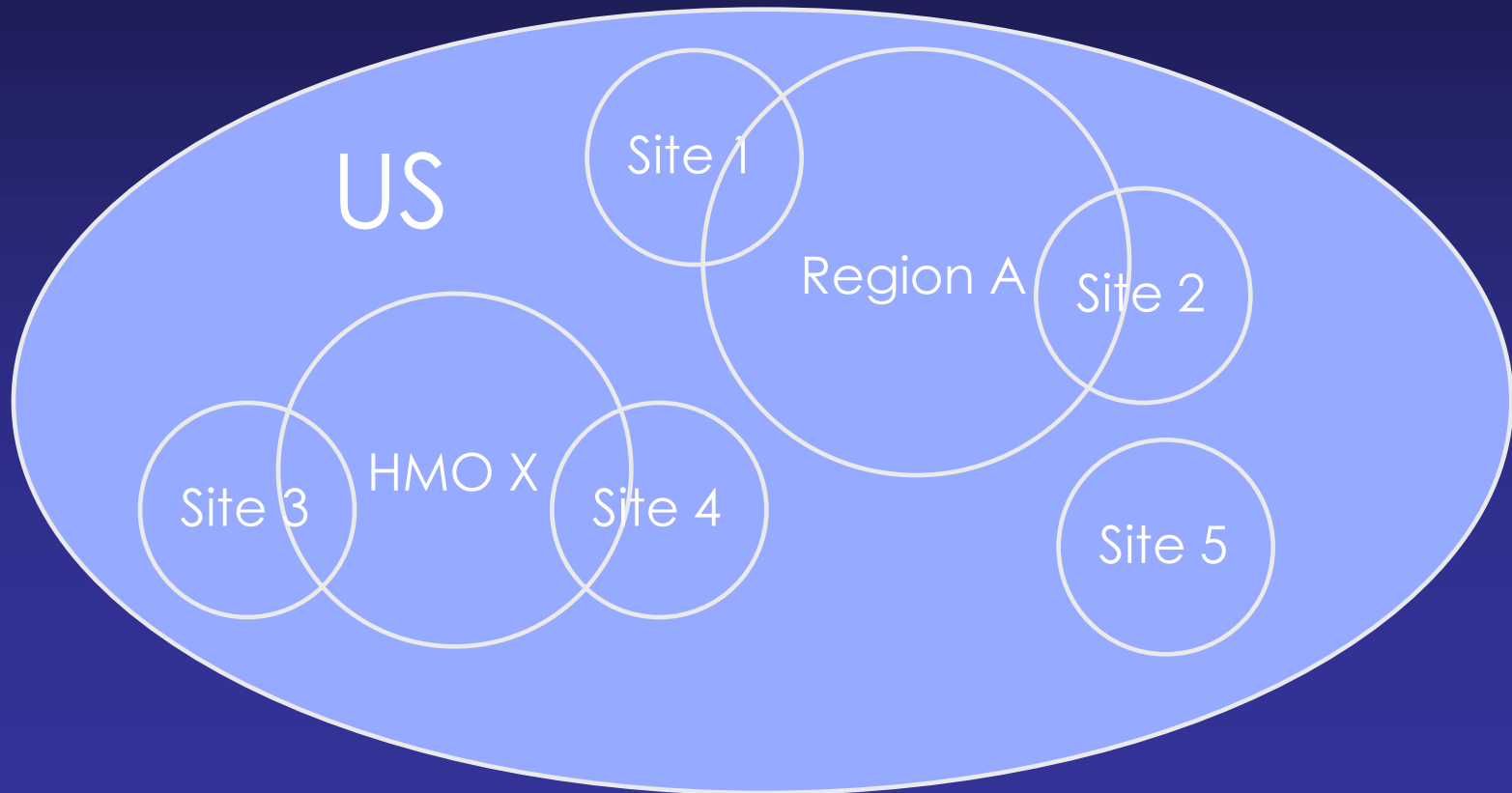
- “The right care is delivered to the right person at the right time, every time.” –Elizabeth McGlynn
- Technical quality is mostly about process of care
- Problems with quality result from
  - overuse
  - underuse
  - misuse

# Starting Points for Assessing Quality in the US

- The healthcare system as a black box
- Various assessment strategies are the possible lights one can shine into the black box; each indicator is a different light
- Shines at many different angles, cutting the quality problem into easily understandable slices
- Focuses on one level of the black box (e.g. women's health within a specific HMO)

# Where Is the Level of Analysis

Study goals determine the population, setting and level of analysis



# Technical Quality and Patient Experience Can Both Be Assessed

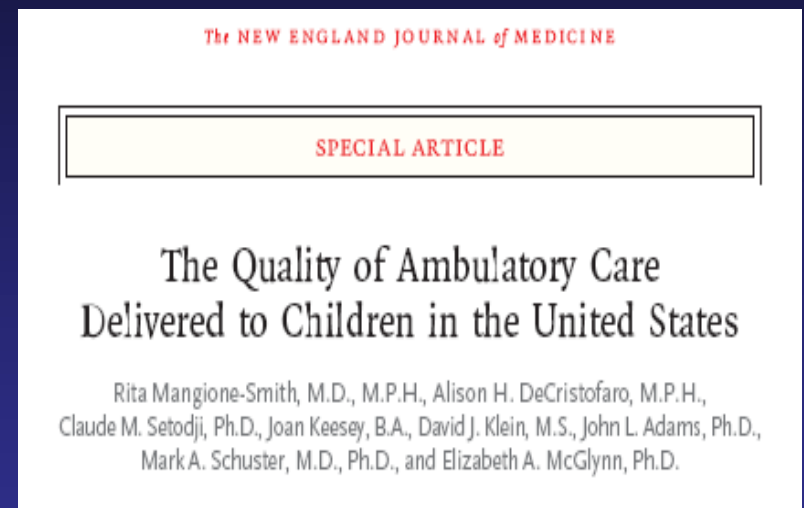
- Technical quality is assessed with quality indicators
- Patient experience is assessed with surveys (CAHPS, Picker, Press Ganey, etc.)
- Quality assessment
  - Is the bedrock of quality of care
  - Allows you to identify the gap between what is proven to work and what is delivered (the quality gap)
  - Provides the starting point of quality improvement

# Technical Quality in the United States

- McGlynn and others at RAND authored two *NEJM* articles using quality assessment tools:



Adults received 54.9% of  
recommended care



Children received 46.5% of  
recommended care

“These deficits, which pose serious threats to the health and well-being of the U.S. public, persist despite initiatives by both the federal government and private health care delivery systems to improve care.”  
—McGlynn

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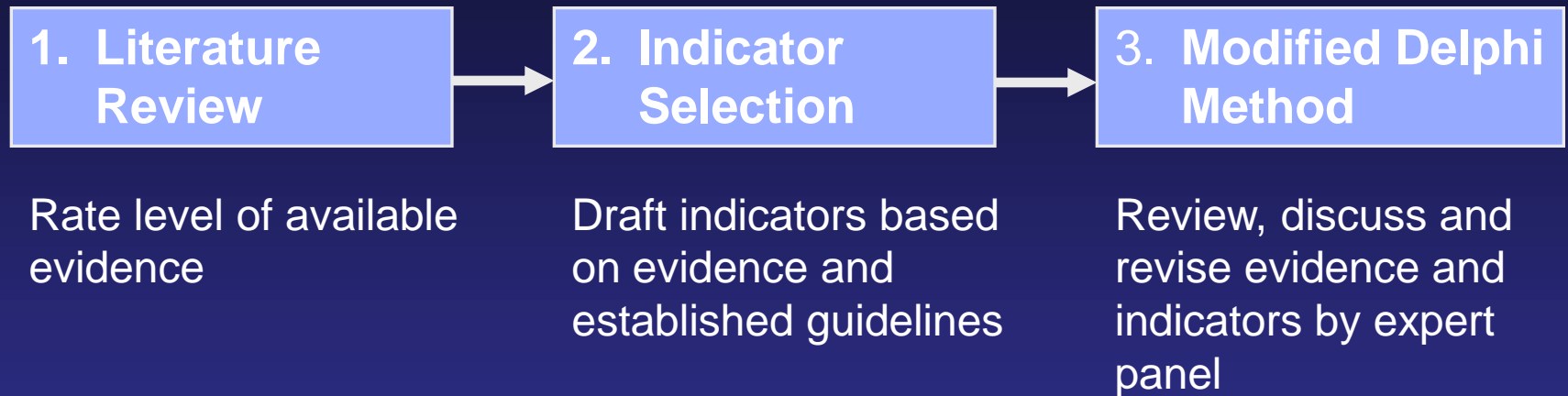
# Desirable characteristics of quality indicators

- Unambiguous descriptions and clear definitions of variables to be measured;
- Explicit definition of the population to be included and the setting to which they apply; and
- Links between process measures to health outcomes for the care being reviewed
- Targets monitored by these indicators should be specific, measurable, achievable, relevant and time-specific

# Step 1: Select Conditions to Measure

- “The clinical context is established by the presenting condition or symptoms”<sup>1</sup>
- Choose conditions that have
  - High morbidity/mortality (e.g. acute myocardial infarction),
  - A high number of associated services (e.g. SCD), and/or
  - Services that are overused, underused or misused (e.g. depression).

# Step 2: Develop Quality Indicators



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## Stage 3: Modified Delphi Method

1. One round of anonymous ratings of the indicators by the panel
  - Rated on a 9-point scale of validity and feasibility: 1 = low, 9 = high
2. A face-to-face panel discussion
3. A second and third round of anonymous ratings following the panel discussions
  - Median score of 7 or higher on validity scale often used as the inclusion criterion; median score of 4 or higher on feasibility score.
  - No significant disagreement among the raters.

# Step 3: Classify the Indicators

## Main three categories

- Type
  - Preventative, acute, chronic, elective
- Function
  - Screening, diagnosis, treatment, follow-up
- Modality
  - Physical exam, history, laboratory or radiology studies, medications, encounters, education or counseling

# Step 3: Other Ways to Classify Indicators

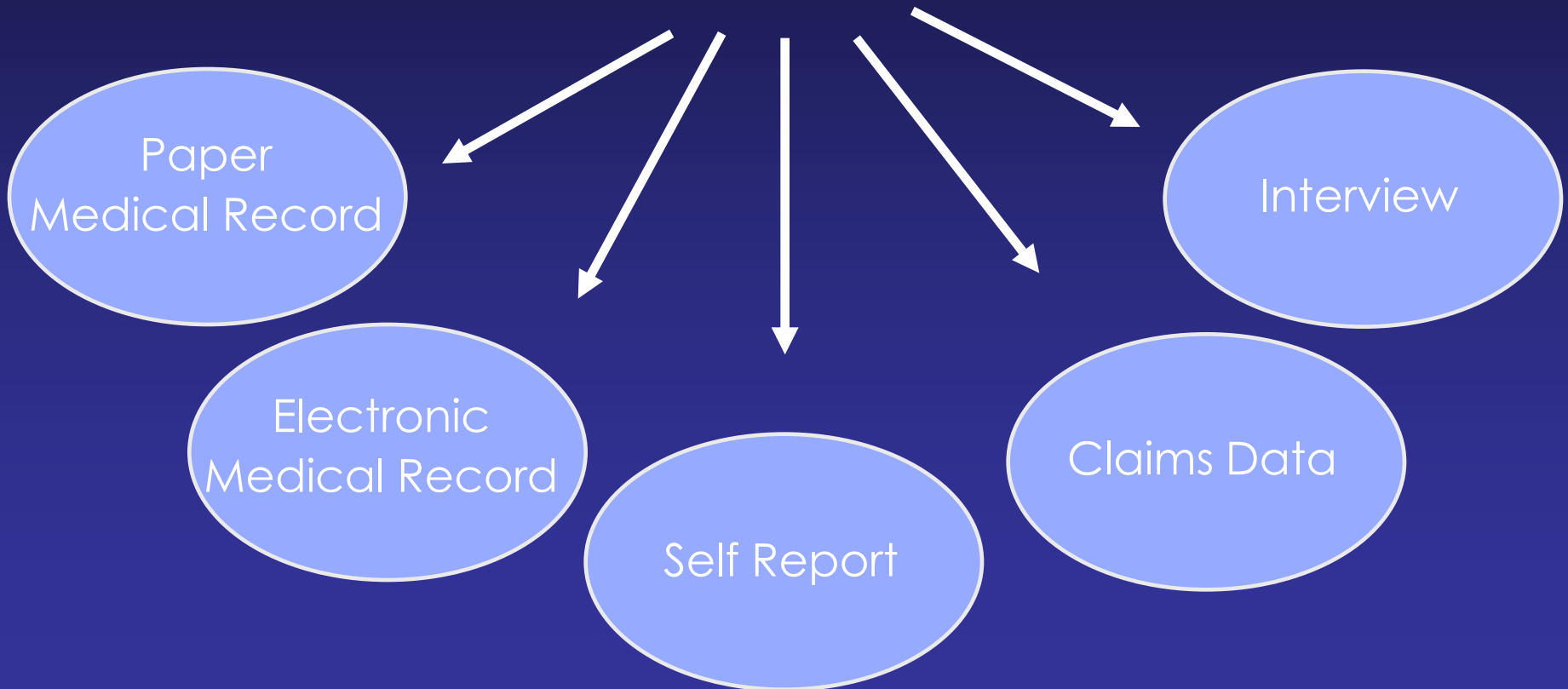
Can expand with other categories

- Setting
  - Inpatient, outpatient, emergency department
- Type of physician
  - Pediatrician, internist, etc.

# Step 4: Operationalize Indicators

Define data elements

Abstract data from



# Step 5: Create Analytic Dataset

- Patient-provider worksheet
  - Abstract data separately for each healthcare provider of each participating patient
- Assess inter-rater reliability at three levels:
  - 1) Presence or absence of a given condition
  - 2) Participating patient's eligibility for the process represented by a given indicator
  - 3) Scoring of a given indicator

# Step 6: Score the Indicators

Combination of variables that

- Determine the patient's eligibility for the indicator's process
- Determine whether the patient "did or did not receive the process or some proportion of it"<sup>1</sup>

# Step 6: Score the Indicators

## Level of analysis

For each participant  
(across all, or a selection, of  
indicators)



$$\frac{\Sigma \{I_1, I_2, I_3 \dots\}}{\Sigma \{\text{total \# eligible}\}}$$

For a total system  
(for each indicator, or across a  
group of indicators)



$$\frac{\Sigma \{\text{total \# passes}\}}{\Sigma \{\text{total \# eligible}\}}$$

# Step 7: Sort, Display and Analyze Results

## Classification matrix for indicators

– Example:

Condition†	Description of Selected Indicator	Classification for Aggregate Scores			
		Type of Care	Function	Mode	Problem with Quality
<b>Asthma (25 indicators)</b>					
Indicator 4	Long-acting agents for patients with frequent use of short-acting beta-agonists	For chronic condition	Treatment	Medication	Underuse
Indicator 6	Inhaled corticosteroids for patients receiving long-term systemic corticosteroid therapy	For chronic condition	Treatment	Medication	Underuse

# Quality Indicators for Children with Sickle Cell Disease: Expert Panel and Affiliations

<b>Robert Adams</b>	Professor of Neuroscience and Director of MUSC Stroke Center, Medical University of South Carolina, Charleston, SC
<b>Daniel Armstrong</b>	Professor of Pediatrics and Psychology and Director of Sickle Cell Center, University of Miami, Miller School of Medicine, Miami, FL
<b>Samir Ballas</b>	Emeritus Professor of Medicine, Thomas Jefferson University, Cherry Hill, NJ
<b>George Buchanon</b>	Professor of Pediatrics, University of Texas School of Medicine and Medical Director, Center for Cancer and Blood Disorders, Children's Medical Center, Dallas, TX

# Quality Indicators for Children with Sickle Cell Disease: Expert Panel and Affiliations

<b>Lanetta Jordan</b>	Professor and Associate Director of Masters in Public Health Program, Barry University, Miami, FL, and Director, Sickle Cell Service, Memorial Healthcare System, Hollywood, FL
<b>Peter Lane</b>	Professor of Pediatrics, Emory University School of Medicine, and Director, Children's Healthcare of Atlanta Sickle Cell Disease Program, Atlanta, GA
<b>William Owen</b>	Associate Professor of Pediatrics, Eastern Virginia Medical School and Medical Director, Comprehensive Sickle Cell Program, Children's Hospital of the King's Daughter, Norfolk, VA
<b>Elliott Vichinsky</b>	Professor of Pediatrics, University of California at San Francisco and Director, Hematology/Oncology, Children's Hospital Oakland, Oakland, CA

# Results: Examples of Indicators for Children with Sickle Cell Disease

## General Care:

1. All children with a newborn screen indicative of SCD should have confirmatory testing by 2 months of age.
2. All children with SCD should have a comprehensive evaluation including a pulse oximetry reading, CBC and reticulocyte count documented, at least annually.
3. Adolescents with SCD should be counseled regarding the transition to adult providers, and counseling should be documented.
4. A transition plan to adult care, which includes a written transfer summary of the medical history, should be developed for pediatric patients with SCD.

# Results: Examples of Indicators for Children with Sickle Cell Disease

## Immunization:

5. Children with SCD should have an annual influenza immunization according to CDC guidelines.
6. Children with SCD should complete PCV7 vaccinations per CDC guidelines.
7. Children and adolescents with SCD should complete PPV23 vaccinations per CDC guidelines.

# Results: Examples of Indicators for Children with Sickle Cell Disease

## Pain:

8. The initial pain assessment should be documented using an age-appropriate pain scale and the assessment should be repeated within 30 minutes of the first dose of analgesic.
9. Children with SCD who present with an acute pain episode should receive a parenteral analgesic within 60 minutes from registration or 30 minutes from triage.

# Results: Examples of Indicators for Children with Sickle Cell Disease

## Antibiotic Prophylaxis:

10. All children with FS on initial newborn screen should receive antibiotic (e.g, penicillin) prophylaxis beginning at 2 months of age or earlier.

11. Children with sickle cell anemia under 5 years of age should receive antibiotic (e.g., penicillin) prophylaxis for pneumococcal disease.

# Results: Examples of Indicators for Children with Sickle Cell Disease

## Transfusion:

10. Children with SCD  $\geq 2$  years old who are receiving a chronic transfusion program should have a comprehensive annual screening assessment for iron overload.
11. Children with SCD should be transfused with ABO, C, D, E, and Kell-matched red cells.

# Results: Examples of Indicators for Children with Sickle Cell Disease

## Fever:

14. Children with SCD who have a fever of  $\geq 38.5$  C should be given parenteral broad spectrum antibiotic treatment within 60 minutes of triage.

## Stroke:

15. Children with SCD with a confirmed clinical stroke should be started on a chronic transfusion program with the goal of HbS levels  $< 30\%$  to prevent recurrent stroke.