Defining an Outcome Measures Framework for Global Surgery

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Principal Investigator: Outcome Measures Framework; Registry of Patient Registries; Registries for Evaluating Patient Outcomes: A User’s Guide (1st, 2nd, 3rd editions) for Agency for Healthcare Research and Quality (AHRQ)

Structures, Processes, Outcomes

From: www.ahrq.gov
Outcomes Metrics: Overview

• How will the outcomes be used?

• How will (or can) you obtain data?

• Which outcomes to measure (and how to find them)?
Outcomes Metrics: Overview

• How will the outcomes be used?
  • Design with the ‘end in mind’
  • Start with the purpose(s), it will define everything else
  • Understand the stakeholders and decisionmakers

Incorporating stakeholder perspectives in developing a translation table framework for comparative effectiveness research

This project used a stakeholder-driven process to understand the factors that drive the selection of study designs for comparative effectiveness research (CER). The project assembled a diverse stakeholder committee to explore the basis of a translation framework and gathered input through surveys, interviews and an in-person meeting. Stakeholders recommended different study designs for the CER topic areas and identified different outcomes as the most important outcomes to study in each area. During the discussions, stakeholders described a variety of factors that influenced their study design recommendations. The stakeholder activities resulted in the identification of several key themes, including the need to have a highly specific detailed research question before discussing appropriate designs and the need to use clinical judgment in the different topic areas.

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Center for Medical Technology Policy, 401 East Pratt Street, Suite 631, Baltimore, MD 21202, USA
National Pharmaceutical Council, 1717
Outcomes Metrics: Overview

- **How will the outcomes be used?**
- **How will (or can) you obtain data?**
  - Starting with the “Ideal”
  - Real-world constraints-resources, data availability, follow-up, etc.
Patient /clinical data registries have become the standard for measuring outcomes for surgery on a global basis.

A patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves a predetermined scientific, clinical, or policy purpose(s).
The Ideal Registry for Outcomes Assessment

- Collects uniform, clinically rich data including risk factors, treatments and outcomes at key points for a particular disease or procedure
- From multiple sources (doctors, patients, hospitals) and across care settings (practices, hospitals, home)
- Leverages HIT systems through interoperability and data sets from other sources through linkage
- Uses standardized methods to assure representative patient sample, data quality (accuracy, validity, meaning, completeness) and comparability (risk adjustment)

Outcomes Metrics: Overview

• How will the outcomes be used?
• How will (or can) you obtain data?
• Which outcomes to measure (and how to find them)?
  • Should be meaningful, collectable and standardized whenever possible
What to Measure: IOM “Crossing the Quality Chasm”

Six aims that health care system must fulfill to deliver quality care

• Safe
• Effective
• Efficient
• Timely
• Patient centered
• Equitable

Access to safe surgery when needed with financial protection

Dr. John Meara
Lancet Commission on Global Surgery
Finding the right measures

Development and applicability of the Outcome Measures Framework

• 2010, U.S. AHRQ and NLM - lack of standardized outcomes measurement a major impediment to collecting, sharing and comparing outcomes data

• Outcome Measures Framework (OMF) project, a part of the Registry of Patient Registries, launched to promote development of a common model and repository
  > Facilitate the use of common metrics, data fields and definitions in similar health conditions

• Hundreds of stakeholders-patient, physicians, payers, government agencies, societies-convened in multiple condition-focused meetings
An Outcome Measures Framework

Framework Data Element Categories

Participant Characteristics
- Demographics
- Genetics
- Family/Participant History
- Functional/performance status
- Health Behaviors
- Environmental Exposures

Disease Characteristics
- Diagnosis
- Risk Factors
- Staging Systems
- Genetics of Disease tissue or infectious agent
- Biomarkers
- Comorbidity/Symptoms
- Assessments/scales
- Labs, radiology and imaging

Provider Characteristics
- Training/experience
- Geography
- Practice setting: academic vs. community

Outcomes
Survival
- Overall mortality
- Disease free survival

Disease Response
- Recurrence
- Progression

Events of Interest
- Adverse events
- Exacerbations

Patient-Reported Outcomes
-- Physical functioning
-- Quality of Life
-- Other

Health System Utilization
- Inpatient hospitalization
- Office visits
- ER visits
- Additional procedures
- Productivity/absenteeism
- Direct cost

## Search for Outcome Measures

### Outcome Measure Attributes

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Finding Outcome Measures

Patient Reported Outcomes Selection Criteria
General concepts in designing/implementing metrics

General Considerations

> Design measurement with respect to its major purposes
> Select data sources, populations, comparison groups
> Determine whether sampling is needed
> Identify possible sources of bias (systematic error) and address them to the extent that is practical and achievable

Data Elements

> Select based on importance and relationship to the primary outcome
> Consider data collection burden and incremental costs for collection
> Whenever possible, use established standards and common data definitions or validated instruments
> Weigh pros/cons of using patient identifiers
> Use pilot testing to assess feasibility and burden as well as reliability, validity, and potential for missing data

Thank you

• More information on how to select metrics see

• Contact Information
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