Incorporating PROs into Registries: Moving Beyond the Hospital Walls

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Why do this?

- Patient-centeredness a core value
- Benchmark institutional performance
- Inform procedural appropriateness
  - Health status the most important (perhaps only) rationale for some treatments
- Predictor & outcome in risk models to support precision medicine
- Support device surveillance
- Key to the value equation
NCDR Strategic Plan*

Mission: To improve patient care and heart health through trusted, real-world evidence.

Vision: A world where NCDR advances patient care, outcomes, and value through knowledge and innovation.

Reduce the Burden and Enhance the Scope of Data Collection
1. Integrate with Clinical Workflow
2. Implement Best Practices in Health Information Technology
3. Expand Data Scope to Include Cost and Patient-Reported Outcomes

Increase NCDR Value to Stakeholders
1. Provide Offerings to Meet Stakeholder Needs
2. Generate a Deeper Understanding of NCDR Services and Benefits

Promote Quality Improvement
1. Deliver Tools and Initiatives to Facilitate Quality Improvement
2. Support the Professional Development of Clinical Quality Teams

Support Population Health Management
1. Support ACC Policy Advocacy
2. Facilitate Development of Population Management Tools and Resources
3. Disseminate Knowledge and Research

*Preliminary

If not part of routine care, what are the incentives?

Value-based Care

\[ \text{Value} = \frac{\text{Quality}}{\text{Cost}} \]

Value= Quality → PROs
Results from STS-ACC TVT-Registry

Distribution of Pre-TAVR KCCQ Scores

Follow up Health Status Improvements At 30-days and 1-year

Data completeness in TVT-R
Even with incentives—how will PROs be collected?

Modern technology has helped medical professionals perform robot-assisted surgeries and sequence whole genomes. But hospital software still can’t handle daylight saving time. [The EHR] can delete records or require cumbersome workarounds when clocks are set back for an hour – prompting many hospitals to opt for paper records for part of the night shift. And it happens every year.

USA Today 11-03-18

Thinking outside of the (hospital) box

A Vision for a Person-Centered Health Information System

Dr. Andrews enters: “Good morning, Ms. Hartnett. Thank you for updating your health status via the clinic app and letting us know why you came to the office. You’ve indicated that you had some difficulty breathing when carrying groceries from your car over the last few weeks, and more recently have been coughing, especially at night when you go to bed.”

National Academy of Medicine 10.01.18
To Summarize

• Health status is fundamental to the future of registries
• Systematic collection requires the right incentives
• Even with incentives, methods of collection must evolve
• The EHR (alone) is not the answer...
• Patient-centered data collection outside of traditional clinical encounter the next frontier