

Incorporating PROs into Registries: Moving Beyond the Hospital Walls

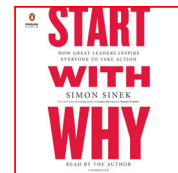
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ACC Forum on Patient Reported Outcomes
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Why do this?





- 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.

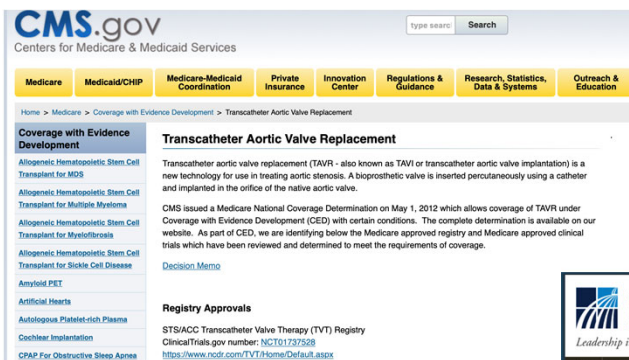
Vision: A world where NCDR advances patient care, outcomes, and value through knowledge and innovation.

 Reduce the Burden and Enhance the Scope of Data Collection <ol style="list-style-type: none"> 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 <ol style="list-style-type: none"> 1. Provide Offerings to Meet Stakeholder Needs 2. Generate a Deeper Understanding of NCDR Services and Benefits 	 Promote Quality Improvement <ol style="list-style-type: none"> 1. Deliver Tools and Initiatives to Facilitate Quality Improvement 2. Support the Professional Development of Clinical Quality Teams 	 Support Population Health Management <ol style="list-style-type: none"> 1. Support ACC Policy Advocacy 2. Facilitate Development of Population Management Tools and Resources 3. Disseminate Knowledge and Research
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*Preliminary

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



The screenshot shows the CMS.gov website. The main heading is "Transcatheter Aortic Valve Replacement". Below it, there is a section titled "Coverage with Evidence Development" which states that CMS issued a Medicare National Coverage Determination on May 1, 2012, allowing coverage of TAVR under Coverage with Evidence Development (CED) with certain conditions. A "Decision Memo" link is provided. There is also a "Registry Approvals" section mentioning the STS/ACC Transcatheter Valve Therapy (TVT) Registry.

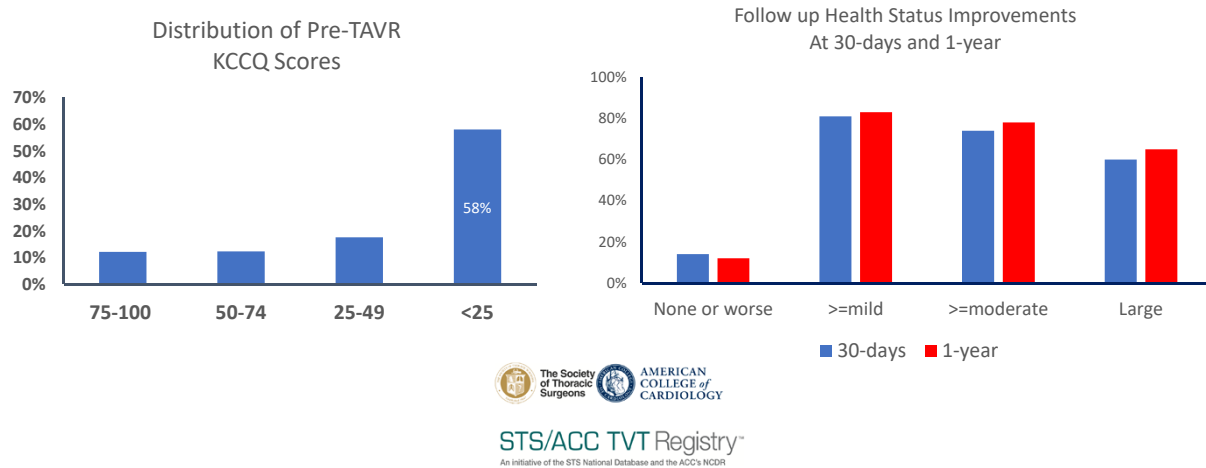
Value-based Care

Value = Quality ← PROs
Cost

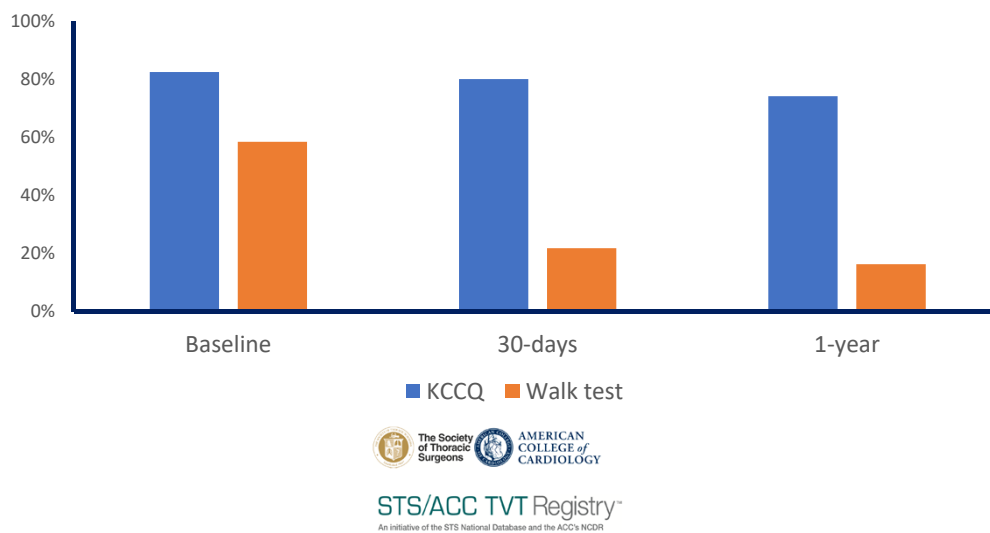


The screenshot shows the California Hospital Association website. The main heading is "CMS Seeks TEP Members for Development of Hospital Patient-Reported PCI Outcome Measure". The article, dated January 12, 2015, states that CMS has contracted with Yale New Haven Health Services Corporation - Center for Outcomes Research and Evaluation (CORE) to develop a patient-reported outcome performance measure for patients undergoing non-emergent percutaneous coronary intervention. CORE is seeking nominations from the hospital field for a technical expert panel (TEP) to provide expert opinion and input on this measure. A photo of David Perotti, MD, DGS, Senior Vice President & Chief Medical Officer, is included.

Results from STS-ACC TVT-Registry



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

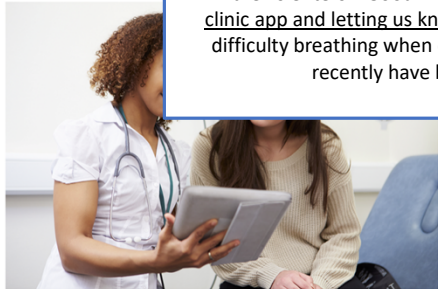
Thinking outside of the (hospital) box



A Vision for a Person-Centered Health Information System

By Keith Horvath, Patricia Sengstack, Frank Opelka, Andrea Borondy Kitts, Peter Basch, David Hoyt, Alexander Ommaya, Pamela Cipriano, Kensaku Kawamoto, Harold L. Paz, J. Marc Overhage

October 01, 2018 | Discussion Paper



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."

The Vision as a Vignette

Setting: Examination room in a doctor's office. Ms. Hartnett, an older woman, is seated in a recliner, awaiting the physician. Occasionally, her cough punctuates background music as she watches health tips play on a large screen.

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."

room. "Clara, have there been any encounters for short-

sit, she has had six average and one oc-18. There have been no temperature of hypertension, with a rate rise to 131. I have

displayed a graph of these events. There have been no previous visits for shortness of breath or heart failure. Perhaps this is relevant: an emergency room observation for a self-limited episode of atrial fibrillation in August of 2004.

"Note, Ms. Hartnett received her flu shot 46 days ago and six patients in her retirement community, which has a total occupant capacity of 900, have had similar complaints over the past two weeks" adds Clara.

Dr. Andrews: "Thank you, Clara. Please show Ms. Hartnett's chest X-ray from today on the monitor, while I listen to her chest." Dr. Andrews then turns to Ms. Hartnett and asks, "Do you remember feeling your heart racing last Tuesday evening?"

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