History of Registries

Seth Blumenthal, MBA
PCPI

David Shahian, MD
Society of Thoracic Surgeons

November 14, 2017
Agenda

• Welcome (5 minutes) Chrystal Price
• Presentation (40 minutes) Seth Blumenthal, MBA & Dr. David Shahian, MD
• Moderated Q&A (15 minutes)
• Wrap-up (5 minutes)

National Quality Registry Network
Housekeeping

- The webinar is being recorded
- The slides and a link to the recording will be posted at thepcpi.org
- For the Q&A portion of the webinar, please enter your questions into the chat window
Speakers

Seth Blumenthal, MBA
Director
Data and Innovation
PCPI

David Shahian, MD
Co-Chair, National Quality Registry Network
Chair, Society of Thoracic Surgeons (STS) Workforce on National Databases
Professor of Surgery, Harvard Medical School
Vice President, Massachusetts General Hospital Center for Quality and Safety
Associate Director, MGH Codman Center for Clinical Effectiveness in Surgery
Where did registries come from?
Earnest Codman, MD

“The common sense notion that every hospital should follow every patient it treats, long enough to determine whether or not the treatment has been successful, and then to inquire, ‘If not, why not?’ with a view to preventing similar failures in the future” – Codman, E.A. 1914 (italics from Codman)

It took awhile for his viewpoint to become more mainstream

“Dear Codman:
God bless you! I suppose I should hate you if I lived in the same town, but my feeling, being remote, is quite other. Indeed the very enemies who lurk in second story windows with muffled rifles are waiting your passing, are the ones who take off their hats in deepest respect as your cold, but beautiful, corpse is carried away” – Dr. Edward Martin, 1914
The First Registry

• Codman bone sarcoma registry founded in 1920
• $1,000 raised from a family of a patient
• American College of Surgeons contributed $8,000
The First Registry

- Recruiting participants was hard – after three years of trying Dr. Codman had solicited 17 cases from the society’s 7,000 members
- Codman also started the ACS Committee for Hospital Standardization which later became TJC

Source: New England Shoulder & Elbow Society
Case reports contained metadata and narrative sections

Instructions: Dictate history so as to cover following headings, and typewrite four copies on standard typing paper.

Sections:
- Clinical note
- Examination
- Treatment
- Gross pathology
- Microscopic

Have sections been preserved by you? Sent to Registry with this? To be returned or preserved? Have X-rays been preserved by you? Sent to Registry with this? To be returned or preserved? Have gross material been preserved by you? Sent to Registry with this? To be returned or preserved?

Make four typewritten copies, keep one and mail three to Dr. E. A. Codman, 227 Beacon Street, Boston, Massachusetts

Data for Registration of a Case of Bone Sarcoma

Name and address—
of doctor registering case
of patient
of friend, with permanent address, who would be likely to answer follow-up letters
of family physician
of surgeon operating
of roentgenologist
of pathologist
of hospital. Record reference or hospital number.

Source: American College of Surgeons
Most of the rest of the 20c

- Registry development continued but slowly
- Cancer registries developed earlier than for other specialties
- Data collection and submission was paper-based
- Registry use was primarily for retrospective clinical research and local QI purposes
Then in 1989 in New York State

- New York State Health Department disclosed death statistics for each heart surgeon, listed by name
- Data were not risk-adjusted
- Disclosure increased risk of high-risk patients being turned away for fear of negatively impacting the score
- Registries still not widespread at that time

Surgeons decided it was time to take control of their data...

Source: (1) (2)
Registry history through the lens of the STS National Database
The STS National Database

November 14, 2017
U.S. RELEASING LISTS OF HOSPITALS WITH ABNORMAL MORTALITY RATES

by JOEL BRINKLEY, Special to the New York Times
Published: March 12, 1986

WASHINGTON, March 11 — The Health and Human Services Department is preparing to release lists of the nation’s hospitals that have mortality rates significantly higher or lower than the national average, the first such lists ever compiled.

The lists, provided to The New York Times and scheduled for general release on Wednesday, indicate that more than twice as many patients died at certain hospitals than would have been expected under national norms.

The lists were derived using case records from 10.7 million patients treated in 1984 whose bills were paid by Medicare, the Government program that assists the elderly and the disabled in paying their hospital costs. Nearly all the nation’s hospitals treat Medicare patients, who make up almost half of all hospital patients. 'It Is Not a Report Card'

Several New York hospitals were identified as having higher-than-average mortality rates for elderly Medicare patients. [ Page A22. ] But Federal officials warned that the statistics...
“In March 12, 1986, the Department of Health and Human Services Health Care Financing Administration (HCFA) released a list of hospitals whose mortality rates for Medicare patients allegedly exceeded “predicted mortality rates” for those hospitals, either overall or for nine specific diagnostic categories. … the implication was clearly made that these raw mortality rates were equated with quality of care in the institutions in question…an incorrect perception of care in certain communities.”
"All of the risk factors that are predictive of operative mortality must be identified and subjected to appropriate statistical analysis before comparisons of mortality rates between institutions can be made."

"Patients who undergo concomitant procedures ..... have operative mortality rates that can differ substantially from those for isolated coronary artery bypass grafting."

"Postoperative complications ... should also be incorporated into any assessment of quality of care."
It Is Time for a National Cardiothoracic Surgical Data Base

Richard E. Clark, MD
Surgery Branch, National Heart, Lung, and Blood Institute, Bethesda, Maryland

The Society of Thoracic Surgeons will soon sponsor an opportunity for its members to participate in a national clinical data base system for cardiac and thoracic operations and outcome. This effort by the STS to establish a national data base is more than 5 years old. An ad hoc committee initiated a pilot program that, unfortunately, did not evolve to national scope. The development of small portable computers that were fast and interactive and had large storage capabilities has made possible the formation of many local data bases for cardiac surgery. The time is now ripe for those with existing data bases and those who have none at present to participate in this national effort.

The reasons for the initiation of this program by the STS are many. The formation of a group to undertake the effort was prompted by the release by HCFA (Health Care Financing Administration), a component of the Department of Health and Human Services, of raw mortality data for Medicare patients undergoing coronary artery bypass grafting procedures without respect to any of the then-known risk factors associated with patients during coronary artery disease.

The Standards and Ethics Committee of the STS released its “Statement of Concern” with approval of Council late in 1986, which was well received by practitioners and hospitals. The Standards and Ethics Committee at the Toronto meeting of the STS in September of 1987 developed a proposal for the Council for the development of a national data base system sponsored by the STS.

The pressing need was clearly evident from a number of artery operations carried little or no risk was perpetuated. A third driving force was the action of the JCAHCO (Joint Commission on Accreditation of Health Care Organizations). Quality assurance programs for every segment of the health care system were required. Recredentialing on a yearly basis was to occur based on the previous year’s clinical performance by the practitioner. Clearly, results of the surgeons were going to be readily evident in contrast to those of psychiatrists. Finally, Congress required HCFA and a suborganization, the PPRC (Physicians Payment Review Commission), a complete study and review of physicians’ billings and payments under the Medicare system with the requirement of reporting the results in late 1989 and early 1990. The purpose was to decrease the rate of increase in health care costs, which have been substantially exceeding the inflationary rate for more than a decade. The initial report by the investigator (Hsiao) to the HCFA recommended a rearrangement of payment schemes with greater weight given to so-called cognitive skills than to technical ones. Cardiothoracic surgeons were to receive a reduction in payments of 25% to 30%. The need, therefore, to determine accurately the amount of services provided in toto by the cardiothoracic community had become acute.

Edmunds and Kaiser, in their preface to the report of the Committee for the state of the art symposium on coronary arterial surgery, made a pertinent strong plea.

Proper solution to the risk-benefit equation requires knowledge of the natural history of the disease and of the incremental risk factors that affect operative mortality and lon-
The STS National Database is the foundation for all STS quality activities.
STS Database: A truly national registry

The Society of Thoracic Surgeons (STS) National Database
Adult Cardiac Surgery Database Participants

1110 Participants as of 1.11.2017
50 US States & Canada
18 International - Argentina, Australia, Brazil, Israel, Italy, Turkey & United Arab Emirates
63 Anesthesiology Participants
Penetration, Completeness, and Representativeness of The Society of Thoracic Surgeons Adult Cardiac Surgery Database

Jeffrey P. Jacobs, MD, David M. Shahian, MD, Xia He, MS, Sean M. O'Brien, PhD, Vinay Badhwar, MD, Joseph C. Cleveland, Jr, MD, Anthony P. Furnary, MD, Mitchell J. Magee, MD, Paul A. Kurlansky, MD, J. Scott Rankin, MD, Karl F. Welke, MD, Giovanni Filardo, PhD, MPH, Rachel S. Dokholyan, MPH, Eric D. Peterson, MD, MPH, J. Matthew Brennan, MD, Jane M. Han, MSW, Donna McDonald, RN, MPH, DeLaine Schmitz, MSHL, RN, Fred H. Edwards, MD, Richard L. Prager, MD, and Frederick L. Grover, MD

Division of Cardiovascular Surgery, Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, Maryland (JP); Division of Cardiovascular Surgery, Department of Surgery, Johns Hopkins All Children’s Heart Institute, All Children’s Hospital and Florida Hospital for Children, Saint Petersburg, Tampa, and Orlando, Florida (JP); Massachusetts General Hospital, Harvard Medical School, Boston, Massachusetts (DMS); Duke Clinical Research Institute (DCRI), Duke University, Durham, North Carolina (XH, SMC, RSD), EDP, JMB; University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania (VB); University of Colorado Denver, School of Medicine, Aurora, Colorado (CC, FLG); Starr-Vowell Cardiothoracic Group, Portland, Oregon (APF); Medical City Dallas Hospital, Baylor University Medical Center Dallas, Dallas, Texas (MJB); Columbia University, New York, New York (PAK); Vanderbilt University, Nashville, Tennessee (ISB); Section of Congenital Cardiovascular Surgery, University of Illinois College of Medicine at Peoria, Children’s Hospital of Illinois, Peoria, Illinois (KFV); Institute for Health Care Research and Improvement, Baylor Health Care System, Dallas, Texas (GF); The Society of Thoracic Surgeons (STS), Chicago, Illinois (JMH, DM, DS); University of Florida College of Medicine, Jacksonville, Florida (FHE) and University of Michigan, Ann Arbor, Michigan (RLP)

Background. The Society of Thoracic Surgeons (STS) Adult Cardiac Surgery Database (ACSD), has been successfully linked to the Centers for Medicare and Medicaid (CMS) Medicare database, thereby facilitating comparative effectiveness research and providing information about long-term follow-up and cost. The present study uses this link to determine contemporary completeness, penetration, and representativeness of the STS ACSD.

Methods. Using variables common to both STS and CMS databases, STS operations were linked to CMS data for all CMS coronary artery bypass graft (CABG) surgery hospitalizations discharged between 2000 and 2012, inclusive. For each CMS CABG hospitalization, it was determined whether a matching STS record existed.

45% in 2000 to 90% in 2012. In 2012, 973 of 1,081 CMS CABG sites (90%) were linked to an STS site.

Patient-level penetration (number of CMS CABG hospitalizations done at STS sites divided by the total number of CMS CABG hospitalizations) increased from 51% in 2000 to 94% in 2012. In 2012, 71,634 of 76,072 CMS CABG hospitalizations (94%) occurred at an STS site.

Completeness of case inclusion at STS sites (number of CMS CABG cases at STS sites linked to STS records divided by the total number of CMS CABG cases at STS sites) increased from 88% in 2000 to 98% in 2012. In 2012, 69,213 of 70,932 CMS CABG hospitalizations at STS sites (98%) were linked to an STS record.

Conclusions. Linkage of STS and CMS databases demonstrates high and increasing penetration and...
<table>
<thead>
<tr>
<th>YEAR</th>
<th>Number</th>
<th>Number</th>
<th>Center-level penetration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$N_1$</td>
<td>$N_2$</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>983</td>
<td>439</td>
<td>45%</td>
</tr>
<tr>
<td>2001</td>
<td>1,006</td>
<td>476</td>
<td>47%</td>
</tr>
<tr>
<td>2002</td>
<td>1,034</td>
<td>550</td>
<td>53%</td>
</tr>
<tr>
<td>2003</td>
<td>1,056</td>
<td>581</td>
<td>55%</td>
</tr>
<tr>
<td>2004</td>
<td>1,071</td>
<td>631</td>
<td>59%</td>
</tr>
<tr>
<td>2005</td>
<td>1,079</td>
<td>715</td>
<td>66%</td>
</tr>
<tr>
<td>2006</td>
<td>1,092</td>
<td>788</td>
<td>72%</td>
</tr>
<tr>
<td>2007</td>
<td>1,101</td>
<td>854</td>
<td>78%</td>
</tr>
<tr>
<td>2008</td>
<td>1,105</td>
<td>925</td>
<td>84%</td>
</tr>
<tr>
<td>2009</td>
<td>1,101</td>
<td>945</td>
<td>86%</td>
</tr>
<tr>
<td>2010</td>
<td>1,095</td>
<td>970</td>
<td>89%</td>
</tr>
<tr>
<td>2011</td>
<td>1,091</td>
<td>974</td>
<td>89%</td>
</tr>
<tr>
<td><strong>2012</strong></td>
<td><strong>1,081</strong></td>
<td><strong>973</strong></td>
<td><strong>90%</strong></td>
</tr>
</tbody>
</table>
Center-level penetration of the STS Adult Cardiac Surgery Database, by state, 2012
Representativeness of STS data

<table>
<thead>
<tr>
<th>YEAR</th>
<th>N(_3) = # of CMS CABG hospitalizations</th>
<th>N(_4) = # of CMS CABG hospitalizations at sites with STS participation during same year</th>
<th>Patient-level penetration</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>169,633</td>
<td>86,358</td>
<td>51%</td>
</tr>
<tr>
<td>2001</td>
<td>165,243</td>
<td>86,887</td>
<td>53%</td>
</tr>
<tr>
<td>2002</td>
<td>164,240</td>
<td>97,260</td>
<td>59%</td>
</tr>
<tr>
<td>2003</td>
<td>153,685</td>
<td>95,671</td>
<td>62%</td>
</tr>
<tr>
<td>2004</td>
<td>146,936</td>
<td>97,397</td>
<td>66%</td>
</tr>
<tr>
<td>2005</td>
<td>135,169</td>
<td>97,840</td>
<td>72%</td>
</tr>
<tr>
<td>2006</td>
<td>123,320</td>
<td>97,870</td>
<td>79%</td>
</tr>
<tr>
<td>2007</td>
<td>111,967</td>
<td>94,409</td>
<td>84%</td>
</tr>
<tr>
<td>2008</td>
<td>104,232</td>
<td>92,829</td>
<td>89%</td>
</tr>
<tr>
<td>2009</td>
<td>95,657</td>
<td>87,405</td>
<td>91%</td>
</tr>
<tr>
<td>2010</td>
<td>89,729</td>
<td>83,639</td>
<td>93%</td>
</tr>
<tr>
<td>2011</td>
<td>82,890</td>
<td>77,988</td>
<td>94%</td>
</tr>
<tr>
<td>2012</td>
<td>76,072</td>
<td>71,634</td>
<td>94%</td>
</tr>
</tbody>
</table>
Patient-level penetration of the STS Adult Cardiac Surgery Database, by state, 2012
<table>
<thead>
<tr>
<th></th>
<th>STS Adult Cardiac Surgery Database</th>
<th>STS Congenital Heart Surgery Database</th>
<th>STS General Thoracic Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>US Participants</td>
<td>1,088</td>
<td>113</td>
<td>285</td>
</tr>
<tr>
<td>US Hospitals</td>
<td>1,113</td>
<td>133</td>
<td>346</td>
</tr>
<tr>
<td>US Surgeons</td>
<td>2,934</td>
<td>372</td>
<td>952</td>
</tr>
<tr>
<td>US Operations</td>
<td>6,078,240</td>
<td>422,931</td>
<td>505,440</td>
</tr>
<tr>
<td>States</td>
<td>50</td>
<td>40</td>
<td>44</td>
</tr>
<tr>
<td>Estimated US hospital-level penetration</td>
<td>&gt;90% – 95%</td>
<td>&gt;95%</td>
<td>?</td>
</tr>
<tr>
<td>% Publicly reporting</td>
<td>59.9%</td>
<td>66.6%</td>
<td>18.1%</td>
</tr>
<tr>
<td>Total Countries (including US)</td>
<td>7</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Non-US Participants</td>
<td>31</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Non-US Hospitals</td>
<td>31</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Non-US Surgeons</td>
<td>174</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Non-US Operations</td>
<td>50,066</td>
<td>12,442</td>
<td>727</td>
</tr>
<tr>
<td>Total Participants</td>
<td>1,119</td>
<td>119</td>
<td>287</td>
</tr>
<tr>
<td>Total Hospitals</td>
<td>1,144</td>
<td>139</td>
<td>348</td>
</tr>
<tr>
<td>Total Surgeons</td>
<td>3,108</td>
<td>394</td>
<td>961</td>
</tr>
<tr>
<td>Total Operations</td>
<td>6,128,306</td>
<td>435,373</td>
<td>506,167</td>
</tr>
</tbody>
</table>
Council on Quality, Research, and Patient Safety
David Shahian, MD, Chair

WF on Research Development
- TF on Longitudinal Follow-up and Linked Registries
  - Access and Publications TF

WF on Evidence Based Surgery
- 13 Guidelines-Related TFs

WF on National Databases
- Adult Cardiac Surgery Database TF
- Congenital Heart Surgery Database TF
- International Database TF
- TF on Quality Initiatives
- Public Reporting TF
- Informatics TF
- Resource Utilization TF
- Quality Measurement TF
- Appropriateness TF
- Dashboard TF

WF on Evidence Based Surgery
- General Thoracic Surgery Database TF
Database operations

- Full-time STS staff
- >100 STS volunteer surgeon members on some Database-related Workforce or Taskforce
- Multiple STS Database vendors offer wide range of options and cost
- Duke Clinical Research Institute staff
Once data elements are defined and performance measures developed, reports are generated by DCRI -- STS cannot interfere or influence
STS National Database: a unique resource

- 28 years registry experience
- Nationally representative benchmark
- Clinically rich, granular, data elements, developed by content experts
- Structured data fields
- Standardized data definitions
- All patients, payers
- Highly trained data managers
- Audited, highly accurate
- Peer reviewed, completely transparent risk models
- Multidimensional, NQF-endorsed performance metrics
Superior Data
The Society of Thoracic Surgeons
Adult Cardiac Surgery Database
Data Collection Form Version 2.81
March 28, 2014

### A. Administrative

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Record ID (software generated)</th>
<th>STS Core Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID (software generated)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient participating in STS-related clinical trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Clinical trial patient</td>
</tr>
</tbody>
</table>

### B. Demographics

<table>
<thead>
<tr>
<th>Patient Last Name</th>
<th>Patient First Name</th>
<th>Middle Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Security Number</td>
<td>Date of Birth</td>
<td>Patient Age</td>
</tr>
<tr>
<td>Street Address</td>
<td></td>
<td>City, State/ZIP Code</td>
</tr>
<tr>
<td>Race</td>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic, Latino, or Spanish Ethnicity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tobacco use</th>
<th>Never smoker</th>
<th>Current every day smoker</th>
<th>Current some day smoker</th>
</tr>
</thead>
</table>

### C. Hospitalization

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Hospital National Provider Identifier</th>
<th>Payor</th>
<th>Government Health Insurance</th>
<th>Medicare</th>
<th>Medicaid</th>
<th>Federal</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Admission Source</th>
<th>Date of Admit</th>
<th>Date of Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elective Admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Department</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer from Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### D. Risk Factors

<table>
<thead>
<tr>
<th>Family History of Premature Coronary Artery Disease</th>
<th>Yes</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes T2 Diabetes Control</td>
<td>Yes</td>
<td>Unknown</td>
</tr>
<tr>
<td>Peripheral Artery Disease</td>
<td>Yes</td>
<td>Unknown</td>
</tr>
<tr>
<td>Tobacco Use</td>
<td>Never smoked</td>
<td>Current every day smoker</td>
</tr>
<tr>
<td>Long Disease</td>
<td>Yes</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

### STS registry data
- clinical
- granular
- structured
- standardized, strictly defined
- entered by highly trained and supported data managers
Data Managers

- 0.5 - 2 FTEs/program
- About 300 - 500 patients/DM
- Biweekly conference calls
- Training manual/FAQs/Newsletter/Listserv
- Direct access to STS and DCRI staff, surgeon leaders
- Annual AQO conference: > 500 attendees
Data accuracy and validity: external audit

- Initial review: missing, inconsistent, out-of-range data
- Verification against hospital and (previously) governmental data sources
- External audit 10% of sites
- 96-97% accurate coding on > 100,000 data elements audited annually
How do we use our data and measures?

- Performance measurement
- Confidential feedback: patient characteristics, processes of care, outcomes
- Performance improvement
- Public reporting
- Government collaborations: FDA, TVT
- State programs: government and private
- Federal government programs
- Research
What about registries today? Interoperability is a priority and PCPI is helping
2015 Registry Landscape Survey

- Conducted by the NQRN, a PCPI program
- Surveyed 152 societies and associations about registry programs: governance, # of registries, purpose, data collection, expenses, funding and interoperability
- 52% response rate. Registries are generally self-funded with smaller budgets. 39% <$1mil/yr
- Most registries collected demographics, treatments, practitioner information and comorbidities; 53% captured PROs
- 88% used manual data entry; 18% linked to external secondary data sources
- **Cost, interoperability were barriers to continued registry development**
Interest in Registry Networks Growing

- National Quality Registry Network (NQRN)
- PCPI and NQRN
- What is NQRN, what does it do and how to participate
- Work to date and current focus

AHRQ Registries Handbook 4th edition will include a chapter on registry networks

Seth Blumenthal, MBA (Lead)
PCPI

Kathleen Blake, MD, MPH
American Medical Association

Christina Mack, PhD, MSPH
QuintilesIMS

Danica Marinac-Dabic, MD, PhD
FDA

Caleb Stowell, MS
ICHOM

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Why Interoperability Matters

• Value-based payment driving measurement that crosses boundaries
• Current lack of interoperability of health care data impairs ability to realize better value for populations & patients
• Clinicians and patients need pertinent data from all sources to make decisions
• Technical interoperability allows access to data; semantic interoperability preserves the meaning of the information in the data so it can reliably be used in decision-making
• Improved semantic interoperability is expected to result in significantly reduced data acquisition costs as well as better data quality
Opportunity for Registries and Registry Networks

• Industry has mostly focused on technical interoperability

• Semantics, or how information or meaning is represented in data, vary widely between specialties, institutions and industry

• Registries collectively capture much important clinical data with validity & specificity that allow for national measurement & analytics

• Opportunity in registries to standardize definitions of common data elements, reducing need for abstraction & data mapping

• Registry networks well-suited to drive consensus on these kinds of standards and demonstrate the hypothesis that the work is value-added.
What do we need to do in informatics?

Because registries:

• Capture structured, specific clinical data for most clinical specialties
• Are relatively small in number and coordinated through registry networks

They are a good platform for data standards & interoperability work

Need to standardize semantics in a way that represents a voluntary, clinician-driven consensus. If clinical stakeholders across the specialties and professions can agree on standardizing common clinical data...

...barriers to adoption, particularly with vendors, will be lowered.

Theory: this work will lower data acquisition cost to a greater extent than the cost of making the changes in systems. It might also improve data quality.
What is NQRN doing to help registries improve interoperability?

- NQRN identified interoperability as a priority in 2016
- “Registries on FHIR” initiative convened bringing registries, vendors and informaticists together
- Completed information-gathering campaign and submitted paper to AMIA 2018 Informatics Summit
- Currently scoping first project – to demonstrate value of common data elements in lowering registry data acquisition cost and/or improving data quality
- Collaborating with NCDR, SVS VQI, HL7 and MDEpiNet
- Formally launching project this quarter
Getting it done: three projects

• **MDEpiNet Project RAPID**: developing a set of common clinical data elements, beginning with the ONC Common Clinical Data Set and FHIR resources

• **Registries on FHIR**: implement these CDEs in two registries: NCDR/CathPVI and SVS VQI. Measure impact in data acquisition cost/data quality

• **HL7 Common Clinical Registry Framework work group**: Update CCRF Domain Analysis Model (DAM) to incorporate these CDEs, then work to create a general registry FHIR profile that incorporates those CDEs. Collaborate with NQRN to push for adoption in registries.
Discussion

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Thank you!

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