The Future of Clinical Registries: Welcome and Opening Remarks

David Hoyt, MD
David W. Parke II, MD
Helen Burstin, MD, MPH

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CMSS Registry Summit: The Future of Clinical Registries
Welcome from the CMSS President

David Hoyt, MD
Executive Director, American College of Surgeons
President, Council of Medical Specialty Societies
The Future of Clinical Registries: Setting the Stage

David W. Parke II, MD
CEO, American Academy of Ophthalmology
CMSS and Specialty Society Registries

- Nov 16, 2012 CMSS CEO’s Session minutes
  - “In the end, this is a physician responsibility...We have a responsibility to create this...We need to solve these together.”
- Data are a nonrivalrous good—use by one person or organization does not diminish ability of others
  - We are noncompetitive
  - Specialty silos, but understand the power of working across silos, of working across datasets
- Common primary motivation: Improve QOC
Specialty Society Registries: Evolving Value Propositions for Physicians, Societies, Profession, and Populations

- Improve quality of care
- Quality reporting under MACRA
- Generating new science
- Informing health policy decisions
- Enhancing society value to members
- Interfacing analytics from
  - EHRs
  - Imaging systems
  - Patient-reported outcome tools
  - Genetics data sets
  - Claims management
Specialty Society Registries: Amazing Successes

- $500,000,000 in aggregate investment
- 31 societies; 49 registries
- Successful reporting under MIPS
- Hundreds of peer-reviewed scientific papers
- Major component of society value proposition
- Recognition in health policy, research, and public health communities
BUT...emerging ‘issues’

- Financial sustainability
- Data curation and integrity
- Analytic frameworks and models
- Access to data for generating new science
- Standard-setting for data elements in EHRs
- Integrating new data sets
- Working across registries
- Relationship with industry, payers, and health systems
- Sustaining value for physicians
- Competing technologies and investments in the for-profit arena
The Future of Clinical Registries: The Registry Landscape

Helen Burstin, MD, MPH
Executive Vice President and CEO
Council of Medical Specialty Societies
CMSS Registry Summit Planning Committee

- David W. Parke II, MD – American Academy of Ophthalmology – CHAIR
- Helen Burstin, MD – Council of Medical Specialty Societies
- Michael Costelloe, JD – American Society of Plastic Surgeons
- Kathleen Hewitt, MSN – American College of Cardiology
- David Hoyt, MD – American College of Surgeons
- Clifford Hudis, MD – American Society of Clinical Oncology
- Paul Pomerantz, CAE – American Society of Anesthesiologists
- William Thorwarth, MD – American College of Radiology
- Elaine Weiss, JD – American Academy of Dermatology
CMSS Registry Survey (1)

- AAAAI Registry
- AACE: Diabetes Collaborative Registry
- AAD: DataDerm
- AAHPM: Palliative Care Unified Registry
- AAN: AXON Registry
- AAO: IRIS Registry
- AAO – HNS: Reg-ENT
- AAOS: AJRR
- AAP: Child Health Registry
- AAPM&R: AAPMR Registry
- ACC NQRN:
  - PINNACLE, Diabetes, CathPCI, ACTION, AFib Ablation, ICD, IMPACT, LAAO, PVI Registry, STS/ACC TVT Registry
- ACEP Registry
- ACOG: Maternal Quality Improvement Program
- ACP: Genesis Registry
- ACRheum: RISE
CMSS Registry Survey (2)

- **ACR:**
  - Mammography, Lung Cancer Screening, General Radiology Improvement, Dose Index Registry, CT Colonography

- **ACS:**
  - Cancer Database, Surgeon Specific, NSQIP, NSQIP Peds, MBSAQIP

- **APA:** PsychPRO

- **ASA:** NACOR

- **ASCO:** CancerLinQ

- **ASCP:** NPQR

- **ASH:** ASH Research Registry

- **ASPS:** GRAFT, TOPS

- **ASRM:** SART Registry

- **ASTRO:** QOPI

- **AUA:** AQUA Registry

- **NASS:** Spine Registry

- **SGO:** Clinical Outcomes

- **SIR:** Quality Registry

- **STS:** STS National Database

- **SVS:** VQI
Data Capture: Very frequent use of automatic data capture (75% registries), though usually in combination with manual entry
- 6 registries: automatic data capture only
- 8 registries: manual data entry only

Data Submission: Many registries submit data for PQRS/MIPS with feedback to participants (60%)

Data Analysis for Research:
- 73% analyzed data for research
- 50% published results in peer review literature
  - Wide range in #publications: 1-1000 (mean: 133)
Almost half of the registries reported evidence that registry was associated with improvements in quality of care.

Many of the registries with impact focused on surgery and procedures.

Most of the registries reporting impact were longstanding registries associated with ten societies: ACC, ACS, STS, AAO, ASRM, AUA, ACR, ASA, SVS, AAD.
Patient Voice in Registries

- CMSS recently selected for PCORI Engagement Award to support strategies to engage patients in specialty society registries
- Registries have begun to use PROs (40%) and engage patients in their registries (30%)
- Strategies to engage patients included:
  - Focus groups
  - Advisory board
  - Measure and guideline development committees
  - Meetings with patient groups
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The Blackstone has an interesting history. Since 1910, the hotel has attracted celebrities, socialites, and US Presidents. The hotel was also favored by mob bosses “Lucky” Luciano and Al Capone.
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@HelenBurstin
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