The Future of Clinical Registries: Welcome and Opening Remarks

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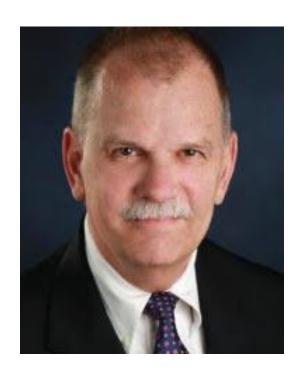Helen Burstin, MD, MPH

May 10, 2018
CMSS Registry Summit: The Future of Clinical Registries

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Council of Medical Specialty Societies

Welcome from the CMSS President

David Hoyt, MD
Executive Director, American College of Surgeons
President, Council of Medical Specialty Societies

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ACOG — The American College of Obstetricians and Gynecologists

NASS — North American Spine Society

AMERICAN COLLEGE of CARDIOLOGY

AMERICAN COLLEGE OF SURGEONS — FOUNDED IN 1913 — OMNIBVS PER ARTEM FIDEMQVE PRODESSE

ASTRO — TARGETING CANCER CARE

AMERICAN PSYCHIATRIC ASSOCIATION

Society of Critical Care Medicine — The Intensive Care Professionals

AGS — THE AMERICAN GERIATRICS SOCIETY — Geriatrics Health Professionals. Leading change. Improving care for older adults.

AMERICAN SOCIETY OF HEMATOLOGY

THE SOCIETY OF THORACIC SURGEONS — Established 1964

aahpm — AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

American Urological Association

ASCP

AAFP

ACPM — American College of Preventive Medicine

AMERICAN ACADEMY OF OPHTHALMOLOGY — Protecting Sight. Empowering Lives.

AMERICAN SOCIETY OF PLASTIC SURGEONS

AMERICAN ACADEMY OF OTOLARYNGOLOGY— HEAD AND NECK SURGERY

asrm — American Society for Reproductive Medicine

shm — Society of Hospital Medicine

ACP — American College of Physicians — Leading Internal Medicine, Improving Lives

ASCO — AMERICAN SOCIETY OF CLINICAL ONCOLOGY — MAKING A WORLD OF DIFFERENCE IN CANCER CARE

ACR — AMERICAN COLLEGE OF RADIOLOGY

AMERICAN EPILEPSY SOCIETY

American Society of Anesthesiologists

AMERICAN COLLEGE OF RHEUMATOLOGY — EDUCATION · TREATMENT · RESEARCH

ASCRS — American Society of Colon and Rectal Surgeons

ACMG

THE AMERICAN ACADEMY OF PEDIATRICS

AAOS — American Academy of Orthopaedic Surgeons

SNMMI

AMERICAN ACADEMY OF NEUROLOGY

AMIA — INFORMATICS PROFESSIONALS. LEADING THE WAY.

AAD — AMERICAN ACADEMY OF DERMATOLOGY — 1938

SVS — Society for Vascular Surgery

AACE — AMERICAN ASSOCIATION OF CLINICAL ENDOCRINOLOGISTS — The Voice of Clinical Endocrinology

American College of Emergency Physicians — ADVANCING EMERGENCY CARE

aaPM&R — American Academy of Physical Medicine and Rehabilitation — Physicians Adding Quality to Life

Society of Interventional Radiology

ACOEM — AMERICAN COLLEGE OF OCCUPATIONAL AND ENVIRONMENTAL MEDICINE — 1916

ASN

SGO — Society of Gynecologic Oncologists

AAAAI — AMERICAN ACADEMY OF ALLERGY ASTHMA AND IMMUNOLOGY

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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

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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

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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

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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

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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

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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

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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

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Data Landscape

▸ *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)

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Registry Impact

▸ Almost <u>half</u> 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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