NQRN Leading Practices Webinar

*Introduction to Clinical Data Registries*

June 13, 2017
## Agenda

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<tr>
<th>Session</th>
<th>Presenter</th>
<th>Duration</th>
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<tr>
<td>Welcome, Introductions and Housekeeping</td>
<td>Chrystal Price</td>
<td>10 minutes</td>
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<tr>
<td>Presentation</td>
<td>Stephanie Peditto</td>
<td>30 minutes</td>
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<tr>
<td>Moderated Q&amp;A</td>
<td>Seth Blumenthal</td>
<td>15 minutes</td>
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<tr>
<td>Wrap-up</td>
<td>Chrystal Price</td>
<td>5 minutes</td>
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NQRN® 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
Speaker and Moderator

Stephanie Peditto, MHS
Senior Director
Science, Quality and Practice
American Academy of Dermatology

Seth Blumenthal, MBA
Director
Data and Innovation
PCPI
Introduction to Clinical Data Registries For PCPI

Stephanie Peditto
Senior Director
Science, Quality and Practice
American Academy of Dermatology
June 13, 2017
Objectives

At the end of this session, participants will know:

• What is a registry
• Value and uses of a registry
• Key factors in planning, implementing and running a registry
• Getting value from the registry
• Resources for further learning
Clinical Registries

What?
Programs that collect and store data containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose.

Why?
Collect information on a particular disease or condition (e.g., diabetes registries)
• Track patients who have a particular disease, condition or risk factor that predisposes them to a health-related event (e.g., implantable device)
• Pre- and post market evaluation
• Public health reporting (e.g., vaccine registries)
• Evaluate patient outcomes
A Clinical Registry is a Powerful Tool

- to observe the course of disease
- to understand variations in treatment and outcomes
- to examine factors that influence prognosis and quality of life
- to describe care patterns, including appropriateness of care and disparities in the delivery of care
- to assess effectiveness
- to monitor safety and harm
- to measure quality of care
- to study quality improvement
Registries’ Value Lies in Aggregating Data From Many Sources

• EMR-based clinical data is valuable understand how disease is treated and the cost and quality of care
  • Clinical data adds important dimensions not available from claims

• Registries are population focused, purpose driven, and designed to derive information. EMRs are focused on the collection and use of an individual patient's health-related information.
  • EMR data sources (for research, etc) to date are uneven, often from a single EMR vendor or health system

• Medical Societies aggregating data for members (quality reporting, analytics) are emerging as a prime source for clinical data
Planning, Implementing and Running a Registry

• Getting started
  • Making the decision
  • Developing the plan
  • Defining the data and data sources

• Implementing and launching
  • Recruiting and Retaining
  • Improving data quality

• Getting value from the registry
  • Using the registry to understand and improve care
Getting Started: Make the Decision

- Articulate the purpose of the registry
  - Define the Why!
  - For medical societies in particular: clinical registry versus CMS reporting platform
- Identify key stakeholders
  - Decision-makers and users
  - Secondary stakeholders who might ultimately want to use the data
- Assess the feasibility of a registry (see NQRN Business Case Tool)
  - Business plan
  - Funding sources
- Do not rush this process!
Getting Started: Develop the Plan

- Identify organizational requirements
  - Identify a registry team
  - Project management, registry expertise, clinical, data analytics, measures (as applicable), marketing/communications, IT, finance, legal, executive leadership
  - Member involvement/oversight
- Map out at a summary level how the registry will be built, tested and made available for use by participants
Getting Started: Define the Data and Data Sources

- Identify the data elements needed to meet the registry's goals
- Develop a data dictionary with defined fields and specifications
- Identify the source(s) for those fields
- Ultimate goal to decrease the effort required of participating providers

The evolution away from manual entry toward EHR integration is a lead in the right direction.

EHR integration is no longer a technical problem for registries— but it is not yet a panacea!
# Identify the Source(s) for the Registry Data Fields

<table>
<thead>
<tr>
<th>Providers--EHRs</th>
<th>Providers- Manual Data Entry</th>
<th>Other health IT</th>
<th>Patients</th>
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<tbody>
<tr>
<td>• Push</td>
<td>• Web data entry</td>
<td>• Linking with different admin/ clinical/billing databases</td>
<td>• Direct from patients</td>
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<tr>
<td>• Pull</td>
<td>• File upload</td>
<td>• Departmental systems (e.g., PACS)</td>
<td>• From their devices</td>
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<tr>
<td>• Certification model</td>
<td></td>
<td>• Other registries</td>
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What EHRs do your providers use?
Do those vendors work well/easily with registries?
Do the organizations work well/ easily with registries?
Do your data elements exist as structured data fields in those EHRs?
Is supplemental manual entry needed?
How will you get patient-reported data? How will it feed back to providers?
Proactively Plan for the Challenges of Data Capture

- Mapping data
  - EMR by EMR
  - Provider by provider
  - Key word searches and natural language processing
- Working with EMR vendors
  - Data push/ data pull
- Working with organizations (e.g., academic medical centers)
  - Legal, IT, QI, clinical department

Understand and plan for data collection challenges

Communicate about registry implementation based on this knowledge

Plan for likely need to increase availability of structured data to meet registry goals (common definitions, standardized documentation, adding structured data fields to EMRs)
Implementing the Registry: Plan for Launch

• Platform development and testing
• Legal, privacy and security considerations
• Recruiting and Enrollment plans
  • Initial pilot group(s) versus wide launch?
  • User testing and feedback
  • Timing (MIPS submissions)
  • Key deadlines
• Training plan
  • Just-in time, easy to access, multiple formats
  • Identify audience (providers? Providers’ office staff?)
  • “Customer service” support
Recruiting and Retaining Providers: Communication is Key

- Define value to providers (participants) and to the specialty (or the field)
  - Why should the provider invest the time?
  - Why should the specialty invest the money?
- Hospital recruitment vs. provider recruitment
- Use communications to engage providers in the vision, but manage expectations for start-up
- Plan Communication strategy
  - Big splash or “build it and they will come” proof of concept first?
  - Who will be able to use the registry initially?

Value is in the eye of the beholder!
Retaining Participants

- Delivery on promises made during recruitment
  - the burden of participation is low
- Pilot testing prior to full recruitment lessens the likelihood that problems will arise that threaten the registry's reputation
- Visible advisory board/users group
- Early and continued engagement with sites
- Awareness and regular demonstration of value
Running the Registry: Ever-Improving Data Quality

- Data completeness is the primary and immediate focus of data accuracy
- Increasing sophistication with data validation rules and/or logical checks for out-of-range values, missing values and values that are logically inconsistent.
No Gold Standard (Yet) for Ensuring Data Quality

- Automated, pre-programmed data checks (simple edit checks, such as range values for laboratories)
- Manual data checks or queries to review data for unexpected discrepancies
- Query reports may include missing data, “out-of-range” data, or data that appear to be inconsistent (e.g., positive pregnancy test for a male patient). They may also identify abnormal trends in data.
Getting Value From the Registry: Using the Data for Understanding and Improving Care

Improving care at the patient level and the population level

- Benchmark reports
  - Provider
  - Disease/condition
  - Specialty level
  - Healthcare system
- Reports of frequency and patterns of various elements of a patient population (descriptive)
- Reports examining associations between patients or treatment characteristics and health outcomes of interest (analytical)
Getting Value From the Registry: AAD’s Quality Improvement Framework

- Understanding External Requirements
  - PQRS
  - MIPS
  - DataDerm as QR
  - DataDerm as a QCDR

- Understanding Measures
  - Measure Definitions
  - DataDerm Only Measures
  - AAD measure development
  - How to collect measures
  - Resources for collecting measures

- Understanding & Using Data
  - How to use data
  - Utilizing Dashboard
  - Critical Analysis Tools
  - Quality Improvement

- Improving Practice
  - Peer-to-peer learning
  - Practice Management Center
  - Manage reporting burden

- Improving Patient Care
  - Implement QI
  - Streamline workflow
  - Improve outcomes
Getting Value From the Registry: Allowing Others to Use Your Registry Data to Improve Care

• Seek continuous input from multiple stakeholders on what questions they would like the data to answer
  • Have clinical and scientific expertise to translate the questions into data elements; have registry expertise to determine data sources
  • Have governance and data field governance in place to review and approve additions to data dictionary
• Develop or outsource data analytics capability
• Consider data request portal
## Ongoing Funding/ Business Planning for Registries

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<th>Description</th>
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<td><strong>Member Funded</strong></td>
<td>Charge Membership for value provided</td>
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<td><strong>Commercial Initiative</strong></td>
<td>Develop Partnership Engagements with Life Science and other parties that will provide funds based on value of data</td>
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<tr>
<td><strong>Commercial Partnership</strong></td>
<td>Develop a partnership with a commercial informatics company who would guarantee infrastructure in return for commercializing the data</td>
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<td><strong>Philanthropy</strong></td>
<td>Seek Philanthropic Supporters to build out and maintain the registry</td>
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Adapted from Merold, 2017
Resources

- NQRN/PCPI
- Each other!

Stephanie Peditto
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Questions and Discussion
Discussion

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National Quality Registry Network
Thank you!

For questions or further information please contact:

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Performance improvement is everyone’s business.