NQRN Webinar

Registry Interoperability

October 10, 2017
Agenda

• Welcome, Introductions and Housekeeping  Chrystal Price, 5 minutes
• Presentation  Seth Blumenthal, 5 minutes
• Presentation  Judy Burleson, 10 minutes
• Presentation  Dr. James Tcheng, 20 minutes
• Moderated Q&A  Dr. Frank Opelka, 15 minutes
• Wrap-up  Chrystal Price, 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 and Moderator

Seth Blumenthal, MBA
Director, Data and Innovation
PCPI

James Tcheng, MD
Professor of Medicine, Cardiology and Informatics, Duke University School of Medicine

Judy Burleson, MHSA
Senior Director, ACR Quality Management Program
American College of Radiology

Frank Opelka, MD
Medical Director for Quality and Health Policy at the American College of Surgeons and NQRN Registries on FHIR Co-chair

National Quality Registry Network
Interoperability and registries: A Brief Introduction

Seth Blumenthal, MBA
Director, Data & Innovation
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
What Can We Do About It and Why Registries?

- Industry has mostly focused on technical interoperability
- Semantics, or how information or meaning is represented in data, vary widely between specialties, institutions and industry
- Out of the many thousands of kinds of data in health care, some are specific and others are commonly used across specialties and workflows
- 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
- NQRN registries willing to collaborate to achieve consensus on these kinds of standards and demonstrate the hypothesis that the work is value-added.
What is NQRN doing to help registries improve interoperability?

• NQRN Steering Committee in-person meeting at 2016 PCPI Fall Conference: interoperability identified as a priority
• “Registries on FHIR” 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
• Kick-off and formal launch anticipated this quarter
NQRN: Interoperability Webinar
ACR National Radiology Data Registry Experience

Judy Burleson
Senior Director, ACR Quality Management Programs
October 10, 2017
Topics to Cover

- Overview of NRDR databases
- Participating sites characteristics, sources of data
- Data submission methods
- Interoperability challenges and efforts
- Future strategies
National Radiology Data Registry

NRDR GRID™
General Radiology Improvement Database
American College of Radiology
2008

NRDR CTC™
CT Colonography Registry
American College of Radiology
2008

NRDR MIPS
MIPS Registry
2009

NRDR QRDR
QCDR
American College of Radiology
2014

NRDR IR
Interventional Radiology Registry™
American College of Radiology
2017

NRDR LCSR™
Lung Cancer Screening Registry
American College of Radiology
2011

NRDR NMD™
National Mammography Database
American College of Radiology
2011

NRDR DIR™
Dose Index Registry
American College of Radiology
2011
NRDR Participating Site Characteristics

**NRDR Facility Count**

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<tr>
<th>Facility type</th>
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<th>NRDR active</th>
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<th>Census region</th>
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<tr>
<td>West</td>
<td>952</td>
<td>584</td>
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</table>

**Trends**

Facility, group, physician level data
Data Sources

- CT scanners
- PACS
- Fluoro equipment
- RIS
- Practice Mgmt Software
- Reporting/speech recognition system
- Service specific mgmt system
Certified Vendor Software Partners
14 Partners 435 facilities

The following software partners have validated direct data export into the ACR LCSP:

- NUANCE
- Insight
- Invivo
- PRIMORDIAL
- LungView
- Aspentran
- PenLung
- LungDirect
- MedInformatix
- Epic
- LungTrack
- AWARE
- DOSEMOMON
- ImagiCare
- GE
- Infinitt

Certified Software Partners

- NMD-Certified™ Software Partners approved for NMD 3.0 (BI-RADS® Atlas, 2013 ed.)
- MedMyne
- SIEMENS Healthineers
- MAGVIEW
- MRS

- NMD-Certified™ Software Partners conditionally approved for NMD 3.0 (BI-RADS® Atlas, 2013 ed.)
- Radiance

- NMD-Certified™ Software Partners approved for NMD 2.0 (BI-RADS® Atlas, 2004 ed.)
- CANDELIS
- Insight
- MagViewer
- MRS
- SIEMENS Healthineers
- PENRAD
- EPIC

American College of Radiology
Data Submission Methods

- Fully automated
- Transmit standard DICOM image data with ACR TRIAD software
- From scanner, PACS, OCR, dose monitoring software

- Radiology report system
- Structured report templates, standardized data elements (not NLP)
- HL7 message through TRIAD software
- Web services API

- Manual entry - web forms
- Registry compatible flat file upload
- Web services API
Interoperability Challenges

- System level
  - Radiology practice models
  - Multiple systems, multiple locations

- Vendor level
  - Unique
  - Practice experiences, ACR experiences
  - Version/upgrades
  - Cost
Interoperability Challenges

- Data element level
  - Accuracy
  - Data completeness
    - Radiology systems/imaging and interpretation data
    - Outcome data – confirming dx - biopsy, pathology, clinical
      - Disparate information systems within or out of institution or health system
      - Manual entry of EHR data to radiology system – burden, inaccuracies
      - Missing data
Addressing Interoperability Challenges

- Use case: cancer screening registries (lung, breast)
  - Outcome data incompleteness
  - Integrating imaging/clinical data at site or within registry
- Hurdles:
  - Patient identifier
  - Institution/system IT support
  - Security
Addressing Interoperability Challenges

- Use case current efforts
  - Site level – reuse of HL7 messages created for state tumor registry, health system MRN; send to ACR
  - Registry level – linking LCS registry data with SEER cancer registries
  - Population level – linking clinical quality registries
Addressing Interoperability Challenges

- NCI/ACR - Linking state SEER registry data with ACR LCS registry data
  - Patient SSN, name
  - Medicare LCS reimbursement registry reporting requirement
  - Finder file/honest broker, link and send data back
  - Pilot with single state - robust registry data, motivated

- Mutually beneficial
  - SEER data supplemented with screening history/outcome data
  - LCS registry data supplemented with cancer dx and characteristics
Addressing Interoperability Challenges

- Population level – linking clinical quality registry data
  - ACS National Cancer Database, ACR National Mammography Database
  - Analysis of relationship between screening and clinical outcomes in breast cancer
  - Feasibility analysis/discussions underway
  - State level data
  - Facility/exam level matching, fields needed
  - Permissions needed
Future Efforts and Strategies

- Continue efforts to link to other data sources
- Radiology reports rich data source for data on quality
- Build on use of structured templates vs use of NLP
- Integrate use of ACR reporting and data systems in informatics tools, vendor systems
- Further develop HL7 or FHIR capabilities for electronic exchange of data
- Vendor engagement events
NQRN and Achieving Interoperability in the Real World

James E. Tcheng, MD, FACC, FSCAI
Professor of Medicine
Professor of Community and Family Medicine (Informatics)
james.tcheng@duke.edu
<table>
<thead>
<tr>
<th>Envisioned</th>
<th>Reality</th>
</tr>
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<tbody>
<tr>
<td>EHR “Meaningful Use”</td>
<td>EHR meaningless burden</td>
</tr>
<tr>
<td>Usability and productivity</td>
<td>Death by clicking</td>
</tr>
<tr>
<td>Patient engagement</td>
<td>AVS drivel</td>
</tr>
<tr>
<td>Better patient outcomes</td>
<td>CDS trivial pursuit</td>
</tr>
<tr>
<td>Better population health</td>
<td>Resource consumption focus</td>
</tr>
<tr>
<td>Bending healthcare cost curve</td>
<td>Penalties and uncertainty</td>
</tr>
<tr>
<td>Better provider work life</td>
<td>NOT!</td>
</tr>
<tr>
<td>Torrent of real world data</td>
<td>Puddles of document exchange</td>
</tr>
<tr>
<td>Big data analytics</td>
<td>Small transactions data</td>
</tr>
<tr>
<td>Leveraged RCTs via registries</td>
<td>20th century paradigms</td>
</tr>
</tbody>
</table>
If you don’t know where you are going, chances are you will end up somewhere else.

-- Yogi Berra (1925-2015)
Interoperability via Data Standards

• Why – and the 2 key “customers”
• What – selecting the candidates
• How – informatics and “info-magic”
• Who – roles and responsibilities
• When – concepts to action NOW!
THE Foundational Issue

Tower of Babel

Pieter Bruegel the Elder and Pieter Bruegel the Younger, 1563
Levels of Interoperability

• **Technical** – allows data to be exchanged between computer systems
  • Word processing documents, text messages

• **Syntactic** – describes the standard syntax (format) of the data
  • Document templates, forms, data structures
  • Message standards

• **Semantic** – requires use of standardized content (vocabularies) within the data structure
Interoperability via Terminology Standards

- **Multiple levels of rigor**
  - Ad hoc – informal development and use
  - Formal process / consensus – role of SDOs
  - *De facto* – large number choose to adopt so it becomes a standard

- **Rigor requires resources and expertise**

- **Not just “interoperability”**
  - Without data standards, semantic harmonization still required between every two interface points
    - (exponential number of harmonization tasks)

- **Common Data Element modeling**
  - ISO 11179, NCI EVS, CIMI
The Foundational Solution
Native, Interoperable Data Standardization

Electronic health information

Electronic Health Records

Procedure info systems

Registries, CRNs

Clinical studies
Data Challenge: Multiple Masters

- Clinical care
- Health system
- Payers
- Patients
- Federal, state programs
- FDA
- Registries
- Research
- Oh yes ... clinicians

Recipients

Producers
(aka Customer #1)
Customer #2: Database Developer

So you want to build a database ...

- Data element **label** (i.e., what do you call the data element, aka the “address” of the data in the database)
- Data **format** (e.g., text string, integer, date, constrained list)
- Business **rules** about the data (e.g., range limits, consistency checks, ...)
The Approach
Native, Interoperable Data Standardization

✓ Device evaluation (FDA/MDEpiNet) – coronary stents, peripheral artery revascularization, bariatric devices, EP CIEDs, …
✓ And their registries – ACC NCDR (CathPVI, ICD), SVS VQI, ACS MBSAQIP, … → all NQRN ???
✓ Core common clinical data concepts – name, DOB, sex, procedures, labs …
✓ Discipline specific …
Selecting Discipline-Specific Concepts

“Clean” clinical concepts that are shared across clinical care, procedure documentation, research, and regulatory spaces that are unique to the discipline and needed for analysis:

- Define the clinical state of the patient
  - Clinical presentation, risk factors
- Describe technical aspects
  - Anatomy, procedure details
- Represent outcomes of interest

Think PARSIMONY!
Core Common Clinical Data Elements

Clinical concepts that are shared across clinical, research, and regulatory contexts that are NOT unique to the discipline and already have bindings to standardized terminologies):

- Demographics, administrative data
- Vital signs, tobacco use history (ONC)
- Procedure codes (CPT)
- Laboratory data (LOINC)
- Medications (RxNorm)
- UDI and reference device data (GUDID)
What is a Data Element?

- A data element is a question – value pair
- Considered the smallest meaningful unit of data exchange
- Formally defined in ISO/IEC 11179-1 and 11179-3
- Typically have a unique identifier, a definition, and valid values
- Interpretation requires context (e.g., date/time of collection, method of measurement, or person, place or thing to which the data pertains)
The Project – Common CDEs

<table>
<thead>
<tr>
<th>Question or prompt</th>
<th>Value, result or answer</th>
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</thead>
<tbody>
<tr>
<td>HCV status:</td>
<td></td>
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1. Long name (e.g., human prompt for CRF, data entry screen)
2. Short db name (all caps, no spaces, underscores only, limited chars ...)
3. Clinical definition of the concept
4. Data type (e.g., free text, constrained list, integer, coded data phrase)
5. Allowed values (aka permissible values = value set)
6. Definitions of allowed values
7. Key business rules (e.g., range / edit checks, consistency, validation)
8. Grouping / synonyms (e.g., atrial fibrillation, PAF, AF, afib, etc.)
9. References
Clinical Terminology Modeling

- Netherlands/ISO Standard
- ISO EN 13606
- UK – NHS and LRA
- Singapore
- Sweden
- Australia
- openEHR Foundation
- Canada
- US Veterans Administration
- US Department of Defense
- Intermountain Healthcare
- Mayo Clinic
- MLHIM
- Others....

- HL7
  - CIMI
  - Version 3 RIM, message templates
  - TermInfo
  - CDA plus Templates
  - Detailed Clinical Models
- Tolven
- ANSI X12
- NIH/NCI – Common Data Elements
- CDISC SHARE
- Korea - CCM
- Brazil
- Norway
Clinical Terminology Modeling (2)

- PCPI - NQRN
- ONC Meaningful Use CCDS
- NLM / VSAC
- National Comprehensive Care Network (NCCN)
- AAO
- ACC
- ACOG
- OPA
- ACEP
- APTA
- RSNA
- ACR
- The Sequoia Project
- Pulse Informatics
- Independence BCBS

- PCORNet Common Data Model
- OMOP Common Data Model
- Sentinel Common Data Model
- AHRQ
- FDA
- ONC
- CMS
- Academy of Nutrition and Dietetics
- Truven Health Analysis
- CDC
- And many others
CIMI - Logical Model Development Lifecycle (opencimi.org)
What is the Clinical Information Interoperability Council?

• We want to create ubiquitous sharing of standardized data across the breadth of medicine for:
  – Direct patient care
  – Research and learning
  – Public health
  – Clinical trials
  – Data from devices
  – Post market surveillance
  – Quality and disease specific registries
  – Billing and health administration
  – Any where that we share health related data and information

.....
From Concepts to Action

Creating the ecosystem ...

- **MDEpiNet Projects** (RAPID, CATNIP, EP PASSION, ...): identify discipline-specific CDEs
  - Long name, short db name, data type, definition, allowed values + definitions, etc.

- **MDEpiNet, NQRN** – **identify common CDEs for native interoperable standardization**
  - Based on FHIR (Fast Healthcare Interoperability Resources)

- **Informatics** – specify (“model”) the technical representation (HL7 CIIC, CIMI, NLM, NCI EVS, others)
“Dammit, Jim, I’m a Doctor, Not a Computer!”
What is Structured Reporting?

• Specific data captured by the person closest to that data, integrated into clinical workflow (e.g. MA, tech, RN, pt)
• Informatics formalisms: universal, well-defined common data elements; data model that parallels (i.e., is representational of) clinical care model
• Data is compiled by the computer to produce most of the content in a report; MD validates data, focuses on cognitive assessment and recommendations
• Output: the \textit{structured report}
• ROI: $\uparrow$ data quality /quantity, $\downarrow$ redundancy / repetition, time to final reports, FTE requirements $\rightarrow$ augmented knowledge, financial gains
How Is Structured Reporting Done?

• Engineered, best-practice workflows
• Just in time, context specific, high usability, point of care data capture via forms
• Lots of business rules
• Optimized IT form factors
• Computer is a compiler

In other words ...

• Command of who does what when, where, and how
Questions?

Never, ever think outside of the box!!!
Common CDE Definition Process

1. Determine common data concepts across MDEpiNet projects (and their registries)
   From registry and industry CRFs

2. Environmental scan to catalog efforts external to MDEpiNet
   ONC Common Clinical Dataset, PCPI NQRN Registries on FHIR (Seth Blumenthal), HL7
   Common Registry Framework, Common Data Models (SENTINEL, PCORNet, OMOP/ODASI), multiple other efforts

3. Develop “spreadsheet” columns of data element concepts
   Apply db developer lens: “What do I need to build the data element in a database?”
   e.g., Long name, db name, data type, data field constraints, allowed / permissible
   values, definitions, references

4. Identify and develop / specify candidate terms
   Domain analysis: cross reference of CDE concepts against existing standards
   FHIR will likely have specified some of this already at a pragmatic, “best fit” level
   ONC Common Clinical Dataset Standards also references existing standards

5. Develop technical representation, bind to existing standards, and test
   Native interoperability level – not just FHIR translation level
   VQI and CathPVI registries – first demonstrations
   Then ACC NCDR and PCPI NQRN family of registries

6. Develop as a full technical standard – logical modeling by CIMI, approval via CIIC
   Engage EHR, CVIS, EHI system vendors in healthcare
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National Quality Registry Network
Thank you!

For questions or further information please contact:

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