PCORnet CDM Implementation Forum

Thursday, October 29, 2015, 1-2 PM Eastern

Hosted by Keith Marsolo, PhD

Facilitated by Shelley Rusincovitch and Michelle Smerek

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The National Patient-Centered Clinical Research Network

Agenda

- Welcome and introductions
- Index of active CDM forum topics
- CDM forum interest groups
- Lab mappings discussion
- SAS implementation discussion

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PCORnet Informal Reception at AMIA

Tuesday, November 17, 6:30-8:30 PM Pacific Time

Conference hotel (Hilton San Francisco Union Square, 333 O'Farrell Street, San Francisco, CA 94102)

Cityscape, 46th Floor, Tower 1

Please join us! This will be a cash bar with reserved seating to socialize and connect with your PCORnet colleagues.

Any questions? Please feel free to contact Shelley Rusincovitch (shelley.rusincovitch@duke.edu; cell: 919-247-1912).

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CDM Forum Topic Index

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Index of Active CDM Forum Topics (1 of 2): Data-Related

- **Lab Mappings**: Local lab result mappings and LOINC references
- **Med Mappings**: Dispensing and prescribing data, including RxNorm practices, order of preference as brand vs generic
- **CONDITION Table**: Including IMO terminology
- **Encounter Classification Practices**
- **Death Data**: Including acquisition, NDI source coding, CDM constraints
- **Smoking and Tobacco History**: Includes legacy data differences from newer MU-mandated structuring

Index of Active CDM Forum Topics (2 of 2): Implementation-Related

- **Datamart Structuring for EHR and Claims Sources**: This topic has overlap with DRNOC-CDRN calls
- **SAS Implementation Practices**
- **Performance Optimization Practices**: Including indexing practices, highly datamart-specific
- **GitHub**: Overview of platform and facilitate understanding of groups already active and posting PCORnet code

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Next steps

- What topics are missing? Special focus around “network of network” commonalities
- Next set of CDM forums for November-January are being scheduled
- Beginning each CDM forum with a run-through of the topics list and brief updates, including interest groups

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Overview of CDM Forum Interest Groups

The vanguard: CDM development working group in Phase I

Products of interest groups may include (but are not limited to):

- Assessments of common practices, factors, challenges, and methods
- Landscape of current state and adoption
- Guidance for implementation

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Examples of CDM working group products (from Phase I)

Pragmatic Data Domain Selection for a National Distributed Research Network: The PCORnet Common Data Model Strategy

Shelley A. Rusincovitch[1], Abel N. Kho, MD, MS[2], Jon E. Puro, MPA:HA[3], Daniella Meeker, PhD[4], Pedro Rivera, MSCS[3], Aaron A. Sorensen, MA[5], Jeffrey S. Brown, PhD[6], and Lesley H. Curtis, PhD[7]

[1]Duke Translational Medicine Institute, Durham, NC; [2]Northwestern University Departments of Medicine and Preventive Medicine, Evanston, IL; [3]OCHIN, Inc., Portland, OR; [4]Department of Health, RAND Corporation, Santa Monica, CA; [5]Temple University School of Medicine, Philadelphia, PA; [6]Department of Population Medicine, Harvard Medical School and Harvard Pilgrim Health Care Institute, Boston, MA; [7]Duke University School of Medicine, Department of Medicine, Durham, NC

Introduction

- The PCORnet Common Data Model (CDM) specifies the data foundation for PCORnet, and is developed with a **phase-based approach**
- Each phase incorporates **new concepts and data tables** to support distributed clinical research (observational and interventional)
- In order to establish priorities for subsequent CDM development, it was necessary to establish a **method of assessing new concepts** and **making decisions for inclusion** to serve the functional, pragmatic focus of the initiative

Methods

- The assessment was **organized by data domains**; i.e., the high-level concepts of data organization based upon existing data sources, workflows, and processes
- Assessment included best practices established by **existing data models** and **advice from external experts**
- Close attention to **PCORnet-specific requirements**

Contact Information

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Data Domain Evaluation Table

The use of "stoplight" colors conveys favorable (green), caution (yellow), or unfavorable (red)

Domain	Effort Needed to Acquire Data	Analytic Utility/Value	Ability to Standardize Across Sites	Availability Across Networks (Anecdotal)
Allergies and/or Contraindications	HIGH	MOD	LOW	MOD
Patient-reported Outcome (PRO) Common Measures (CDM v2.0)	MOD	MOD	HIGH	N/A (prospective)
Condition (CDM v2.0)	LOW	MOD	MOD	HIGH
Death and Death Cause	HIGH	HIGH	HIGH	LOW
Facility	MOD	MOD	LOW	HIGH
Family history	MOD	MOD	LOW	LOW
Inpatient Medication Administration	HIGH	LOW	LOW	LOW
Laboratory Result Common Measures (CDM v2.0)	MOD	HIGH	LOW	HIGH
Medication Reconciliation	MOD	MOD	MOD	HIGH
Outpatient Pharmacy Dispensing (CDM v2.0)	MOD	HIGH	HIGH	LOW
Primary Care Provider (PCP)	MOD	MOD	MOD	MOD
Provider Orders (including Medication Orders)	MOD	MOD	LOW	MOD
Social History & Lifestyle Choices	HIGH	LOW	LOW	MOD
State Vaccine	HIGH	LOW	LOW	MOD
Study Enrollment	LOW	HIGH	MOD	N/A (prospective)
Study Visits	MOD	MOD	MOD	N/A (prospective)

Data Model Landscape Scanning

- Mini-Sentinel Common Data Model, v4.0
- i2b2 Data Repository Cell, v1.7.00
- OMOP Common Data Model, v5.0
- HMORN VDM, v3.2
- ESPnet Data Form, 2013
- National Quality Forum, Quality Data Model, Version 4.1.1.

Results

- Assessment resulted in recommendation for **prioritization of data domains**
- Initiative has subsequently **formalized a process** for stakeholder review, facilitated discussion, and the approval process for adoption

Discussion

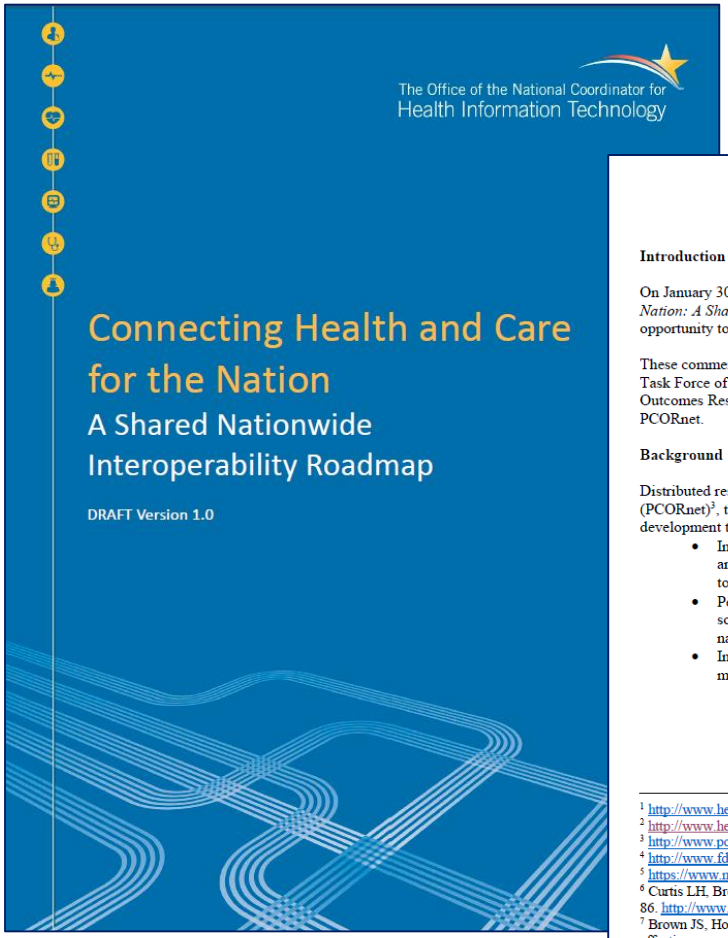
- Key lesson learned: **Importance of identifying and articulating foundational strategic decisions**, including **interoperability** within the analytic framework
- Limitation: Dimensions were **assessed by the CDM Working Group**, rather than by a formal survey of all participants; however, the working group represented individuals with the deep expertise necessary to make informed recommendations

Acknowledgments The project described was supported by the PCORnet National Patient-Centered Clinical Research Network. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the Patient-Centered Outcomes Research Institute.

AMIA
INFORMATICS PROFESSIONALS. LEADING THE WAY.
2015 Joint Summits on Translational Science, March 23-27, 2015

Download the poster:
https://pcornet.centraldesktop.com/p/aQAAAAACUtd4

Informed by CDM Development Experience: Response to ONC Interoperability Roadmap, April 3, 2015



Response to ONC Interoperability Roadmap by Curtis, Brown, et al
Comments Submitted on April 3, 2015

Introduction

On January 30, 2015 the Office of the National Coordinator (ONC) issued the draft version of the Interoperability Roadmap, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Draft Version 1.0*[1]. This document is in response to the call for public comments[2], and we appreciate the opportunity to provide our feedback.

These comments represent the individual views of the authors, each of whom collaborate on the Data Standards, Security, and Network Infrastructure (DSSNI) Task Force of PCORnet, the National Patient-Centered Clinical Research Network. These comments do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), the PCORI Board of Governors, or other organizations and governmental entities collaborating in the development of PCORnet.

Background

Distributed research networks repurposing clinical and administrative data, such as the PCORnet National Patient-Centered Clinical Research Network (PCORnet)[3], the FDA's Sentinel Initiative[4], and the NIH Collaboratory Distributed Research Network[5], are an important area of national infrastructure development to benefit healthcare and research[6]. There are several key elements of this infrastructure pertinent to our assessment for the Interoperability Roadmap:

- In a distributed research network, the source data held by individual data partners never leave their institutional firewalls[7]. This distributed systems architecture is distinct from the IT platforms that typically support clinical care delivery, but both approaches benefit from infrastructure development to support interoperability.
- Performing analysis of data on distributed data stores is a specialized activity that has different systems requirements than typical clinical care software; however, these distributed analytic methods may be particularly pertinent as the Interoperability Roadmap vision fosters scalability to a national Learning Health System.
- Interoperability has important benefit to research initiatives repurposing data generated in the delivery of healthcare. However, the clinical drivers must be recognized and appreciated for appropriate repurposing of these data for research.

[1] http://www.healthit.gov/sites/default/files/nationwide-interoperability-roadmap-draft-version-1.0.pdf
[2] http://www.healthit.gov/policy-researchers-implementers/interoperability-roadmap-public-comments
[3] http://www.pcornet.org/
[4] http://www.fda.gov/Safety/FDAsSentinelInitiative/ucm2007250.htm
[5] https://www.nihcollaboratory.org/
[6] Curtis LH, Brown J, Platt R. Four health data networks illustrate the potential for a shared national multipurpose big-data network. Health Aff (Millwood). 2014 Jul;33(7):1178-86. http://www.ncbi.nlm.nih.gov/pubmed/25006144
[7] Brown JS, Holmes JH, Shah K, Hall K, Lazarus R, Platt R. Distributed health data networks: a practical and preferred approach to multi-institutional evaluations of comparative effectiveness, safety, and quality of care. Med Care. 2010 Jun;48(6 Suppl):S45-51. http://www.ncbi.nlm.nih.gov/pubmed/20473204

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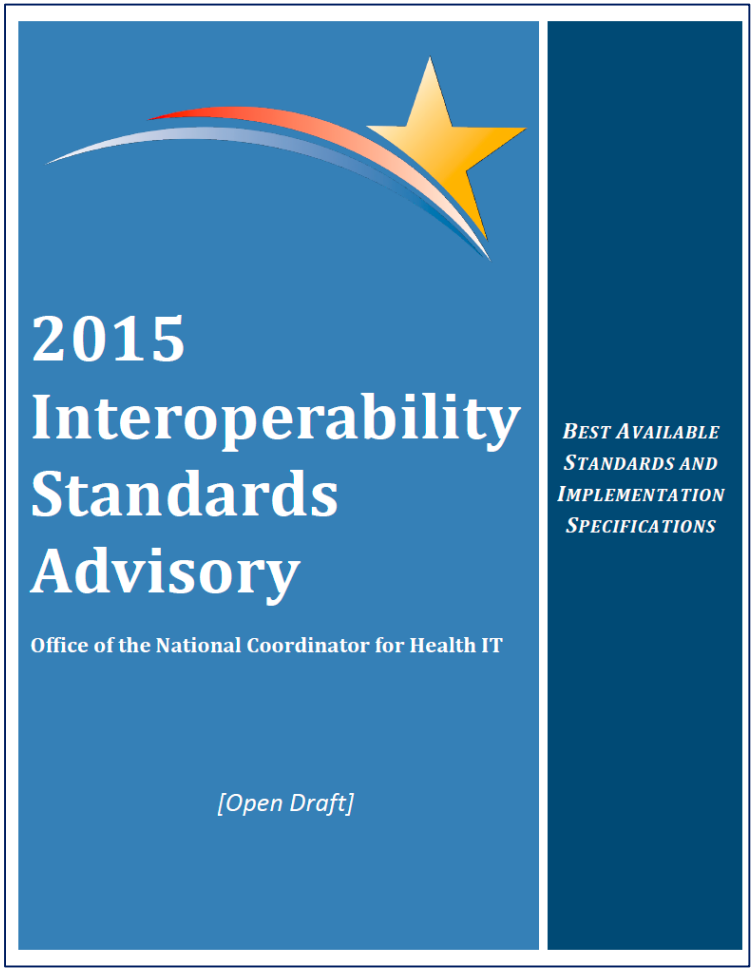
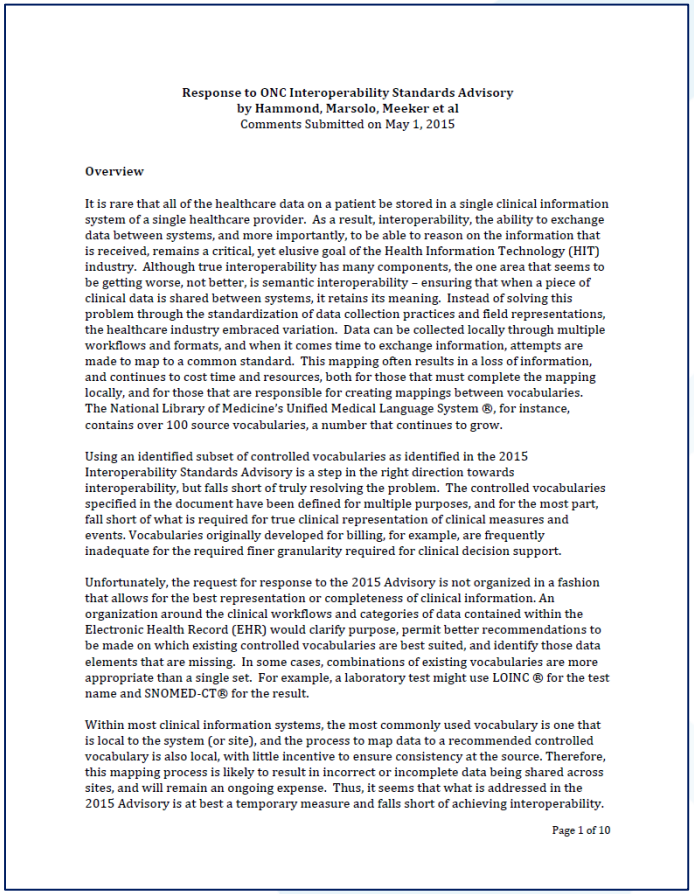
Download the response:
https://pcornet.centraldesktop.com/p/aQAAAAACVGOC

Informed by CDM Development Experience: Response to ONC Standards Advisory, May 1, 2015





Response to ONC Interoperability Standards Advisory
by Hammond, Marsolo, Meeker et al
Comments Submitted on May 1, 2015

Overview

It is rare that all of the healthcare data on a patient be stored in a single clinical information system of a single healthcare provider. As a result, interoperability, the ability to exchange data between systems, and more importantly, to be able to reason on the information that is received, remains a critical, yet elusive goal of the Health Information Technology (HIT) industry. Although true interoperability has many components, the one area that seems to be getting worse, not better, is semantic interoperability – ensuring that when a piece of clinical data is shared between systems, it retains its meaning. Instead of solving this problem through the standardization of data collection practices and field representations, the healthcare industry embraced variation. Data can be collected locally through multiple workflows and formats, and when it comes time to exchange information, attempts are made to map to a common standard. This mapping often results in a loss of information, and continues to cost time and resources, both for those that must complete the mapping locally, and for those that are responsible for creating mappings between vocabularies. The National Library of Medicine's Unified Medical Language System ®, for instance, contains over 100 source vocabularies, a number that continues to grow.

Using an identified subset of controlled vocabularies as identified in the 2015 Interoperability Standards Advisory is a step in the right direction towards interoperability, but falls short of truly resolving the problem. The controlled vocabularies specified in the document have been defined for multiple purposes, and for the most part, fall short of what is required for true clinical representation of clinical measures and events. Vocabularies originally developed for billing, for example, are frequently inadequate for the required finer granularity required for clinical decision support.

Unfortunately, the request for response to the 2015 Advisory is not organized in a fashion that allows for the best representation or completeness of clinical information. An organization around the clinical workflows and categories of data contained within the Electronic Health Record (EHR) would clarify purpose, permit better recommendations to be made on which existing controlled vocabularies are best suited, and identify those data elements that are missing. In some cases, combinations of existing vocabularies are more appropriate than a single set. For example, a laboratory test might use LOINC ® for the test name and SNOMED-CT® for the result.

Within most clinical information systems, the most commonly used vocabulary is one that is local to the system (or site), and the process to map data to a recommended controlled vocabulary is also local, with little incentive to ensure consistency at the source. Therefore, this mapping process is likely to result in incorrect or incomplete data being shared across sites, and will remain an ongoing expense. Thus, it seems that what is addressed in the 2015 Advisory is at best a temporary measure and falls short of achieving interoperability.

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Download the response:
https://pcornet.centraldesktop.com/p/aQAAAAACZkWx

CDM Forum Interest Groups

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Interest Groups (for discussion)

Active DRNOC-facilitated interest group:

- **Lab Mappings:** Local lab result mappings and LOINC references

Proposed DRNOC-facilitated interest group:

- **Med Mappings:** Dispensing and prescribing data, including RxNorm practices, order of preference as brand vs generic

Proposed network-facilitated interest group:

- **CONDITION Table**: Including IMO terminology

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Medication mapping interest group

- **RxNorm chapter**
  - Content presented during CDM Stakeholder meetings on April 28th and 29th, 2015.
  - Now posted in “Rethinking Clinical Trials” Living Textbook:

http://sites.duke.edu/rethinkingclinicaltrials/using-the-rxnorm-system/

- **How to get involved**
  - Send email to michelle.smerek@duke.edu if you would like to participate in this interest group.

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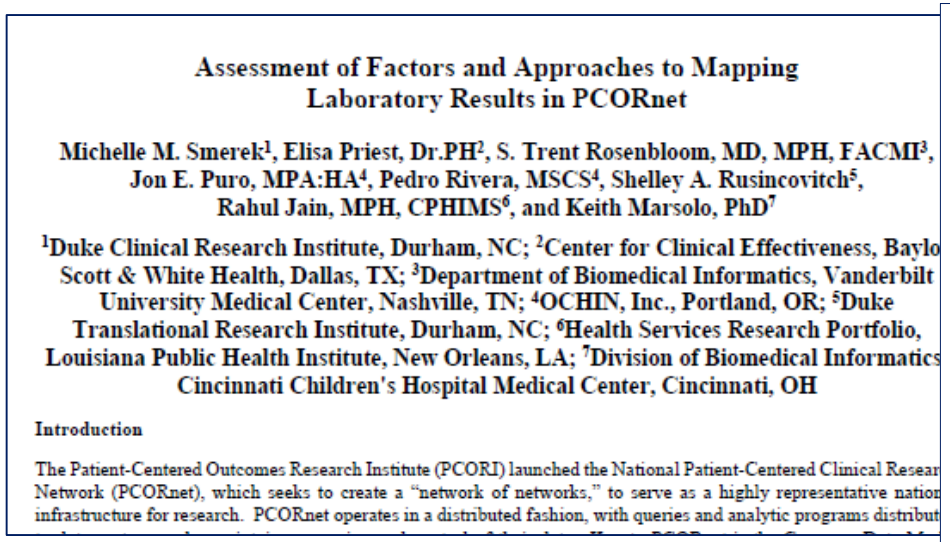
Lab mapping interest group updates



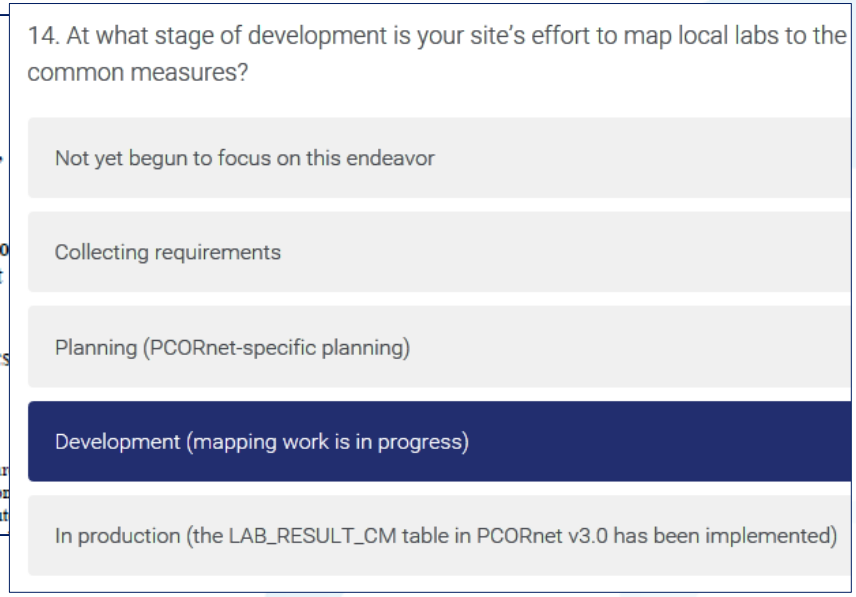
Assessment of Factors and Approaches to Mapping Laboratory Results in PCORnet

Michelle M. Smerek[1], Elisa Priest, Dr.PH[2], S. Trent Rosenbloom, MD, MPH, FACMI[3], Jon E. Puro, MPA:HA[4], Pedro Rivera, MSCS[4], Shelley A. Rusincovitch[5], Rahul Jain, MPH, CPHIMS[6], and Keith Marsolo, PhD[7]

[1]Duke Clinical Research Institute, Durham, NC; [2]Center for Clinical Effectiveness, Baylo Scott & White Health, Dallas, TX; [3]Department of Biomedical Informatics, Vanderbilt University Medical Center, Nashville, TN; [4]OCHIN, Inc., Portland, OR; [5]Duke Translational Research Institute, Durham, NC; [6]Health Services Research Portfolio, Louisiana Public Health Institute, New Orleans, LA; [7]Division of Biomedical Informatics Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Introduction

The Patient-Centered Outcomes Research Institute (PCORI) launched the National Patient-Centered Clinical Resear Network (PCORnet), which seeks to create a "network of networks," to serve as a highly representative natio infrastructure for research. PCORnet operates in a distributed fashion, with queries and analytic programs distribut



- Public Laboratory LOINC Workshop & Committee Meeting Dec 2-3

https://loinc.org/meetings/20151202/public-laboratory-loinc-workshop-committee-meeting-12-02-15-12-03-15.ics/view

- Will hold interest group meeting in December after LOINC Workshop
- Please email michelle.smerek@duke.edu if you are interested in participating in this group

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LOINC

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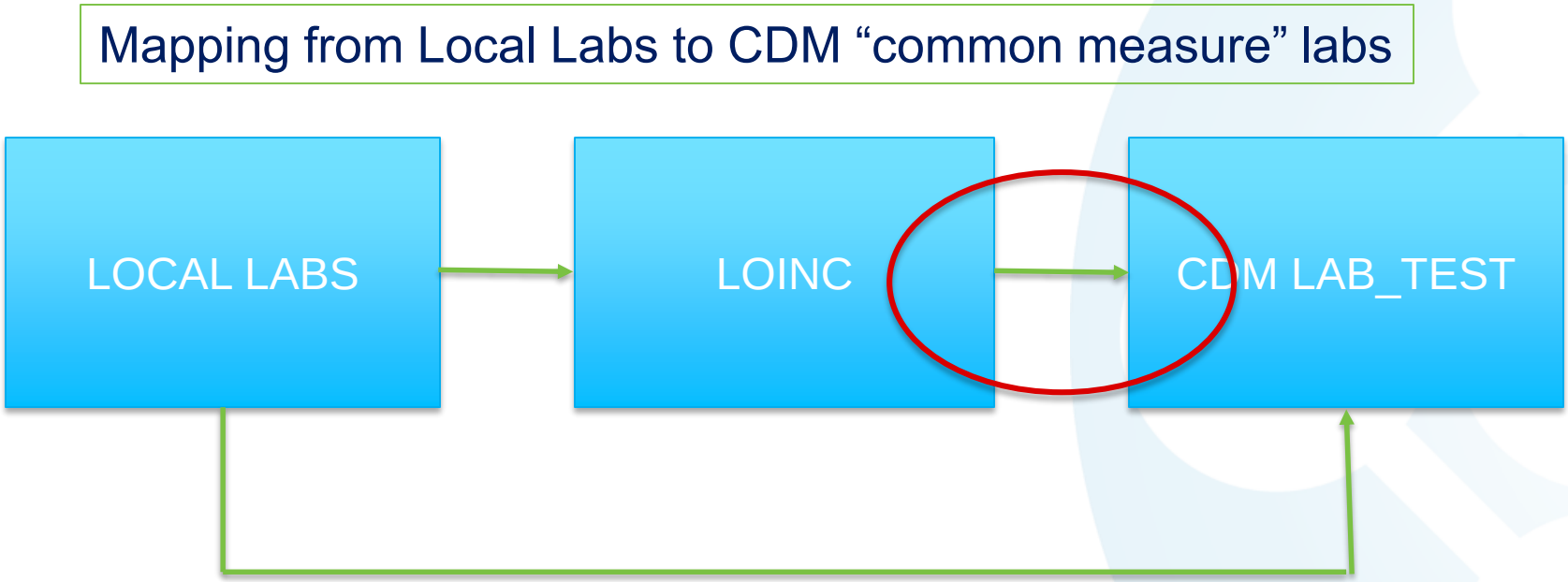
Lab Mapping: Setting

- Excited to have Regenstrief colleagues join us on the call today
- LDL example from one network



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SAS

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This slide from 2015-10-05 DRNOC-CDRN meeting:
https://pcornet.centraldesktop.com/p/ZgAAAAAAZytY

Data Stores for RDBMS-SAS

- Each site has 2 basic options:
  1. Most straightforward configuration: the site stores their data in 2 parallel instances: an RDBMS schema, and a SAS dataset collection
  2. Option for advanced technical teams: The site configures their SAS instance to run distributed SAS programs against 1 data store in their RDBMS tables
- Essential for each site to work with their institution's SAS technical team to determine the optimal SAS configuration at the site

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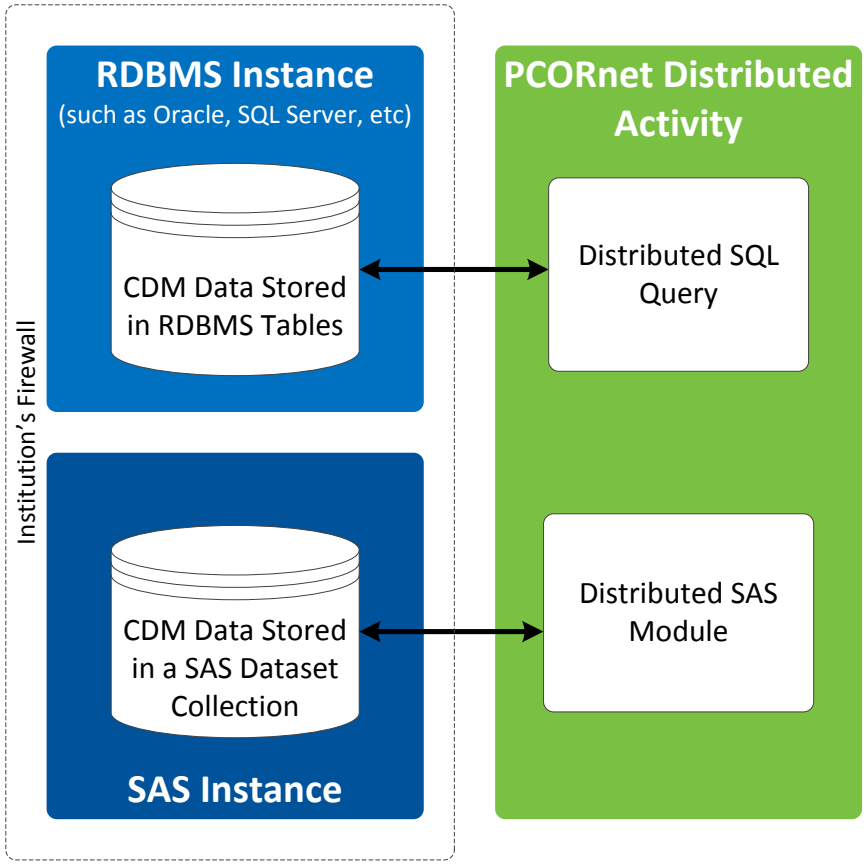
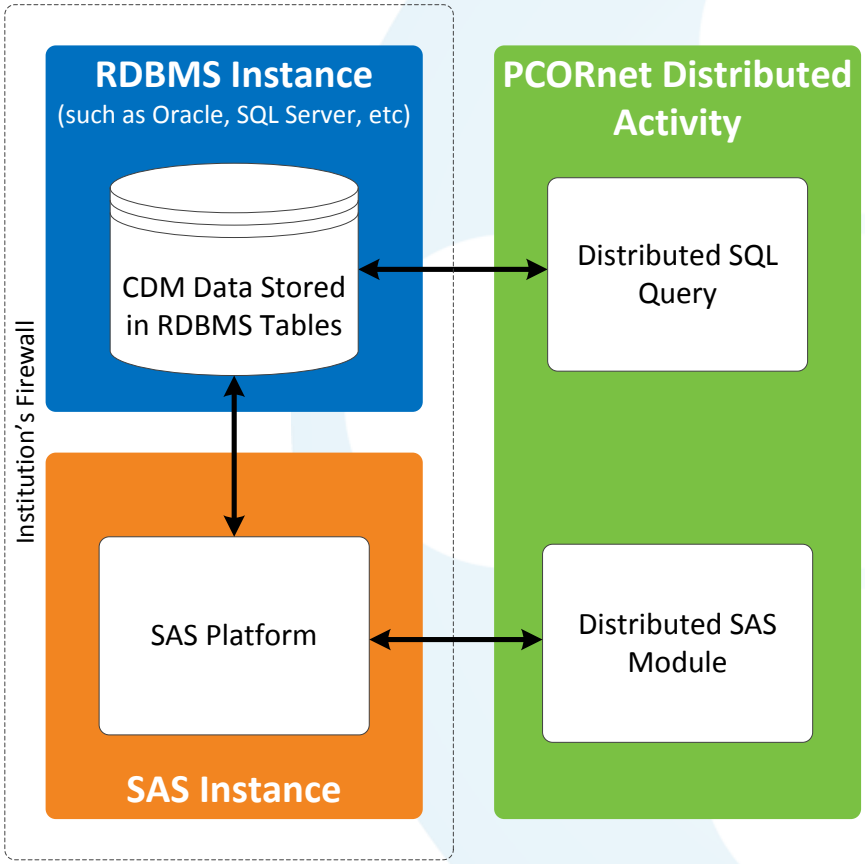
Read the complete SAS FAQs at
https://pcornet.centraldesktop.com/p/aQAAAAACXx_y

This slide from 2015-10-05 DRNOC-CDRN meeting: https://pcornet.centraldesktop.com/p/ZgAAAAAAZytY

Configuration A: Parallel Data Stores



Configuration B: Stand-alone RDBMS Data Store



- Both configurations need the SAS platform

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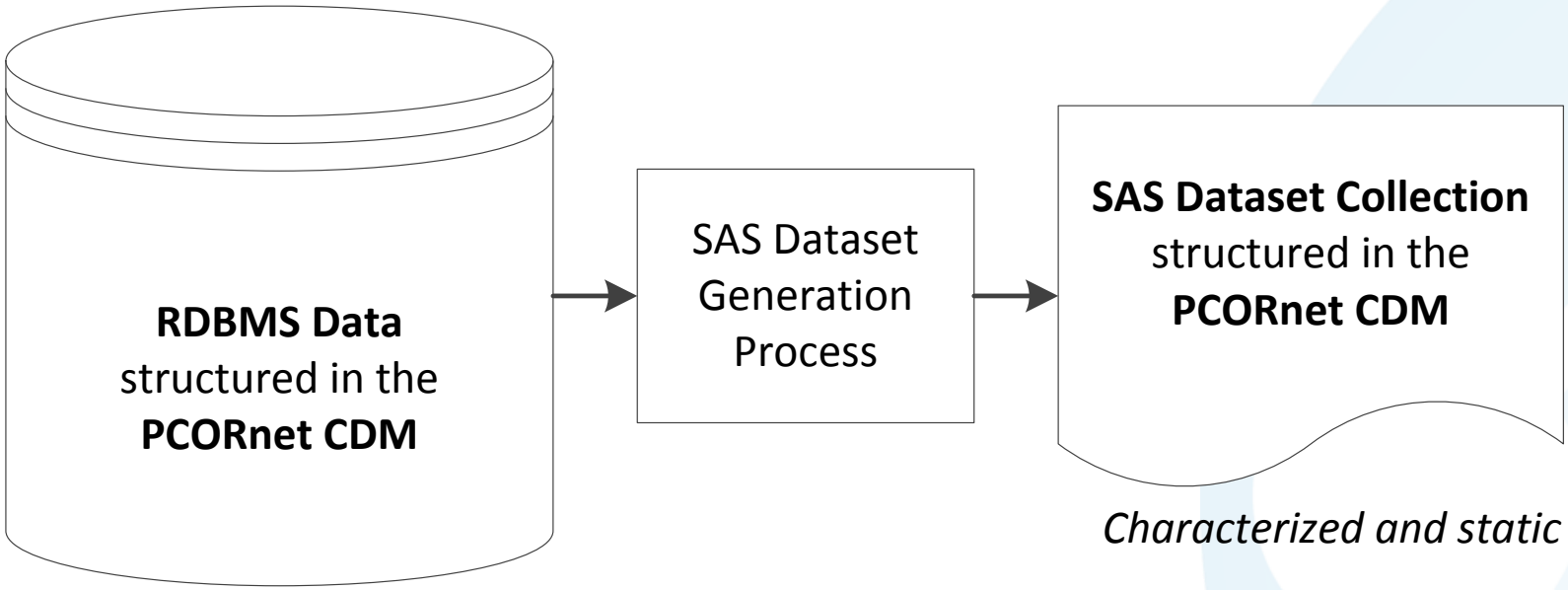
An anticipated “typical setup”*** for data partners



*Often configured as **near-real time** or regular, frequent updates*

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SAS Datamart Implementation Considerations

- Interfacing with IT to stand up a SAS datamart
- Effort required to accomplish implementation
- Licensing considerations
- Words of wisdom for those who may be new to this process

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