NQRN Registry Work Group Webinar

Research in Registries
The ASH Registry
Melissa Francisco, MBA
Director, ASH Registry

July 19, 2018
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Speaker and Moderator

Melissa Francisco, MBA
Director, ASH Registry
American Society of Hematology

Yosef Khan, MD, PhD, MPH
National Director for Healthcare Quality Research and Bioinformatics
American Heart Association

NQRN Research Work Group Chair
• 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
• What is NQRN?
  – NQRN® is a PCPI program and a network of PCPI members interested in clinical registries.
  – Participants include: registry stewards, registry vendors, payers, researchers and others who use registry information to improve patient health outcomes.
  – NQRN exists to support the clinical registry community and increase the ability of registries to support the kind of measurement and improvement increasingly needed to power value-based payment models.

• NQRN Structure
  – NQRN Advisory Committee
    • Research Work Group
    • Learning Work Group
    • Interoperability Work Group
    • QCDR Work Group
• NQRN’s newest work group!

• Our charge
  – Focus on establishing and disseminating leading practices for clinical registries in research and quality improvement
  – Promotes increased use of registry data for research and quality improvement to improve health outcomes
  – Identifies opportunities for researchers to collaborate with registry providers and establish a program to facilitate collaboration

• Join us today!
  – Contact Chrystal Price or Dr. Yosef Khan for more information
ASH Registry
Capabilities & Opportunities

Presented by:
Melissa Francisco, MBA
Director, ASH Registry
<200,000
This is how most registries are designed.

1. List every question you may ever want to answer with the registry.
2. Determine the minimum set of data you need to answer those questions.
3. Define every code set, clinical concept, unit conversion, etc. for each piece of data.
4. Design data models that can store every piece of data and support each of your analyses.
5. Determine every analysis you may want to run against the data.
6. Turn these choices into “software requirements” and communicate them to a vendor.
The process is expensive, time consuming, and susceptible to “analysis paralysis.”

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Even highly-focused registries can take months or years to design.
This is how most registries work.
The newer, “automated” ones work like this.
And this is what it’s like for researchers to work with most registries.
What has been **holding back** registries?

**Technical Limitations**
- Lack of consensus on how to define and validate health data
- Site-by-site variability in how and where data was stored
- Few good options for exchanging data between Health IT systems

**Regulatory Constraints**
- Common Rule requires consent for every specific use of data
- Uncertainty about HIPAA and secondary uses of health data
- Finite IT resources dedicated to supporting CMS payment reform
What’s different now?
## What’s different now?

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<th>Technical Empowerment</th>
<th>Regulatory Refinement</th>
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<tr>
<td>• Consensus on how to define and validate health data</td>
<td>• Common Rule being updated to allow for broad consent</td>
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<td>• Variability diminishing in how and where data was stored</td>
<td>• Clarity from OCR/HHS on how HIPAA affects research</td>
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<td>• A good option for exchanging data between Health IT systems</td>
<td>• Focus shifting from payment reform to data reuse initiatives</td>
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This enabled the design for **ASH Registry**.

- Bring together data from many different activities and sources.
- Organize all of the data in a way that makes it possible to reuse it in a variety of ways.
- Support many different kinds of research and partnerships.
And this is what ASH Registry makes possible.
This is what it’s like for researchers to work with ASH Registry.
Is anyone else doing “registries” like this yet?
Highly-respected informaticists recently published an independent confirmation of our design.

The Pluripotent Rendering of Clinical Data for Precision Medicine

Christopher G. Chute\textsuperscript{a}, Stanley M. Huff\textsuperscript{b}
\textsuperscript{a} Chief Research Information Officer, Johns Hopkins Medicine, Baltimore, MD, USA, \textsuperscript{b} Chief Medical Informatics Officer, Intermountain Healthcare, Murray, Utah, USA

Abstract

Health care and biomedical research are awash in data. Traditional data warehouse methodologies do not scale to this challenge; nor do their schema match the variety of analytic use cases. An alternative model, which shreds data into well-formed constituent data elements, conformant with the emerging CIMI-FHIR standards and stored together with the complete, raw, source data using modern and scalable data utilities such as Hadoop and its derivatives, affords the creation of pluripotent data repositories. Such repositories can be leveraged to generate any number of data marts, registries, and analytic data sets, each of which "just in time" binds an appropriate use-case specific data model. We call this notion PiCaRD: Pluripotent Clinical Repository of Data. We believe such nimble biomedical data management strategies are crucial for Precision Medicine discovery and application.

Keywords:

Traditional methods for managing these tsunami of detailed, heterogeneous, and complex data will not scale to the emergent challenges of discovery research, population health management, continuous quality improvement, comparative effectiveness analyses, patient centered outcomes research or operations research. We propose a re-thinking of how health systems regard health-related data, curate it for inferencing and discovery, and engage in information partnerships with their populations and patients.

Precision Medicine

The advent of Precision Medicine poses additional demands on data access. Based on the principle that detailed knowledge of a patient can precisely inform optimal treatments and interventions, the idea relies on access to vast clinical information resources that can inform these decisions. During the process of assembling such data resources, the problems of large data volume, heterogeneous semantics and syntax, and disconent data schema all present challenges.
Informaticists at Google just proved an identical data architecture is well-suited for applying advanced analytics.

Scalable and accurate deep learning for electronic health records

Alvin Rajkomar*,1, Eyal Oren*,1, Kai Chen1, Andrew M. Dai1, Nissan Hajaj1, Peter J. Liu1, Xiaohing Liu1, Mimi Sun1, Patrik Sundberg1, Hector Yee1, Kun Zhang1, Yi Zhang1, Gavin E. Duggan1, Gerardo Flores1, Michaela Hardt1, Janie Irvine1, Quoc Le1, Kurt Litsch1, Jake Marcus1, Alexander Mossin1, Justin Tansuwan1, De Wang1, James Wexler1, Jimbo Wilson1, Dana Ludwig2, Samuel L. Volchenboum4, Katherine Chou1, Michael Pearson1, Srinivasan Madabushi1, Nigam H. Shah3, Atul J. Butte2, Michael Howell1, Claire Cui1, Greg Corrado1, and Jeff Dean1

1Google Inc, Mountain View, California
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4University of Chicago Medicine, Chicago, Illinois

October 2017

Abstract

Predictive modeling with electronic health record (EHR) data is anticipated to drive personalized medicine and improve healthcare quality. Constructing predictive statistical models typically requires extraction of curated predictor variables from normalized EHR data, a labor-intensive process that discards the vast majority of information in each patient’s record. We propose a representation of patients’ entire, raw EHR records based on the Fast Healthcare Interoperability Resources (FHIR) format. We demonstrate that deep learning methods using this representation are capable of accurately predicting multiple medical events from multiple centers without site-specific data harmonization. We validated our approach using de-identified EHR data from two U.S. academic medical centers with 216,221 adult patients hospitalized for at least 24 hours. In the sequential format we propose, this volume of EHR data unrolled into a total of 46,864,534,945 data points, including clinical notes. Deep learning models achieved high accuracy for tasks such as predicting in-hospital mortality (AUROC across sites 0.93-0.94), 30-day unplanned readmission (AUROC 0.75-0.76), prolonged length of stay (AUROC 0.85-0.86), and all of a patient’s final diagnoses (frequency-weighted AUROC 0.90). These models outperformed state-of-the-art traditional predictive models in all cases. We also present a case-study of a neural-network attribution system, which illustrates how clinicians can gain some transparency into the predictions. We believe that this approach can be used to create accurate and scalable predictions for a variety of clinical scenarios, complete with explanations that directly highlight evidence in the patient’s chart.

*These authors contributed equally
In Summary

ASH Registry would not have been possible five years ago.

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Advancements in technology, interoperability, and regulatory requirements make it possible now.

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ASH Registry is much better able to support researchers and facilitate ASH initiatives than traditional registries.

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It is designed to curate a lasting ASH resource that can be leveraged across research endeavors and disease areas.
Discussion

Melissa Francisco, MBA
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American Society of Hematology

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National Director for Healthcare Quality Research and Bioinformatics
American Heart Association

NQRN Research Work Group Chair
Wrapping Up

• Shape the discussion of how registries are and should be involved in research - Join the Research Work Group – ask either Dr. Khan or Chrystal Price for more details.

• Stay tuned for the next webinar in this two-part series as we explore established registry research programs.

• Join us on **August 21, 2018** from 2-4 pm for our first NQRN Focus Group on Registry Sustainability and Business Planning hosted by our Learning Work Group.
Thank you!

For questions or further information please contact:

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