Leading Edge Acceleration Projects in Health IT

ONC Annual Meeting
January 28th 2020
LEAP in Health IT

Addresses well-documented and emerging challenges inhibiting the development, use and/or advancement of well designed, interoperable health IT scalable across the healthcare industry.

https://www.healthit.gov/topic/onc-funding-opportunities/leading-edge-acceleration-projects-leap-health-information
ONC Coordination for LEAP in Health IT Across Offices

Immediate Office - Chief Scientist Division

Office of Technology

Office of Policy
LEAP Focus Areas

2018
• Expand population-level data-focused APIs
• Advance clinical knowledge at point-of-care

2019
• Implement HL7® FHIR® Consent Resource
• Enhanced patient engagement technologies for care and research

2020
To Be Determined

Significantly enhance the performance of health IT solutions for care and research
LEAP 2018 Funded Projects

Pop Health on FHIR
A SMART Approach to Universal Healthcare Reporting
Bulk Data Export

Mobilizing a Million Hearts - Leveraging Health IT Architecture to Advance Clinical Knowledge and Care Coordination
LEAP 2019 Funded Projects

Scalable Consent Framework for the Advancement of Interoperability with FHIR based APIs

The Problem

Today, *facilities*, not humans, determine what information is shared with whom, when and under what conditions.
The Solution

5 Workflows:

- Privacy
- Medical
- Social
- Consent Registry Utility
- Community

Exchange

Permission

Data

Research

Advanced
For each use case will consider applicable CA and Federal laws and regulations governing the form of the:

- Consent
- Contents
- Period of effectiveness
- Description of the info. the consent covers
- Purpose(s) for which the information may be disclosed
- Any restrictions on disclosure
- Timeframe the consent is valid
- Methods for tracking expiration of the consent (or early termination)
- The ability to document additional information necessary to permit the individual to make an informed decision before giving consent
The Problem

Patient’s ability to access, share, and contribute relevant healthcare data for medical care and research is limited.

Patients and healthcare ecosystems have been largely disconnected for too long.

Patient engagement technologies (PET) are evolving too quickly for patients and providers to keep up with them.

- Inconsistent Design (lack standardization)
- Varied Functionality (different info needed)
- Multiplicity (each provider has one)
- Continuously Changing (pace of innovation)
The Solution

Design, Develop, and Demonstrate patient engagement platform (FHIRedApp) to make it easy for patients to access and provide access to their data.
Community Engagement

- CAB - Community Strategy Team
- CST - Community Advisory Board
- CES - Community Engagement Studios

Use-centered Design

- HIL - Human information interaction Lab
- Generative research phase
- User evaluation phase

Technical Solution

- Health Information Exchange (HIE) and Patient Reported Outcomes (PRO) data transformed to FHIR
- Use of FHIR APIs
- Privacy Preserving Record Linkage
- Aunt Bertha (social care) + StudyApp (research)
Rethink COMMUNITY

Rethink CARE

Rethink HEALTH

Rethink Everything

✉️ anjum.khurshid@austin.utexas.edu
@Akhurshid1
National Center for Human Factors in Healthcare
ONC LEAP: Mobilizing a Million Hearts: Leveraging Health IT Architecture to Advance Clinical Knowledge and Care Coordination

Kristen Miller, DrPH, CPPS
Scientific Director, National Center for Human Factors in Healthcare, MedStar Health
Associate Professor of Emergency Medicine, Georgetown University School of Medicine
Affiliate Faculty, Innovation Center for Biomedical Informatics, Georgetown Medical Center
Project Aims

ONC Leap addresses well-documented and fast emerging challenges inhibiting the development, use, and/or advancement of well-designed interoperable health information technology. The purpose of the project is to:

1. Support evidence-based clinical cognitive support that prompts management and preventative care.

2. Serve as proof-of-concept to transform risk calculators into active surveillance tools leading to guideline based workflow support through SMART on FHIR technology.

3. Leverage the technology to facilitate communication and coordination within providers, and between providers and patients as engaged members of their care with reduced clinical burden.
Background: Million Hearts

- Cardiovascular disease remains the leading cause of death in the US.

- The American Heart Association and American College of Cardiology recommend use of the Atherosclerotic Cardiovascular Disease (ASCVD) risk estimator: evaluates 10-year and lifetime risk for ASCVD.

- Variables include: age, race, total and high-density lipoprotein (HDL) cholesterol levels, low level lipoprotein (LDL) cholesterol, systolic blood pressure, use of statin therapy, antihypertensive medication, use of aspirin therapy, smoking status, and diabetes status.
Million Hearts Optimization

Our research addresses the following:

• Optimizing health IT tools that currently exist: removing the burden of active surveillance, pushing technology to bring relevant data to the clinician

• Reducing time required to integrate clinical guidelines at the point of care by leveraging different technological advancements in a single solution

• Developing solutions that are not product centric – our solution sits outside of the EHR and does not rely on the vendor to support modifications

• Developing solutions that are truly integrated into clinician and patient workflow

• Developing scalable solutions that change the way we think about patient data and decision support (multi-layered support and visualizations)
Barriers to Advancing Clinical Knowledge at the Point of Care (Years 1&2)

**OBJECTIVE 1: DESIGN FOR WORKFLOW**  
Mobilize Million Hearts into SMART on FHIR application

- Characterize information needs and develop cognitive support
  - Workflow Analysis
- Create continuous surveillance mechanism of ASCVD risk factors
  - Application Development

**OBJECTIVE 2: DESIGN FOR CLINICIANS**  
Integrate clinical workflow and user-centered design

- Optimize design and development of the user interface
  - Usability Testing
- Develop mechanisms to facilitate team communication/coordination
  - Application Refinement

**OBJECTIVE 3: DESIGN FOR PATIENTS**  
Integrate patient preferences to support shared decision making

- Understand patient perception of risk and risk management
  - User-Centered Design
- Develop app populated personalized patient education
  - Application Refinement

**OBJECTIVE 4: IMPLEMENTATION AND EVALUATION**  
Launch the Mobilizing Million Hearts tool as an iterative pilot at MedStar Health
• Systematic literature review initiated of how cardiovascular risk is measured and communicated across various CDS tools.

• Stakeholder interviews and clinical observations to conceptualize and develop thorough workflow analysis.

• Detailed technical specifications mapping desired prototype functions to features to technical capabilities. These specifications were developed by the research team and delivered to the technical team to guide prototyping.

• Finalizing of visual mockups to illustrate UX needs and to incorporate technical specifications into a visual reference for the technical team to guide prototyping.
### Technical Specifications (sample)

#### Features of Dynamic Risk Educator

<table>
<thead>
<tr>
<th>Function</th>
<th>Feature</th>
<th>Tech</th>
</tr>
</thead>
</table>
| Calculate & Recalculate scores | • Auto populate.  
  o Auto populate risk score and patient values into dynamic risk calculator.  
  o Option for MD to free type and edit value.  
  o Option for MD to use a slider bar within validated ranges to change values.  
  • Auto populate the Yes/No boxes for hypertension treatment, on a statin, etc. have ability when opened. | FHIR and CCL Call, MSH |
| Display                   | • Clear indication that this dynamic calculator does NOT write to record.  
  • Consider reference ranges tailored to individuals’ demographic baseline and comorbidities.  
  • Consider different graphic representations of risk besides bar. | *MPage with custom component FHIR |
| Date stamp                | • Show time frame of when data was captured next to each lab value.  
  • Hover over for specific date. | *FHIR |
| Patient Portal            | • Explore integration potential. | .. |
| Educational Engagement    | • Discharge summaries.  
  • Links to education resources (diet, exercise, smoking cessation programs, etc.). | .. |
| Risk Level Indicators     | • Explore risk bar to provide context and "best case" scenario.       | App Programming  |
Barriers to Advancing Clinical Knowledge at the Point of Care (Years 1&2)

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**OBJECTIVE 4: IMPLEMENTATION AND EVALUATION**
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Usability Testing Methods:

- Stakeholder Interactions with Prototype and Interview
  - 8 Cardiologists
  - 7 Primary Care Physicians
  - Eye Tracking

- Data Analysis
  - Qualitative Coding
  - Video Analysis

- Synthesis
  - Revision of prototype functions and specifications
Barriers to Advancing Clinical Knowledge at the Point of Care (Years 1&2)

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**OBJECTIVE 4: IMPLEMENTATION AND EVALUATION**
Launch the Mobilizing Million Hearts tool as an iterative pilot at MedStar Health
User-Feedback Methods

- Stakeholder Interactions with Different Prototypes and Interview
  - 9 Patients
  - 3 Prototypes
- Interviews focused on patient understanding and engagement with their cardiovascular health
- Data Analysis
  - Qualitative Coding
- Synthesis
  - Revision of prototype functions and specifications
Participant Feedback

Strong preference for:

- Personalized displays that provide actional steps and guidance aligning with their care plan
  - Translating numeric risk into words (qualitative interpretation of output)
  - Access to tools outside of care visit
Barriers to Advancing Clinical Knowledge at the Point of Care (Years 1&2)

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OBJECTIVE 4: IMPLEMENTATION AND EVALUATION
Launch the *Mobilizing Million Hearts* tool as an iterative pilot at MedStar Health

@MedicalHFE www.MedicalHFE.org
Current State ASCVD Risk Calculation
Mobilizing Million Hearts Future State
Clinician-Facing ASCVD Risk Estimator

This calculation is based on asymptomatic, normative population samples and is not intended to be a substitute for clinical judgment.

<table>
<thead>
<tr>
<th>Last Updated: Total Cholesterol (mg/dL):</th>
<th>6 days ago</th>
<th>Last Updated: Systolic Blood Pressure (mmHg):</th>
<th>6 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Cholesterol (mg/dL):</td>
<td>167</td>
<td>Systolic Blood Pressure (mmHg):</td>
<td>125</td>
</tr>
<tr>
<td>HDL Cholesterol (mg/dL):</td>
<td>39</td>
<td>Diastolic Blood Pressure (mmHg):</td>
<td>78</td>
</tr>
<tr>
<td>LDL Cholesterol (mg/dL):</td>
<td>148</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Age:                                    | 65        | History of Diabetes:                          | No        |
| Sex:                                    | Male      | Smoker:                                       | No        |
| Race:                                   | Other     |                                               |           |
| Hypertension Treatment:                 | No        |                                               |           |
| Statin:                                 | No        |                                               |           |
| Aspirin Therapy:                        | Yes       |                                               |           |

Risk of Having a Heart Attack or Stroke within 10 Years

11.2%
Intermediate Risk

Quick Links: Clinical Guidelines ASCVD Risk Educator

@MedicalHFE www.MedicalHFE.org
# Clinician-Facing ASCVD Risk Estimator

This calculation is based on asymptomatic, normative population samples and is not intended to be a substitute for clinical judgment.

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<th>Last Updated:</th>
<th>6 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Cholesterol</strong></td>
<td><strong>187</strong></td>
<td><strong>Systolic Blood Pressure (mmHg):</strong></td>
<td><strong>125</strong></td>
</tr>
<tr>
<td><strong>HDL Cholesterol (mg/dL):</strong></td>
<td>39</td>
<td><strong>Diastolic Blood Pressure (mmHg):</strong></td>
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</tr>
<tr>
<td><strong>LDL Cholesterol (mg/dL):</strong></td>
<td>148</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Age: | 65 |
| Sex: | Male |
| Race: | Other |

| Hypertension Treatment: | No |
| Statin: | No |
| Aspirin Therapy: | Yes |

**Risk of Having a Heart Attack or Stroke within 10 Years**

11.2%
Intermediate Risk

[Write Score to Record]
Clinician-Facing ASCVD Risk Estimator

This calculation is based on asymptomatic, normative population samples and is not intended to be a substitute for clinical judgment.

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</tr>
<tr>
<td>LDL Cholesterol (mg/dL):</td>
<td>148</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Age: | 65 |
| Sex: | Male |
| Race: | Other |

| History of Diabetes: | No |
| Smoker: | No |

| Hypertension Treatment: | No |
| Statin: | No |
| Aspirin Therapy: | Yes |

Quick Links: Clinical Guidelines, ASCVD Risk Educator

Risk of Having a Heart Attack or Stroke within 10 Years

Score Submission

Risk Score: 11.2
Risk Level: Intermediate Risk

Notes:
this is a test note for the ONC midpoint demo
Patient-Facing ASCVD Risk Educator

This calculation is based on asymptomatic, normative population samples and is not intended to be a substitute for clinical judgment.

Total Cholesterol (mg/dL): 206
HDL Cholesterol (mg/dL): 39
LDL Cholesterol (mg/dL): 148
Systolic Blood Pressure (mmHg): 138
Diastolic Blood Pressure (mmHg): 78

On Hypertensive Treatment: Yes
On a Statin: Yes
History of Diabetes: Yes
Smoker: Yes
Current Age: 65
Sex: Female
Race: White

Risk of Having a Heart Attack or Stroke within 10 Years: 14.1%
Intermediate Risk
3 Month Pilot

- **System Outcomes** (usage, API calls, load time)
- **Provider Outcomes** (surveys, video capture, interviews)

6 Month Pilot

- **Developer Outcomes** (technical challenges, resources)
- **Patient Outcomes** (preference, usability)

**OBJECTIVE 4: IMPLEMENTATION AND EVALUATION**
Launch the *Mobilizing Million Hearts* tool as an iterative pilot at MedStar Health
Challenges to Date

Strategic
• Optimizing inputs from multiple stakeholders and perspectives
• Validation costs and IT security challenges

Legal/Ethical
• Personalizing population-level risk prediction
• Legal liability

Technical
• Applying SMART on FHIR and CDS Hooks solutions to systems that have not (yet) adopted
• Not all the desired data can easily and consistently be found in the FHIR resources (or may be documented in multiple places)
• SMART-on-FHIR apps behave differently within Cerner depending on the “profile”.
Thank you!

Kristen Miller
kristen.e.miller@medstar.net
ONC LEAP:
Mobilizing a Million Hearts:
Leveraging Health IT Architecture to Advance Clinical Knowledge and Care Coordination

Kristen Miller, DrPH, CPPS
Scientific Director, National Center for Human Factors in Healthcare, MedStar Health
Associate Professor of Emergency Medicine, Georgetown University School of Medicine
Affiliate Faculty, Innovation Center for Biomedical Informatics, Georgetown Medical Center
Leading Edge Acceleration Projects (LEAP)

SMART/HL7 Bulk Data Export

Population Health on FHIR

Kenneth D. Mandl, MD, MPH

Director, Computational Health Informatics Program
Boston Children’s Hospital

Donald A.B. Lindberg Professor of Pediatrics
Professor of Biomedical Informatics
Harvard Medical School

@mandl
I and my spouse/partner have no relevant relationships with commercial interests to disclose.
Invention of the World Wide Web

- Built over the existing TCP and IP protocols, it consisted of 4 building blocks:

  - A textual format to represent hypertext documents, the **HyperText Markup Language** (HTML).

  - A simple protocol to exchange these documents, the **Hypertext Transfer Protocol** (HTTP).

  - A client to display these documents, the first Web browser called **WorldWideWeb**.

  - A server to give access to the document, an early version of **httpd**.
Problem #1

Apps don’t connect to health systems data
But has been hard to use the point of care
No Small Change for the Health Information Economy
Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

The economic stimulus package signed by President Barack Obama on February 17 included a $19 billion investment in health information technology. How can we best take advantage of this unprecedented opportunity to computerize health care and stimulate the health information economy while also stimulating the U.S. economy? A health care system adapting to the effects of an aging population, growing expenditures, and a diminishing primary care workforce needs the support of a flexible information infrastructure that facilitates innovation in wellness, health care, and public health.

Flexibility is critical, since the system will have to function under new policies and in the service of new health care delivery mechanisms, and it will need to incorporate emerging information technologies on an ongoing basis. As we seek to design a system that will constantly evolve and encourage innovation, we can glean lessons from large-scale information-technology successes in other fields. An essential first lesson is that ideally, system components should be not only interoperable but also substitutable.

The Apple iPhone, for example, uses a software platform with a published interface that allows software developers outside Apple to create applications; there are now nearly 10,000 applications that consumers can download and use with the common phone interface. The platform separates the system from the functional-
Designing the app store for health
Notice of Proposed Rulemaking to Improve the Interoperability of Health Information

The U.S. Department of Health and Human Services (HHS) recently proposed a new rule to support seamless and secure access, exchange, and use of electronic health information (EHI).

The proposed rule is designed to increase innovation and competition by giving patients and their healthcare providers secure access to health information and new tools, allowing for more choices in care and treatment. It calls on the healthcare industry to adopt standardized application programming interfaces (APIs), which will help allow individuals to securely and easily access structured EHI using smartphone applications.

The proposed rule places a strong focus on a patient’s ability to access their health information through a provision requiring that patients can electronically access all of their EHI (structured and/or unstructured) at no cost. Finally, to further support access and exchange of EHI, the proposed rule implements the information blocking provisions of the Cures Act. The rule proposes seven exceptions to the definition of information blocking.

The public comment period is now open for the proposed rule. We value all of your feedback – both positive and negative as it helps inform the rulemaking process. Below are the steps to submitting your comments:

Download the Proposed Rule (PDF - 3.2 MB)
Comment on the Proposed Rule

Comments on the proposed rule are due by 11:59 pm ET on May 3, 2019.

Fact Sheets on the Proposed Rule

Implementation of Cures Act and Executive Orders (PDF - 1.4 MB)
Conditions and Maintenance of Certification Requirements (PDF - 805 KB)
Information Blocking - Summaries of the 7 Exceptions (PDF - 578 KB)
Parsimonious Standards to Create Interop

1. SUBSTITUTABLE APPS
2. TRIGER-ABLE DECISION SUPPORT
3. PATIENT-GENERATED DATA
4. PUSH BUTTON POPULATION HEALTH
Problem #2

Can’t launch apps

at just the right moment
Triger-able decision support

1. EHR triggers a CDS hook and invokes a remote service.
2. CDS Service executes its own rules, leveraging FHIR data as needed.
3. Returns CDS cards (rendered and displayed by EHR).

EHR Med Order

Toprol XL
50 mg daily

information card
$200 per month
(patient pays $30)

suggestion card
Try HCTZ as first-line
Switch to HCTZ

smart app link card
Managing hypertension?
Launch JNC 8 Rx Pro
Problem #3

Patient generated data are non-standardized and in a separate silo
Modularity of software and sensor products to detect atrial fibrillation through connected technologies

<table>
<thead>
<tr>
<th>Operating System (OS)</th>
<th>Sensor Data Collection (&quot;Raw&quot; Data)</th>
<th>Algorithm Signal Data Processing</th>
<th>Algorithm to Inform, Diagnose, and/or Intervene/Treat</th>
<th>User Interface &amp; User Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>AliveCor</td>
<td>AliveCor KardiaBand for Apple Watch</td>
<td>AliveCor App &amp; Afib algorithm</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Apple OS, Apple Watch</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CardioGram</td>
<td>Hardware &amp; OS Agnostic</td>
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<tr>
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<td>Apple OS, Apple Watch</td>
<td>Apple PPG Analysis SaMD Algorithm</td>
<td>Apple OTC ECG SaMD App</td>
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<td>Fitbit</td>
<td>Smartphone OS Agnostic</td>
<td>Fitbit Hardware</td>
<td>Fitbit App, Purepulse Data, &amp; Afib algorithm</td>
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<td>Xiaomi</td>
<td>Smartphone OS Agnostic</td>
<td>Xiaomi Heart Rate Sensor &amp; Data Processing</td>
<td>API open to Developers</td>
<td>MI Fit App</td>
</tr>
</tbody>
</table>

NPG Digital Medicine 2019
Interoperable, PRO apps—patient or provider generated

SMART Markers (coming soon)
Problem #4

Getting data out of EHRs into analytic platforms tends to require specialized teams.
Hospital IT needs to create reports on the same data in hundreds of different formats (many of those data are in the USCDI)
The Genomics Research and Innovation Network: creating an interoperable, federated, genomics learning system

Kenneth D. Mandl, MD, MPH,1,3,9 Tracy Glauser, MD,4,9 Ian D. Krantz, MD,4,7 Paul Aviailich, MD, PhD,1,7, Anna Bartels, MScPhD,7, Alan H. Beggs, PhD,4,8,9,10 Sawona Biwas, MS, CGC,8,9,10 Florence T. Bourgeois, MD, MPH,4,5,6,10 Jeremy Corso, MPh,5,11, Andrew Bauber, MD, MMSc,5,12, Batsai Devkota, PhD,12, Gary R. Fletcher, MD, PhD,5,10, Allison P. Heath, PhD,13, Ingo Helbig, MD,7,14,11, Joel N. Hirschhorn, MD, PhD,4,8,17, Judson Kilbourn,14, Selk Won Kong, MD,8,9, Susan Kornetsky, MPH,4,6,10, Joseph A. Majzoub, MD,4,10,11, Keith Marzolo, PhD,8,9, Lisa J. Martin, PhD,5,21, Jeremy Nie, BS,8,11, Amy Schwachhoff, MS, MBA,8,23, Jason Stedman, BA,27, Arnold Strauss, MD,8,24, Kristen L. Sund, PhD, MS,25, Deanne M. Taylor, PhD,4,7,27, Peter S. White, PhD,3,8,15, the Genomics Research and Innovation Network

Purpose: Clinicians and researchers must contextualize a patient’s genetic variants against population-based inferences with detailed phenotyping. We sought to establish a globally scalable technology platform that supports informed consent across sites of care.

Methods: Three of the nation’s leading children’s hospitals launched the Genomic Research and Innovation Network (GRIN), with federated information technology infrastructures, harmonized biobanking protocols, and material transfer agreements. Pilot studies in epilepsy and short stature were completed to design and test the collaboration model.

Results: Harmonized, broadly consented institutional review board (IRB) protocols were approved and used for biobank enrollment, creating ever-expanding, compatible biobanks. An open-source federated query infrastructure was established over genotype-phenotype databases at the three hospitals. Investigators securely access the GRIN platform for prep to research queries, receiving aggregate counts of patients with particular phenotypes in genotypes in each biobank. With proper approvals, de-identified data is exported to a shared analytic workspace. Investigators at all sites harmonistically collaborated on the pilot studies, resulting in multiple publications. Investigators have also begun to systematically utilize the infrastructure for grant applications.

Conclusions: The GRIN collaboration establishes the technology, policy, and procedures for a scalable genomics research network.

Genetics in Medicine (2019) https://dx.doi.org/10.1038/s41436-019-0096-3

Keywords: genomic medicine; federated networks; electronic health records; biobanking; information technology

© Boston Children’s Hospital 2019
Existing Genomic Research and Innovation Network (GRIN)

Central GRIN Access

Discover Portal

Analysis Portal

Extend modularly with dockerized software, pre-fab agreements. Align consenting, biobanking processes

Institutionally-funded Samples, Sequences, and Phenotypes Augmented with Grants and Collaborations

Investigators

PIC-SURE API

Scaling-up
Federated EHR Networks: engaging health systems by making the data important to them

Federalist Principles for Federated Networks
Mandl, Nature Biotechnology
• Don Rucker: “If the health system is going to care about the data, they should be about payment.”
Push button population health /FLAT FHIR

December 2017 Enhancing FHIR to support Bulk Data access

November 2019 Follow-up meeting
SMART/HL7 FHIR Bulk Data

- Reuse as much of existing FHIR semantics as possible
  - Data models
  - API format and data types
  - Implementation guide structure
- Use existing standards based authentication and authorization
  - Base on widely used OAuth (SMART) standard
- Structure for efficiently generating and loading large datasets
  - Asynchronous operation
  - One data type per file
  - Streaming data
A 21st-Century Health IT System — Creating a Real-World Information Economy

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., M.P.H.

Data generated as a by-product of the day-to-day work of delivery systems are a fundamental currency of the 21st Century Cures Act. How efficiently of real-world evidence to advance treatment and research. Fortunately, lawmakers included in the 21st Century Cures Act a provision that could transform contains hundreds of thousands of apps because developers have a well-documented API that enables them to create software that seamlessly integrates with the op-
Focus on BCH ACO

- Each organization uses an internal data model and architecture for reporting
Resulting Output

- This is the outgoing report to MassHealth for Adolescent Childhood Immunizations
- The output from the internal BCH data warehouse SQL query is below

<table>
<thead>
<tr>
<th>Current Age</th>
<th>General PCP Name</th>
<th>Last Primary Care Appt Date</th>
<th>Last Primary Care Appt Clinic</th>
<th>Meningococcal Count</th>
<th>Meningococcal Last</th>
<th>Tdap Count</th>
<th>Tdap Last</th>
<th>HPV Count</th>
<th>HPV1</th>
<th>HPV2</th>
<th>HPV3</th>
<th>Measure Met</th>
</tr>
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<tbody>
<tr>
<td>13</td>
<td>Joseph, Luc</td>
<td>10/19/2018</td>
<td>PCL</td>
<td>1</td>
<td>08/25/2017</td>
<td>1</td>
<td>08/25/2017</td>
<td>1</td>
<td>08/25/2017</td>
<td>N</td>
<td></td>
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Query with FHIR Bulk Data Analytics

- Here’s a query on top of FHIR using Bulk Data Exports as the data source
- The query is written on the Presto SQL query engine
- The output is exactly the same as the one that BCH currently runs

WITH patientVaccineRows as (SELECT
  json_extract_scalar(p.json, '$.id') AS patientId,
  json_extract_scalar(p.json, '$.name[0].family[0]') AS familyName,
  json_extract_scalar(p.json, '$.name[0].given[0]') AS givenName,
  json_extract_scalar(dr.json, '$.name.family[0]') AS drFamilyName,
  json_extract_scalar(dr.json, '$.name.given[0]') AS drGivenName,
  json_extract_scalar(i.json, '$.vaccineCode.coding[0].code') AS code,
  json_extract_scalar(i.json, '$.vaccineCode.text') AS text,
  split_part(json_extract_scalar(i.json, '$.date'), 'T', 1) AS date
The proposition

- Bulk data exports in a consistent, standardized format
- Generalizable analytics on top
Design Sprint Process

The sprint gives teams a shortcut to learning without building and launching.
LEAP POP-HEALTH APP

Population-level app based on bulk data
BOSTON CHILDREN’S HOSPITAL EHR

- Boston Children’s Hospital Cerner EHR
- Cerner Ignite API
- FHIR DSTU-2 and R4
- Does NOT support bulk data
BULK DATA SERVER

- Connects to any FHIR-enabled EHR
- Exposes standard bulk-data API
- Can act as a proxy
- Synchronizes automatically
- Caches data
- Acts as data aggregator
ANALYTICS QUERY ENGINE

- Consumes standard bulk-data NDJSON
- Converts and stores data in Presto
- Improves performance in large datasets
- Exposes SQL interface
POP-HEALTH APP

- Sends SQL queries to AQE
- Caches historical data
- Provides user management
- Supports multiple pre-configured QMs
- Includes SQL query builder
CLAIMS DATA

- Claims data from various sources can be merged into the bulk-data database.

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SYNTHETIC DATA

- More than 1.22M Patients
- Close to 200M Observations
- Close to 380M Resources
- About 49M Claims
- About 24GB data
- About 2.2GB data with gzip
REAL-WORLD DIAGRAM

Boston Children's Hospital

Cerner EHR (Ignite API)

Anonymization

JSON Files

Import Script

VM 1
Bulk Data Server

VM 2
Bulk Data Database

Cloud

VM 3
Analytics Query Engine

Bulk Data Client

VM 4
PopHealth Backend

PopHealth App

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POP-HEALTH APP
Federal Health Agencies Coming Aboard

Notice of Proposed Rulemaking to Improve the Interoperability of Health Information

The U.S. Department of Health and Human Services (HHS) recently proposed a new rule to support seamless and secure access, exchange, and use of electronic health information (EHI).

The proposed rule is designed to increase innovation and competition by giving patients and their healthcare providers secure access to health information and new tools, allowing for more choice in care and treatment. It calls on the healthcare industry to adopt standardized application programming interfaces (APIs), which will allow individuals to securely and easily access structured and unstructured data from smartphones and other sources.

The proposed rule places a strong focus on a patient’s ability to access their health information through a smartphone, ensuring that patients can electronically access all of their EHI regardless of the vendor or entity that contains or manages it.

The public comment period is now open for the proposed rule. We value all of your feedback—both positive and negative. To help us form the upcoming decisions, please see the steps to submitting your comments.

Download the Proposed Rule [PDF, 3.3 MB]

Comment on the Proposed Rule

Comments on the proposed rule are due by 3:00 pm ET on May 2, 2019.

Implementation of Core Act and Executive Order (EO) 13.840
Conditions and Maintenance of Certification Requirements (CMCR) for Registries
Information Blocking

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Computational Health Informatics Program

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LEAP Focus Areas

2018

- Expand population-level data-focused APIs
- Advance clinical knowledge at point-of-care

2019

- Implement HL7® FHIR® Consent Resource
- Enhanced patient engagement technologies for care and research

2020

- Consent for regulated vs. unregulated research?
- Security of data at rest and transit?

Significantly enhance the performance of health IT solutions for care and research
Discussion: LEAP Areas for 2020?

- Data anonymization
- Digital footprint
- Data security at rest and transit
- Unregulated vs. regulated research
- Patient education and misinformation
- Open source tools for health research apps
Contact ONC

ONC-LEAP@HHS.GOV

Phone: 202-690-7151

Health IT Feedback Form: https://www.healthit.gov/form/healthit-feedback-form

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