Structured Data Capture (SDC) & Data Access Framework (DAF)

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The utility of electronic health record (EHR) data for supplemental purposes has been limited due to a lack of uniformity in the terminology and definitions of data elements across EHRs. This limitation is compounded by the fact that clinician workflow often records patient information in unstructured free-text data well after the episodes of care. Linking EHR data with other data in a uniform and structured way could accelerate quality and safety improvement, population health, and research.
Structured Data Capture Workflow

1. Sends request for form/template
2. Sends requested form/template
3. Converts, populates and displays form
4. Fills, stores/transmits structured data
5. Extract, Transform, and Load Data by form/template

Actor Key:
- Green: Forms Filler
- Blue: Forms Manager
- Purple: External Repository

CDE Library
Form Library
Metadata Source
SDC Accomplishments

- **Project Charter**: February 2013
- **SDC Use Case**: May 2013
- **SOAP/SAML Implementation Guide**: March 2015
- **SDO Published Profiles**:  
  - **IHE SDC Profile**  
    - First published in October 2015  
    - Version 2.1 published in October 2016  
    - Successfully tested and demonstrated at IHE NA Connectathon and HIMSS in 2015, 2016 and 2017
  - **FHIR SDC Profile / FHIR Data Element Profile**  
    - First published in December 2015  
    - Latest version published March 2017  
    - Successfully tested at multiple FHIR Connectathons
SDC Accomplishments (2)

• **Pilots**
  - Kickoff in October 2015 with focus on testing and implementing the Integrating Healthcare Enterprise (IHE) SDC Profile
  - Participation in IHE NA Connectathon and HIMSS – January 2017 / February 2017
  - Community Demonstrations and Report Outs - October 2016

• **SDC transition into real-world use cases**
  - Secondary use of information in EHRs
  - Public health reporting
  - Cancer reporting
  - Use of SDC to collect structured radiology data
  - Use of SDC for electronic Cancer Checklists (eCC)
  - Clinical content management
SDC Path Forward

• SDC has transitioned to a community – led project
• All artifacts and materials will continue to be maintained on the SDC Wiki
• The IHE Profile will be managed by the IHE Quality, Research Public Health(QRPH) workgroup
• The FHIR Profile will be managed by the HL7 FHIR workgroups
Goals of Data Access Framework

• Launched in July 2013 to:
  » Reduce barriers in extracting granular data and documents from clinical data sources
  » Simplify data mapping challenges
  » Enable researchers to access data extracted from clinical data sources using standard mechanisms
  » Enable development of third party applications using the data access application programming interface (APIs) to add value for clinical and research activities
  » Enable access to both patient level and population level data using modular, substitutable standards controlled by appropriate privacy and security controls
DAF Phases

Built incrementally to enable data and document access:

- **Phase 1:** From within an organization - **Local DAF**
- **Phase 2:** Between organizations with pre-existing business relationships - **Targeted DAF**
- **Phase 3:** Across multiple organizations which are part of a research network such as PCORnet for distributed/federated access known as **DAF for Research**
DAF Outputs: Phases 1 and 2

- **US-Core FHIR® IG**
  - Standardizes data elements for Common Clinical Data Set (CCDS) using FHIR® APIs that uses consistent terms of data elements supported, extensions and value sets
  - Enables a platform for data access that is reliable and widely supported across EHR vendors
  - SMART App developers can rely on the US-Core APIs across vendors for app development
  - Creates a basic, minimum foundation that can be leveraged for future standardization activities
DAF Outputs: Phase 3

• DAF Phase 3 (DAF-Research)
  » Led to the creation of the DAF-Research FHIR® IG
  » Re-used everything that was done in the DAF-Core (US-Core) FHIR® IG
  » Added capabilities
# Phase 3 Capabilities

<table>
<thead>
<tr>
<th>Capability</th>
<th>Description</th>
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<tbody>
<tr>
<td>C1</td>
<td>Standardize data extraction mechanism from clinical data sources to populate data marts. <em>Impacts Step 1 of the PCORnet Abstract Model</em></td>
</tr>
<tr>
<td>C2</td>
<td>Standardize metadata about data marts, CDRN’s, PPRN’s and data sources. <em>Impacts Step 2 of the PCORnet Abstract Model</em></td>
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<tr>
<td>C3</td>
<td>Standardize Query Distribution mechanism. <em>Impacts Step 3 of the PCORnet Abstract Model</em></td>
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<tr>
<td>C4</td>
<td>Standardize Query Results for returning aggregate data. <em>Impacts Step 5 of the PCORnet Abstract Model</em></td>
</tr>
<tr>
<td>C5*</td>
<td>Standardize Query Results for returning de-identified or identified patient data. <em>Impacts Step 5 of the PCORnet Abstract Model</em></td>
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<tr>
<td>C6*</td>
<td>Standardize Query Structure and Queries for identifying cohorts/populations. <em>Impacts Step 4 of the PCORnet Abstract Model</em></td>
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<table>
<thead>
<tr>
<th>DAF Pilot Sites</th>
<th>Capabilities Piloted</th>
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<tbody>
<tr>
<td>Lincoln Peak Partners</td>
<td>C2, C3, C4</td>
</tr>
<tr>
<td>pSCANNER</td>
<td>C1, C2</td>
</tr>
<tr>
<td>REACHnet</td>
<td>C1, C2, C3, C4</td>
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*This Capability was not tested in our pilots.*
Looking Forward: The Importance of DAF

- **US-Core FHIR® IG**
  - This IG is one of the widely implemented IGs for FHIR® amongst EHR vendors
  - What does that mean?
    - Start expecting products to roll out with support for FHIR® APIs which are based on US-Core FHIR® IG.
    - Provides a reliable platform for extracting data

- **DAF-Research FHIR® IG**
  - Standardization of data extraction using FHIR® APIs: Using a single mapping for each target model reduces the on-boarding time for data sources to provide data for research
  - Enabling participation in multiple query networks: Using multiple data models, query formats and result structures promotes interoperability within and across networks
CONTACT INFORMATION

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