

Diabetes Data Strategy Project (‘Diabe-DS’)

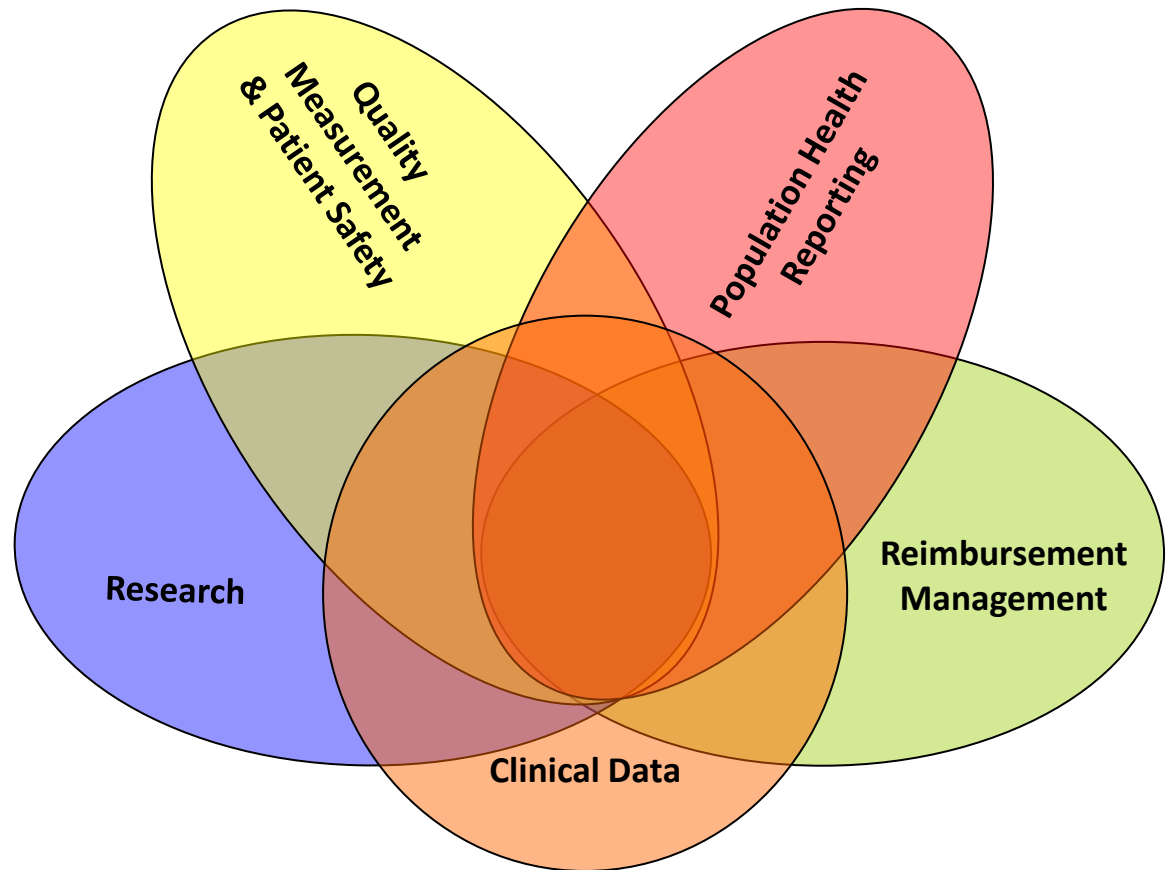
Overview and Status Update

May 2010

Uses of Data Have Significant Overlap

Premise of project:

- Develop a process to identify a common set of data elements in the center of overlap for a given clinical domain/therapeutic/disease area.
- Establish the framework to repeat the process in other domains.



Project Goals

1. Develop a small set of data elements for the outpatient diagnosis of Type 1 Diabetes(T1D) that overlap* between electronic health record (EHR) and some secondary uses – like research and quality monitoring.
2. Look at how elements can be harmonized to support the “collect once, use many” paradigm.
3. Tie data elements and data use requirements to EHR system functions
4. Document the process, procedures, & lessons learned for subsequent projects.
5. Set the stage for T1D stakeholders to vet/enhance the elements to produce a true clinical T1D DAM.

* Because the goal was to pick research measures that were likely to have related content in the EHR, we did not produce a comprehensive set of research data elements for T1D.

HL7 Workgroup Sponsors

- EHR Workgroup (primary sponsor)
- Clinical Interoperability Council (co-sponsor)
- Patient Care Workgroup (co-sponsor)
- RCRIM (co-sponsor)
- Interoperability Workgroup (co-sponsor)

Stakeholders

- EHR vendors
- EHR users/clinicians (specifically those caring for kids/diabetics)
- Secondary data users (research, quality, etc.)
- Standards groups looking at methods for domain-specific data standards
- Professional groups (ADA, clinical societies, etc.)

Sampling of Data Elements

- Hunted and gathered
 - research forms
 - practice guidelines
 - quality measures
 - expert interviews
 - two outpatient diabetic clinic information systems
- Added elements from national efforts in The Netherlands and Canada
- Filtered by “they-are-in or could/should be” in EHR

Result: Sample of important data elements, but not an exhaustive or representative list

“Data Cleaning”

- Naming conventions for data elements
 - E.g., Hypoglycemia
 - Versus---
 - Hypoglycemia indicator
 - Hypoglycemia symptom
 - Hypoglycemia onset date
- Value set ‘quality’ (comprehensive, exhaustive, exclusive)
- Definition clarification

Analysis of Data Elements

- Organized by conceptual groups
- Resolution of similar elements
- Annotated by relationship to EHR standards

Use Case Development

- Mini Use Cases
 - Appointment with the Pediatrician (Primary Care Provider)
 - Appointment with the Specialist
 - Laboratory Orders and Results
 - Ordering and dispensing of pharmaceuticals
 - Medication Administration and Result Monitoring
 - Specialist Visit (Follow up)
 - Education: Foot care
 - Follow-up Laboratory Orders and Results
 - Research Use Case (data reuse)
 - Quality Use Case (data reuse)
- Incorporate sample of data elements from our spreadsheet

Data Modeling

- Model the sample of use case data elements
 - create a graphical depiction of data elements
 - exhibit relationship to existing standards (e.g., diabetes DCM, HITSP C154, BRIDG, etc.)
 - identify atomic data elements and relationship to reuse elements
 - demonstrate how patterns can be identified in support of future large scale harmonization efforts

Data Mapping to EHR-S FM

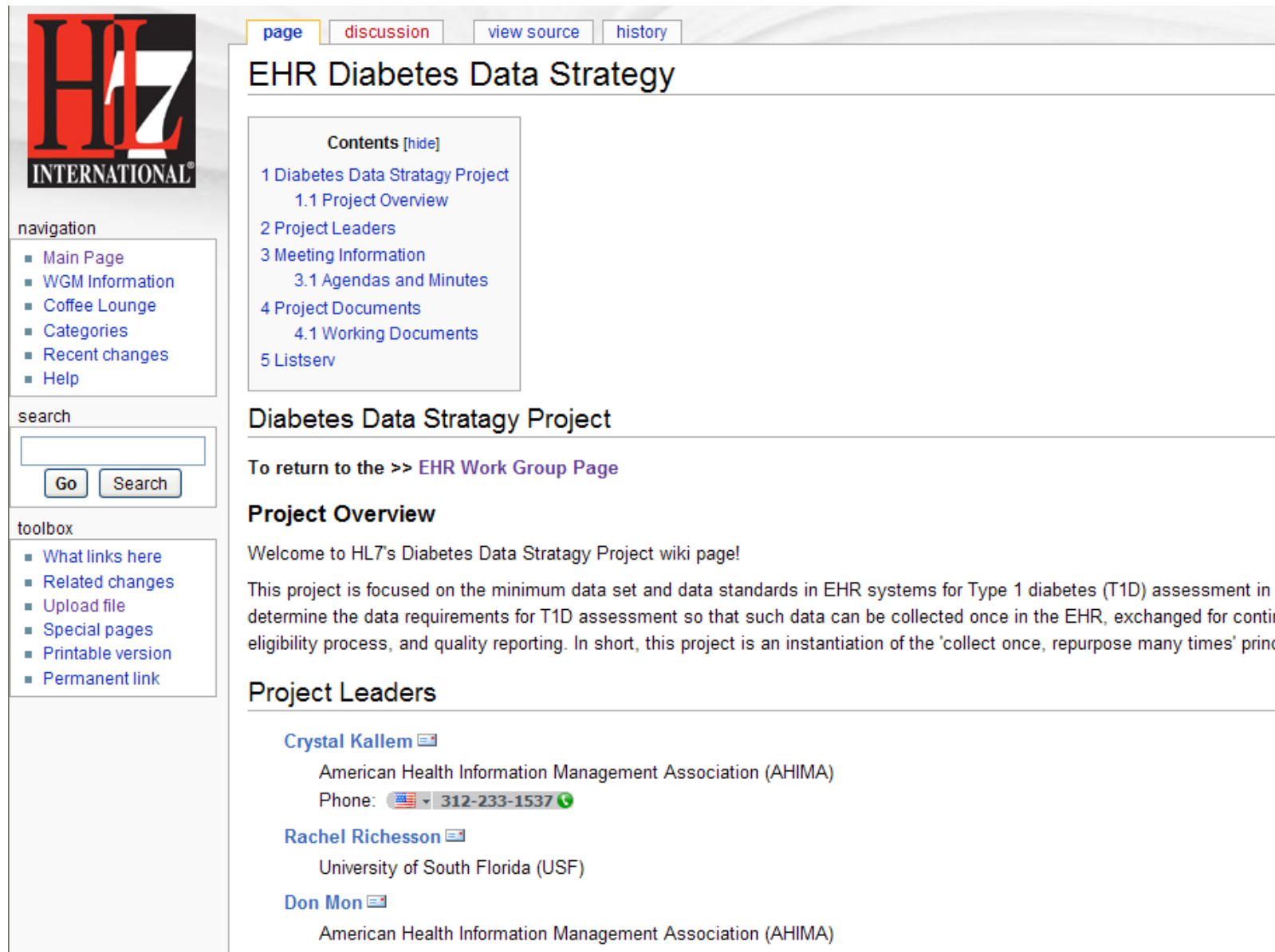
- Map the Diabe-DS data elements to the EHR-S FM
- Prototype to test the feasibility and support future EHR WG data profile development

ID#	Type	Name	Statement/Description	See Also	Conformance Criteria	Row #	Data Requirement(s)	Corresponding Use Case(s)	Corresponding Standard(s)
DC.1.1.2	F	Manage Patient Demographics	<p>Statement: Capture and maintain demographic information. Where appropriate, the data should be clinically relevant and reportable.</p> <p>Description: Contact information including addresses and phone numbers, as well as key demographic information such as date of birth, time of birth, gestation, gender, and other information is stored and maintained for unique patient identification, reporting purposes and for the provision of care. Patient demographics are captured and maintained as discrete fields (e.g., patient names and addresses) and may be enumerated, numeric or codified. Key patient identifiers are shown on all patient information output (such as name and ID# on each screen of a patient's record). The system will track who updates demographic information, and when the demographic information is updated.</p>	<p>S.1.4.1 S.2.2.2 IN.2.1 IN.2.2 IN.2.4</p>	1. The system SHALL capture demographic information as part of the patient record.	38			
					2. The system SHALL store and retrieve demographic information as discrete data.	39	<p>Person Name: The system SHALL provide the ability to capture last name, first name, and middle name as two word names.</p> <p>Other data requirements in this section might address:</p> <ul style="list-style-type: none"> • birth name • maiden name • legal names • aliases • address • gender/ administrative sex • date of birth 	Public Health	HITSP C154 Data Dictionary
					3. The system SHALL provide the ability to retrieve demographic data as part of the patient record.	40			
					4. The system SHALL provide the ability to update demographic data.	41			
					5. The system SHOULD provide the ability to report demographic data.	42			

Next Steps

- Finalize use case scenarios
- Conduct data modeling and analyze results
- Map data elements to EHR-S FM
- Complete prototype analysis
- Assess the process, methodology, and outcome
- Summarize/publish prototype results
- Determine how to advance/expand the work
- Formally engage various T1D experts and stakeholders
 - Coordinate with CIC, CIIC and Child Health WG to engage with professional groups (e.g., ADA, endocrinology, pediatrics) to endorse EHR standard elements (which also support data reuse)

Follow the Project on the EHR WG Wiki



The screenshot shows the HL7 International Wiki page for the EHR Diabetes Data Strategy. The page features a navigation menu on the left, a search box, and a main content area with a table of contents and project details.

HL7 INTERNATIONAL

navigation

- Main Page
- WGM Information
- Coffee Lounge
- Categories
- Recent changes
- Help

search

Go Search

toolbox

- What links here
- Related changes
- Upload file
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- Printable version
- Permanent link

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EHR Diabetes Data Strategy

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Diabetes Data Strategy Project




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Project Overview


Welcome to HL7's Diabetes Data Strategy Project wiki page!

This project is focused on the minimum data set and data standards in EHR systems for Type 1 diabetes (T1D) assessment in order to determine the data requirements for T1D assessment so that such data can be collected once in the EHR, exchanged for continuing eligibility process, and quality reporting. In short, this project is an instantiation of the 'collect once, repurpose many times' principle.

Project Leaders

Crystal Kallem 
American Health Information Management Association (AHIMA)
Phone:  312-233-1537 

Rachel Richesson 
University of South Florida (USF)

Don Mon 
American Health Information Management Association (AHIMA)

Questions/Comments

Don Mon

donald.mon@ahima.org

Crystal Kallem

crystal.kallem@ahima.org

Rachel Richesson

Rachel.Richesson@epi.usf.edu

