EHDI Data Integration Across Heterogeneous Systems

An Experience Report on CHARM

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Overall Objectives for Sharing Data

- Improve health-care services
- Improve data quality
- Reduce costs
Purpose of CHARM

Provide real-time data sharing among appropriate health care programs, partners, and state agencies.
Goals of CHARM

- Alert users of exceptional conditions
- Ensure that Participating Programs (PP) retain stewardship over their own data – not copied into other databases
- Allow Participating Programs to define what will be shared and with whom
Goals of CHARM

- Ensure security and confidentiality of all data
- Satisfy HIPAA and FERPA requirements
- Allow for individual information systems to evolve independently
- Facilitate CHARM’s growth in scope & size
Some Guiding Principles and Concepts

- Maintain security, confidentiality, and privacy
- Respect organizational boundaries and policies
- Minimize impact on participating programs’ information systems
- Keep data close to the data stewards
- Stay true to the long-term architectural design (service-oriented architecture)
- Tune record matching to data sources
- Ongoing monitoring and adjustment
CHARM Integration Infrastructure

- Immunizations
- CHARM Web Interface
- Birth/Death Registry (Vital Statistics)
- Neonatal Follow-up
- WIC
- Early Intervention
- cHIE
- ORSIS (DHS)
- Newborn Blood Screening
- SAFE (DHS)
- Birth Defects Registry
- Early Hearing Detection and Intervention
- CSHCN

CHARM Integration Infrastructure
Primary CHARM-II Components

- **CHARM Agent**
- **ID Mapper**
- **Alert Agents**
- **Sync Agents**

**Participating Programs**

**PP-Specific CHARM Components**

**Shared CHARM Components**
Sample Data Query

User Interfaces
- WebKids User (Web Browser)
- HiTrack User (Web or App)
- VS User (Stand-alone App)

PP Information Systems
- USIIS (Utah’s Immunization System)
- HiTrack
- Vital Statistics

PP-specific CHARM Components
- USIIS Agent
- EHDI Agent

Shared CHARM Components
- CHARM Server
- VS Agent
A WebKids User requests the Hearing Screening History and Risk Factors for a child.
Sample Data Query - Step 1
The USIIS system formulates the query using the USIIS ID for the child and submits the query to its agent.
The USIIS Agent translates the USIIS ID to a CHARM ID and passes the query onto The CHARM Server.
Sample Data Query - Step 4

The CHARM Server determines that it needs data from both HiTrack and Vital Records and send out appropriate service requests in parallel.
The EHDI Agent receives a service request, translates the CHARM ID to a HiTrack ID, and executes the necessary service in the HiTrack system. Similar events occur in VS Agent.
The HiTrack system returns the requested Hearing Screening History data. Similarly, Vital Records returns the requested Risk Factor data.
The respective agents translate program-specific IDs to CHARM IDs and returns the results to The CHARM Server.
The CHARM Server combines the results and returns them to USIIS Agent.
The USIIS Agent translates CHARM IDs to USIIS IDs and returns the results to USIIS.
Sample Data Query - Step 10

The USIIS displays the results in a web page.
This information is brought to you by CHARM...

Hearing Test History From HiTrack

(last, first middle)
Male, Birth Date: 05/25/2000 (mm/dd/yyyy)

<table>
<thead>
<tr>
<th>Date (mm/dd/yyyy)</th>
<th>Test/Ear</th>
<th>Result</th>
<th>More info</th>
</tr>
</thead>
<tbody>
<tr>
<td>05/30/2000</td>
<td>TEOAE(L)</td>
<td>Pass</td>
<td></td>
</tr>
<tr>
<td>05/30/2000</td>
<td>TEOAE(R)</td>
<td>Pass</td>
<td></td>
</tr>
</tbody>
</table>
This information is brought to you by CHARM…

**Immunization History from USIIS**

**Gender:** Male  
**Birth Date:** 05/25/2000  
**Deceased:** No

<table>
<thead>
<tr>
<th>Immunization Date (mm/dd/yyyy)</th>
<th>Vaccination Name</th>
<th>Vaccination Series</th>
</tr>
</thead>
<tbody>
<tr>
<td>05/25/2000</td>
<td>HEPATITIS B - PEDIATRIC OR ADOLESCENT</td>
<td>HEP-B</td>
</tr>
<tr>
<td>11/19/2002</td>
<td>INFLUENZA - SPLIT</td>
<td>FLU</td>
</tr>
</tbody>
</table>

[More info]
Data monitoring example

User Interfaces

- WebKids User (Web Browser)
- HiTrack User (Web or App)
- VS User (Stand-alone App)

PP Information Systems

- USIIS (Utah’s Immunization System)
- HiTrack (Utah’s EHDI System)
- Vital Statistics

PP-specific CHARM Components

- USIIS Sync Agent
- EHDI Sync Agent
- VS Sync Agent

Shared CHARM Components

- CHARM Server

United States Immunization System (USIIS)
EHDI System (HiTrack)
Vital Statistics System (VS)
Data monitoring example – Step 1

The VS Sync Agent detects a change to a child’s legal name and publishes that change to the Sync Engine (part of The CHARM Server).
The Sync Engine receive the name change notification from VS and publishes it to all PPs subscribed to that kind of notification, e.g. USIIS and HiTrack.
The EHDI and USIIS Sync Agents receive the name change notification and stores that information in a holding bin in the respective PP database.
A HiTrack user can use that change notification to update their program’s record for the child.
Alert example

User Interfaces
- WebKids User (Web Browser)
- HiTrack User (Web or App)
- VS User (Stand-alone App)

PP Information Systems
- USIIS
  (Utah’s Immunization System)
- HiTrack
  (Utah’s EHDI System)
- Vital Statistics

PP-specific CHARM Components
- USIIS Alert Agent
- EHDI Alert Agent
- VS Alert Agent

Shared CHARM Components
- CHARM Server
The EHDI Alert Agent detects the condition that Tommy needs hearing screening follow-up and sends that alert to The CHARM Server.
The CHARM Server keeps track of the alert and will automatically provide it to any agent that queries information for Tommy.
Alert example – Step 3

A VS user (through the Oliver system) queries basic information about Tommy.
Alert example – Step 4

The VS Agent maps the ID’s in the query and sends it on to the CHARM server, as described above.
The CHARM Server processes the query as described above, but then also attaches the hearing screening alert to the results before sending them back to the VS Agent.
The VS agent receives the query results with the attached alert and sends that information back to the user.
**Alert example – Step 6**

![Image of a software interface showing a list of patient data under the title 'HI-TRACK'. The interface includes columns for 'Baby Name', 'DOB', 'Medical ID', 'Birth', 'Inpatient', 'IP Day', 'Outpatient', and 'OP Day'. The list includes rows for various patients with their respective details. There are also options to add or delete babies, and a message at the bottom mentioning 'CONFIRMED LOSS: 07/08/06 Milestones: D01' and 'Inactive record. Use Tracking Options to re-activate this record.' Additionally, there are links to 'External Links' such as 'Vital Records' and 'Immunizations'.
Alert example – Step 6

Risk Factors from VS

Alert | Info:
--- | ---
Date (mm/dd/yyyy) | Severity | Message | From
12/03/2003 | Urgent | Child has an overdue on HepB | USIIS

(last, first middle)

Gender: Male
Birth Date: 05/25/2000 (mm/dd/yyyy)
Deceased: No

Risk Factor Info:
Does the Family have a history of hearing loss?
false
<table>
<thead>
<tr>
<th>Risk Factors/Delivery Information/Birth Abnormalities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Anemia:</td>
</tr>
<tr>
<td>Acute Or Chronic Lung disease:</td>
</tr>
<tr>
<td>Hemoglobinopathy:</td>
</tr>
<tr>
<td>Chronic Hypertension:</td>
</tr>
<tr>
<td>Eclampsia:</td>
</tr>
<tr>
<td>Previous Infant 4000+ Grams:</td>
</tr>
<tr>
<td>Previous Small for Gestational Age Infant:</td>
</tr>
<tr>
<td>RH Sensitation:</td>
</tr>
<tr>
<td>Uterine Bleeding:</td>
</tr>
<tr>
<td>Other:</td>
</tr>
<tr>
<td>Pre Existing Diabetes:</td>
</tr>
<tr>
<td>Specify:</td>
</tr>
<tr>
<td>Vaginal Cessarian:</td>
</tr>
<tr>
<td>Repeat Cessarian:</td>
</tr>
<tr>
<td>Vaccum:</td>
</tr>
<tr>
<td>Birth Weight(lbs):</td>
</tr>
<tr>
<td>Birth Location:</td>
</tr>
<tr>
<td>APGAR 1:</td>
</tr>
<tr>
<td>Neonatal Meningitis:</td>
</tr>
<tr>
<td>Assisted Ventilation (Less than 30 minutes):</td>
</tr>
</tbody>
</table>
A Look Back

1997
UDOH adopts an Information System Vision
Leadership makes long-term commitment to systems integration
CHARM is born as one of five strategies
PP Meetings and System Analysis Activities

1998
Tool evaluations and design activities
Three prototypes completed and NYC site visit
Version 1.0 complete

1999
Data Integration Master Plan established
VR signs first data sharing agreement

2000
Change in development platforms to reduce deployment costs
USLIS and EHI sign data sharing agreement

2001
Address correction and new matcher
ExI Integration goes into testing

2002
First non-UDOH PP integrated
Laying the foundation
Building consensus, collaboration, and technology
Making data sharing a reality

2003

2004

2005

2006

2007

2008

2009

Expanding
Started integration with Utah's CHIE
Better Tracking & Follow-up

- Vital Statistics data for EHDI users
- EHDI data for EI Part-C users
- NBS data for EHDI users
- EI Part-C data for EHDI users
- Obtain Parent Opt Out information for EHDI data
Improved EHDI Data Quality

• Notification of new, unknown children from Vital Records

• Notification of name changes and deaths from Vital Records

• Notification of address changes from EI Part-C
Challenges addressed by CHARM

• Data Stewardship
• Record Matching, linking and merging
• Data Accuracy (in the face of shifting semantics)
• Confidentiality of patient data
Data Stewardship - Push vs. Pull?

- Two general techniques for accessing shared data:
  - **Pushing**: copies of data to data consumers
    - The data consumer becomes responsible for the copy
    - Data consumers must be able to accept data on demand and handle that data with confidentiality
    - Data consumers must stay-updated with data sources
  - **Pulling**: retrieves data from data sources as needed
    - Data steward remains responsible for the data
    - Data is “live” and up-to-date
Data Stewardship – Retained vs. On Demand

• Two approaches for managing shared data:
  – **Retaining** Data
    • Requires knowledge about data integrity and domain specific logic
    • Requires physical resources to keep data
    • Introduces data expiration issues
    • The data steward is disconnected from the copy; it is not necessarily updated when the data steward makes changes
  – **Retrieving** Data on demand
    • Available as needed
    • Data is “live” and up-to-date
Data Stewardship – Direct vs. Brokered

- Two approaches to handling communication for data sharing:
  - **Direct Communication**
    - Requires data consumers to communicate directly with data providers
    - Requires data consumers to have "domain specific knowledge" about other providers
  - **Data Brokering**
    - "Arms length" data access reduces impact on data providers
    - Gives a buffer that protects data providers
    - Fosters "Plug and Play" architecture
Data Stewardship - Doing it right

• Benefits of keeping data close to the stewards:
  – Simplifies organizational boundaries and data stewardship policies
  – Allows participating programs to specialize: focus on what they do best and grow in their own directions
  – Provides up-to-date information for all data consumers on an on-demand basis
  – Simplifies data sharing arrangements
  – Reduces complex cross-program integration efforts
Data Quality

• The value of an integrated system depends on the quality of the data in the individual PPs and on the quality of the matching of records among these PPs
  – Matching must be tuned to the characteristics of the individual data sources
  – The characteristics can involve subtle data semantics, e.g. the encoding of race
  – These characteristics can shift over time, due to software changes, procedural changes, user turnover, or new policies
Confidentiality of patient data

• An integrated system must preserve patient privacy
• Two general approaches for allowing or restricting data sharing across HIT systems
  – Opt-in
    – By default no data is shared. Patients must explicitly grant permission for their information to be shared with other health-care system
  – Opt-out
    – By default data is shared, but patients are always given the ability to choose not to have their data shared.
Ongoing Challenges & Next Steps

• Expansion
  – Additional participating programs within the DOH
  – Participating programs outside the DOH
  – Other Health Information Exchanges

• Data provenance

• Operations
  – Setting systems, networks, firewalls, etc.
• CHARM is the culmination of a decade of data sharing experience
• CHARM provides a real-time data sharing system that accommodates existing programs
• CHARM promotes effective data stewardship
• CHARM “bridges the gap” between today’s public health information systems