Sharing Databases: The Challenges and Opportunities

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“The greatest change is the rate of change.”

- Daphne Kis

**Agenda**
- Historical Context (2014-now)
- About Me
- FindCancerServices.com
- 4 Use Cases
- Things to think about

**Caveats**
- Resource databases (not PHI)
- I’m not techie
Historical Context (2014- now)

• AIRS XML Schema 3.1 (since 2012), Taxonomy
• Q1 2014: AIRS Technology Committee: software selection guidelines
• Feb 4 Announcement:
  “AIRS requires an I&R service/practitioner to collect and maintain a set of resource database records from organizations that provide a national service within the United States.”
• Feb 24: speaker request
• March 3: posted Code for America exploring relationship with AIRS
  • Interoperability (API, Linked Data, and Open)
My Background: MSSW

• Salesforce.com Experience
  • 2005: Client
  • User Group Leader
  • Frequent Speaker
    (2007: 211/311)
  • Nonprofit Consultant
  • Product Developer

• Salesforce.com
  • CRM
  • 1999
  • Cloud based
  • 21,000 nonprofits
  • 1/1/1 model (10 donated)

>> Use technology to improve operations and outcomes in the health & human services sector
Say what?

$310

Hospital Outreach
FindCancerServices.com: Mission & Need

**Mission**

Connect everyone in the USA touched by cancer with the services they need

**Need**

“There are many local organizations throughout the country that offer a variety of practical and support services to people with cancer. However, people often don’t know about these services or are unable to find them.”

- National Cancer Institute
Hospitals & Cancer Clinics

• 100% of cancer patients

• “I feel useless and irresponsible when patients identify needs and I don’t know where to send them.”
  – Anonymous Hospital Social Worker
FindCancerServices.com is a Health IT platform for hospitals to screen and refer patients to services across the USA, which improves care while reducing hospital expenses.
Assessment

- HIPAA PHI (18 identifiers)
- Unique Identifier (not Medical Record #)
- Patient Information:
  - Disease type
  - Gender
  - Zip code
  - Age range
Portfolio

- Data Subset from which to select
- The art of referral
- Remain a high contact process
- Goal: support patients in settings without social work staff
Our Resource Database

• 7,000 services (mostly one service per organization)
• Target Population: People with Cancer
• Service Type: non-medical
  • Emotional
  • Practical
  • Financial
• AIRS Taxonomy
  • Synonyms
• Salesforce.com Platform (Force)
Vision

An interoperable human services system that efficiently provides high-quality, evidence-based, cost-effective services to improve the lives of people touched by Cancer.

I can’t do this alone.
How to make it work

Health IT tool in hospitals

Cancer Services Database

I&R Call Center

Basic Needs Database
Organization that want more services for cancer patients

Organization that have general services that could help cancer patients

Organization that want to exchange services

Data Exchange

Data Out

Data In

Hospitals
Use Cases

• NYC 311

• Pennsylvania 211 Southwest

• Cancer Care Connection

• AIRS National
Use Case 1:

- FindCancerServices Pilot: Montefiore Hospital, Bronx
- Population: Bronx residents, BMT
- NYC: 211 is part of 311
- 311: Not interested in our data (at this time)
- Technology: Open API
Use Case 1: Challenges

• Which datasets to use? How much do I want?
• Format of data
• Update process
Use Case 2: Montefiore Metrics

• # times FCS tool was used (opportunity for access)
• # times a 211 service:
  • Appeared in a service selection
  • Added to a portfolio
  • Patient contacted service
  • Patient received service
  • Patient satisfaction with service
  • Social worker satisfaction with referral
  • Social worker satisfaction with service
  • Health outcomes of patient
What goes in?

- Transportation: more!
- Homeless shelters: more!
- HIV services?
- Everything?
Use Case 2:

• March & April 2014: 55 requests from people needing financial assistance of some sort in a large part due to an inability to work or reduced work hours due to cancer

• “There must be something more that we can do for them”

• Technology: VisionLink
Use Case 2:

• Phases:
  1. Give 211 FCS data for a manual upload (test)
  2. Give 211 FCS data through an API for auto update process
  3. Jointly Approach Hospital: FCS & UW program: new way to get information distributed
  4. API to get 211 data back to FCS for deliver to hospital
Use Case 2: 211 Win / Win

• 211
  • Gives 211 more ways to give people access to services
  • Metrics to show the good they are doing
  • Low effort

• Moves both organizations in the direction of fulfilling our mission
Use Case 3:

- **Current:** CCC distribute services to 211
  - Same technology
  - Funding from the State
  - 211 data does not go to them

- **Potential**
  - FCS gives data to CCC to expand database
  - CCC manage data update process

- **Technology:** iCarol
Use Case 3:  

- CCC
  - Greater service offering for clients
  - Press opportunity to double the size of the database
  - Grant opportunity to grow capacity

Win / Win
Use Case 4:

- Many I&Rs updating same records (redundant effort)
- National organizations contacted by many I&R’s (annoying)
- Technology: all I&R vendors + any custom programs
Data Systems
How do you distribute data?

- XML File extracts – easy to get it out, hard to get in (different data structures)
- Download change files
- Standard data exchange methodology (everyone would have to change their system)
- Central Hub – check in and check out data
- Distributed - go to each organization
- Services self-maintained and get picked up like a search engine
What this entails

• Technical Systems
• Data Maintenance
• Human Systems
API: Application Programming Interface

• Transforms an information system from something you have to be inside to a set of tools that you can ask to do things for you even outside.

• You can be outside and use tools to get info

• Go in and get the pieces out
Middleware

• **Database Middleware.** Database middleware allows direct access to data structures and provides interaction directly with databases. There are database gateways and a variety of connectivity options. Extract, Transform, and Load (ETL) packages are included in this category.

• Examples from corporate America
Data Things to think about
Data Flow

• Unilateral or Bilateral

• One time or ongoing

• Updated in >1 place
One Time: Easy
Which one Wins?

• Organization
• Most recent change
• Record Owner
• Notification of change
What Happens with Data?

- Insert only
- Update only
- Upsert (Insert or Update if it already exists)
- View only
What makes Databases Incompatible?

• Structure of Data
  • Object Model (Agency table, services directly)
  • Field compatibility
    • lookup vs. picklist
    • age range vs. age category

• Mechanics
  • File Formats (CSV, XML, JSON)
  • Communication protocol (Security, Authentication, API)

• Meaning & Usability
  • Taxonomy, Key Words, Classification
Data Models

Ex: American Cancer Society
Look Good Feel Better
Linked Data

Flexible Data Model
3 Attributes:

Triples

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<th>Object</th>
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</tr>
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<td>Program</td>
<td>Is located at</td>
<td>A site</td>
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</tbody>
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- Pricing Considerations
  - Build an API
  - API calls
- MSA - flat fee monthly
- Pay per usage
  - query dataset
  - when detailed data is viewed (click on search results)
  - when added to portfolio

- Replicated into our system:
  - SFTP: post & download (automated with sftp secure file transfer protocol)
  - API: FCS query api to get file
Opportunities

• Greater reach
• Leveraged expertise
• Focused effort
• Economies of scale
• Cost sharing
• Innovation
When you are trying to make the world a better place, your competition is the status quo.

-me
How do we do more for people in need?

Universal Availability

Partnerships
Stay in Touch!

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Evaluations

Give me your card for updates!