Evolving Databases for Birth Defects Systems:
The Texas Experience

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Texas Department of State Health Services
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Today’s presentation

- Describe the evolution of our system as needs, requirements and resources changed.
- Describe the Texas BD registry model and how decisions were made for ongoing changes to the data systems.
- Describe how efficiencies were gained including:
  - Is the data system off the shelf or built from scratch for you?
  - Is the data system an "add on" to another system?
  - Is the data system actively linked to other systems?
  - Casefinding or case verification piece when in the hospital
  - Issues working through
  - What are the pros/cons of the way chosen?
  - Lessons learned
Texas Birth Defects Registry Model

- Active surveillance program where staff go to 220+ hospitals to find potential cases, read medical records, and abstract case data

- The hospitals are located in over 262,000 square miles - where possible, remote access to the electronic medical record is used (currently 30 hospitals)

- In 2010, over 92,000 medical records were reviewed yielding over 22,000 cases with 81,000+ diagnoses
Facilities Visited by BDES Staff
2005

Number of Facilities in City:
- 1
- 2 - 4
- 5 - 9
- 10 - 19
- 20 and up

BDES Office by City:
- Office (n = 4)
- Sub-Office (n = 1)
- Satellite (n = 3)

Source: Birth Defects Epidemiology & Surveillance, March 2006
Texas Birth Defects also does:

- Data Analysis (routine & ad hoc)
- Outreach to Family
- Communication
- Research
- Education & Training
The need for a new system

Current “old” system

- Aging, fragmented, designed at the turn of the century, went live February 2002, web-based SQL server
- Hard-coded ➔ need programmer for even small changes
- Designed for an old business model, abstract to paper first, staff physically in hospitals to review records
- Based on smaller case load without much scalability
- Changes to fix problems were estimated $600+K.

No longer met the needs of the growing registry and need re-design for improved efficiency.
Please Sir
Can We Have Another?

- Case for replacement made “up the line” and added to request list for legislature

- Meanwhile, other disease registries were in similar situations and also submitting requests and all wanted to go forward to the Legislature

- Agency created an overall Health Registries Improvement Project
Health Registries Improvement

- For multiple registries/surveillance systems the applications/supporting software technology are old, not compliant with current federal regulations, and many no longer supported by the vendor.
- Data are fragmented based on differing data standards, stored in separate application database silos, and gathered in response to different federal or state mandates.
- Can impact the ability to share associated health information
- Registries are not sufficiently meeting the needs of the public, the agency, or the unit responsible for the daily monitoring and reporting as required by federal law.
Legislative Response

• You want How Much?

• Can you all use one access database/excel spreadsheet?

• Ok. Fine. Here is a little money....... BUT, systems must become uniform, consistent, linkable, brew coffee, reduce the national debt, improve gas mileage, etc
Selection Decision

- High level decision at agency looking at very big picture wanting an integrated solution system to work for multiple registries now (Trauma, Lead, HAI, Cancer, HIV/STD/TB) and more registries in the future
- BD staff got questions answered but really not much impact on final decision
- Much trepidation......
Drumroll Please

- Decision = MAVEN by Consilience Software
- Customizable Off the Shelf Product
- Web based Person Centric Case Management System
- Much trepidation –
  - how can anything work for us that is not designed from the ground up with only us in mind?........

Believe me, it can
Pros

- Web-based Customizable, Person Centric System with Multiple Events or Types of Events
- Flexible, Scalable, Secure, Stable
- Has Reports
- Has Record Printing
- Has logic/error check rules
- Has Workflows (think tasks) to prioritize work
- Has Roster Import ability to bring in lists of data
- Gives us power
Pros- Power

- POWER – Model Manager: Ability to add/change fields w/o programmer and start/end dates for fields or answer choices
- POWER – Administrative Rights to do a lot of things
- POWER - De-Duplication rule modifiable
- POWER – Ability to add workflows & reports w/o programmer
- Record Linkage within the BD system

POWER!!!!! `
<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>DETAILS</th>
</tr>
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<tbody>
<tr>
<td>Maven Information</td>
<td>Maven 4.1.201103280854-TRUNK</td>
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<tr>
<td></td>
<td>Licensed to Consilience Software Internal Development Use (non-production) (8000 users)</td>
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<tr>
<td></td>
<td>License expires 12/31/2030</td>
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<tr>
<td>Server</td>
<td>qatest02 (192.168.1.221) [4 CPUs]</td>
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<td></td>
<td>Linux 2.6.24-27-server i386</td>
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<tr>
<td>Database</td>
<td>Operational Database: SQLServer</td>
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<td>Reporting Database: None</td>
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<tr>
<td>Java</td>
<td>1.5.0_22 Sun Microsystems Inc. (986 MB)</td>
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<tr>
<td>System</td>
<td>Last restart: 03/28/2011 01:07 PM</td>
</tr>
<tr>
<td></td>
<td>Web sessions: 1 (current), 3 (max)</td>
</tr>
<tr>
<td></td>
<td>Database connections: 1 (current), 12 (max)</td>
</tr>
<tr>
<td></td>
<td>Content compression: Enabled</td>
</tr>
<tr>
<td></td>
<td>Scheduled Maintenance: 01:00 am - 03:00 am</td>
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<tr>
<td></td>
<td>Enter Maintenance Mode</td>
</tr>
<tr>
<td>Performance</td>
<td>Response time (avg): 80 ms</td>
</tr>
<tr>
<td></td>
<td>Requests: 773</td>
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<tr>
<td></td>
<td>Errors: 6</td>
</tr>
<tr>
<td>Links</td>
<td>Consilience Software Documentation Portal</td>
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<td></td>
<td>Consilience Software Issue Tracker</td>
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<tr>
<td></td>
<td>Maven Model Manager Download</td>
</tr>
<tr>
<td>System Notifications</td>
<td>None</td>
</tr>
</tbody>
</table>
More on Maven power

- Users – Create, update, and delete user accounts
- Roles – Create and update roles
- Groups – Create and update user groups
- Workflow Queries – create/update/delete
- Reports creation/update/delete
- Denormalization Tables set up
- Reference codes management
- Print Templates
- Processing Modules
Pros – what we did

OLD way
One database for cases, another for casefinding, another for controls, another for special projects, another for each type of QA

NEW Way
One database system for all needs including cases, controls, casefinding, special projects, QA-reabstraction, QA-rerecord review, QA-re-casefinding
Pros - Vendor

- Vendor staff: knowledgeable, personable, flexible
- Not the only one DSHS registry so can get a bigger bang for the buck
- Issues worked out for one DSHS registry are shared with the other registries
- Updates to core system provided to us in the future
No matter what system

- Proper Planning Prevents Poor Performance....
- Proper Planning takes lots and lots of time
- Did I mention the time commitment?
Our Planning included

Way before decisions made went through business process analysis

• analysts meeting with program staff
• to document and evaluate current process
• discover opportunities for improvement to increase program efficiency and effectiveness
8.0 HIGH-LEVEL FLOWCHART OF BDES PROCESSES

BDES – High-Level Flowchart of BDES Processes Page 1

I. Regional Office Activities

Start

1.0 Casefinding Process

Note: Field QA occurs in these processes:
1.0 Casefinding
2.0 Medical Record Review
3.0 Abstraction

2.0 Medical Record Review Process

3.0 Abstraction Process

4.0 Field Review Process

5.0 Clinical Review Process

6.0 Record Completion Process

7.0 Diagnosis Code Review Process

II. Central Office Activities
Planning (continued)

- Long before a system was chosen, bd staff decided for every case field and answer choices to add/drop/modify
- Developed system requirements that selected vendor had to answer
  - Data Collection
  - Notification (audits/tracking)
  - Data Analysis
  - Reports
  - And so on
<table>
<thead>
<tr>
<th>Number</th>
<th>Category</th>
<th>Requirement Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>DC1</td>
<td>Data Collection</td>
<td>The system must uniquely identify individual records.</td>
</tr>
<tr>
<td>DC2</td>
<td>Data Collection</td>
<td>The system must have the capability to accommodate manual data entry. For batch or manual entry, system must maintain external identifiers.</td>
</tr>
<tr>
<td>DC3</td>
<td>Data Collection</td>
<td>The system must have the capability to import and filter data from a variety of sources (hospitals, prenatal diagnosis facilities, fetal death certificates, statewide hospital discharge databases, etc). Users shall be able to modify import format specifications as needed to keep up with format changes.</td>
</tr>
<tr>
<td>DC4</td>
<td>Data Collection</td>
<td>The system must have the capability to grey-out fields if not applicable and pre-fill as applicable, based on context or linked records. (ex: region of jurisdiction is based on county of residence, using case finding data to pre-fill new abstraction).</td>
</tr>
<tr>
<td>DC5</td>
<td>Data Collection</td>
<td>For manual entry, the system must perform data validation on the data entry screen for each field. (ex: real time correction)</td>
</tr>
<tr>
<td>DC6</td>
<td>Data Collection</td>
<td>The system must provide processes to validate and filter automatically imported data from all sources.</td>
</tr>
<tr>
<td>DC7</td>
<td>Data Collection</td>
<td>The system must provide the ability to take batches of off-line data entry of abstraction records and update, process, and synchronize them to online system.</td>
</tr>
<tr>
<td>NOT1</td>
<td>Notification (Audit and Tracking)</td>
<td>The system must provide tracking log of changes made to all individual patient records (case finding and abstracts) allowed through the normal user interface. Tracking includes who, when, and what the change was.</td>
</tr>
<tr>
<td>NOT2</td>
<td>Notification (Audit and Tracking)</td>
<td>The system must provide error and success reports to users for all batch data loaded into the system. The report must include error type (ex: rejection, empty or inaccurate data fields or duplicate) and specific definition.</td>
</tr>
<tr>
<td>NOT3</td>
<td>Notification (Audit and Tracking)</td>
<td>The system must allow user to set predetermined notifications (alerts) based on workflow conditions, including dates, timeliness, number of pending items, and similar workflow-related items. Note: The administrator would set the majority of alert criteria. Where possible, permit other users to set some criteria.</td>
</tr>
<tr>
<td>NOT4</td>
<td>Notification (Audit and Tracking)</td>
<td>The system will allow event driven (time/date or data modification) reports, emails and alerts.</td>
</tr>
<tr>
<td>DA2</td>
<td>Data Analysis</td>
<td>The system must have data extraction tools to support multidimensional (using criteria from multiple data tables and multiple fields) for external analysis of the data. The tool must accommodate both basic and advanced users.</td>
</tr>
<tr>
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<tr>
<td>DA3</td>
<td>Data Analysis</td>
<td>The system must allow analysis to include use of linked data. Ability to cross reference and match with any other imported data. Must minimally link for individuals, facility, location.</td>
</tr>
<tr>
<td>DA4</td>
<td>Data Analysis</td>
<td>The system must provide standard reports for all standard BDES registry tasks.</td>
</tr>
<tr>
<td>DA5</td>
<td>Data Analysis</td>
<td>The system must allow reporting and analysis of workflow tasks and activities.</td>
</tr>
<tr>
<td>REP1</td>
<td>Reporting</td>
<td>The system must provide reports in multiple printable formats, including HTML and pdf.</td>
</tr>
<tr>
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<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>REP2</td>
<td>Reporting</td>
<td>The system must allow for the export of any report as data in XML and CSV.</td>
</tr>
<tr>
<td>REP3</td>
<td>Reporting</td>
<td>The system must allow for users to save reports in any given allowable export format.</td>
</tr>
<tr>
<td>REP4</td>
<td>Reporting</td>
<td>The system must include development and processing of common reports. The users will have the ability to modify these reports and develop new common reports. Common reports that are developed will be available on the system to all authorized users.</td>
</tr>
<tr>
<td>REP5</td>
<td>Reporting</td>
<td>The system must support the sharing of other reports.</td>
</tr>
<tr>
<td>REP6</td>
<td>Reporting</td>
<td>The system must provide immediate notification of a failed report to the requesting user, providing reason or error code.</td>
</tr>
<tr>
<td>REP7</td>
<td>Reporting</td>
<td>The system shall provide real-time monitoring and viewing of record workflow status.</td>
</tr>
<tr>
<td>GEN2</td>
<td>General</td>
<td>The system shall give administrators the ability to lock out all or a group of non-administrator users.</td>
</tr>
<tr>
<td>------</td>
<td>---------</td>
<td>-----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>GEN3</td>
<td>General</td>
<td>The system must provide a completely dynamic query tool that allows searching by any single data point. Search results must be sortable and allow user to view and perform appropriate actions on records found. Note: this focuses on finding, viewing, and performing actions on the record inside the system.</td>
</tr>
<tr>
<td>GEN4</td>
<td>General</td>
<td>The system must provide context appropriate standard query tools that allow searching for case findings or abstracts. Search results must be sortable and allow user to view and perform appropriate actions on records found.</td>
</tr>
<tr>
<td>GEN5</td>
<td>General</td>
<td>The system must allow inclusion of all historical data migrated from the IAS. Historical data must be accessible in the new system even if some historical data fields are no longer actively updated.</td>
</tr>
<tr>
<td>GEN6</td>
<td>General</td>
<td>The solution must include a separate test system.</td>
</tr>
<tr>
<td>GEN7</td>
<td>General</td>
<td>The system shall give users capability to flag a record to indicate a question and the flag will follow the record until the question is answered and the flag is turned off.</td>
</tr>
</tbody>
</table>
Once selected, how did things actually work?

- Lots of meetings: big and small groups
- Meetings on the Model (fields, answers, layout, restrictions)
- Meetings on Data Conversion
- Meetings on Reports
- Meetings on Workflows
- Meetings on Security rules
- Meetings on De-duplication rules
Issues Worked/Working Through

- Including in system things previously separate and local
- Getting people in the room (I’m too busy)
- Taking the opportunity to think in different ways
- Getting IT resources
- Getting people in the room (It’s a waste of time)
- Scheduling
- Finding meeting rooms
- Trying to doing “regular “ work
- Getting people in the room (I’m the wrong person)
Cons

With the process (no matter the system):
- Not the only program making the change so competition for needed resources
- Since we are part of a larger picture, meetings related to dealing with those issues take up time
- So much to learn

With the Maven System:
- ........not much
- Once model fields in, cannot move them around
What’s Happening Now?

- User Acceptance Testing this week and next
- Creating on our own additional reports and workflows
- Figuring out what else has to be done before go-live
  - Process change decisions
  - Revised documentation
  - Training of staff
  - Modifying epi programs to use new field names
- etc
Lessons Learned

Spend the time up front

Get all the people in the room early (ignore their screams)

Lather, Rinse, Repeat
Questions?
For More Information:

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512-776-2058