Plenary II
Pitfalls and Realities of Working with Big Data
Disclosure

- I am a provider of commercial services that may be alluded to in this CME activity

- I do not intend to discuss an unapproved or investigative use of a commercial product or device in my presentation

- I will not be discussing any use of products used on patients
Outline

- The Problem
- Methodology
- Experience with Solutions/Lessons Learned
- Stakeholder Engagement
- Solution Design Brief
- Solution Description/Data Collection Architecture
- Key Barriers and resolution
- Conclusion
>75% of primary care physicians in Ontario use EMR\(^1\):
>60% of rheumatologists use EMR (~85% signed up)

- Offers opportunities for population-based care, QI, research and surveillance

- Current EMRs are not able to
  - Capture standardized data across EMRs
  - Transmit data to a central repository
  - Present guideline recommendations at point of care

\(^1\)National Physician Survey 2013
Assumption

- Big data requires structured data
  - Not necessarily true (lots of counter examples), but much easier to work with

- Big data requires ability to conduct many small experiments rapidly (Amazon phenomenon)

- Need to speed up the feedback cycle between research findings and bedside application
Motivation

- Increasing demand for structured data from EMRs from Researchers and System/Program Evaluators
- Looking for
  - High quality data (for research and for patients/families)
  - Quality indicators (for policy analysis, program evaluation)
  - Quality improvement and guideline delivery (for guideline implementation)
- EMR vendors not able to serve needs effectively
- Need a more scalable and effective solution that meets the needs of multiple stakeholders
Methods

- Review of previous projects, experiences, lessons learned
- Stakeholder Analysis
  - Identified 8 distinct groups
- Stakeholder interviews
  - N = 90, 8-12 per stakeholder group
- Iterative process of asking about problems and designing solutions
Clinician Point-of-Care Tools

Patient Reported Outcomes

Standardized data coding
Clinical guidelines
Practice quality indicators

Phase 1
Phase 2
Phase 3
InfoClin Experience to Date

• Over 15 years of experience
• Multiple vendors, forms, diseases and projects
• Data collection projects are costly
• EMR vendors not able to focus on data projects
  • Too many other priorities
  • Not geared for clinical forms
  • Researchers are not their customers
• Not scalable to multiple diseases
• Poor version control
• Difficult updating to new evidence
Example of EMR Forms

Highly successful Heart and Stroke Foundation High Blood Pressure Management Initiative

Form is now used in 40 clinics across Ontario
Monthly feedback reports are highly effective in improving rates of monitoring and disease control.
Ontario Biologics Research Initiative: Safety and Effectiveness Study

Site: Patient Number: Patient Initials: AA

Visit Information:
Date: 24/07/2013 (dd/mm/yyyy)  Signature:  Date: 24/07/2013 (dd/mm/yyyy)

Physician Global Assessment of Current Disease Activity:
Not Active At All  0 1 2 3 4 5 6 7 8 9 10  Extremely Active

Patient Global Assessment of Current Disease Activity:
Not Active At All  0 1 2 3 4 5 6 7 8 9 10  Extremely Active

Co-Morbidities & Serious Events:

- NONE
- NO CHANGE at Follow-up
- Depression:
  - Cardiovascular: □ Coronary Artery Disease  □ CHF  □ Arrhythmia  □ HTN
  - OTHER:
- CNS: □ Stroke  □ TIA  □ Other:
- Lung Disease:
  - Asthma  □ COPD  □ Pulmonary Embolism  □ LD  □ Other:
- GI: □ Ulcer  □ Other:
- Kidney Disease:
- Diabetes:
  - Type I  □ Type II
- Hematologic:
  - Anemia  □ Other:
- Liver Disease:
- Osteoporotic or Degenerative Arthritis:
- Autoimmune Disease:
  - SLE  □ Vasculitis  □ Other:

Laboratory:
ESR: 15 mm/hr  □ Not Done  CRP: 34 mg/l  □ Not Done
Date: Jul 24, 2012 (dd/mm/yy)  Date: Jul 24, 2012 (dd/mm/yy)

Joint Assessment:
We have provided a 68 joint homunculus. However, we only require a 28 joint count assessment (selected joints are highlighted). Please shade in all tender & swollen joints. If a joint has been replaced or injected with corticosteroids within the last 3 months, it should NOT be counted. Please use an arrow to indicate these joints.

Tender Joint Count  Swollen Joint Count

Number of Tender Joints:  Number of Swollen Joints:

► Erosions on X-ray? □ No □ Unsure □ Yes, Year of X-Ray:
Solution Design Brief

- Collect structured evidence-based data on multiple diseases from all EMRs across Ontario
  - Send to data repository in real-time
- Real-time guideline advice to practitioners and patients and families
- Standardized calculation of quality indicators including patient experience indicators
- Rapid updates as new evidence becomes available
- Ability to monitor knowledge translation effectiveness
- Support new models of care and Chronic Care Model
- Faster and less expensive ways of updating forms and guideline knowledge across all EMRs in Ontario
...we could design clinical forms that were usability tested (with researchers, policy makers, patients and providers)

met evidence-based clinical requirements and

incorporated into EMRs instantly or almost instantly?

Independent of the EMR vendor
Solution - A Browser Window in Every EMR

• Work with vendors to include browser window in their EMR
• Providers select template from EMR the way they currently do
• Instead of a local form, the EMR gets the form from a website
• Form data can be provided to the EMR using standard XML
• Allows dynamic forms (single form customized for each patient)
• Allows A/B testing of forms
• Allows decision support to be provided in the form
Structured Data Collection Architecture

Standard Data

EMR 1

EMR 2

EMR 3

Forms Server

Research Database

Forms Authoring System
Scalability of Architecture
Issues Identified and Solved

- Privacy – Privacy Architecture
- Governance – Governance infrastructure
- Balancing needs of various stakeholders
  - Usability for clinicians vs. structured/coded for research
Longer Term Goals for Research Platform

- Make research easier, faster and cheaper
- Make privacy a built-in feature
- Make patient input and patient involvement a built-in feature
- Make usability testing and improvement (#1 issue with EMRs in the US and likely in Canada also) a built-in feature
  - Make A/B testing and forms feedback mechanisms a built-in feature
- Make analytics capabilities a built-in feature
- Make form intervention testing a built-in feature
Advantages of Solution

- Much less onus on vendor than current approaches
- Faster updates to forms and evidence
- Faster time to data collection and research
- Allows evaluation of knowledge translation
- Ability to design for new models of care
- Ability to create information for patients and families
- Version control
- Scalable to larger groups, when appropriate
- Balances needs of multiple stakeholders
Big data pitfalls can only be solved by new designs, not by accepting the limitations of current EHRs.

New designs need to balance the needs of multiple stakeholders to be successful.

New designs need to allow for
- easy data capture at the point of care,
- provide guideline recommendations in real-time,
- analyze provider and patients behaviors quickly,
- reject hypotheses daily.