

Plenary II

Pitfalls and Realities of Working with Big Data

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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

The Problem



**>75% of primary care physicians in Ontario use EMR¹:
>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



¹National Physician Survey 2013

Assumption

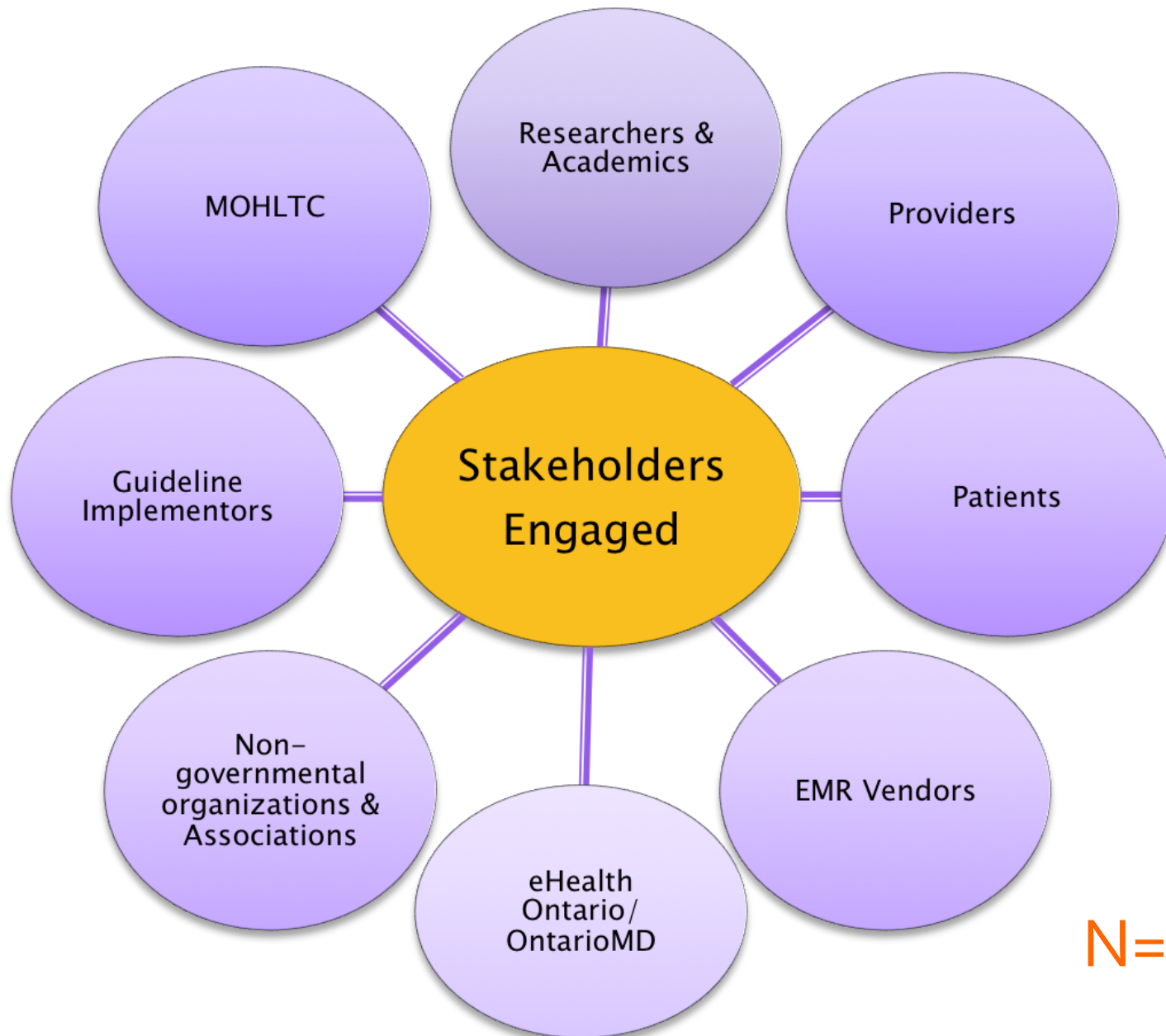
- Big data requires structured data
 - Not necessarily true (lots of counter examples), but much easier to work with
- Big data requires ability to conduct many small experiments rapidly (Amazon phenomenon)
- Need to speed up the feedback cycle between research findings and bedside application

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



N=90

OBRI & ORA Experience to Date

Phase 1



Clinician Point-of-Care
Tools

Phase 2



Patient Reported
Outcomes

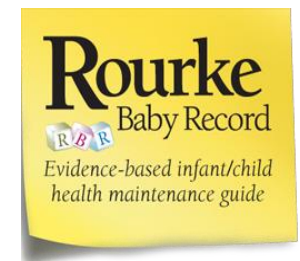
Phase 3



Standardized data coding
Clinical guidelines
Practice quality indicators

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



Cumulative Report for Dr. A. Hcpname

For the period ending 2007-10-31. All data as at 2007-11-24 (report creation date).

200 enrolled patients include:
 150 (75%) with diagnosed hypertension
 48 (24%) with elevated BP readings but without diagnosed hypertension
 2 (1%) without a reported assessment of BP status
 16 (8%) with diabetes
 6 (3%) with kidney disease
 19 (10%) with diabetes or kidney disease

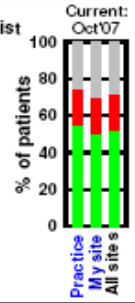
150 patients with diagnosed hypertension include:
 135 without reported diabetes or kidney disease
 12 with diabetes
 5 with kidney disease
 15 with diabetes or kidney disease

1. Demographics and most recent waist circumference in enrolled patients:

	Practice	My site	All sites
Mean age (y)	68.2	69.2	70.2
M:F (%:%)	48:52	46:54	44:56
M: Waist (cm)	110.4	112.4	114.4
F: Waist (cm)	95.2	97.2	99.2

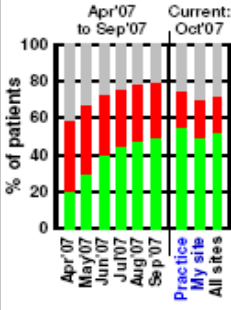
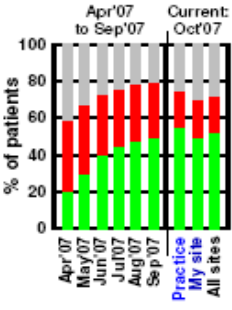
Most recent Waist circumference

- At target (< 102 for M; < 88 for F)
- Not at target (> 102 for M; > 88 for F)
- Not reported (in last 6 mo.)



2a. Most recent Systolic BP readings in patients with diagnosed hypertension and:

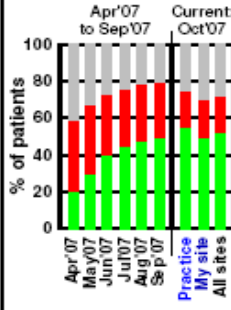
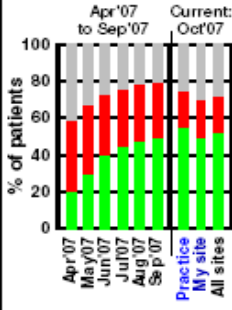
(a) without diabetes or kidney disease (b) with diabetes or kidney disease



Legend: At target (< 140 or < 130), Not at target (> 140 or > 130), Not reported (in last 6 mo.)

2b. Most recent Diastolic BP readings in patients with diagnosed hypertension and:

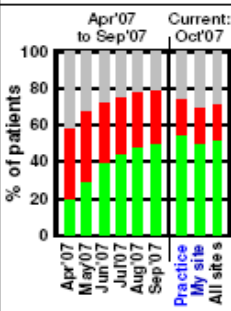
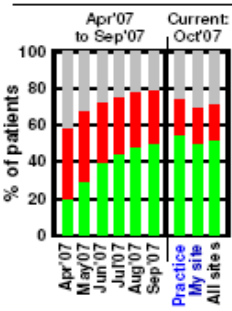
(a) without diabetes or kidney disease (b) with diabetes or kidney disease



Legend: At target (< 90 or < 80), Not at target (> 90 or > 80), Not reported (in last 6 mo.)

3. Most recent TC/HDL results in patients with diagnosed hypertension and:

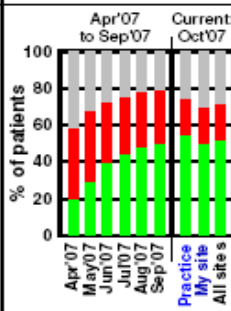
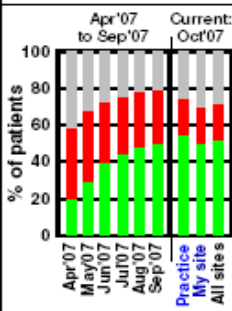
(a) without diabetes (b) with diabetes



Legend: At target (< 4.0), Not at target (> 4.0), Not reported (in last 12 mo.)

4. Most recent A1C results in patients with diabetes and:

(a) without diagnosed hypertension (b) with diagnosed hypertension



Legend: At target (< 7.0), Not at target (> 7.0), Not reported (in last 6 mo.)

Monthly feedback reports are highly effective in improving rates of monitoring and disease control




File

Ontario Biologics Research Initiative: Safety and Effectiveness Study

Site: _____ Patient Number: _____ Patient Initials: AA

STUDY ASSESSMENT FORM
PLEASE FAX TO: 1-888-757-6506



Visit Information:

Date: 24/07/2013 (dd/mm/yyyy)

Form Completed By:

Signature: _____

Baseline Follow-up

Date: 24/07/2013 (dd/mm/yyyy)

University Health Network
Toronto General Hospital • Toronto Western Hospital • Princess Margaret Hospital

Physician Global Assessment of Current Disease Activity:

Not Active At All Extremely Active

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)

Patient Global Assessment of Current Disease Activity:

Not Active At All Extremely Active

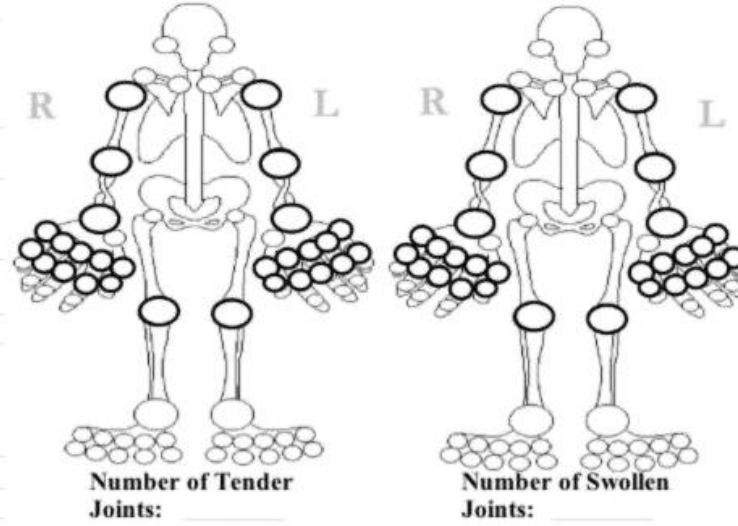
Joint Assessment:

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.

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: _____
- Osteoporosis or Degenerative Arthritis: _____
- Autoimmune Disease:
 - SLE Vasculitis Other: _____
- Cancer: _____

Tender Joint Count	Swollen Joint Count
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► Erosions on X-ray? No Unsure Yes, Year of X-Ray: _____

Discard

Add to Notes

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



What if....



...we could design clinical forms that
were usability tested
(with researchers, policy makers, patients and providers)

met evidence-based clinical requirements and

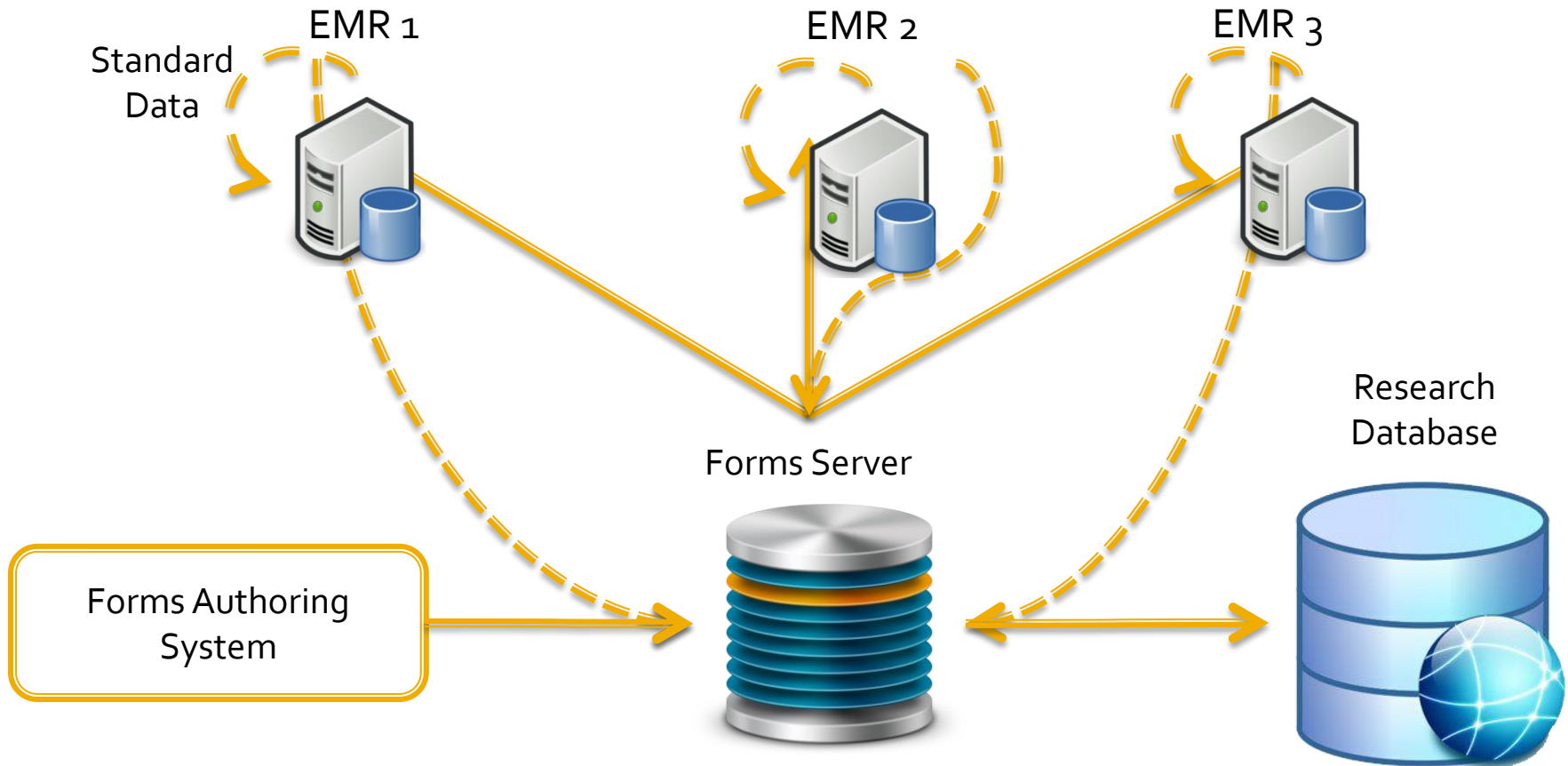
incorporated into EMRs instantly or almost instantly?

Independent of the EMR vendor

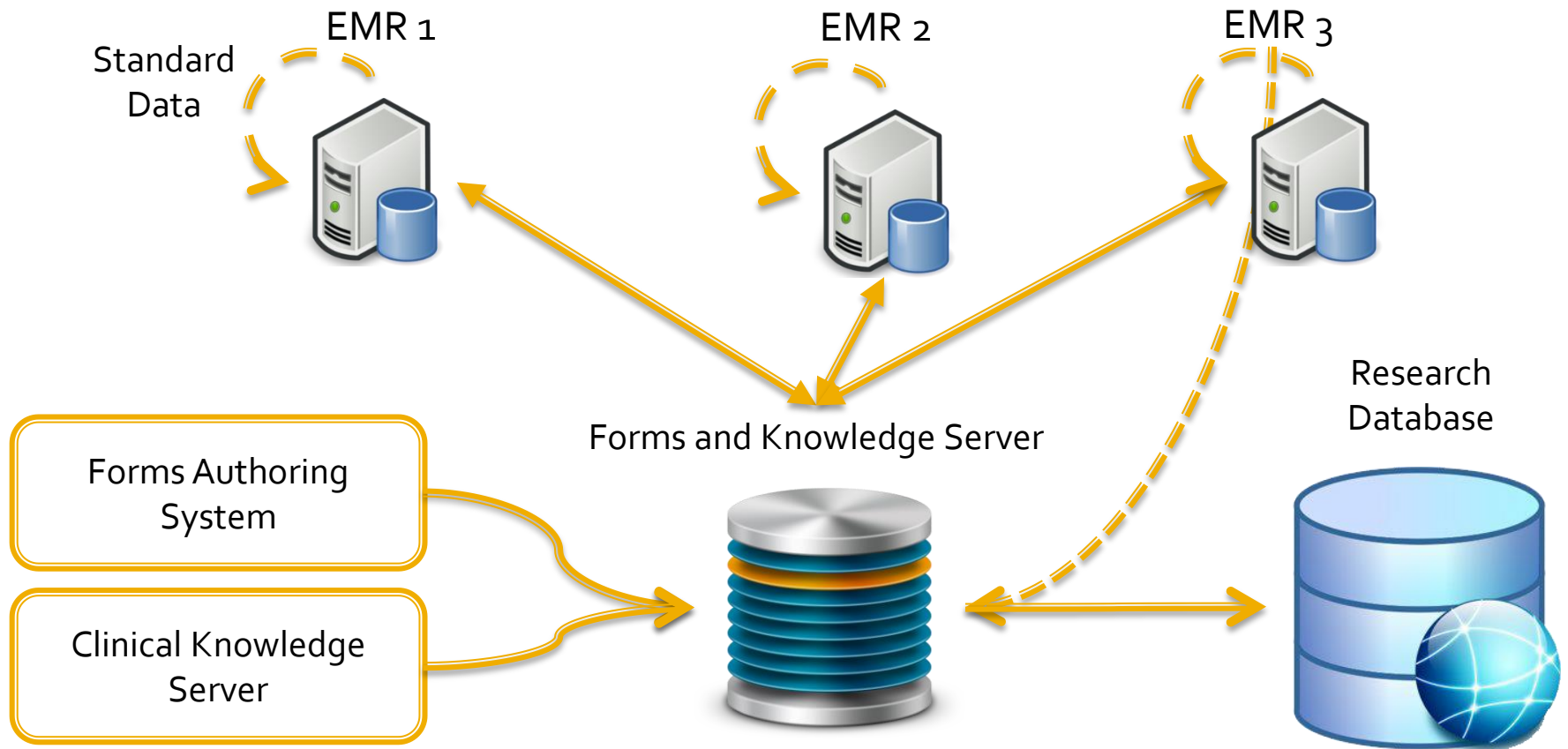
Solution - A Browser Window in Every EMR

- 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



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

Conclusion

- 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

