A Pan-Canadian Core Dataset for Rheumatoid Arthritis
Thursday, October 27th, 2016, 8:00 am-10:00 am
InterContinental Hotel, Montreal

1. GETTING STARTED:
a) Welcome and Introduction
b) Meeting Objectives/Session Overview

Dr. Dianne Mosher
Division Chief of Rheumatology, Department of Medicine, University of Calgary, AB

Session Objectives

A Pan-Canadian Core Clinical Dataset for Rheumatoid Arthritis
■ Review work from the Core Clinical Dataset Models of Care work group. Including an update on testing of the System-Level Performance Measures for IA and expansion of the measurement framework to include provider-level process measures and patient outcomes. This work provides context for the importance of the current project: Development of a Pan-Canadian Core Clinical Dataset for RA ■ Review and discussion of the proposed Pan-Canadian Core Clinical Dataset for RA ■ Provincial examples and discussion of the incorporation of the core clinical dataset into practice

Today's Agenda

Item	Presenter

1. Getting Started
    a) Welcome and introduction
    b) Meeting objectives/session overview
	Dr. Dianne Mosher

2. Context: What do we know and why is it important to clinical practice?
    a) Project background, lessons learned
    b) System Level Performance Measurement Framework update
    c) Provider level key performance indicators: Literature review
	Dr. Claire Barber

3. A Pan-Canadian Core Clinical Dataset for inclusion in a quality measurement framework
    a) Review of proposed core clinical dataset for RA
    b) OBRI/Fig P Core Variable EMR Data Extraction Pilot
	Dr. Claire Barber
	
	Dr. Vandana Ahluwalia

4. Provincial roundtable: Provincial champions share how they will incorporate the core dataset into their practice	**Facilitated by Dr. Michel Zummer**
5. Wrap up and next steps	**Dr. Cheryl Barnabe**

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AAC IA Model of Care Executive Team

Co-Chairs:

1. **Dr. Vandana Ahluwalia**, Vice-President, Canadian Rheumatology Association; Corporate Chief of Rheumatology, William Osler Health System, Brampton, ON

2. **Dr. Dianne Mosher**, Professor of Medicine, Chief Division of Rheumatology, University of Calgary, Calgary, AB

3. **Dr. Michel Zummer**, Chief of Rheumatology, CH Maisonneuve-Rosemont; Associate Professor, Université de Montréal, Montreal, QC
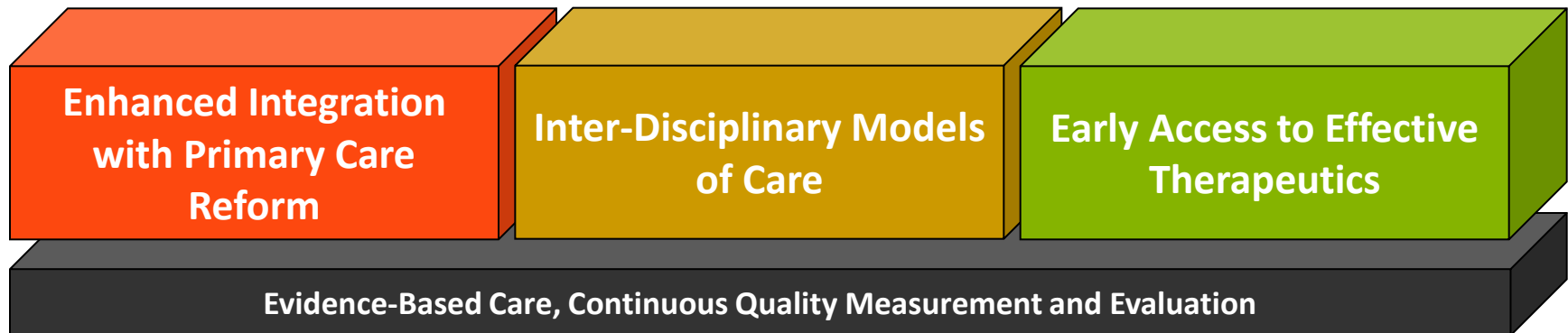
Dr. Claire Barber, Rheumatologist, Division of Rheumatology, University of Calgary, AB

Dr. Cheryl Barnabe, Chair, Access to Care Committee, Canadian Rheumatology Association
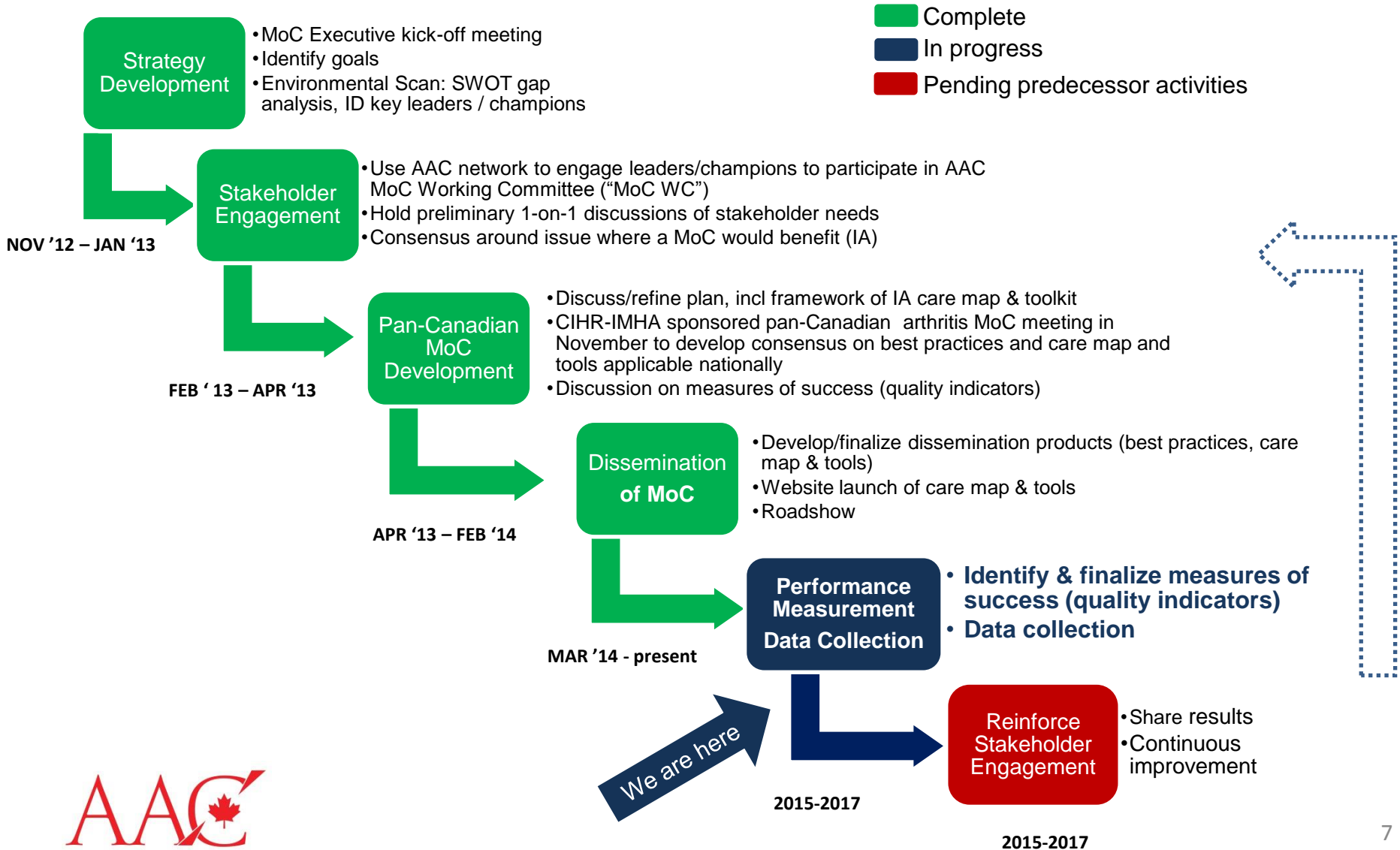
Ms. Anne Lyddiatt, Patient Representative, Ingersoll, ON

Improving Prevention and Care

Access to and Delivery of Care
Models of Care (MoC)

Enhanced Integration with Primary Care Reform

Inter-Disciplinary Models of Care

Early Access to Effective Therapeutics

Evidence-Based Care, Continuous Quality Measurement and Evaluation

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Pan-Canadian IA MOC: Development, Dissemination and Measurement

Strategy Development
- MoC Executive kick-off meeting
- Identify goals
- Environmental Scan: SWOT gap analysis, ID key leaders / champions

Complete (green)
In progress (dark blue)
Pending predecessor activities (red)

NOV '12 – JAN '13

Stakeholder Engagement
- Use AAC network to engage leaders/champions to participate in AAC MoC Working Committee ("MoC WC")
- Hold preliminary 1-on-1 discussions of stakeholder needs
- Consensus around issue where a MoC would benefit (IA)

FEB '13 – APR '13

Pan-Canadian MoC Development
- Discuss/refine plan, incl framework of IA care map & toolkit
- CIHR-IMHA sponsored pan-Canadian arthritis MoC meeting in November to develop consensus on best practices and care map and tools applicable nationally
- Discussion on measures of success (quality indicators)

APR '13 – FEB '14

Dissemination of MoC
- Develop/finalize dissemination products (best practices, care map & tools)
- Website launch of care map & tools
- Roadshow

MAR '14 - present

Performance Measurement Data Collection
- **Identify & finalize measures of success (quality indicators)**
- **Data collection**

We are here

2015-2017

Reinforce Stakeholder Engagement
- Share results
- Continuous improvement

2015-2017

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A Pan-Canadian Approach to Inflammatory Arthritis Models of Care

Purpose

- Establish a framework for the development of high quality models of care that are evidence informed and reinforced by best practices.

Users

- Health policy decision-makers and system planners; rheumatologists, allied health providers and other primary care providers; and, people living with arthritis.

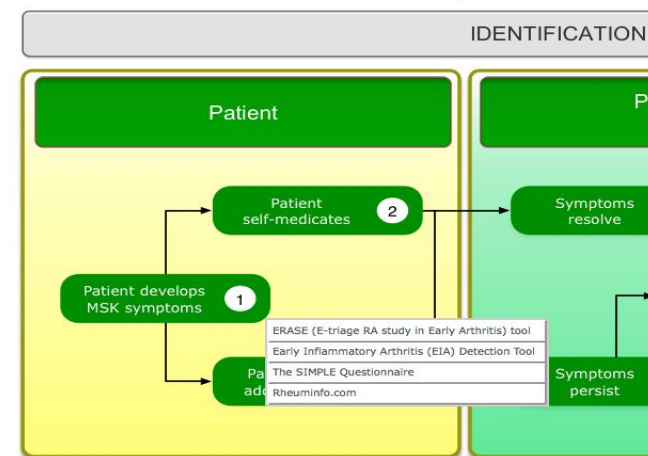A pan-Canadian Approach to Inflammatory Arthritis Models of Care

April, 2014

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Toolkit for Implementation: Standardized IA Care Map

❑ The pan-Canadian report describes the approach to the delivery of care and is accompanied by a drop down menu care map/toolkit for implementation.

❑ The Care Map illustrates the flow of patients through the continuum of care, to ensure the patient has access to the **right** care provider at the **right** time in the care path.
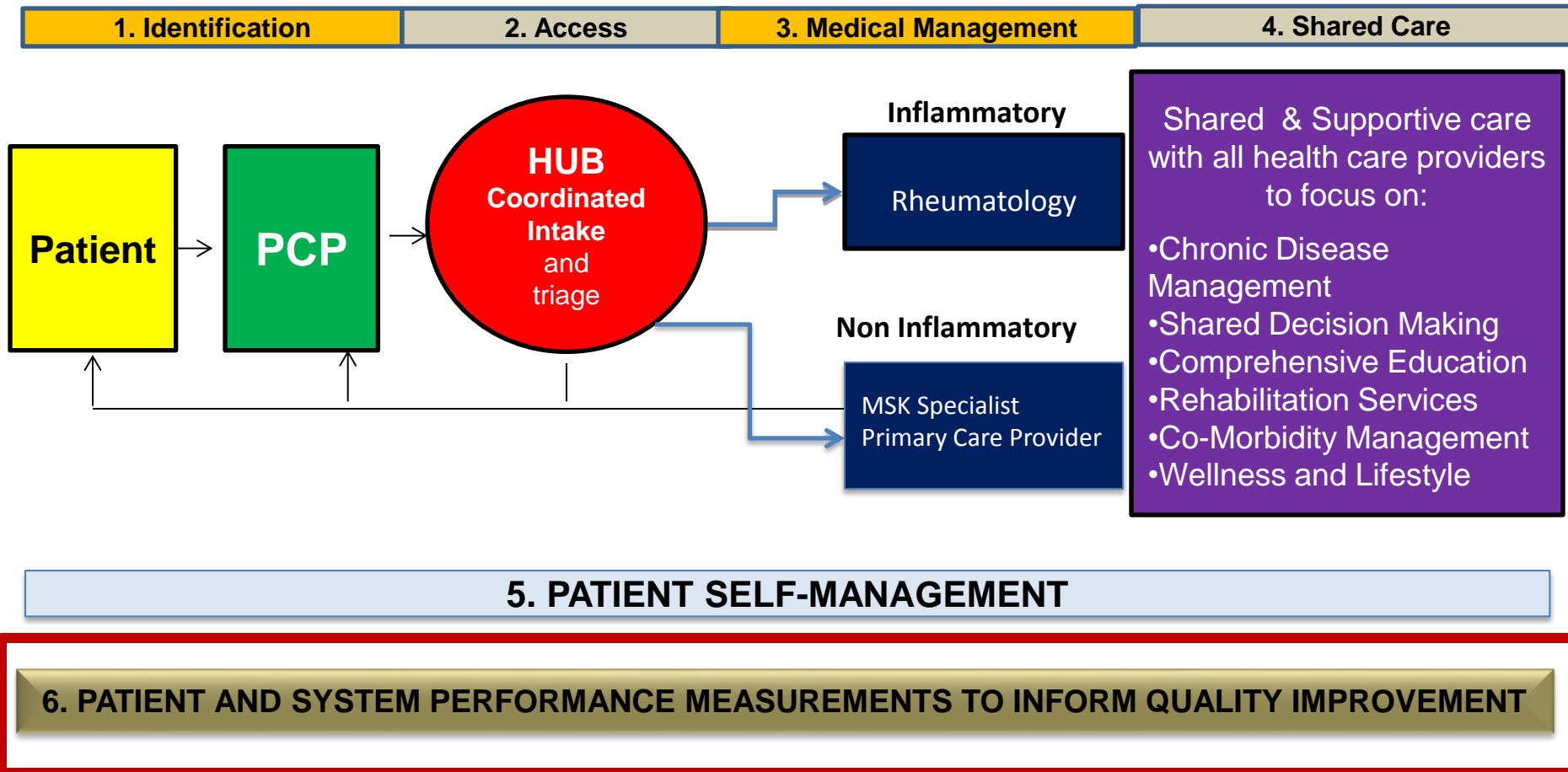
Rheumatoid Arthritis Care Map

Inflammatory Arthritis Care Map

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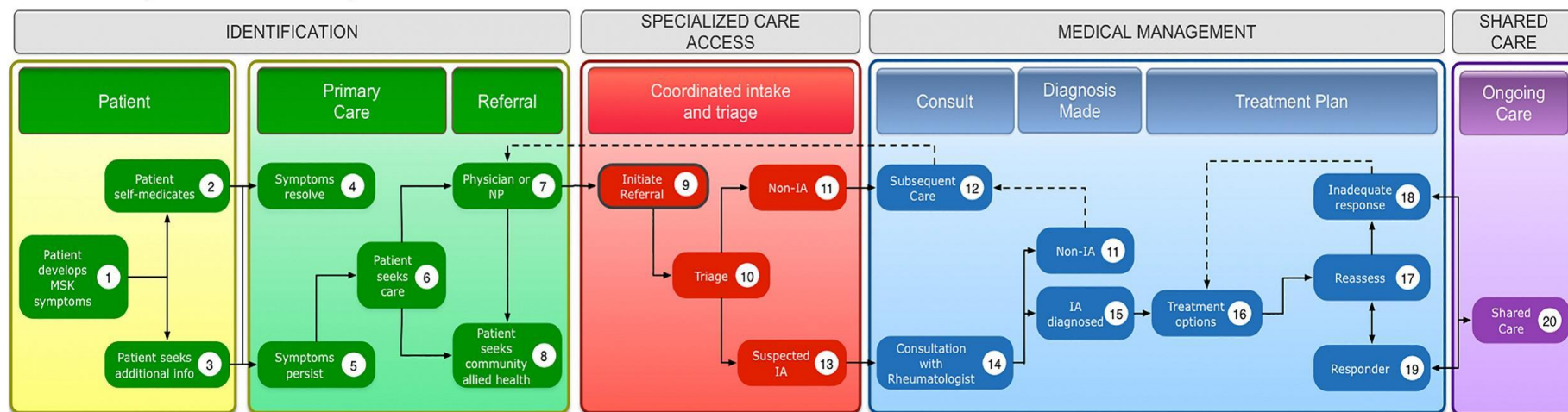
Pan-Canadian Approach to IA MoC: **6 Key Elements**

1. Identification	2. Access	3. Medical Management	4. Shared Care

Patient → **PCP** → **HUB Coordinated Intake and triage**

Inflammatory
Rheumatology

Non Inflammatory
MSK Specialist
Primary Care Provider

Shared & Supportive care with all health care providers to focus on:

- Chronic Disease Management
- Shared Decision Making
- Comprehensive Education
- Rehabilitation Services
- Co-Morbidity Management
- Wellness and Lifestyle

5. PATIENT SELF-MANAGEMENT

6. PATIENT AND SYSTEM PERFORMANCE MEASUREMENTS TO INFORM QUALITY IMPROVEMENT

2. **Context: What do we know and why is it important to clinical practice?**

a) Project background, lessons learned
b) System-Level Performance Measurement update
c) Systematic Review of Provider Level Measures

Dr. Claire Barber
Rheumatologist, Division of Rheumatology,
University of Calgary, AB

Measuring a Model of Care for Inflammatory Arthritis

How many patients are <u>not</u> getting seen?

Are patients are getting to the rheumatology clinic in a <u>timely</u> manner for diagnosis?

Are patients being treated <u>appropriately</u>? Is <u>treatment timely</u> once diagnosis made?

Are patients are getting <u>lost</u> to follow-up?

Identification

Specialized Access

Medical Management

Ongoing care

Patient self Management

WORKFORCE CAPACITY

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Barber et al. J Rheum 43(3):530-40

Testing Performance Measures: Update

- Testing of the measures in 5 provinces (BC, AB, MB, NL, ON) in 11 different arthritis care settings using different data sources (e.g., administrative data, early arthritis cohort, early arthritis clinics, EMR)
- CATCH data analysis nearly complete. To be presented at ACR Nov 16th 9AM (#3137) "Assessing System-Level Performance Measures for Early RA in a Large Multicenter Cross-Country Prospective 8-Year Observational Cohort Study."
- Waiting Time data from 3 centers analyzed and a CRA abstract has been submitted
- Ethics approval at all sites has been obtained, data for administrative analysis obtained at all sites with plans to start analysis shortly

CATCH Data Highlights

See Barber CEH et al. *Arthritis Rheumatol.* 2016; 68 (suppl 10). http://acrabstracts.org/abstract/assessing-system-level-performance-measures-for-early-rheumatoid-arthritis-in-a-large-multicenter-cross-country-prospective-8-year-observational-cohort-study/. Accessed October 20, 2016

Catch Lessons

- Represents "Best-Case" scenario and will be useful for benchmarking

- Delays in referral not captured so waiting times could not be measured

- Decline in follow-up and DMARD use over time need further exploration

- Currently working on different methods of operationalizing measures to avoid confounding by duration of disease

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Waiting Time: Lessons in Feasibility of Measurement

- WTs for RA measured in 5 models of care in 3 provinces for 2014/15

- All sites required chart reviews (even those with triage databases as lacking diagnosis and/or date seen by rheumatologist)

- WTs could not be readily measured in 2 sites that offered self-referral to indigenous communities

- Large regional variations noted in WTs, only one center meeting benchmarks…. Stay tuned.

Abstract submitted to CRA 2017 abstract competition, details to follow

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Measurement Framework Expansion

- Current AAC measurement framework does not capture measures at physician-provider level or patient outcomes

- CIHR grant submitted to develop a balanced scorecard for RA care:

  - Objective to measure and report on RA quality measures for continuous improvement

- First step: Systematic Review to Identify Existing measures

Systematic Review

- See Barber CEH et al. *Arthritis Rheumatol.* 2016; 68 (suppl 10). http://acrabstracts.org/abstract/assessing-system-level-performance-measures-for-early-rheumatoid-arthritis-in-a-large-multicenter-cross-country-prospective-8-year-observational-cohort-study/. Accessed October 20, 2016

Cooper M, Barber CEH. Systematic Review and Appraisal of Quality Measures for Inflammatory Arthritis [abstract]. *Arthritis Rheumatol.* 2016; 68 (suppl 10). http://acrabstracts.org/abstract/systematic-review-and-appraisal-of-quality-measures-for-inflammatory-arthritis/. Accessed October 20, 2016.

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Next Steps: Balanced Scorecard

Determine priorities for quality improvement → **Select measures and targets for scorecard** → **Implement & test scorecard**

STRATEGY

SCORECARD

REPORT

Link to Core Dataset

- Data needed to measure quality of care

- Currently no consistent recommendations about what data to routinely collect on patients for provision of routine care and quality assurance

3. A Pan-Canadian Core Clinical Dataset for Inclusion in a Quality Measurement Framework

a) Review of proposed core clinical dataset for

Dr. Claire Barber
Rheumatologist, Division of Rheumatology,
University of Calgary, AB

A Standardized Pan-Canadian Core Clinical Dataset for Inclusion in a Quality Measurement Framework

The Need

- Utilizing EMR's and existing databases can drive quality improvements in care but data collected is not standardized.

  Also, duplication of data collection for research purposes is costly and a burden on healthcare providers and patients.

The Vision

- A standardized, rheumatology specific core clinical dataset to mitigate variability in data collection and result in high quality data that is comparable between physicians, sites and provinces.

Big data

"Big data"- linked dataset combining sources including administrative data, and EMR data

Comparative effectiveness dataset

Comparative effectiveness dataset for use in registries and trials

Core clinical data for best practices

Core clinical dataset for use in everyday practice
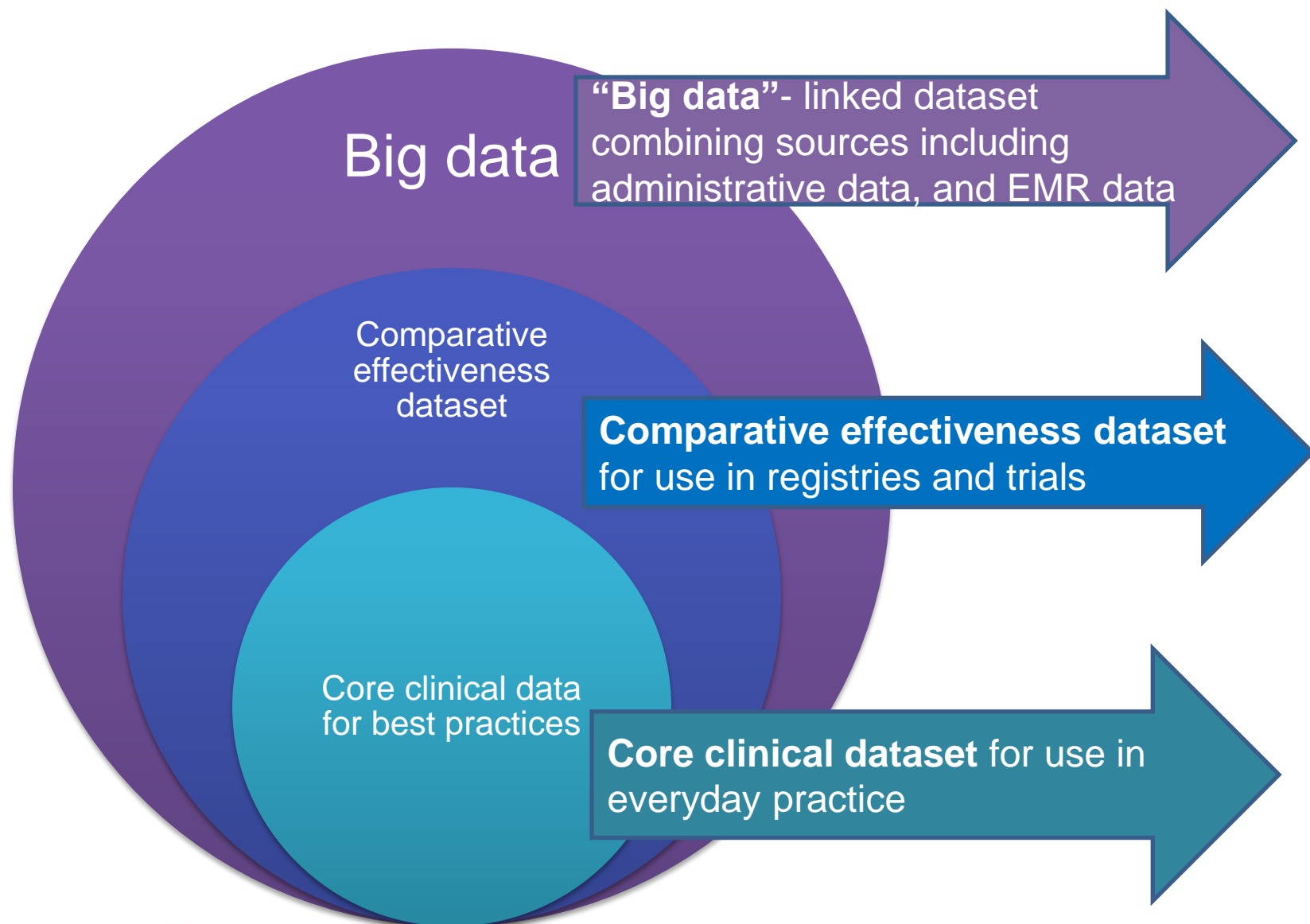
What is a "core dataset"

- **The minimal dataset needed to provide high-quality care for patients with arthritis**
  - Should reflect what is done (or *should* be done) in practice
  - Enhance and facilitate efforts for quality measurement
  - A benefit to research but not the primary reason for collection

Methods Developing a Pan-Canadian Core Clinical Dataset

Meeting 1 **June 26-27, 2015, Calgary**	→	Meeting 2 **October 22, 2015, Kananaskis**	→	Meeting 3 February 17, 2016, Lake Louise	→	Meeting 4 WebEx June/July 2016	→	**Core Dataset Consensus Process: RAND Modified Delphi**

Obtain consensus on the need for a standardized core Canadian rheumatology dataset	Broaden stakeholder engagement	Broaden stakeholder engagement	Review the results of researched elements and further refine the core clinical dataset	3-round Modified Delphi Platform to obtain consensus on the Core Clinical Dataset for RA
Develop project plan	Summarize best practices in quality measurement	Obtain consensus on core clinical dataset elements: 23 elements agreed for inclusion, 14 elements requiring literature review		
	Reviewed the landscape of investigator led cohorts and EMR data collection in Canada			

Delphi

- **Participants asked to rate 2 questions about each element on a Likert scale of 1-9 (1= not important/feasible and 9=very important/feasible)**

- *How important is it to include this element in the core data set for the provision of care and clinical decision making for RA?*

- *How feasible is it to collect this element routinely on patients with RA?*

Core Dataset Next Steps

Manuscript preparation & dissemination

Development of tools for implementation

Implementation & Assessment of impact

AAC Pan-Canadian Core Clinical Dataset Working Group

Dr. Vandana Ahluwalia

Dr. Stephen Aaron

Dr. Antonio Avina-Zubieta

Dr. Claire Barber

Dr. Murray Baron

Dr. Cheryl Barnabe

Dr. Susanne Benseler

Dr. Louis Bessette

Dr. Claire Bombardier

Ms. Jennifer Burt

Dr. Denis Choquette

Dr. Vinod Chandran

Dr. Alex Charlton

Dr. Mathew Cooper

Ms. Sandra Couto

Ms. Andrea Emrick

Dr. Stephen Edworthy

Dr. Hani El-Gabalawy

Dr. Jaime Guzman

Dr. Jill Hall

Dr. Linda Hiraki

Dr. Joanne Homik

Dr. Steven Katz

Dr. Stephanie Keeling

Dr. Jason Kur

Dr. Dianne Lacaille

Dr. Deborah Levy

Ms. Anne Lyddiatt

Ms. Terri Lupton

Dr. Deborah Marshall

Dr. Dianne Mosher

Dr. Bindu Nair

Dr. Sylvie Ouellette

Dr. Namneet Sandhu

Ms. Orit Schieir

Dr. Evelyn Sutton

Dr. Regina Taylor-Gjevre

Dr. Carter Thorne

Dr. Marinka Twilt

Dr. John Woolcott

Dr. Michel Zummer

b) OBRI/Fig P Core Variable EMR Data Extraction Pilot

Dr. Vandana Ahluwalia
On behalf of the OBRI Investigators and Dr. Claire Bombardier
Corporate Chief of Rheumatology, William Osler Health System, Brampton, ON

OBRI /Fig P
Core Variable EMR Data Extraction Pilot

Dr. Vandana Ahluwalia

AAC Annual Conference

October 27 2016

Created in 2008, the OBRI is a collaboration of stakeholders, representing rheumatologists, patients, researchers, payers.

The OBRI focused on improving the quality of care and clinical outcomes of patients living with Rheumatoid Arthritis by gathering long-term information on the therapies used in daily clinical practice

OBRI platform

Rheumatoid Arthritis

Ankylosing Spondylitis

Psoriatic Arthritis

Pregnancy

OBRI
ONTARIO BEST PRACTICES RESEARCH INITIATIVE
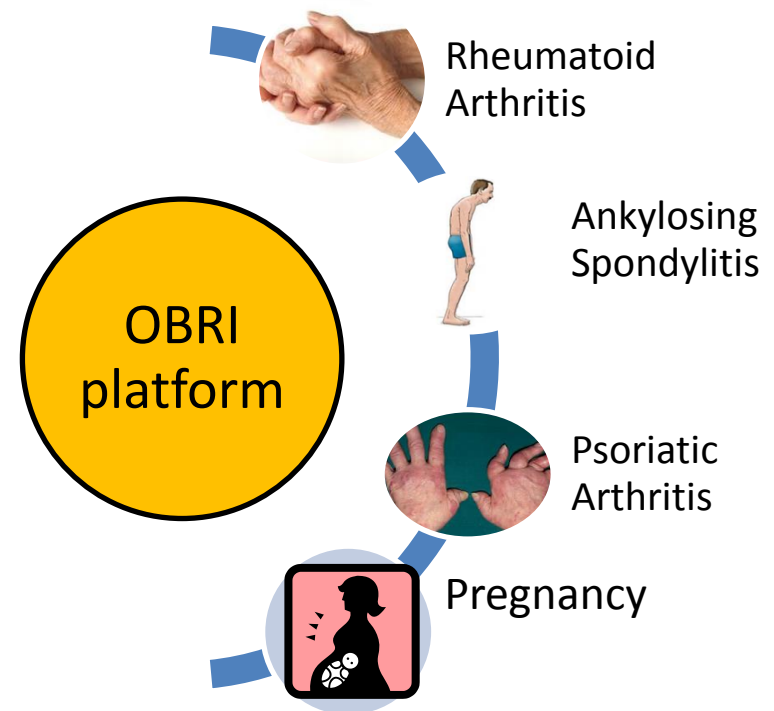
We are linking real-world data

CLINICAL COHORT

PHYSICIAN REPORTED

- Personal Health Information
- RA History
- Previous RA medications
- Physician Global Assessment
- Patient Global Assessment
- Co-morbidities
- Serious Events
- Laboratory (ESR, CRP)
- Tender Joint Count
- Swollen Joint Count
- Erosions
- Current RA Medications

PATIENT REPORTED

- Demographics
- RA History
- Previous Anti-rheumatic Medications
- Current Medication
- HAQ / RADAI
- Patient Global Assessment/Q of L
- Fatigue And Sleep
- Socio-economic Status
- Work Productivity
- Serious Events / Tuberculosis
- Pregnancy
- Pharmacy/Labs/Imaging

ADMINISTRATIVE DATABASE LINKAGE*

Lifelong

SERIOUS ADVERSE EVENTS

- Fatal
- Life-threatening
- Hospital stay
- Significant disability
- Congenital anomaly
- Serious Infections
- Congestive heart failure
- Central Demyelination
- Aplastic anemia
- Lymphoporliferative tumors
- Autoimmune disease
- Hepatoxicity death

HEALTH SERVICES USED

- Drug information
- Physician claims
- Diagnostic tests
- Patient demographics
- Hospitalizations
- Cancer registry
- Home Care service use

investigators

patients

32

Participating Investigators (RA)

Dr. Vandana Ahluwalia
Dr. Zareen Ahmad
Dr. Pooneh Akhavan
Dr. Lori Albert
Dr. Catherine Alderdice
Dr. Michael Aubrey
Dr. Sangeeta Bajaj
Dr. Bill Bensen
Dr. Claire Bombardier
Dr. Arthur Bookman
Dr. Doreen Campbell
Dr. Simon Carette
Dr. Raj Carmona
Dr. Dana Cohen
Dr. Patricia Ciaschini
Dr. Alf Cividino
Dr. Andrew Chow
Dr. Sanjay Dixit
Dr. Darek Haaland
Dr. Brian Hanna
Dr. Nigil Haroon

Dr. Jackie Hochman
Dr. Anna Jaroszynska
Dr. Sindu Johnson
Dr. Raman Joshi
Dr. Allan Kagal
Dr. Arthur Karasik
Dr. Jacob Karsh
Dr. Nader Khalidi
Dr. Ed Keystone
Dr. Bindee Kuriya
Dr. Maggie Larche
Dr. Arthur Lau
Dr. Nicole Leriche
Dr. Felix Leung
Dr. Frances Leung
Dr. Dharni Mahendra
Dr. Mark Matsos
Dr. Heather McDonald Blumer
Dr. Shikha Mittoo
Dr. Ami Mody
Dr. Angela Montgomery

Dr. Manisha Mulgund
Dr. Edward Ng
Dr. Erin Norris
Dr. Tripti Papneja
Dr. Viktoria Pavlova
Dr. Louise Perlin
Dr. Janet Pope
Dr. Jane Purvis
Dr. Gina Rohekar
Dr. Sherri Rohekar
Dr. Lawrence Rubin
Dr. Nooshin Samadi
Dr. Saeed Shaikh
Dr. Ali Shickh
Dr. Rachel Shupak
Dr. Elaine Soucy
Dr. Doug Smith
Dr. Jonathan Stein
Dr. Andy Thompson
Dr. Carter Thorne
Dr. Sharon Wilkinson

Ontario Rheumatologists have adopted EMRs

Paper chart

EMR chart
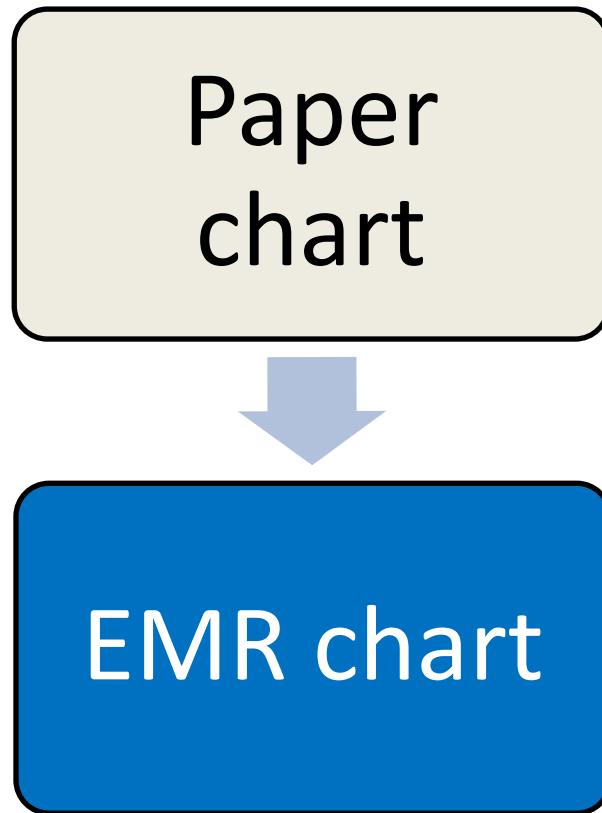
Over **93%** of community
Rheumatologists
in Ontario are using EMR
Highest among specialty groups
Supported by OMD and the ORA

Academic rheumatologists
pending EMR selection by their hospitals

2015

Evolution of OBRI Data Collection

Phase I – Paper CRFs

Phase II - Paper CRFs embedded into Physician's EMR platforms

Phase III- pilot . Working towards seamless data extraction

Can we seamlessly extract clinical data from Ontario Rheumatology EMRs?
(a self- funded leadership initiative)

EMRs

EMR Physician Analytics

Dashboards
Reports
Versioning

Databases & Registries

Practice tool for Quality Improvement

Aggregated Real world data for Research
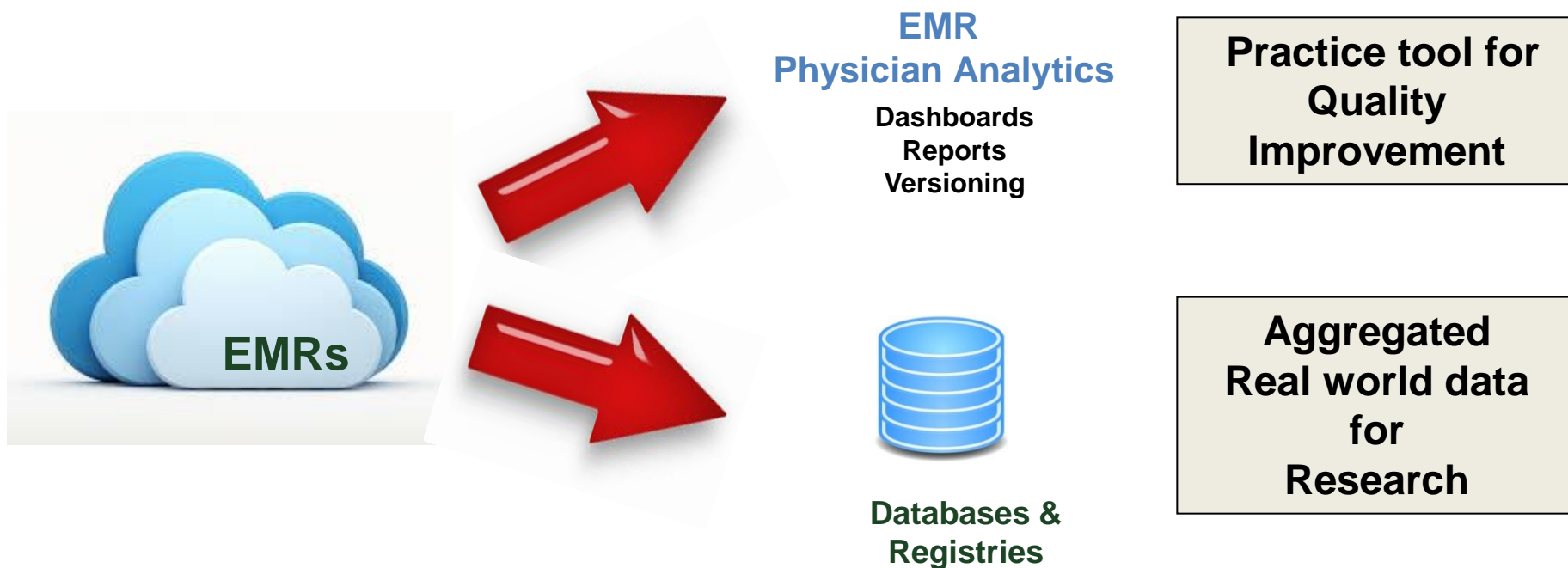
Rationale for EMR Pilot

❖ The OBRI took a leadership role to explore how clinical data could be extracted from clinicians EMRs seamlessly and for meaningful use – for both quality improvement and research purposes

To **Develop a secure central repository web based platform**

1 **Development**
Design, develop and validate by pilot-testing an automated, secure, and scalable data fetch and transfer process for OBRI participants

3
- **Retrieval by OBRI**
- For OBRI staff to securely retrieve data batches

2
- **Central Repository**
- Directly complete or edit data in the central repository (by EMR participants)
- Directly enter and submit data to the central repository (by non-EMR participants)

4
- **Review by Users**
- Overview participant's accumulating registry data (dashboards)

OBRI's EMR Project Partnerships

FIG P
Serving the specialized Data Management needs of Clinicians and Scientists since 1988

ORA-
Representing Ontario Rheumatologists and focused on Arthritis care in Ontario through Leadership, Advocacy, Education and Communications

Pilot Participants

EMR Pilot Dec 2015- October 2016

Data extraction Accuro	Data Extraction EPIC	Web based
• Dr. Vandana Ahluwalia • Dr. Carter Thorne • Dr. Derek Haaland • Dr. Art Karasik	• Women's College (EPIC)	• Ottawa General Hospital and non-EMR sites
Completed	**On HOLD**	**Pending Ethics**

Oscar and Telus PS in Phase 2

OBRI Data Variables

CLINICAL OUTCOME DATA (collected by MD)	PERSONAL HEALTH INFORMATION	INTERVIEW DATA
TJC **SJC** **Patient Global** **MD Global** **ESR** **CRP** **RA Medication Names** **RA Medication Start/Stop Dates**	**Name** **Gender** **Date of Birth** **Telephone Number** **Address** **OHIP Number**	HAQ RADAI RA Medication Names RA Medication Start/Stop Dates Previous RA Medications Co-morbidities Work Productivity Socioeconomic Status

The data variables that were included in the EMR pilot

Data extraction Project

- FigP identified OBRI participants in EMRs

- The results were compared to what is currently available at OBRI

- Data extraction was based on the 3 OBRI case report forms:

  1. Enrollment

  2. Assessment

  3. Medication

Results: **Enrollment Form**

Table 2. Agreement Between Fig.P Extracted Data and OBRI Data, by Site

Variable	Site 1 (n = 35)	Site 2 (n = 21)	Site 3 (n = 13)	Site 4 (n = 38)
Health Card No.	97%	100%	100%	97%
Anti-CPP	40%	19%		34%
Rheumatoid Factor	43%	52%		45%
RA Duration (yr of diagnosis)	27%	0		5%

Results: **Assessment Forms**

Table 3. Agreement Between Fig.P Extracted Data and OBRI Data, by Site

Variable	Site 1 (n = 705)	Site 2 (n = 395)	Site 3 (n = 83)	Site 4 (n = 95)
Physician Global	93%	63%		34%
Patient Global	82%	58%		35%
Total Tender Joints	94%	56%		90%
Total Swollen Joints	94%	65%		85%
ESR Value	87%	72%		54%
CRP Value	78%	67%		48%

Summary of Data Extraction

Data Domain	Results	Notes
Demographics	☑	
OBRI "active" patients	☑	Need for site training for consistent standardize
Visit dates	☑	
Medical history / co- morbidities	☑	Dates cannot be extracted Need for site training to populate in CPP
Lab results: RF, anti-CCP, ESR, CRP	☑	Need for site training to populate in CPP(Rf, anti- ccp)
Physical findings / Standard scores: 28-TJC, 28-SJC, Pt GA, MD GA	☑	No joints can be extracted individually Need for site training to populate in CPP(globals)
X-ray results: re: Erosions	☑	Dates cannot be extracted Need for site training to populate in CPP
Medications: Prescribed / Started, Discontinued / Stopped	☑ "DMARDs": Name "Current Rheum Meds": Name "Rx meds": Name Name only	Need for site training to retrieve start, stop dates

Collaborations & Partnerships

- Work with OMD and EMR vendors to improved extraction of   medications
- Leverage the work of the Arthritis Alliance of Canada to identify a minimum clinical core data set for extraction
- Partner with ORA to create messaging and advocacy for meaningful use of EMR data
  1. Benefits of seamless data extraction for members
  2. Tools/guides to expedite population of members' CPP – this way data can be easily extracted from EMR
  3. Quality Improvement and Dashboards for members – individual vs cohort
  4. Source of real world data for payers and the pan- Canadian Pharmaceutical Alliance

Next steps

- Expand data extraction work for OBRI Investigators that use Oscar or Telus-PS EMRs

- Direct non EMR sites to use Web based interface

- Develop rheumatology dashboards

- Explore new funding model

4. **PROVINCIAL ROUNDTABLE**
Provincial champions share how they will incorporate the core dataset into their practice

Dr. Michel Zummer

Division Chief of Rheumatology, CH Maisonneuve-Rosemont, Associate Professor, Université de Montréal, QC

Provincial Model of Care champions

5. WRAP UP AND NEXT STEPS

Dr. Cheryl Barnabe
Associate Professor, Departments of
Medicine and Community Health Sciences,
University of Calgary
Rheumatologist, Alberta Health Services

A Pan-Canadian Core Clinical Dataset – **next steps**

Phase 1: Environmental scan – complete ✔
Assess the current status of data collection in Canada

Phase 2: Development of a Canadian core dataset - in progress
Generate a core clinical dataset for rheumatology

Phase 3: Systematic Review of Quality Measures in IA -complete ✔
Conduct a systematic review of quality measures in IA

Phase 4: Patient engagement-ongoing
Ensure variables important to patients are included in the dataset and framework.

Phase 5: Mapping of dataset variables and core clinical datasets
(clinic and research)

Phase: 6 Consensus complete-complete ✔
A 3 round modified Delphi will review any areas of debate to achieve consensus on the dataset.

Phase 7: Development of tools for implementation and dissemination of the program
Create tools for implementation of the common dataset for effective knowledge translation.

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End of Session

If you have any questions or would like to follow-up on any topic on today's agenda, please contact Jaime Coish at jcoish@arthritisalliance.ca or
visit our website www.arthritisalliance.ca

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