



SHAPING THE FUTURE OF ARTHRITIS CARE

OBRI ANNUAL REPORT 2015



OBRI

ONTARIO
BEST PRACTICES
RESEARCH INITIATIVE



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MESSAGE FROM OUR PRINCIPAL INVESTIGATOR



The Ontario Best Practices Research Initiative (OBRI) was formed in 2005 through collaborative efforts between rheumatologists, payers, researchers and patients to monitor the safety and effectiveness of treatments for people living with Rheumatoid Arthritis (RA). Since its inception, OBRI's clinical cohort has grown to include more than 3,000 RA patients and 64 rheumatologists across Ontario.

OBRI's unique platform integrates clinical data from rheumatologists, patient-reported data from participants, and administrative data from the Institute for Clinical Evaluative Sciences (ICES) to monitor drug safety and efficacy, and patient quality of care. Our research priorities include the examination of **pharmacotherapy** (safety and efficacy), **clinical outcomes and practice patterns** (clinical measures, quality indicators, practice guidelines), and **population health** (epidemiology, models of care, economics).

2015 has been an exciting year at OBRI – we expanded our clinical registry to include Spondyloarthritis, grew our RA clinical cohort, held numerous Patient Information Sessions, and developed a research working group focused on pregnancy-related outcomes. We also presented research at a number of national and international scientific meetings and worked closely with our Patient Advisory Committee and Clinical Advisory Committee to advance our research initiatives.

This report provides an overview of our activities in 2015. For up to date information, news, and details on current presentations and publications, please visit our website: www.obri.ca. We look forward to another busy and productive year!

A handwritten signature in black ink, appearing to read 'C Bombardier', written in a cursive style.

Dr. Claire Bombardier, OBRI Principal Investigator



ABOUT OBRI

Who We Are

The Ontario Best Practices Research Initiative (OBRI) is a clinical cohort linked to administrative data where patients are followed in routine care along their clinical path. It is a collaborative research platform involving rheumatologists, researchers, and patients who are working together to improve the treatment outcomes of Ontarians living with RA. Originally created as the Ontario Biologics Research Initiative, the OBRI was officially renamed in 2013 to reflect the expansion of the organization's research goals beyond the scope of biologic treatments.

Our Mission

To improve the care and health outcomes for Rheumatoid Arthritis (RA) patients by gathering long-term information on therapies, clinical practice patterns, and health care utilization in the real world. Our goals are to:

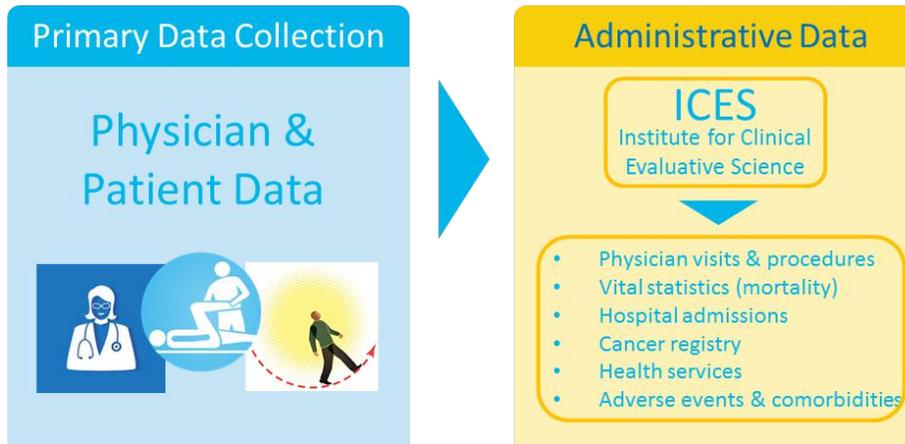
1. Define safety, effectiveness, and sustainability of available RA therapies
2. Identify clinical practice patterns that improve patient health outcomes
3. Use clinical and economic data to inform efficient health care decisions

What We Do

The OBRI generates outcome data specifically related to pharmacotherapy, health system efficiencies, clinical outcomes, and practice patterns. OBRI is dedicated to working with clinicians, patients, government, industry, and the scientific community to gather and analyze high-quality data on the safety and effectiveness of RA treatments for the improvement of patient health care outcomes. The OBRI team also provides leadership in best practices for ethics and electronic consent, data management, and administrative database validations.

Our Data Linkages

The OBRI clinical data is linked to provincial administrative databases held by the Institute for Clinical Evaluative Sciences (ICES). The administrative databases include: physician visits and procedures, vital statistics, hospital admissions, cancer registry, health service utilization, adverse events, and comorbidities.



Technology and evidence informed guidelines are being used to examine clinical outcomes, quality of care, and practice patterns leading to health system innovations through initiatives addressing models of care, epidemiology, and health economics.



2015 IN REVIEW

The OBRI continues to make the dissemination of research outcomes a focal priority.

In 2015, OBRI expanded its clinical registry to include Spondyloarthritides, developed a research working group focused on pregnancy-related outcomes, and hosted numerous Patient Information Sessions. Research outcomes were presented at a number of National and International Annual Scientific Meetings including the Canadian Rheumatology Association (CRA) meeting in Quebec City, the European League Against Rheumatism (EULAR) meeting in Rome, and the American College of Rheumatology (ACR) meeting in San Francisco. In 2015 we also hosted our Annual Research Day for researchers, rheumatologists, patients, and stakeholders, and worked closely with our Patient Advisory Committee and Clinical Advisory Committee to exchange expertise, engage with patients, communicate research outcomes, and advance research activities. Currently, 64 Ontario rheumatologists and over 3,000 patients living with RA participate in the OBRI.

Recruitment Activity (as of Dec. 31st, 2015)

	RA Cohort N (%)	SpA Pilot N (%)
Patients referred to OBRI	3664 (100.0)	177 (100.0)
Patients refused*	495 (13.5)	16 (9.0)
Patients with consent pending	25 (0.7)	8 (4.5)
Patients consented	3144 (85.8)	153 (86.4)
ICES linkage	3127 (99.5)	153 (100.0)
Interviewer data	3008 (95.7)	144 (94.1)
Physician data	3075 (97.8)	153 (100.0)
Withdrawals	207 (6.6)	0 (0.0)
Patients lost to follow-up*	64 (2.0)	0 (0.0)
Patients deceased	92 (2.9)	0 (0.0)
Patients who have completed:		
1 year follow-up	2646 (84.2)	n/a
2 year follow-up	2214 (70.4)	n/a
3 year follow-up	1804 (57.9)	n/a
4 year follow-up	1260 (40.1)	n/a
5 year follow-up	670 (21.3)	n/a

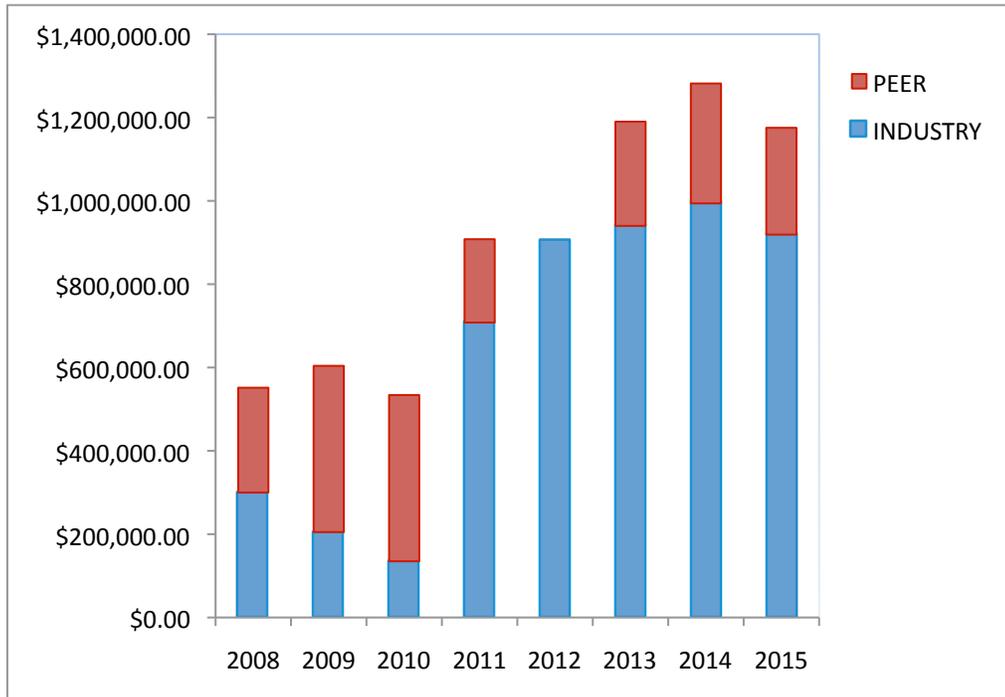
* Interviewer not able to contact patient for ≥ 18 months AND no physician reported data has been received for ≥ 18 months

Financial Report

OBRI's main source of revenue comes in the form of sponsorship, however peer-reviewed funding has been awarded to OBRI to support specific research activities.

In 2015 OBRI expanded its industry partner collaboration, receiving sponsorship from 11 industry partners.

OBRI Funding Revenue

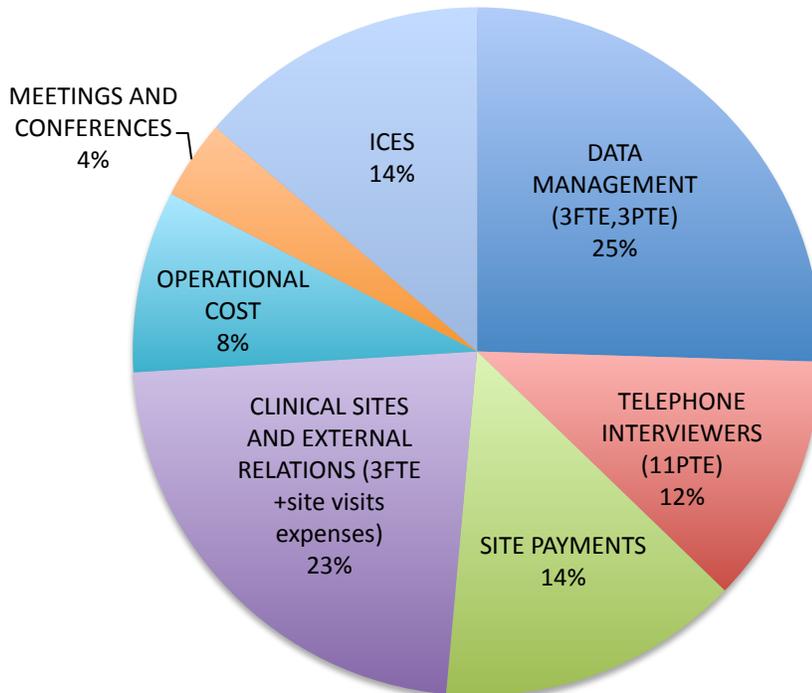


OBRI Expenditures

OBRI expenditures in the 2014/2015 fiscal year totaled \$ 1,321,000. Data Management costs were the highest expenditure (25%) followed by expenditure on clinical sites and external relations (23%), site payments (14%), ICES payments (14%), telephone interviews (12%), operational costs (8%), and meetings and conferences (4%).

Expenditures

Fiscal Year April 2014 - March 2015



Tiered Sponsorship Plan

To date, the OBRI has been granted peer-reviewed funding from organizations such as the Canadian Institutes for Health Research (CIHR) and the Ministry of Health and Long Term Care (MOHLTC) to support piloting activities which began in 2008.

The OBRI has also worked collaboratively with industry partners since its inception and has secured financial support that has enhanced its ability to fulfill its mission. In order to ensure that OBRI continues to engage in sound relationships that enhance the value of its research platform, a new Corporate Sponsorship Framework was developed in 2015 with specific funding levels and respective offerings within each sponsorship level. This new framework was created to facilitate engagement with all pharmaceutical partners interested in collaborating with the OBRI.

Level 1: LEADER

Pharmaceutical companies with an established leadership presence in the arthritis marketplace (>3 years) are invited to participate at a **Leader Level**.

Level 2: PARTNER

Pharmaceutical companies with a growing presence in the arthritis marketplace (<3 years) are invited to participate at a **Partner Level**.

Level 3: COLLABORATOR

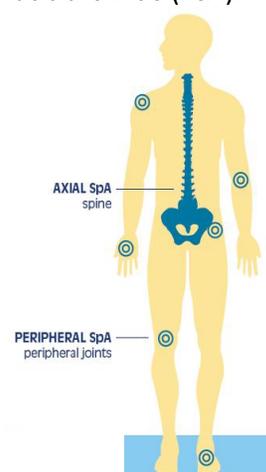
To accommodate for more limited budgets, the OBRI has created a new level of sponsorship for companies that are either in a pre-launch phase or have recently launched a new molecule to market within the last 6-12 months. This new level of sponsorship is intended for companies who are interested in working with the OBRI but may have a limited budget for a given period of time.

New Initiatives

Spondyloarthritis Expansion

The Spondyloarthritides (SpA) are a group of inflammatory arthritides that affect 0.5-1% of the population. SpA represents a major burden on society due to its high prevalence, propensity to affect young adults, and the need for lifelong treatment. The most common clinical subsets of SpA are ankylosing spondylitis (AS) and psoriatic arthritis (PsA).

Current challenges in SpA include delay in diagnosis, inability to predict disease course and disease severity, and marked heterogeneity in clinical progression and treatment response. A tailored approach to treatment based on disease severity and long term functional and economic impact is not the norm. Data on disease spectrum, activity and severity, functional and economic impact, as well as drug effectiveness and safety in patients with SpA seen in community-based settings are limited. There is also limited data on whether tight control of disease leads to better long-term outcomes.



In order to determine 'real world' disease spectrum, management, and impact of SpA in Canada and to provide valid comparisons to patients with RA, we have expanded the OBRI to include SpA patients. Our aim is to recruit 840 patients living with SpA over a period of 2 years from 12 community-based rheumatology practices across Ontario. To date, over 150 patients have been recruited from 11 rheumatology sites. The SpA initiative is led by Dr. Vinod Chandran.

Research Pilot with JSS Medical Research

To support the work of our Clinical Advisory Committee (CAC), OBRI has partnered with JSS Medical Research to advance investigator-led research questions as part of a new pilot initiative. Researchers from OBRI, JSS, and the OBRI CAC have been working closely to advance research questions using OBRI data. We are excited about this new partnership and look forward to sharing outcomes with you in 2016.

Meetings & Conferences Attended

- EULAR Registers and Observational Drug Studies (RODS) Annual Meeting, Prague, Czech Republic. Dec. 7-8, 2015
- American College of Rheumatology (ACR) Annual Scientific Meeting, San Francisco, CA, USA. Nov 7-11, 2015
- CIHR Institute for Musculoskeletal Health and Arthritis (IMHA) Annual Meeting, Calgary, AB. Oct. 22-23, 2015
- 5th Abu Dhabi Advanced Rheumatology Review Course (ADARRC), Abu Dhabi, United Arab Emirates. Oct. 17-19, 2015
- Toronto General Research Institute (TGRI) Annual Research Day, Toronto, ON. Sep 18, 2015
- European League Against Rheumatism (EULAR) Annual Scientific Meeting, Rome, Italy. Jun 10-13, 2015
- Ontario Rheumatology Association (ORA) Annual Meeting, Minnett, ON. May 22-24, 2015
- 3rd World Congress on Controversies, Debates & Consensus in Bone, Muscle & Joint Diseases (BMJD) Meeting. Montreal, QC. April 25, 2015

Patient Advisory Committee (PAC)

The OBRI Patient Advisory Committee (PAC) is a volunteer-led committee comprised of patient representatives. Its role is to represent and communicate patient perspectives to OBRI staff, investigators and stakeholders; and motivate and engage patients through education, knowledge transfer, and ongoing communication.

Accomplishments in 2015 include:

- The production of an annual patient newsletter to keep patients informed about OBRI research, news, and events
- The co-facilitation of three 2015 OBRI Patient Information Sessions in Barrie, Hamilton, and Sault Ste. Marie to communicate OBRI research activities and identify patient research priorities
- The development of plain-language summaries to communicate OBRI research findings to patients
- The provision of ongoing support/direction to OBRI team related to project development, expansion, recruitment, and dissemination

Patient Advisory Committee:

- Catherine Hofstetter
- Jennifer Boyle
- Anne Lyddiatt
- Michael Mallinson
- Nancy Roper
- Denis Morrice
- Attia Qamar
- Christine Fyfe



Clinical Advisory Committee (CAC)

OBRI has received an influx of research questions from its stakeholder groups over the past few years. In an effort to support growing research demands, a new working group comprised of OBRI rheumatologists has been established to lead and manage the completion of research questions from the clinical cohort.

This Clinical Advisory Committee (CAC) provides leadership with the development and investigation of clinically-relevant research questions. In 2015, members worked closely with OBRI staff and JSS Medical Research to explore new research questions in rheumatology care.

Clinical Advisory Committee:

- Dr. Vandana Ahluwalia
- Dr. Edward Keystone
- Dr. Janet Pope
- Dr. Carter Thorne
- Dr. Claire Bombardier
- Dr. Vinod Chandran



OBRI Investigators

Dr. Vandana Ahluwalia*	Dr. Jackie Hochman	Dr. Manisha Mulgund*
Dr. Zareen Ahmad	Dr. Anna Jaroszynska	Dr. Edward Ng
Dr. Pooneh Akhavan	Dr. Sindhu Johnson	Dr. Tripti Papneja
Dr. Lori Albert	Dr. Raman Joshi	Dr. Viktoria Pavlova
Dr. Catherine Alderdice	Dr. Allan Kagal	Dr. Louise Perlin
Dr. Michael Aubrey	Dr. Arthur Karasik*	Dr. Janet Pope
Dr. Henry Aaverns**	Dr. Jacob Karsh	Dr. Jane Purvis
Dr. Sangeeta Bajaj	Dr. Edward Keystone	Dr. Gina Rohekar
Dr. William Bensen*	Dr. Nader Khalidi	Dr. Sherri Rohekar
Dr. Sankalp Bhavsar	Dr. Imtiaz Khan**	Dr. Thanu Ruban
Dr. Claire Bombardier	Dr. Bindee Kuriya	Dr. Nooshin Samadi
Dr. Arthur Bookman	Dr. Margaret Larché	Dr. Saeed Shaikh
Dr. Simon Carette	Dr. Arthur Lau*	Dr. Ali Shickh
Dr. Raj Carmona	Dr. Nicole Le Riche***	Dr. Rachel Shupak
Dr. Andrew Chow*	Dr. Felix Leung	Dr. Doug Smith
Dr. Patricia Ciaschini*	Dr. Frances Leung	Dr. Elaine Soucy
Dr. Alfred Cividino	Dr. Dharini Mahendira	Dr. Jonathan Stein
Dr. Dana Cohen	Dr. Mark Matsos	Dr. Andy Thomspen
Dr. Sanjay Dixit*	Dr. Heather McDonald-Blumer	Dr. Carter Thorne*
Dr. Derek Haaland*	Dr. Shikha Mittoo	Dr. Sharon Wilkinson***
Dr. Brian Hanna	Dr. Ami Mody	
Dr. Nigil Haroon	Dr. Angela Montgomery	

* RA & SpA
** SpA
*** Retired

OBRI Interviewers

- Andrea McClintock
- Janet Money
- Colleen Perrin
- Joanne Kennedy
- Sharon Szwarych
- Lindsey Tashlin
- Matthew Hayes
- Linda Rosengarten
- Lynda Linderman
- Lisa Guerin
- Gail Walker

OBRI Staff

- Dr. Claire Bombardier, OBRI Principal Investigator
- Sandra Couto, Director of Partnership and Stakeholder Relations
- Dr. Vinod Chandran, Principal Investigator, SpA Initiative
- Angela Cesta, Clinical Research Coordinator
- Dr. Mohammad Movahedi, Research Associate II
- Carol Mously, Study Site Coordinator
- Xiuying Li, Data Manager
- Laura Fullerton, Research Associate I
- Leanie Culanding, Budget and Finance Manager (part-time)
- Sunita Timilshina, Data Entry Clerk (part-time)
- Cheryl Dawson-Titus, Administrative Assistant (part-time)

OBRI Students

- Mark Tatangelo, PhD Student
- Kangping Cui, Medical Student
- Apoorva Kelkar, Pharmacy Student

SPONSORS & PARTNERS



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