

SHAPING THE FUTURE OF ARTHRITIS CARE

OBRI ANNUAL REPORT 2017



OBRI

ONTARIO
BEST PRACTICES
RESEARCH INITIATIVE





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MESSAGE FROM OUR PRINCIPAL INVESTIGATOR



The initial pilot and efforts for the Ontario Best Practices Research Initiative (OBRI) began in 2005. Since then, and through the collaboration between physicians, payers, researchers and patients, the Ontario cohort now includes more than 3500 patients, 71 rheumatologists and focuses on safety and effectiveness of treatments for people living with Rheumatoid Arthritis (RA).

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 comparative drug safety and effectiveness and patient quality of care. Our research priorities include the examination of **Drug Impact and Outcomes** (effectiveness, safety, adherence persistence/survival); **Clinical Management and Practice Patterns vs. Guidelines** (clinical measures, quality indicators, practice guidelines), and **Population Health** (epidemiology, models of care, economics).

2017 has been a busy and successful year – we have made improvements in our data management strategies, including refinements to our data collection and validations methods for data extractions from EMRs, presented research and generated insights at various international and national scientific meetings, hosted our 10th patient information session, completed enrollment into our SpA pilot initiative, and formed new linkages with our pediatric colleagues. We also hosted our 4th Annual Scientific Meeting for rheumatologists, researchers, and stakeholders; we worked closely with our Patient Advisory Committee and Clinical Advisory Committee to engage patients, exchange expertise, and advance our research initiatives; and we continued our successful face-to-face patient sessions.

This report provides an overview of our activities in 2017. For up to date information, news, and details on current presentations and publications, please visit our website at www.obri.ca. We look forward to another productive year in 2018!

A handwritten signature in black ink, appearing to read 'C Bombardier'.

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 that follows patients in routine care along their clinical path. It is a collaborative data platform involving rheumatologists, researchers, and patients. Originally created as the Ontario Biologics Research Initiative, it was officially renamed in 2013 to reflect the expansion of the organization's goals beyond the scope of biologic treatments.

Our Mission & Mandate

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

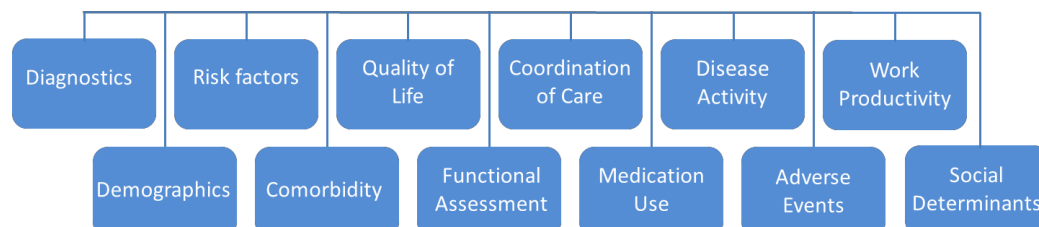
- Define safety, effectiveness, and sustainability of available RA therapies in the real world
- Identify clinical practice patterns that improve patient health outcomes
- Use real world clinical data to inform health care decisions

The OBRI generates outcome data specifically related to pharmacotherapy, clinical outcomes, practice patterns and population health. The OBRI team also provides leadership in best practices for ethics and obtaining consent, data management, real world data analysis, and administrative database validations.

Our Value Proposition

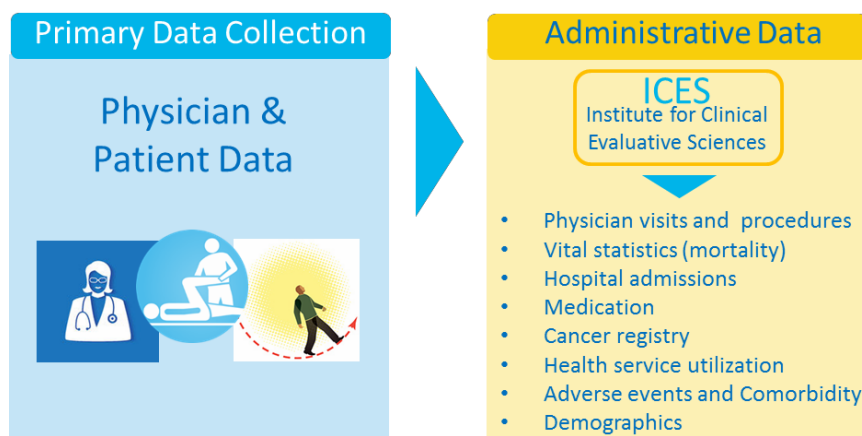
The OBRI has evolved into a powerful decision making tool that is used to shape and inform the future of arthritis care. This rich source of comparative data combines real-world outcomes with administrative data. It is vetted through scientific rigor and the active involvement of a clinical advisory committee so that it may be used by policy makers to influence health care and clinical treatments decisions.

What's in our Data?

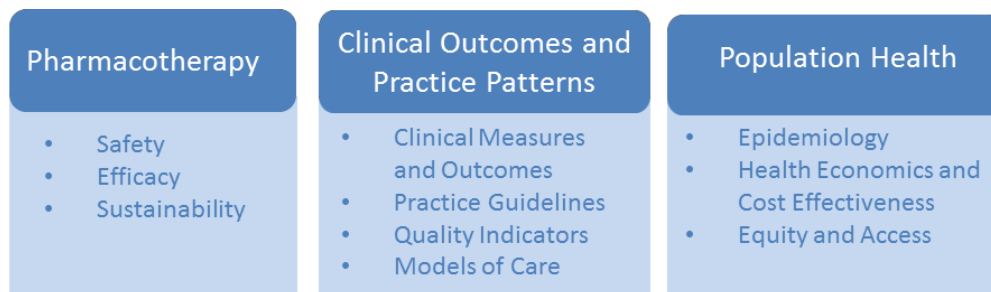


Our Data Linkages

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, medication, cancer registry, health service utilization, adverse events, comorbidities, and demographics.



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.



Celebrating 10 years of success

After 10 years, today the provincial data platform has evolved to encompass a broader mandate focused on long-term comparative effectiveness and safety of all therapies for inflammatory arthritis. In addition to real world drug effectiveness, the OBRI has become a novel comparative data platform that informs on best practices and quality improvement.

A snap shot of our evolution:

- **In phase I (2008-2010)**, we focused efforts on program development by reviewing the international registry landscape, gathering operational intelligence, identifying stakeholders, proposing a framework for our structure and governance, developing the protocol, preparing the operational plan and processes, and establishing patient, ethics and advisory committees.
- **In Phase II (2010-2012)**, we recruited 16 key investigators for the initial pilot testing (Drs. Carter Thorne, Janet Pope, Alf Cividino, Jane Purvis, Vandana Ahluwalia, Sanjeeta Bajaj, Arthur Karasik, Andrew Chow, Brian Hanna, Catherine Alderdice, Nader Khalidi, Ali Shaikh, Frances Leung Bindee Kuriya, Ed Keystone and Jacqueline Hochman), with emphasis on the feasibility and validation of the data collection forms, methods for patient and physician data collection, the in-house development of the data management centre and the final preparations for the larger provincial implementation including recruitment and hiring of staff.
- **In Phase III (2012-2017)**, we implemented the scientific protocol to address the targeted outcomes related to real-world effectiveness and safety, recruited 55 additional investigators to participate in the data collection activities, established the clinician advisory committee (2015), and launched the Spondyloarthritis Pilot.
- **Now in Phase IV (2017-future)** of the initiative, we are exploring innovative methods to extract data from EMRs and networking with other groups that are interested to link to our data platform -specifically in pediatric juvenile inflammatory arthritis, inflammatory skin disease and ulcerative colitis.

With the adoption of electronic medical records (EMRs) in clinical practice, more than 70 academic and community rheumatologists voluntarily participate and share clinical data with the OBRI data management centre. Today, the data platform consists of comprehensive clinical and patient-reported long term follow up data of over 9 years for the RA cohort.

Key Findings

We are pleased to highlight some of our research findings from the past decade.

Predictors of Anti-Rheumatic Medication Adherence in OBRI cohort

OBRI patients are more likely to remain on their RA medications if they have other diseases/conditions. Married patients are also more likely to remain on their RA medications. However, when the disease is more severe and when patients are on multiple RA medications, patients are more likely to stop their RA medications.¹

In patients who have had a relapse, what are the predictors of recapturing remission?

Clinical remission in routine care is achievable but relapses to states of low or moderate disease activity are common and may last several months. Recapturing remission after a relapse appears possible but occurs at a lower frequency than initial remission.²

Defining primary and secondary non-response in the OBRI cohort

Rheumatologists' decision to discontinue a drug treatment for lack of efficacy is not always based on established measures of disease activity.³

Impact of concomitant use of DMARDs on first biologic durability in OBRI cohort

Half of the OBRI patients are still on their biologic at year 4. OBRI patients taking a DMARD with their first biologic are more likely to stay on their biologic compared to patients not taking a DMARD.⁴

Pain medications reported in OBRI cohort

80% of OBRI patients report using at least one pain medication in addition to their RA therapies. The most commonly reported pain medication is NSAID monotherapy (41%), followed by opioid analgesics (16%), non-opioid analgesics (16%), antidepressants (14%), benzodiazepines (8%) and anti-epileptics (6%).⁵

Biologic Use in OBRI Cohort

Biologic use in the OBRI cohort has increased from 23% in 2008 to 44% in 2015. There has also been a change in the proportion of TNFs vs anti-TNFs being used over this time period, with a decrease of 31% in TNFs and an increase of 33% in non-TNFs.⁶

Disease Activity Patterns

30% of RA patients in the OBRI cohort present with new onset disease. For these patients, transitions from high disease activity to a low activity state occurred rapidly and a steady state is reached after the first 12 months.⁷

Attrition Rates in OBRI

OBRI participants are less likely to drop out when compared to similar RA registries. Their continued participation may be attributed to the frequent follow up by OBRI telephone interviewers as well as the dedicated commitment of participating rheumatologists and the insights provided by the Patient Advisory Committee.⁸

Cardiovascular disease in OBRI cohort

One in six OBRI patients report cardiovascular disease. These patients also report more severe RA disease and more difficulty functioning day to day.⁹

Disease activity and depression in OBRI cohort

25% of patients who participate in OBRI report depression. Depression occurs more frequently among patients with more severe RA.¹⁰

Socioeconomic factors in OBRI cohort

OBRI patients with higher household income respond to treatment earlier.

OBRI patients living alone are less likely to have a sustained response to treatment.¹¹

The influence of age at disease onset on disease activity and disability

Late onset rheumatoid arthritis patients (age at RA onset ≥ 60 years of age) have different clinical characteristics with greater disease severity at baseline compared to younger counterparts (age at RA onset < 60 years of age). Age of disease onset appears to be independently associated with higher baseline disease activity and disability. Despite this, early and initial treatment is less aggressive in late onset RA patients and may have implications for future response to therapy and development of comorbidities.¹²

References:

- ¹Ahluwalia V, Rampakakis E, Movahedi M, Cesta A, Li X, Couto S, Sampalis J, Bombardier C. Predictors of patient decision to discontinue anti-rheumatic medication in patients with rheumatoid arthritis: Results from the Ontario Best Practices Initiative. *Clinical Rheumatology*, 2017: 36 (2421-2430).
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- ³Keystone E, Movahedi M, Cesta A, Li X, Couto S, Rampakakis E, Sampalis JS, Bombardier C and OBRI Investigators. What is the Rate of Primary and Secondary Failure of Anti-TNF in RA Patients? An Analysis from a Prospective, Observational Registry. CRA Annual Scientific Meeting. Lake Louise, AB, Feb 17-20th, 2016. (Poster Presentation)
- ⁴Lau A, Thorne C, Movahedi M, Cesta A, Li X, Couto S, Sampalis JS, Rampakakis E, Bombardier C and OBRI investigators. Impact of Concomitant Use of Disease Modifying Antirheumatic Drugs and Methotrexate Administration Route on Durability of Biologic Treatment: Results from the Ontario Best Practice Research Initiative (OBRI) Cohort. CRA Annual Scientific Meeting, Ottawa, ON. Feb. 9, 2016. (Poster Presentation)
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- ⁶Annual OBRI Investigator Report, 2017
- ⁷Tatangelo M, Tomlinson GA, Kuriya B, Bombardier C. Disease Activity Patterns in Incident Onset Rheumatoid Arthritis Patients in the First 3-Years of Follow up. ACR Annual Scientific Meeting, San Francisco, CA. Nov. 7-11, 2015. (Poster Presentation)
- ⁸Cesta A, Li X, Tatangelo M, Bombardier C and OBRI Investigators. Attrition and Participant Characteristics in a Rheumatoid Arthritis Cohort. CRA Annual Scientific Meeting. EULAR Annual Scientific Meeting. London, UK. June 8-11th, 2016. (Poster Presentation)
- ⁹Cui K, Jacob B, Widdifield J, Pope J, Kuriya B, Akhavan P, Bombardier C. Characteristics of rheumatoid arthritis patient with and without cardiovascular disease – Data from the Ontario Best Practices Research Initiative. EULAR Annual Scientific Meeting, Rome, Italy. Jun 11-13, 2015. (Poster Presentation)
- ¹⁰Joshi R, Kuriya B, Movahedi M, Rampakakis E, Cesta A, Li X, Couto S, Sampalis JS, Bombardier C, and OBRI investigators. High disease activity is a Predictor of Depression and Persistent Depression in Early Rheumatoid Arthritis: Results From the Ontario Best Practices Research Initiative (OBRI). CRA Annual Scientific Meeting, Ottawa, ON. June 16, 2017 (Poster Tour)
- ¹¹Cui K, Bombardier C, Tomlinson GA, and OBRI Investigators. Contributions of Social Determinants of Health on Treatment Responses in Rheumatoid Arthritis Patients. EULAR Annual Scientific Meeting. London, UK. June 8-11th, 2016. (Poster Presentation)
- ¹²Ruban TN, Jacob B, Pope JE, Keystone EC, Bombardier C, Kuriya B. The influence of age at disease onset on disease activity and disability: results from the Ontario Best Practices Research Initiative. *Clinical Rheumatology*. August 2015.

2017 IN REVIEW- key highlights

High Quality Insight Creation and Dissemination

The OBRI has participated and presented at national and international scientific meetings – this year 8 new abstracts and 4 manuscripts have been developed. The OBRI hosted its fourth Annual Scientific Meeting, which was attended by 25 OBRI Investigators and their coordinators, ICES researchers, consumer and advocacy groups from the Arthritis Society and Best Medicine Coalition. The meeting featured presentations by David Schachow, *Director of the Drug Programs Delivery Branch*, on the value of real world data and Ariane Siegel, *Chief Privacy Officer at OntarioMD*, regarding data privacy requirements for clinicians working with EMR platforms.

The aggregated clinical reports created by OBRI provide unique information that benefits payers, government and pharmaceutical companies.

Patient Engagement and Connectivity

The OBRI Patient Advisory Committee, represented by patients and patient advocates, is the active voice for patients participating in the OBRI. The committee's mandate includes the dissemination of key findings, the development of lay summaries, the creation of annual patient newsletter "In the Loop" (<http://www.obri.ca/for-patients/patient-newsletters/>) and the organization of local and regional information sessions for participants. The volunteer led committee plays an active role in research activities and is called upon to identify key clinical questions alongside the scientific advisory committee.

2017 RECRUITMENT ACTIVITY (as of December 31, 2017)

	RA Cohort N (%)	SpA Pilot N (%)
Patients referred to OBRI	4231 (100.0)	418 (100.0)
Patients refused*	606 (14.3)	51 (12.2)
Patients with consent pending	25 (0.6)	0 (0.0)
Patients consented	3600 (85.1)	368 (87.8)
ICES linkage	3581 (99.5)	366 (99.5)
Interviewer data	3439 (95.6)	327 (88.9)
Physician data	3564 (99.0)	364 (98.9)
Withdrawals		
0-2 years	164 (4.6)	11 (3.0)
2-5 years	134 (3.7)	N/A
Patient lost to follow-up**	132 (3.7)	0 (0.0)
Patients deceased	149 (4.1)	2 (0.5)
Patients who have reached & completed:		
Baseline	3375 (99.9)	347 (94.3)
1 year follow-up	2760 (85.4)	246 (75.2)
2 year follow-up	2343 (72.5)	N/A
3 year follow-up	1968 (60.9)	N/A
4 year follow-up	1621 (50.2)	N/A
5 year follow-up	1087 (33.6)	N/A
6 year follow-up	1019 (28.3)	N/A
>6 year follow-up	529 (14.7)	N/A

*Patient refused to participate in any aspect of OBRI.

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

Ongoing Initiatives

Leading edge research - collaboration with JSS Medical

To support the work of our Clinical Advisory Committee (CAC), the OBRI continues to partner with JSS Medical Research to advance investigator-led research questions. Researchers from the OBRI, JSS, and the CAC have been working closely to advance research questions using OBRI data. For a list of completed research questions, please visit: www.obri.ca.

Innovative data collection methods with EMRs

With the adoption of EMRs and the growing number of paperless offices, the collection of clinical data and outcomes for research and practice improvement activities will only be feasible if it is accomplished seamlessly without interrupting workflow. In an effort to support this endeavor, the OBRI is working closely with IT partners to identify best practices and to support clinician documentation of clinical data in their EMRs in a structured format. We are promoting the standardized collection of data that is aligned with the recent recommendations by the Arthritis Alliance of Canada (AAC) (*Journal of Rheumatology*, 2017 Oct 1. pii: jrheum.170421 [Epub ahead of print]).

Continuous data refinements

Data integrity is very important to the OBRI. We continue to invest considerable time and effort into minimizing missing data and ensuring the data we collect is accurate and reliable. Our focus this year has been on RA reported medications, as this data is vital for our safety and effectiveness research questions. The OBRI collects RA medications data from both patients and rheumatologists. We found there is strong agreement between these two data sources. While it is costly to collect this information from both patients and rheumatologists, these findings allow us to draw on two sources of data and provide a more complete and accurate record of RA medications being used by our patients.

Advocacy for comparative real world data

The availability of an increasing number of medications for the treatment of rheumatoid arthritis, although beneficial to patients and providers, has put tremendous financial strain on payers thereby increasing the need for comparative effectiveness studies. Through the OBRI, we can compare real world (and long-term) effectiveness of different treatment groups with similar indications rather than relying on historical data for comparisons. The large number of patients in the OBRI also allows for comparisons of “matched” controls or similar patients using different treatments. Payers, providers, and decision-makers are turning to the OBRI to provide comparisons of treatments that previously could only be studied in single arm cohorts.

Focused evaluation of biosimilars

New biosimilars continue to be approved in Canada. They will continue to emerge at a rapid rate as they offer a potential and real cost savings in the treatment of many chronic diseases – particularly in Rheumatology, Gastroenterology and Dermatology. With many new products entering the Canadian market, the growing need to understand the long-term safety, effectiveness, and economic benefit of biosimilars remains an important priority. OBRI continues to identify and monitor the long-term safety and effectiveness of all biologics, including biosimilars, so that it can document and provide comparative real world insights and evidence for physicians, patients, researchers, and policy makers when evaluating these new molecules.

Expansion to inflammatory arthritis

Dr. Vinod Chandran, MB, BS, MD, Assistant Professor of Medicine, Division of Rheumatology, University of Toronto and Staff Physician, Division of Rheumatology Toronto Western Hospital, continues to lead the evaluation of the real-world disease impact, spectrum, and management of SpA. We have enrolled 365 patients into the OBRI-SpA cohort. Of those enrolled, 187 (53%) have Ankylosing Spondyloarthritis (AS), 145 (41%) have Psoriatic Arthritis (PsA), 4% have other types of SpA, and 2% have mechanical back pain. Our interim analysis has revealed that those with AS have a mean age at enrollment of 49 years, and experience morning stiffness (76%) and chronic back pain (70%). 60% are HLA-B27 positive and 36% experience extra-articular disease. Those

with PsA, have a mean age at enrollment of 53 years, and experience morning stiffness (72%) and chronic back pain (26%). 15% are HLA-B27 positive and 77% experience extra-articular disease. The disease activity scores were generally low with a mean ASDAS (CRP) score of 2.5 for AS, mean DAPSA score of 19 for PsA, and BASDAI of 3.7 and 4.2, for AS and PsA respectively. 43% of PsA patients were in a state of minimal disease activity. The disease activity scores were higher in patients commencing biologic therapy compared to those on conventional therapy.

We are currently collecting follow up data (up to 2 years) for the patients enrolled. Results from this pilot study will inform future community-based studies on the prevalence and the impact of SpA in Ontario.

Upcoming Initiatives Planned

Building a comparative real world data platform for quality improvement – platform for Ontario specialists

The physician practice landscape continues to evolve. Today, there is an abundance of clinical health data that can be easily collected, analyzed and processed with the adoption of EMRs. Physicians, regardless of their practice, are encouraged to document and report on outcomes and quality of care they provide to their patients. Rheumatologists in Ontario have been participating voluntarily in the OBRI for over the past 10 years so that aggregated clinical data can be used for research activities as well as for their collective and individual practice improvement purposes. It is no surprise that other speciality groups are excited and interested in the OBRI and the value and services it offers. In an effort to support the collection of comparative long-term clinical outcomes for their patients and the medications prescribed, other specialists, including dermatologists and gastroenterologists - are now collaborating with the OBRI to create their respective data centres.

Expansion to Dermatology & Gastroenterology

We are pleased to welcome Dr. Aaron Drucker, MD, ScM, FRCPC, who has been recruited as a new faculty member in the Division of Dermatology at the University of Toronto and Women's College Hospital. Under Dr. Drucker's leadership, this expansion will make use of the existing OBRI expertise and infrastructure to create a province-wide comprehensive skin registry. New work will be prioritized to include: a dermatology specific protocol, the submission to regional and institutional research ethics boards, the definition of minimum core variables, and the integration of data collection tools within existing EMR platforms. We continue to collaborate with leaders in gastroenterology interested in leveraging the OBRI data platform for monitoring the long term safety and effectiveness of biologics used for the treatment of gastric diseases.

Expansion to Cardiology

We are pleased to recognize OBRI investigator Dr. Bindee Kuriya, MD, SM, FRCPC, Assistant Professor of Department of Medicine, University of Toronto and Director, Rapid Access Rheumatology Clinic, Mount Sinai Hospital. Dr. Kuriya leads the new CARDIA - Cardiovascular Assessment in Rheumatic Diseases and Inflammatory Arthritis - project. Research indicates

that patients with rheumatoid arthritis may be at increased risk of cardiovascular disease (CVD) compared to the general population. It is known that CVD is documented as one of the most prevalent co-morbidity associated with inflammatory arthritis. Through this multi-disciplinary, collaborative and innovative project, CARDIA will provide patients with evidence-based management of their RA with a focus on primary and secondary prevention of CVD.

The pilot will examine the proportion of RA patients with known risk factors for CVD (high blood pressure, diabetes, smoking, elevated cholesterol) and document the CVD risk factors that are associated with RA (high inflammation levels, certain medications). It will also identify if risk factors are appropriately treated, intervene if they are not, and determine how RA and RA therapies (DMARDs, biologics) may affect CVD risk. Finally, it will also provide lifestyle counseling, education and medication options to treat CVD and monitor for long-term CVD events (e.g. hospitalizations for heart attacks, strokes) by linking to provincial healthcare databases. As an initial first step, the OBRI will collaborate with CARDIA through the Mount Sinai Hospital site where patients participating in OBRI who present with CVD risk factors will be invited to participate.

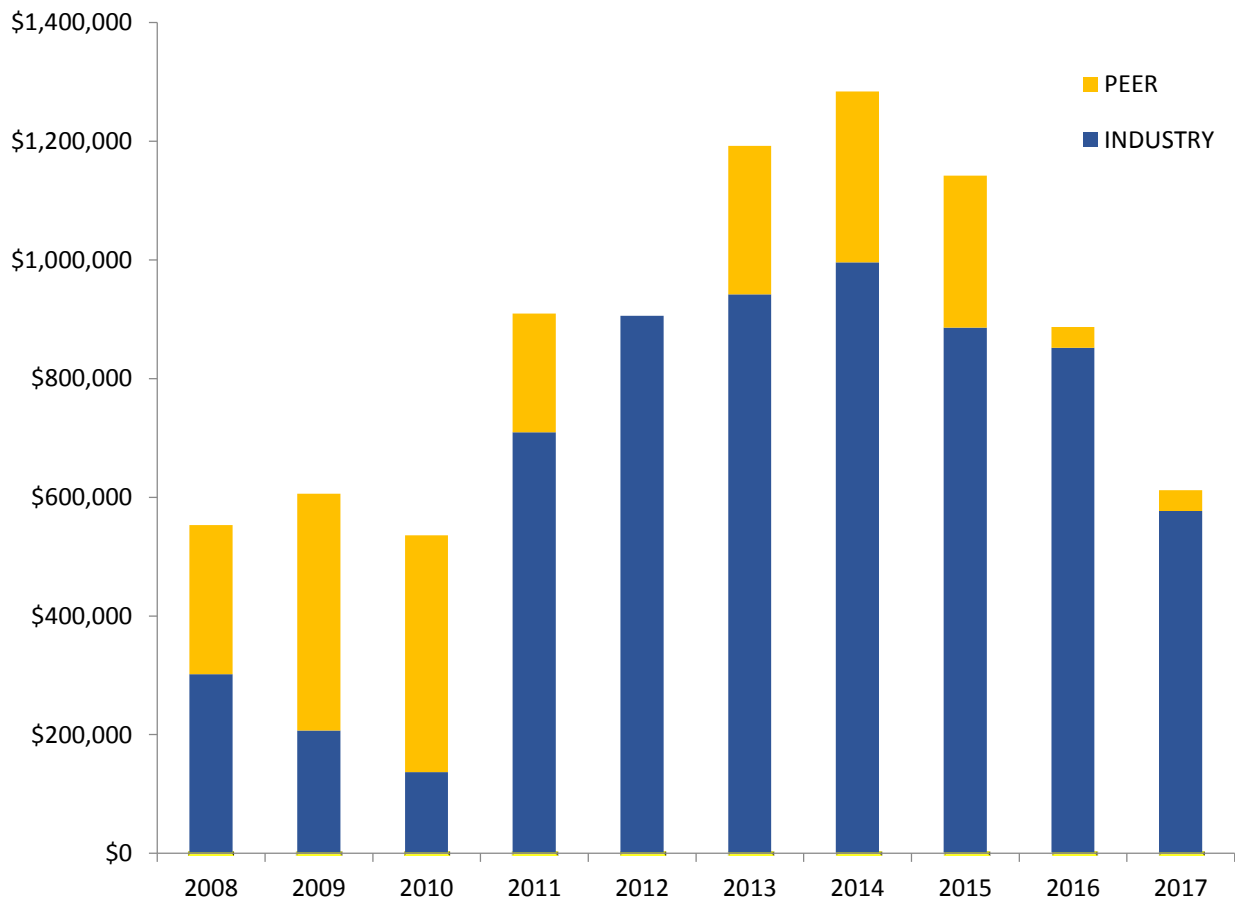
Expansion to Pediatrics

After ongoing discussions, the OBRI is pleased to announce its collaboration with the pediatric rheumatology team at the Hospital for Sick Children. Under the leadership of Dr. Brian Feldman, MD, MSc, FRCPC division head of Rheumatology and Senior Scientist at Child Health Evaluative Sciences, the Childhood Arthritis Network-Database for Improved Outcomes (CAN-DIO) is working with the OBRI. The mandate of this pediatric registry is to collect clinical data on patients living with juvenile idiopathic arthritis as they transition into adulthood and inform on quality of care, long-term safety and effectiveness of treatments. As patients graduate from pediatric to adult rheumatology care, patients will continue to participate in sharing their respective clinical data by transitioning from CAN-DIO to OBRI. This important collaboration will establish the first pediatric-adult clinical arthritis cohort within North America.

Financial Report

At OBRI, our main source of revenue comes from sponsorship; however peer-reviewed funding has been awarded to OBRI for specific research activities. In 2017, OBRI received sponsorship from 8 industry partners. Sources of funding revenue from 2009-2017 are presented below.

OBRI Funding Revenue



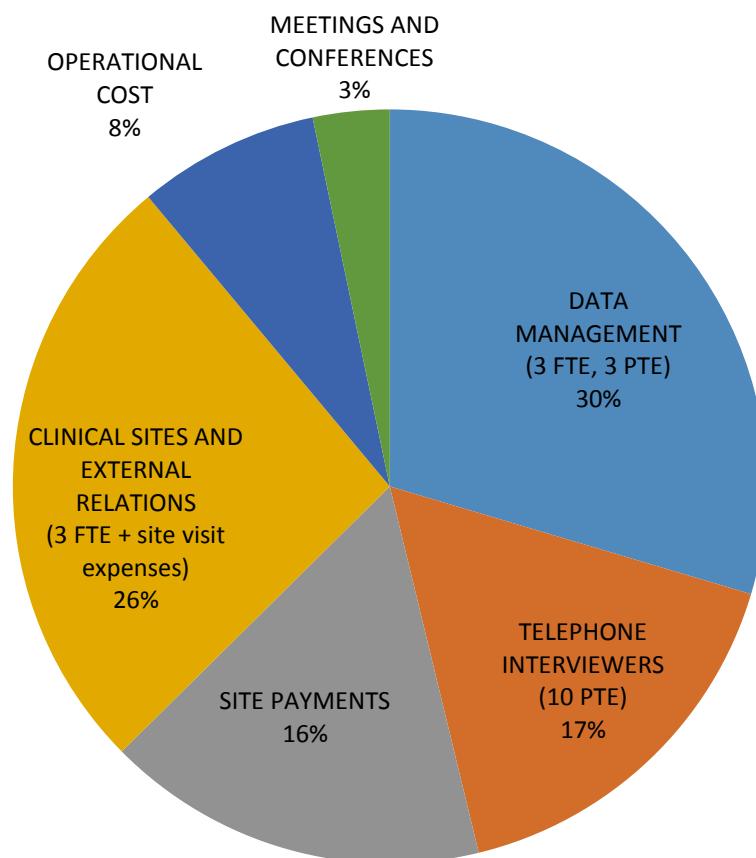
OBRI Expenditures-

OBRI's expenditures for the 2016/2017 fiscal year totaled \$1,138,778.

Costs for data management were highest (30%), followed by support for clinical sites and external relations (26%), site payments (16%), telephone interviews (17%), operational costs (8%), and costs for meetings and conferences (3%).

Expenditures-

Fiscal Year: April 2016 – March 2017



Meetings & Conferences

- American College of Rheumatology (ACR) Annual Scientific Meeting, San Diego, CA. November 3-8, 2017
- Canadian Rheumatology Association (CRA) Annual Scientific Meeting. Ottawa, ON. February 7-11, 2017
- European League Against Rheumatism (EULAR) Congress 2017, Madrid, Spain. June 14-17, 2017
- Health Quality Ontario Transformation Meeting, Toronto, ON. October 24, 2017
- International Conference of Pharmacoepidemiology (IPCE). Montreal, PQ, August 26-30, 2017
- Ontario Rheumatology Association (ORA) Annual Meeting. Minnett, ON. May 25-27, 2017
- RA Summit, Abu Dhabi Advanced Rheumatology Review Course, Abu Dhabi, United Arab Emirates. October 23, 2017

Awards Received

- William Osler Health System Physician Philanthropy Leadership Award, awarded to Dr. Vandana Ahluwalia. Co-Chair of the Holi Gala committee, under her guidance, this event has grown over 50 per cent in the last two years (2017).
- Canadian Rheumatology Association Young Investigator Award given in Recognition of a young Canadian Investigator who has contributed significant, original research in rheumatology, was awarded to Dr. Vinod Chandran, February 2017.
- 2017 Ted Goldberg Award, awarded to Mark Tatangelo, PhD candidate affiliated with OBRI.
- 2017 Gordon Cressy Student Leadership Award University of Toronto, awarded to Mark Tatangelo, PhD candidate.

Patient Advisory Committee (PAC)

The OBRI Patient Advisory Committee (PAC) is a volunteer-led group comprised of patient representatives with rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis. The PAC works to improve patient wellbeing through the promotion of rights detailed in the *Canadian Arthritis Patients Charter*.

The OBRI PAC provides guidance to the OBRI research team through:

- The communication of patient perspectives to research staff, students, investigators and other stakeholders
- Priority setting, project planning, and decision making
- Patient engagement, communication, and retention activities
- The dissemination of research/knowledge to patients and caregivers

Accomplishments in 2017 include:

- The production of an annual patient newsletter “In the Loop” (<http://www.obri.ca/for-patients/patient-newsletters/>) to keep patients informed about OBRI research, news, and events
- The co-facilitation of the 2017 OBRI Patient Information Session to communicate OBRI research activities
- The development of plain-language summaries to communicate OBRI research findings for 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
- Gerald Major
- Janet Money
- Denis Morrice
- Nancy Roper



Clinical Advisory Committee (CAC)

The Clinical Advisory Committee (CAC) was developed in 2015 to provide the OBRI with leadership for the development and investigation of clinically-relevant research questions. Members of the CAC work closely with OBRI staff and JSS Medical Research to explore new research questions relevant to rheumatology care.

Accomplishments in 2017 include:

- Three scientific poster presentations at the Canadian Rheumatology Association (CRA) Annual Scientific meeting in Ottawa, ON.
- One oral presentation and one scientific poster presentation at the American College of Rheumatology (ACR) Annual Scientific meeting in San Diego, CA.
- One oral presentation and one scientific poster presentation at the European League Against Rheumatism (EULAR) Annual Congress in Madrid, Spain.
- The development of 4 manuscripts for peer-reviewed publication.

Clinical Advisory Committee:

- Dr. Vandana Ahluwalia
- Dr. Claire Bombardier
- Dr. Vinod Chandran
- Dr. Alfred Cividino
- Cathie Hoffstetter (PAC)
- Dr. Edward Keystone
- Dr. Janet Pope
- Dr. Carter Thorne



OBRI Investigators

Dr. Vandana Ahluwalia*	Dr. Rafat Faraawi <i>NEW 2017</i>	Dr. Shikha Mittoo
Dr. Zareen Ahmad	Dr. Derek Haaland*	Dr. Ami Mody
Dr. Pooneh Akhavan	Dr. Brian Hanna***	Dr. Angela Montgomery
Dr. Lori Albert	Dr. Nigil Haroon	Dr. Manisha Mulgund*
Dr. Catherine Alderdice	Dr. Jackie Hochman***	Dr. Edward Ng
Dr. Michael Aubrey	Dr. Anna Jaroszynska	Dr. Tripti Papneja
Dr. Henry Averbs**	Dr. Sindhu Johnson	Dr. Viktoria Pavlova
Dr. Sibel Aydin	Dr. Raman Joshi	Dr. Louise Perlin
Dr. Sangeeta Bajaj	Dr. Allan Kagal	Dr. Janet Pope
Dr. Mary Bell <i>NEW 2017</i>	Dr. Arthur Karasik*	Dr. Jane Purvis
Dr. William Bensen***	Dr. Jacob Karsh	Dr. Raman Rai <i>NEW 2017</i>
Dr. Sankalp Bhavsar	Dr. Edward Keystone	Dr. Gina Rohekar
Dr. Raja Bobba	Dr. Nader Khalidi	Dr. Sherri Rohekar
Dr. Claire Bombardier	Dr. Imtiaz Khan**	Dr. Thanu Ruban
Dr. Arthur Bookman	Dr. Bindee Kuriya	Dr. Nooshin Samadi
Dr. Julie Brophy <i>NEW 2017</i>	Dr. Margaret Larché	Dr. Sharron Sandhu <i>NEW 2017</i>
Dr. Antonio Cabral	Dr. Arthur Lau*	Dr. Saeed Shaikh
Dr. Simon Carette	Dr. Nicole Le Riche***	Dr. Ali Shickh
Dr. Raj Carmona	Dr. Felix Leung	Dr. Rachel Shupak
Dr. Andrew Chow*	Dr. Frances Leung***	Dr. Doug Smith
Dr. Shirley Chow* <i>NEW 2017</i>	Dr. Dharini Mahendira	Dr. Elaine Soucy
Dr. Gregory Choy <i>NEW 2017</i>	Dr. Mark Matsos	Dr. Jonathan Stein
Dr. Patricia Ciaschini*	Dr. Heather McDonald-Blumer	Dr. Andy Thompson***
Dr. Alfred Cividino	Dr. Emily McKeown <i>NEW 2017</i>	Dr. Carter Thorne*
Dr. Dana Cohen	Dr. Ines Midzic	Dr. Sharon Wilkinson***
Dr. Sanjay Dixit*	Dr. Nataliya Milman	

* RA & SpA

** SpA only

*** Retired/No longer participating in OBRI

Interviews: Collecting Patient Reported Outcome Measures

Part of what makes the OBRI unique is our ongoing collection of patient reported outcome measures through structured telephone interviews with patients. Patient reported data is collected on a regular basis to document patient experiences with disease activity, quality of life, comorbidity, socioeconomic status, functional ability, and work productivity. These interviews, combined with physician-reported data and administrative data, provide us with a holistic picture of the RA care landscape in Ontario.

We'd like to thank our dedicated team of interviewers for their ongoing role in ensuring patient data is collected in a standardized manner.

OBRI Interviewers

- Lisa Guerin
- Joanne Kennedy
- Lynda Linderman
- Andrea McClintock
- Janet Money
- Colleen Perrin
- Linda Rosengarten
- Gail Walker
- Sharon Zwarych



OBRI TEAM

The data management centre is staffed by a specialized team with competency in clinical trial management, biostatistics, ethics approvals, privacy, data management, health IT, stakeholder engagement and business development. Since inception, the OBRI has disseminated knowledge insights globally, nationally and provincially through abstracts (70), presentations, and manuscripts (12) for a variety of vested stakeholders including clinicians, patients, manufactures and payers.



OBRI Staff

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

OBRI Student(s)

- Mark Tatangelo, PhD candidate, University of Toronto



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