SHAPING THE FUTURE OF ARTHRITIS CARE

OBRI ANNUAL REPORT 2019

OBRI
ONTARIO
BEST PRACTICES
RESEARCH INITIATIVE

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MESSAGE FROM OUR PRINCIPAL INVESTIGATOR

The Ontario Best Practices Research Initiative (OBRI) pilot began in 2005. Through the collaborative efforts of physicians, payers, researchers and patients, the Ontario cohort has grown to include almost 3900 patients and 72 rheumatologists (both community and academic). The OBRI focuses on the safety and effectiveness of treatments for patients 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. This platform has prepared OBRI for the Real World Data (RWD) and "big data" trends in Canada today. These approaches to data, which combine information collected across multiple registries, are being adopted by government, payers and researchers. With our years of experience, the OBRI team is well prepared to collaborate with these RWD stakeholders.

2019 marked OBRI's collaboration with the Quebec RA registry, Rhumadata. This collaboration is the first example of sharing Canadian RA data at the patient level and opens the door to many new research questions. The OBRI also finalized an agreement with the Institute for Clinical Evaluative Studies (ICES) to link clinical data to the Ontario provincial administrative database. A new ICES process will grant the OBRI analytic team off-site access to this unique data set. Working closely with our Clinical and Patient Advisory Committees in the coming year, OBRI will work with these expanded data sets to answer many more research questions.

We are pleased to share this overview of our activities in 2019 and we look forward to 2020.

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) and Psoriatic Arthritis (PsA) 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 and PsA 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?

Physician Reported Data

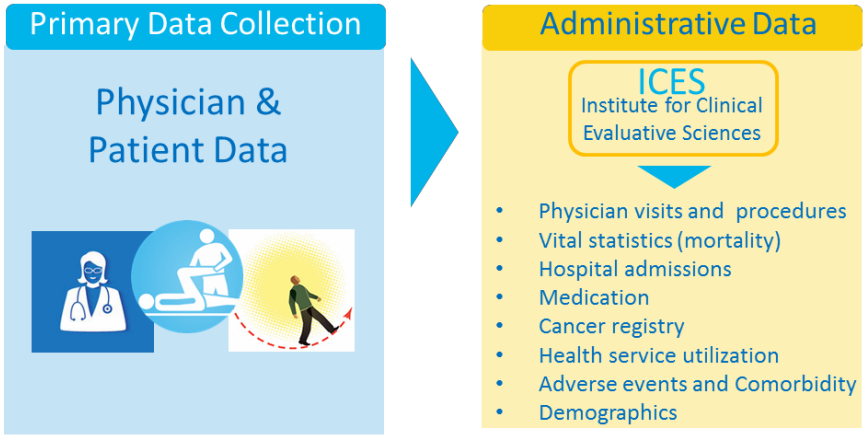
- Personal Health Information
- RA History
- Previous RA Medications
- Physician Global Assessment
- Patient Global Assessment
- Co-morbidities
- Serious Events
- Laboratory (ESR, CRP)
- Tender Joint Count
- Swollen Joint Count
- Erosions
- Current RA Medications

Patient Reported Data

- Demographics
- RA History
- Previous Anti-Rheumatic Meds
- Current Medications
- HAQ / RADAI
- Patient Global Assessment
- Quality of Life
- Fatigue and Sleep
- Socio-economic Status
- Work Productivity
- Serious Events / Tuberculosis
- Pregnancy
- Pharmacy/Labs/Imaging

Our Data Linkages

The OBRI clinical data is linked to the provincial administrative databases held by the Institute for Clinical Evaluative Sciences (ICES).



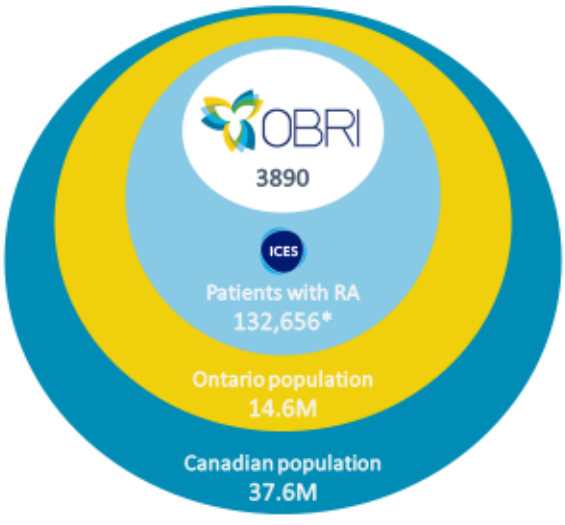
Our Research Pillars

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.

Pharmacotherapy	Clinical Outcomes and Practice Patterns	Population Health
• Safety • Efficacy • Sustainability	• Clinical Measures and Outcomes • Practice Guidelines • Quality Indicators • Models of Care	• Epidemiology • Health Economics and Cost Effectiveness • Equity and Access

Representative RA Sample

The population of Ontario comprises approximately 40% of the Canadian population. The 2017/2018 Ontario administrative data identified 132,656 RA patients. Linking the OBRI clinical data to the ICES datasets will provide a unique opportunity to answer many research questions.



Physician visits in OBRI = 43,342

Patient interviews in OBRI = 45,607

Key Findings for 2019

OBRI's 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). We are pleased to highlight our research publications from 2019.

Is there agreement between patient-reported and physician-reported anti-rheumatic medications?

One of the unique features of the OBRI is the collection of anti-rheumatic medication (ARM) information from both patients and rheumatologists. We examined the agreement between patient- and rheumatologist-reported conventional synthetic disease-modifying anti-rheumatic drug (csDMARD) and biologic disease-modifying anti-rheumatic drug (bDMARD) use. The results suggest that there is strong agreement between patient- and rheumatologist-reported ARM use. This agreement is even better for patients who have lower disease activity and pain. Medication discontinuation was reported more frequently by patients, which may indicate that patients may be discontinuing use of their RA medications before consulting their rheumatologist.[1]

Do rheumatologists consistently classify non-response in RA patients treated with anti-TNFs as primary or secondary?

This collaborative study followed patients from the BioTRAC and OBRI registries on their first anti-TNF. Although most patients respond to anti-TNF treatment, some present with initial ('1ry') non-response or lose initial responsiveness ('2ry' non-response). We compared the rate of real-world 'non-response' to first anti-TNF as reported by treating physicians to the non-response rate per accepted definitions and recommended treat-to-target strategies. Results from both registries showed that physician reported '1ry non-response' was more correlated with non-achievement of LDA (DAS28-ESR or CDAI), whereas '2ry non-response' with the actual time of discontinuation (rather than prior achievement of LDA).[2]

Is there a link between frailty and the risk of fractures in RA patients?

Frailty is defined as a dynamic condition of increased vulnerability that limits one's social, psychological, and physical functioning. Rheumatoid arthritis (RA) patients are at high risk of skeletal bone loss and increased risk of fractures due to multiple factors including chronic inflammation, use of glucocorticoids, and reduced mobility. This study examined the relationship between frailty and risk osteoporotic fractures in patients with RA participating in OBRI. Results indicated that higher frailty status is significantly related to increase of osteoporotic fractures in patients with RA. Quantifying the frailty status as a research tool may aid in fracture risk assessment, management and decision-making in RA.[3]

Does where you live in Ontario impact biologic use by RA patients?

Access to care and management of rheumatoid arthritis patients may differ based on residential area (rural vs. urban). Cross-sectional analysis of 793 OBRI participants initiating their first biologic disease modifying anti-rheumatic drug (bDMARD) showed that there was no difference between residential area and type of bDMARD used. However, patients living farther from their treating clinic were significantly less likely to initiate intravenous (IV) bDMARD. Furthermore, use of subcutaneous (SC) vs. IV bDMARD was associated with being seen in a rural clinic, being treated by a female rheumatologist and living farther from the treating clinic. This suggests possible prescription bias in bDMARD selection and/or patient preferences due to convenience.[4]

Does the concomitant use of DMARDs (and route of administration) make a difference to the durability of biologic treatment?

Prior studies have suggested that concurrent conventional synthetic disease-modifying antirheumatic drug (csDMARD) therapy enhances the efficacy of biologic DMARDs (bDMARDs). In this study, we assessed the impact of i) concomitant csDMARD use and ii) methotrexate route of administration on time to bDMARD discontinuation in the OBRI cohort. Of the patients using bDMARDs, those patients taking concomitant csDMARDs were more likely to remain on their bDMARD therapy. Neither the dose nor the route of administration of MTX were significant predictors of bDMARD durability.[5]

References

1. Movahedi M, Cesta A, Li X, Bombardier C. **Collection of Anti-Rheumatic Medication Data from Both Patients and Rheumatologists Shows Strong Agreement in a Real World Clinical Cohort: Results from The Ontario Best Practices Research Initiative (OBRI) a Rheumatoid Arthritis Cohort.** J Clin Epidemiol. 2019 Oct;114:95-103. doi: 10.1016/j.jclinepi.2019.06.012. Epub 2019 Jun
2. Keystone E, Rampakakis E, Movahedi M, Cesta A, Stutz M, Sampalis JS, Nantel F, Maslova K and Bombardier C. **Towards Defining Primary and Secondary Non-Response in Rheumatoid Arthritis Patients Treated with Anti-TNFs: Results from the BioTRAC and OBRI Registries**. Journal of Rheumatology, 2019 Jul 1. pii: jrheum.190102. doi: 10.3899/jrheum.190102. [Epub ahead of print]
3. Li G, Chen M, Li X, Cesta A, Lau A, Thabane L, Adachi JD, Tian J, Bombardier C. **Frailty and risk of osteoporotic fractures in patients with rheumatoid arthritis: Data from the Ontario Biologics Research Initiative**. Bone. 2019 Oct;127:129-134. doi: 10.1016/j.bone.2019.06.006. Epub 2019 Jun 8
4. Movahedi M, Joshi R, Rampakakis E, Thorn C, Cesta A, Sampalis JS, Bombardier C. **Impact of residential area on the management of rheumatoid arthritis patients initiating their first biologic DMARD: Results from The Ontario Best Practices Research Initiative (OBRI).** Medicine (Baltimore). 2019 May;98(20):e15517. doi: 10.1097/MD.0000000000015517
5. Lau Arthur, Thorne Carter, Movahedi Mohammad, Rampakakis Emmanouil, Cesta Angela, Li Xiuying, Couto Sandra, Sampalis John, Bombardier Claire and OBRI investigators. **Effect of Concomitant Disease-modifying Antirheumatic Drugs and Methotrexate Administration Route on Biologic Treatment Durability in Rheumatoid Arthritis: OBRI Cohort Results**. J Rheumatol. 2019 Aug;46(8):874-886. doi: 10.3899/jrheum.180486. Epub 2019 Apr 15. PMID: 30988121

New Initiatives

Data Linkage with the Institute for Clinical Evaluative Sciences (ICES)

OBRI is working on an agreement with ICES that will grant the OBRI analytic team remote access to their administrative databases. This new working arrangement will facilitate the analysis of important research questions related to adverse events, comorbidities and health care utilization associated with RA medications.

Expansion to Psoriatic Arthritis

Over the last decade, the OBRI has developed a sophisticated infrastructure to study therapeutics in rheumatology, including RA and SpA and is well poised to be leveraged by other chronic conditions. In collaboration with the OBRI, Dr. Sibel Aydin will be leading a new province-wide community based psoriatic arthritis (PsA) registry. Over the past year, Dr. Aydin has been working closely with the OBRI team to develop an OBRI PsA protocol, data collection forms, and identify community-based rheumatologists to participate in this new registry.

Medical Cannabis

In 2019, the OBRI conducted a survey of OBRI investigators. The rheumatologist survey explored attitudes, knowledge and prescribing patterns. Currently, OBRI is conducting a patient-reported survey focused on the prevalence of use and the symptoms being treated by medical cannabis. OBRI is excited to be involved in this timely project which also hopes to determine whether the use of medical cannabis is affecting the use of prescribed RA medications.

Ongoing Initiatives

Data Sharing and Collaborations

OBRI's vast experience with the intricacies pertaining to issues of privacy, ethics, data collection, data management and analysis has made OBRI a valuable resource and partner to industry, payers, researchers and government.

i. Rhumadata - OBRI is excited to collaborate with Rhumadata. This is the first example of merging individual data collected by Canadian RA registries. The initial analyses will focus on sub-sets of patients treated with Tofacitinab from both cohorts. Findings were presented at both the 2019 European League Against Rheumatism (EULAR) Congress and the 2019 American College of Rheumatology Meeting (ACR). Moving forward, collaborations such as this will enhance the power of studies with new drugs and treatments available, thereby increasing the strength of the reported findings.

ii. Canadian Clinical RA Registries - Led by Dr. Claire Barber, under the auspices of the Canadian Rheumatology Association (CRA), clinical rheumatoid arthritis registries across Canada are coming together in a national collaboration. Collaborations between RA registries will be particularly relevant when studying rare events such as pregnancy.

iii. Canadian RA Guidelines - The Canadian Rheumatology Association (CRA) is updating the clinical guidelines for the management of patients with rheumatoid arthritis. Treatment guidelines typically rely on the data collected by randomized clinical trials. For the first time, the CRA RA guidelines committee, headed by Dr. Glen Hazlewood, are also reviewing the findings of real-world data to make recommendations for the management of RA.

iv. Drug Safety and Effectiveness Network (DSEN) - Under the umbrella of The Canadian Institutes of Health Research, DSEN working groups are tasked with increasing the evidence on drug safety and effectiveness available to regulators, policy-makers, health care providers and patients. Leading a DSEN working group, Dr. Sasha Bernatsky is collecting existing data from Canadian clinical registries, including OBRI, in rheumatoid arthritis, sero-negative arthritis, gastroenterology and dermatology. She will be examining the use of biosimilars (Inflectra and Brenzys) and their originator biologics (Remicade and Enbrel) in these populations.

Knowledge Translation

In 2019, the OBRI developed 5 peer-reviewed manuscripts and presented 5 oral presentations and 7 unique abstracts at 11 scientific meetings (5 national, 6 international).

The 6th Annual Scientific Meeting was held on May 3, 2019. This annual meeting brings together arthritis stakeholders from across the province for the presentation of cohort findings, investigator led work, and new research linkages and collaborations. The 70 registrants included 25 OBRI Investigators, 14 industry partners, 5 researchers, and 7 patients. The remaining attendees were comprised of consumer and advocacy groups, research coordinators and members of the OBRI team. The plenary speaker, Dr. Andrea Furlan, presented on Pain Management with Opioids and Cannabis. This informative presentation was followed by a panel discussion on Opioids and Medical Cannabis with the panel members each presenting a different perspective on the topic. Dr. Mary-Ann Fitzcharles focused on cannabis research; Laura Murphy, pharmacist - focused on cannabis access and the patient experience; Gerald Major, OBRI Patient Advisory Committee member - shared his personal journey.

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 the 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.

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 of 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.

The OBRI creates individualized yearly aggregated reports for investigators. This report provides information that allows clinicians to compare their practice outcomes to those of the entire OBRI cohort. The stakeholder yearly report provides unique information on the cohort status, patient characteristics and aggregated drug use. This aggregated data is of interest to payers, government and pharmaceutical companies.

Focused evaluation of biosimilars and targeted small molecules

New biosimilars continue to be approved in Canada and 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.

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.

Young Investigators, students and trainees

The OBRI is an exciting place for young investigators, students and trainees to expand their research experience. The OBRI team provides assistance defining their research questions, creating their protocols and analyzing their data. We encourage students and trainees from Ontario and across Canada to contact our team (obri@uhnresearch.ca).

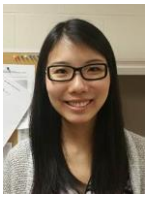
OBRI Investigator Dr. Bindee Kuriya, Director, Rapid Access Rheumatology Clinic, Mount Sinai Hospital, obtained a master's degree in clinical epidemiology from the Harvard School of Public Health. Dr. Kuriya leads the new CARDIA - Cardiovascular Assessment in Rheumatic Diseases and Inflammatory Arthritis - 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.

Dr. Pooneh Akhavan is a Consultant Rheumatologist at Mount Sinai Hospital in Toronto, with a M.Sc. in Clinical Epidemiology. She runs the Early Arthritis clinic at Mount Sinai Hospital. Her main research interests include outcome measures and prognostic modeling in early RA, knowledge transfer, clinical practice guidelines and quality indicators in rheumatic diseases. As an OBRI investigator, Dr. Akhavan is working with the OBRI team to examine the relationship between patient global assessment of disease activity and physician assessment of disease activity at baseline and after one year in patients with early RA.

Mark Tatangelo, PhD candidate at the University of Toronto, is measuring the costs and clinical consequences of rheumatoid arthritis by applying new statistical methods. The outputs of his research will assist clinicians, policymakers, payers, and patients to deliver better care for patients with rheumatoid arthritis.

Over the past two years, Dr. Elliot Hepworth (rheumatology resident at the University of Ottawa) and Dr. Reza Mirza (rheumatology resident at the University of Toronto) worked with the OBRI team to examine the Longitudinal Changes in Relative Market Share Proportions of Biologic and Targeted Synthetic Disease-Modifying Anti-Rheumatic Drugs for Treatment of Rheumatoid Arthritis. This work is now being submitted for publication. In 2020, they will continue to work with the OBRI team to explore the differences and/or similarities of practice and treatment pattern outcomes in rheumatoid arthritis between OBRI academic and community rheumatology practices.

We look forward to the return of Dr. Kangping Cui, as a rheumatology resident at the University of Toronto. As a medical student, Kangping worked on 3 OBRI abstracts which have been presented at both national and international scientific meetings: “Development of an Algorithm for the Classification of Cardiovascular Comorbidity in Rheumatoid Arthritis: Data from the Ontario Best Practices Research Initiative”; “Cardiovascular Disease Risk Factors May Negatively Impact Rheumatoid Arthritis Disease Outcomes: Findings from the Ontario Best Practices Research Initiative”; and “Contributions of Social Determinants of Health on Treatment Responses in Rheumatoid Arthritis Patients”.



As a pharmacy student at the University of Toronto, Nancy Guo worked with the OBRI team to develop the abstract “Disease activity in moderate rheumatoid arthritis patients – Results from the Ontario Best Practices Research Initiative” which was presented at the 2015 CRA Annual Scientific Meeting. Nancy, now a practicing oncology pharmacist in Kingston, ON, has revived this research question. Using more recent and sophisticated data analyses, she is now preparing this work for publication.

2019 Recruitment Activity (as of January 11, 2019)

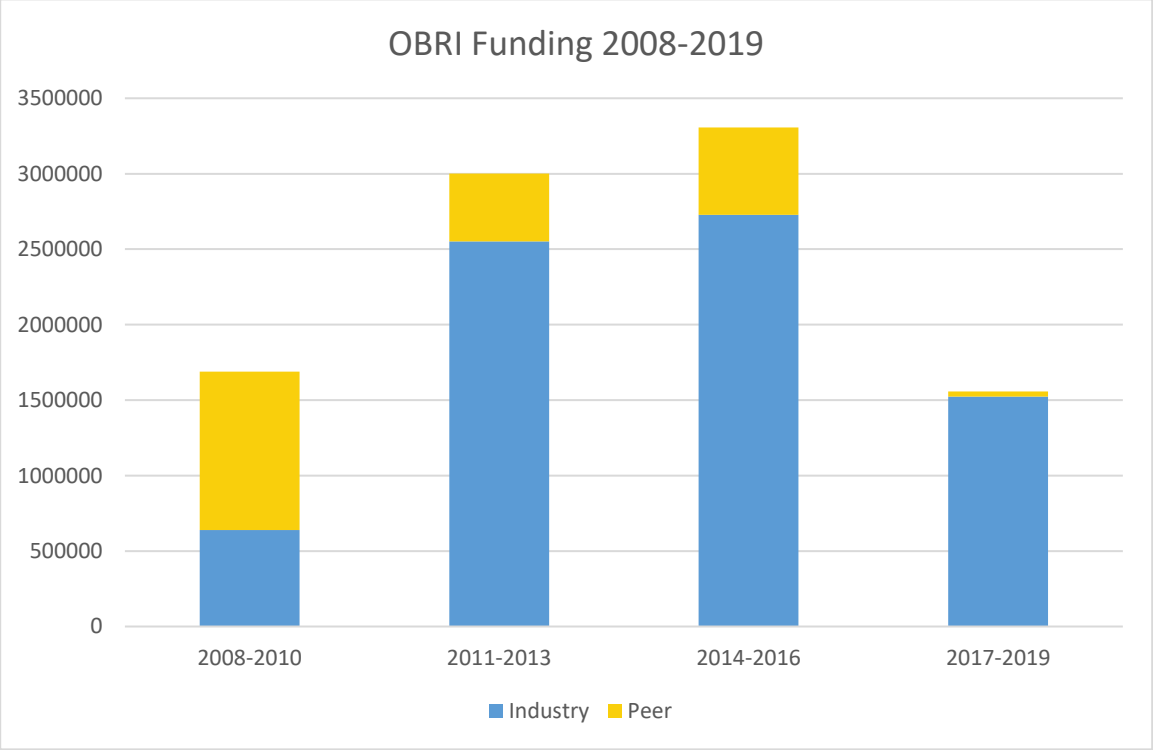
	RA Cohort N (%)
Patients referred to OBRI	4574 (100.0)
Patients refused[1]	674 (14.7)
Patients with consent pending	7 (0.2)
Patients consented	3893 (85.1)
Physician data	3887 (99.8)
Interviewer data	3707 (95.2)
ICES linkage	3866 (99.3)
Withdrawals	
0-2 years	178 (4.6)
>2 years	157 (4.0)
Patient lost to follow-up[2]	219 (5.6)
Patients deceased	198 (5.1)
Patients who have reached & completed:	
Baseline	3893 (100)
1-year follow-up	3542 (91.0)
2-year follow-up	3185 (81.8)
3-year follow-up	2820 (72.4)
4-year follow-up	2502 (64.3)
5-year follow-up	2148 (55.2)
6-year follow-up	1446 (37.1)
7-year follow-up	1090 (28.0)
8-year follow-up	679 (17.4)
9-year follow-up	360 (9.2)
10-year follow-up	162 (4.2)

[1]Patient refused to participate in any aspect of OBRI.
[2]Interviewer not able to contact patient. No data from patient for ≥ 18 months AND no physician reported data has been received for ≥ 18 months

Financial Report

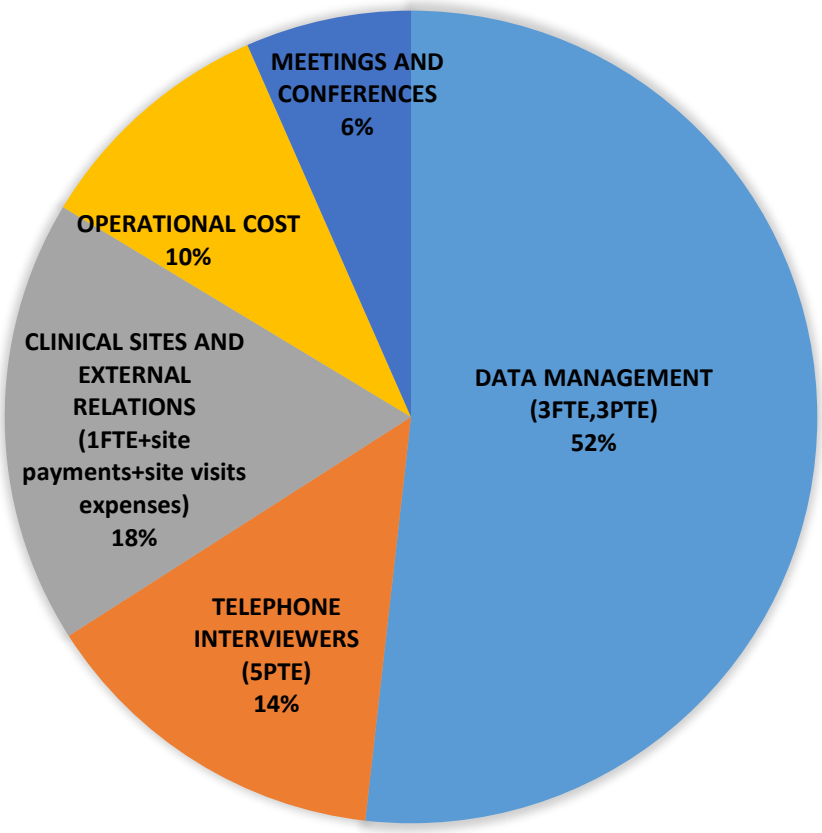
At OBRI, our main source of revenue comes from sponsorship; however, peer-reviewed funding has been awarded to OBRI for specific research activities. In 2019, OBRI received sponsorship from 8 industry partners. Sources of funding revenue from 2008-2019 are presented below.

OBRI Funding Revenue



OBRI Expenditures

OBRI expenditures for the fiscal year April 2018 – March 2019 totaled $646,026.



Meetings & Conferences

In 2019, the OBRI participated in and presented at the following national and international scientific meetings:

- Canadian Rheumatology Association (CRA) Annual Scientific Meeting, Montreal, QC. February 27-March 2, 2019
- New England Rheumatology Society (NERS) Spring 2019 Meeting, Boston, MA. May 9, 2019
- Institute for Work & Health Systematic Review Workshop, Toronto, ON. May 17, 2019
- Ontario Rheumatology Association (ORA) Annual Meeting, King City, ON. May 24-26, 2019
- European League Against Rheumatism (EULAR) Congress 2019, Madrid, Spain. June 12-15, 2019
- Research Methodology Academy, Co-Chair.. 9th Abu Dhabi Advanced Rheumatology Review Course (ADARRC), Workshop. Abu Dhabi, United Arab Emirates. October 11, 2019
- EULAR Registers and Observational Drug Studies (RODS) Meeting, Amsterdam, Netherlands. October 18-19, 2019
- Canadian Association for Population Therapeutics (CAPT), Toronto, ON. October 21-22, 2019
- American College of Rheumatology (ACR) Annual Scientific Meeting, Atlanta, GA. November 8-13, 2019
- Real-World Evidence: Key Concepts and Insights. AbbVie Kick off Meeting "the ESPOIR": Evaluating Studies: Program to Improve the Interpretation and Clinical Application of Research in RA Program, Montreal, QC. November 15, 2019
- French Congress of Rheumatology Association Meeting, Paris, France. December 8-10, 2019

Awards and Recognition

Dr. Claire Bombardier, OBRI principal investigator, was recognized by The Arthritis Society (TAS) as one of Canada's Leading Women in Arthritis on March 7, 2019, International Women's Day. Dr. Bombardier is the inaugural recipient of a lifetime achievement award and the Arthritis Society's Gala honouree. Her reputation is recognized on an international level for her achievements in the field of rheumatology. In addition to being the OBRI Principal Investigator, she is also a Senior Scientist at the Toronto Research Institute and former Co-Scientific Director at the Canadian Arthritis Network.

Catherine Hofstetter, Chair of the OBRI Patient Advisory Committee, was also recognized during the Gala honouring the Canadian trailblazing women who have made an impact on arthritis research and care. For many years, Cathie has been an active advocate for people with arthritis, having served on Patient Partners in Arthritis, the Canadian Arthritis Network, the Ontario Rheumatology Association 'Models of Care' committee, and the OMERACT worker productivity special interest group.

Dr. Edward Keystone received the 2019 CRA Distinguished Rheumatologist Award at the Annual CRA meeting in Montreal. Dr. Keystone established The Rebecca Macdonald Centre for Arthritis and Autoimmune Disease – a centre devoted to research of genomics, therapeutics, and outcomes in autoimmune inflammatory joint disease. He is Director of the Centre and heads the Advanced Therapeutics Division which focuses on novel therapeutics in Rheumatoid Arthritis. Dr. Keystone is a member of the OBRI Clinical Advisory Committee and recently published "Towards Defining Primary and Secondary Non-Response in Rheumatoid Arthritis Patients Treated with Anti-TNFs: Results from the BioTRAC and OBRI Registries".

Anne Lyddiatt, member of Patient Partners in Arthritis, was involved with the OBRI at its' inception. For many years, she brought her patient perspective to the OBRI by participating on the Patient Advisory Committee. Anne has served on many committees and has received many awards, including the Queen Elizabeth II Diamond Jubilee medal in 2010. We congratulate Anne on receiving the distinguished Qualman-Davies Arthritis Consumer Community Leadership Award award.

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 well-being 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

The OBRI PAC oversees 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 committee also co-facilitates the Patient Information Sessions to communicate OBRI research activities to participants.

Patient Advisory Committee:

- Catherine Hofstetter
- David Barker
- Jennifer Boyle
- Maureen Forbes
- Lynda Linderman
- Gerald Major
- Erinn McQueen
- Denis Morrice

Clinical Advisory Committee (CAC)

The Clinical Advisory Committee (CAC) was developed in 2015 to serve as an oversight committee to:

- provide expert advice on matters relating to OBRI internal operations
- provide strategic leadership for communications and interactions with external stakeholders (i.e., Patients, Payers, Providers, Professional Associations) and industry relations
- engage and mentor junior investigators
- prioritize research questions to ensure alignment with OBRI overall goals and diversification of funding.
- 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. This collaboration resulted in 3 publications in 2019 (see publication summaries highlighted in Key Findings for 2019).

Clinical Advisory Committee:

- Dr. Vandana Ahluwalia
- Dr. Sibel Aydin
- Dr. Claire Bombardier
- Dr. Vinod Chandran
- Catherine Hoffstetter (PAC)
- Dr. Edward Keystone
- Dr. Arthur Lau
- Dr. Janet Pope
- Dr. Carter Thorne

Thank you to the OBRI Investigators

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Dr. Nicole Le Riche[3]
Dr. Felix Leung
Dr. Frances Leung[3]
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Dr. Mark Matsos[3]
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Dr. Edward Ng
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Dr. Louise Perlin
Dr. Janet Pope
Dr. Jane Purvis
Dr. Raman Rai
Dr. Gina Rohekar
Dr. Sherri Rohekar
Dr. Thanu Ruban
Dr. Nooshin Samadi
Dr. Sharron Sandhu
Dr. Saeed Shaikh
Dr. Ali Shickh
Dr. Rachel Shupak
Dr. Doug Smith[3]
Dr. Elaine Soucy
Dr. Jonathan Stein
Dr. Andy Thompson[3]
Dr. Carter Thorne[1]
Dr. Sharon Wilkinson[3]

[1]RA & SpA
[2]SpA only
[3]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 would like to thank our dedicated team of interviewers for their role ensuring that patient data is collected in a standardized manner.

OBRI Interviewers

- Lynda Linderman
- Andrea McClintock
- Colleen Perrin
- Linda Rosengarten
- Sharon Zwarych



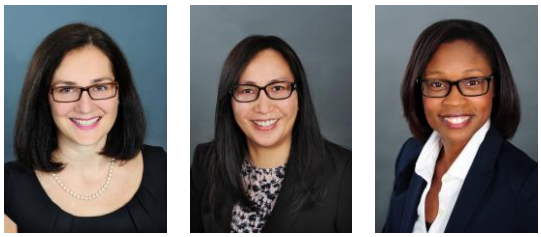


OBRI TEAM

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, presentations, and manuscripts for a variety of vested stakeholders including clinicians, patients, manufactures and payers.

OBRI Staff

- Claire Bombardier, MD, OBRI Principal Investigator
- Angela Cesta, Clinical Research Coordinator
- Mohammad Movahedi, MD, PhD, Research Associate II
- Xiuying Li, Data Manager
- Carol Mously, Site Coordinator
- Leanie Culanding, Budget and Finance Manager (part-time)
- Cheryl Dawson-Titus, Administrative Assistant (part-time)



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