

# **BRIDGING THE GAP TO ACCESS: PATIENT-CENTERED CARE IN EVOLVING HEALTHCARE SYSTEMS**



# Message from The President

## Welcome to the CAPT-ACTP 2024 Conference!

It's my pleasure to extend a warm welcome to everyone joining us at the 2024 Canadian Association for Population Therapeutics (CAPT) / Association Canadienne pour la Thérapeutique des Populations (ACTP) annual conference. We are thrilled to connect and reflect on the critical issues facing those of us engaged in population therapeutics, real-world evidence, and health technology assessment in Canada.

This year's theme, "Bridging the Gap to Access: Patient-Centered Care in Evolving Healthcare Systems," underscores our commitment to placing patients at the heart of our discussions. As we navigate the complexities of modern healthcare, it is essential to consider patient perspectives and bring together stakeholders from across Canada to brainstorm solutions, share innovations, and highlight best practices.

Healthcare in Canada continues to face substantial challenges. From changes in the healthcare workforce composition to the redeployment of healthcare funding as we recover from recent disruptions, the landscape is evolving rapidly. At CAPT-ACTP, we believe that learning from each other is the best way to find success. We look forward to hearing how collaboration and innovation can benefit all Canadians.

I would like to extend my heartfelt thanks to all our partners at every level of sponsorship for their support. Your commitment to CAPT-ACTP is crucial for us to hold our annual conference and continue these meaningful conversations. We are also pleased to recognize and welcome our invited speakers, moderators, and poster presenters who will share their expertise with us.

This event would not be possible without the dedication of our CAPT/ACTP board and committees. I would like to acknowledge the Scientific Planning Committee for building the program, the Partnership Committee for liaising with our partners, the Membership Marketing and Students Committee for focusing on our students' experience, and the local organizing committee for implementing the vision.

Please enjoy your time at the CAPT/ACTP annual conference. Follow us on X/Twitter (@CAPT\_ACTP), join our group on LinkedIn, and mention the conference with the hashtag #CAPT\_ACTP2024. We are looking forward to an inspiring and productive event.

*Julia Shen*

**CAPT-ACTP President**

**October 21 & 22, 2024**  
**MaRS Discovery District, Toronto ON**

# Conference Overview

## Conference Overview

Welcome to the 2024 CAPT-ACTP conference! We are so grateful to see everyone in person again. The theme of this year's conference, "Bridging the Gap to Access: Patient-Centered Care in Evolving Healthcare Systems," aims to be thought-provoking and solutions-oriented as we explore innovative approaches in the healthcare space.

Given Canada's vast geographical area and complex healthcare systems, silos in decision-making, communication, and policy creation often exist. This conference brings stakeholders together to explore ways of simplifying processes and improving the wellbeing of Canadians.

Over the past year, the Scientific Program Committee, our partners, and invited speakers have meticulously prepared for this event. We are pleased to have an incredible keynote address this year, presented by Reshma Amin, who will discuss the challenges and gaps in data collection and evidence related to rare diseases, along with her work to find solutions.

Our panel sessions will cover a range of critical topics, including rare disease policy, oncology drug access, Type 1 Diabetes (T1D), societal elements for Canadian Health Technology Assessment (HTA) submissions, and infrastructure related to registries and disease testing. We are also excited to offer a poster session and a career fair as part of the conference programming. We hope attendees take part in all of the offerings brought to you this year!

The Scientific Program Committee would like to thank our partners, without whose support and collaboration, this year's conference would not be possible. We have a great agenda lined up and hope everyone takes the opportunity to learn, engage in meaningful discussions, and network.

*Julia Shen & Adam Haynes*

**CAPT-ACTP Scientific Program Committee Co-Chairs**

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# Day 1

**Monday, October 21, 2024**

**7:00AM – 8:30AM** Registration / Breakfast

**Location:** Lower Concourse Auditorium Foyer

**8:30AM – 8:45AM** Welcome to the 2024 CAPT-ACTP Conference

**Location:** Lower Concourse Auditorium

**Speaker:** Julia Shen, CAPT-ACTP President

**8:45AM – 9:30AM** **Keynote Address**

**Speaker:** Dr. Reshma Amin, *University of Toronto, Sick Kids, ICES*

**Title:** Closing The Gap by Understanding The Burden of Rare Diseases

**Session Overview:** At present, knowledge gaps in the clinical management and outcomes of individuals with rare diseases result in unnecessary variation in clinical practice across Canada. This session will focus on closing the gap by understanding the burden of rare diseases across the healthcare system. Although administrative data can improve epidemiologic and health system knowledge, specific challenges for rare diseases exist which include cohort identification, low disease prevalence potentially limiting analyses across provinces and lack of patient reported outcomes. Using the Canadian Neuromuscular Disease Registry as an exemplar, this presentation will discuss how clinical registries, one form of real world data, offer a unique opportunity to overcome the challenges faced when using health administrative data alone to evaluate the impact of rare disease on the healthcare system. Implementation barriers as well as lessons learned will be discussed.

**9:30AM – 10:30AM** Sponsored by Bayer

**Title:** What's up with TAT (Turn-Around-Time)? Tackling Cancer Genomic Testing Inequities in Ontario

**Moderator:** Filomena Servidio-Italiano, *President and CEO of CCRAN*

**Speakers:** Dr. Michael Raphael, *Medical Oncologist at the Odette Cancer Centre, Sunnybrook Health Sciences Centre*

Dr. Bryan Lo, *Molecular Pathologist and Assistant Professor at The Ottawa Hospital, General Campus, Division of Anatomical Pathology*

Dr. Ken Craddock, *Molecular Pathologist at Sunnybrook Health Sciences Centre in Toronto*

Steve Slack, *Patient Advocate, Colorectal Cancer Resource & Action Network (CCRAN)*

**Session Overview:** Over the past decade there has been an exciting increase in the detection of targetable genomic biomarkers in cancer that has led to great improvements in patient outcomes. Despite these advances, a persistent challenge has emerged. Increasing demand for multiple biomarkers in many cancer types can lead to delays in reported results, thus delaying treatment, and in some cases leading to negative patient outcomes. In this session panelists tackle this issue by first outlining barriers that impact testing “turn-around-time” and how it can lead to patient inequities in accessing timely and accurate reports. Participants will learn of the negative clinical patient impacts and consequences of delays in TAT and learn/discuss potential new solutions to improve on this issue, with a focus on Ontario based initiatives.

**10:30AM – 11:00AM** Morning Break

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# Day 1

**Monday, October 21, 2024**

**11:00AM – 12:00PM** Sponsored by Takeda

**Title:** A Wave of Innovative Rare Disease Drugs is Coming – Is Canada's Healthcare System Ready?

**Moderator:** Brad Millson, General Manager, Real World Solution (RWS) IQVIA Canada

**Speakers:** Whitney Ayoub-Goulstone, Executive Director, ImmUnity Canada

Christine Elliott, Counsel, Fasken Health Law and former Ontario Minister of Health and Deputy Premier

Muhammad Mamdani, VP of Data Science and Advanced Analytics, Unity Health and Director, T-CAIREM, UofT

Jim Dowling, Staff Clinician and Senior Scientist, Hospital for Sick Children, Pediatrics and Molecular Genetics, UofT

**Session Overview:** This dynamic panel will bring together a diverse set of healthcare system stakeholders to address the readiness of Canada's healthcare system for the increased number of drugs for rare diseases (DRDs) expected to launch in the next decade. The main objectives of the panel session are to explore key considerations, challenges, and collaborative solutions for enhancing healthcare system readiness.

*The session will discuss several important topics:*

- Current barriers to access treatments for rare diseases from the perspective of patients, clinicians, researchers, and government and how they may be impacted with the pipeline of DRDs expected to launch.
- The need for broader awareness of rare diseases, consistent screening and diagnostic pathways across Canada, infrastructure to ensure equitable access and government collaborations at the inter-ministry or inter-provincial level
- A short-list of policies and potential solutions that should be prioritized in the near-term and long-term to incrementally improve health system readiness

**12:00PM – 12:45PM** Lunch and Networking

**Location:** Lower Concourse Auditorium Foyer

**12:45 – 1:45PM** Sponsored by Alexion

**Title:** Filling the gap: The case for a policy observatory to serve the Canadian rare disease policy ecosystem

**Moderator:** Dr. Judith Glennie, President, J.L. Glennie Consulting Inc.

**Speakers:** Dr. Rebecca Marsh, Director – HTIP, Institute for Health Economics

Dr. Gail Ouellette RQMO and Co-chair, Health Canada IAG for the National Strategy for Drugs for Rare Diseases

Marcel Saulnier Health policy consultant and former Associate ADM, Strategic Policy Branch, Health Canada

Dr. Hernan Gonorazky Neuromuscular and Movement Disorders Specialist and Neuromuscular Program Coordinator, The Hospital for Sick Children

**Session Overview:** While there are a number of rare disease (RD) initiatives underway in Canada, there are no programs specifically targeting RD policy research, particularly as it relates to medication access and reimbursement policies. There is a need for concerted and collaborative efforts in policy research, to move the Canadian RD ecosystem forward in an evidence-informed manner. A Canadian RD Policy Observatory (PO) is proposed, to serve as an evidence-support organization for RD policy and provide a key tool for long-term policy research and stakeholder engagement. The Observatory would convene a diverse group of multidisciplinary subject matter experts, with the objective of conducting policy research and generating practical solutions that will contribute to the Canadian RD policy ecosystem. The Observatory could also serve as a central point for sharing and coordination among existing entities and stakeholders, fostering collaboration and policy development tailored to the unique needs of RD patients.

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# Day 1

**Monday, October 21, 2024**

**1:45PM – 2:45PM** Sponsored by AstraZeneca

**Title:** An RWE case study in oncology: Generating timely and meaningful Canadian real-world evidence to support an outcomes-based market access agreement

**Moderator:** Allison Wills, 20Sense Consulting

**Speakers:** Dr. Winson Cheung, University of Calgary Oncology Outcomes Program

Dr. Aryn Sayani, Head, Medical Evidence, AstraZeneca Canada

Jessica Arias, Manager, Provincial Drug Reimbursement Programs, Ontario Health

Graham Statt, Former Vice-Chair of the pCPA and ADM of the Pharmaceutical and Supplementary Benefits Division at Alberta Health

**Session Overview:** This session will explore practical learnings for the utilization of Canadian real-world data (RWD) to support an outcomes-based market access agreement (OBA), based on the preliminary findings from a retrospective observational study (the “ASCOT” study: Alberta Small Cell Lung Cancer Study on Outcomes and Treatments Since the Introduction of Durvalumab). Key principles and success factors of the simulated OBA will be discussed, as will perspectives from various healthcare system stakeholders. The panel will address specific considerations that should be given to operationalizing an OBA using RWE as an enabler.

**2:45PM – 3:15PM** Afternoon Break

**3:15PM – 4:15PM** Sponsored by Pfizer

**Title:** Are healthcare systems ready for advanced therapeutics?

**Moderator:** Monika Sloviniec D’Angelo, Health Policy and Technology Assessment Consultant

**Speakers:** Don Husereau, University of Ottawa (Researcher)

Cynthia Di Lullo, Oncology Canada Lead, Pfizer Canada ULC

**Session Overview:** Patients may increasingly be faced with barriers to timely access to new advanced therapeutics, such as T-cell-based therapy and T-cell-binding antibodies, due to heightened requirements for multidisciplinary administration and toxicity monitoring and management. This includes requirements for access to urgent care specialists, other specialized therapeutics, and out of hours imaging. In the Canadian context, this will be particularly challenging for stand-alone cancer centres outside of urban environments. This may put a patient with a life-threatening cancer in a situation where a new therapy is marketed, and payers are committed to funding it, but access is prohibited by the availability of capital and human resources or other key aspects that relate to the organization and financing of high-quality care.

*This panel will explore key questions such as:*

- How big is the problem facing Canadian healthcare systems?
- How do we ensure patients, care providers, regulators, administrators, payers, and technology producers are creating collaborative solutions?
- How can we change healthcare systems to accommodate specialized requirements of advanced therapeutics?

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# Day1

**Monday, October 21, 2024**

**4:15PM – 5:15PM** Student Oral Presentations

**5:15PM – 5:30PM** Day One Closing Remarks

**Location:** Lower Concourse Auditorium

**Speaker:** Julia Shen, CAPT-ACTP President

**5:30PM – 6:30PM** Reception and Poster Exhibition

Drinks and Hors D'oeuvres

**Location:** Lower Concourse Auditorium Foyer

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# Day<sup>2</sup>

**Tuesday, October 22, 2024**

**7:00AM – 8:30AM** Registration / Breakfast and Networking

**Location:** Lower Concourse Auditorium Foyer

**8:30AM – 8:45AM** Welcome to Day 2

**Speaker:** Julia Shen, CAPT-ACTP President

**8:45AM-9:45AM** Sponsored by IQVIA

**Title:** Maximizing the Impact of Patient Registries in Rare Disease

**Moderator:** Brad Millson, General Manager, Real World Solution (RWS) IQVIA Canada

**Speakers:** Angie Wong, Director, Drug Programs Policy and Strategy Branch, Ontario Ministry of Health

Trish Caetano, Director, Drug Data Services and Analytics, Canada's Drug Agency

Dung Pham, Medical Affairs Director, Mitsubishi Tanabe Pharma Canada

Joan Paulin, Pulmonary Hypertension Association Canada (PHA Canada) Board Chair and Patient Representative

**Session Overview:** In 2023, the Canadian Government committed \$1.5 billion over three years to launch the first National Strategy for Drugs for Rare Diseases. This significant investment aims to enhance research, infrastructure, and treatment options for rare conditions. A portion of this funding is allocated to supporting patient registries, providing an opportunity to elevate the quality and importance of data collected through patients. Given the inherent differences among registries, it is crucial to maintain flexibility and recognize the unique value each registry offers, while simultaneously seeking opportunities to improve their utility to advance research and improve patient care and access.

This panel will bring together multidisciplinary experts to discuss actionable strategies for registry holders. The focus will be on practical approaches to enhance data quality, utility, and acceptance, ultimately maximizing the impact of patient registries in advancing rare disease understanding and improving patient outcomes as well as informing HTA assessments and paving the way for value-based agreements.

**9:45AM – 10:45AM** Sponsored by Roche

**Title:** Collaborative Approaches for Incorporating Societal Value in Canadian HTA

**Moderator:** Sarah Vaselenak, Health Economist at Roche Canada

**Speakers:** Jaclyn Beca, Director of Pharmacoeconomics and RWE, MORSE

Homira Osman, Vice President of Research and Public Policy at Muscular Dystrophy Canada

Graham Statt, Former Vice-Chair of the pCPA and ADM of the Pharmaceutical and Supplementary Benefits Division at Alberta Health

Man Wah Yeung, Senior Policy Advisor in the Centre for Vaccine and Therapeutics Readiness at the Public Health Agency of Canada

**Session Overview:** In 2024, CDA-AMC began considering the societal perspective in economic evaluations for drugs reviewed through the complex review process - a pilot that is aligned with the existing INESSS and NACI processes for drug and vaccines. This panel will focus on key considerations for the shift towards incorporating broader value elements in HTA, and the impact this shift will have on reimbursement decision making in Canada. Panelists will discuss potential quantitative and qualitative best practices, and how to foster a collaborative approach to support this ongoing evolution of HTA in Canada.

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# Day<sup>2</sup>

**Tuesday, October 22, 2024**

**10:45AM – 11:15AM** Morning Break

**Location:** Lower Concourse Auditorium

**11:15AM – 12:15PM** Sponsored by Sanofi

**Title:** Beyond the Diagnosis: Rethinking Type 1 Diabetes Care

**Moderator:** Lara Green, National Manager, Research and Training Programs at JDRF Canada

**Speakers:** Dr. Bruce Perkins, Professor of Medicine and Clinician-Scientist, University of Toronto

Sonia Sidhu, Member of Parliament for Brampton South, Chair of the All-Party Diabetes Caucus in Parliament

Jennifer Bizzarri, Individual living with T1D and Board Member, JDRF

**Session Overview:** This panel will delve into the critical issues surrounding autoimmune type 1 diabetes in Canada, highlighting the existing gaps in care and the significant burden placed on caregivers. We will explore the profound impact on patient quality of life and the current lack of comprehensive screening for early detection. Our discussion will focus on actionable strategies to better prepare Canada for the future, ensuring robust support systems for patients and their families. Join us as we bring together experts, caregivers, and patients to envision a more inclusive and supportive healthcare landscape for those affected by this chronic condition.

*Objectives from the discussion include:*

- Dive into the complexity of autoimmune T1D and learn about patient disease burden
- Panel perspectives discussing gaps in infrastructure and current treatment
- Brainstorm actionable multi-stakeholder strategies and initiatives including the early detection of aT1D

**12:15PM – 1:30PM** Lunch, AGM, and Awards Ceremony

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# Day<sup>2</sup>

**Tuesday, October 22, 2024**

**1:30PM – 2:30PM** Sponsored by I2U

**Title:** Closing the Last Mile: How Improving System Readiness is Key to Faster Patient Access

**Moderator:** Ross Wallace, Advisor for I2U and Principal at Santis Health

**Speakers:** Caroline Barber, Vice President of Public Affairs and Government Relations at Novartis Canada

Graham Statt, Former Vice-Chair of the pCPA and ADM of the Pharmaceutical and Supplementary Benefits Division in Alberta Health

Martine Elias, Executive Director at Myeloma Canada and Chair of CONECTed

Zayna Khayat, Health Futurist at Deloitte

**Session Overview:** After reimbursement in Canada an entirely new challenge emerges for complex breakthrough therapies: how to ensure that health systems have the capacity and capability to optimize patient access. Focused on accelerating the path from “Idea to Utilization,” I2U was launched to help payers and policymakers better evaluate and improve the readiness of health systems to maximize the value of breakthrough therapies. I2U recently developed a Breakthrough Therapy Implementation Toolkit to provide government officials, patient groups, manufacturers and other interested parties with a practical tool that not only helps evaluate health system readiness, but also identifies the assets and resources already available to help optimize uptake of new breakthrough therapies. Through our participation in the 2024 CAPT-ACTP conference, I2U is hoping to accomplish 3 goals:

- Highlight how health system readiness plays a critical role in determining how quickly, easily and effectively breakthrough therapies are implemented.
- Review the key conclusions and insights I2U has gathered through its research into the importance of implementation excellence.
- Introduce the Breakthrough Therapy Implementation Toolkit and outline its relevance to the multiple audiences committed to optimizing patient access.

**2:30PM – 2:45PM** Closing Remarks

**Location:** Lower Concourse Auditorium

**Speaker:** Adam Haynes, CAPT-ACTP President-Elect 2024

For any inquiries (abstracts, hotel, registration, etc.), please contact [captannualmeeting@gmail.com](mailto:captannualmeeting@gmail.com), Ms. Alyssa Ennis ([Alyssa.ennis@sunnybrook.ca](mailto:Alyssa.ennis@sunnybrook.ca)), or visit the CAPT-ACTP website ([www.capt-actp.ca](http://www.capt-actp.ca)) for more information.

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# Conference Abstracts

[Click HERE to view the Abstract Booklet](#)

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