

# ANNUAL REPORT 2020/2021



Changing the way pain is managed in Canada

# **MISSION**

To innovate and improve the quality and delivery of pain prevention, assessment, management and research for all Canadians.

Officially launched in 2016, the Chronic Pain Network is a pan-Canadian collaboration of patients, researchers, healthcare professionals, educators, industry and government policy advisors to direct new research in chronic pain, train researchers and clinicians, and translate findings into knowledge and policy. The Network also provides direct funding to more than twenty research projects, covering population studies, behavioural studies, basic science and clinical trials.

Patients are engaged as partners to identify priorities to improve health outcomes, identify new treatments and deliver a more effective healthcare system to fellow Canadians

The ultimate goal of the Network is to reduce pain and improve function, participation and quality of life for those affected, while alleviating the economic burden of pain over one's lifespan.

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**Dr. Norm Buckley**Scientific Director

# A MESSAGE FROM THE SCIENTIFIC DIRECTOR

It came as some surprise that, of all people, it would be Lady Gaga who would raise significant global awareness to the challenges of those living with chronic pain and other invisible illnesses. Yet, this is a perfect representation of the scope of chronic pain and its widespread impact. Chronic pain effects both young and old alike. It does not discriminate against height or weight. There is no guaranteed solution or method

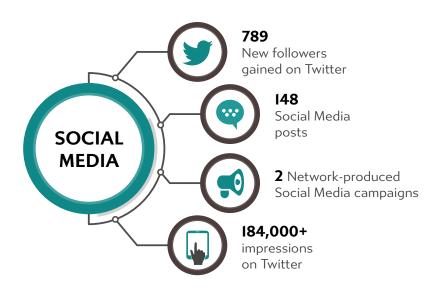
of avoidance, and there is no one-size-fits-all solution. In her Netflix documentary, Gaga: Five Foot Two, the singer chronicles the challenges faced by those living with a poorly understood chronic illness .

The funding of the Chronic Pain Network in 2016 marked an exceptional level of investment in pain research by the Canadian Institutes of Health Research. The challenge now is maintaining the momentum created so that Canadians see knowledge generated by this increased awareness translated into tangible actions.

In its third and final report, the Canadian Pain Task Force utilized an illustration, consisting of concentric circles, to show action plan outcomes supported by four central goals, with overarching goals of equity, coordination and stakeholder involvement. Many of the actions identified are already underway through current Network projects and work being done through committees in the Network's governance structure.

The call from CIHR now is for a Chronic Pain Network focused directly upon mobilizing knowledge into action. The plan that we have submitted describes a cohesive process engaging with people with lived experience, learners, educators, clinicians, administrators and policy makers across Canada to engineer changes that will improve the lives of people living with pain in Canada.

# BY THE NUMBERS - 2020/2021





**1,284** Trainees reached through Network-supported activities



**114** Members in the Network's Governance Structure



**10** New plain language summaries produced for PainPLUS CPN



**95** Peer-reviewed publications by Network members



**4** New Clinical Research Network sites



**7** Multi-Site Clinical Research Network Projects



**122** Single-Site Clinical Research Network Projects

# **HIGHLIGHTS**



# **KEY ACHIEVEMENTS**

One of five networks addressing chronic disease funded through the Canadian Institute of Health Research's Strategy for Patient Oriented Research (SPOR), the Chronic Pain Network is awarded a five-year grant for \$12.5 million. This marks an unprecedented investment in pain research, as well as collaboration amongst 27 different institutes across the country.

# **KEY ACHIEVEMENTS**

The process of signing contracts concluded and funds start flowing to support the activities of the six committees supporting the Chronic Pain Network's governance structure and 22 individual Networkaffiliated research projects. Policies surrounding the recognition and payment of people with lived experience are put into place. Hosted McMaster Health Forum. Deliberative Dialogue to produce a Canadian Pain Strategy document.

# **KEY ACHIEVEMENTS**

The Network presents its first webinar series, led by the Patient Engagement committee, and PainPLUS CPN is launched. First year of funding is successfully transferred to all projects. Clinical Research Network sites are fully staffed and have more than 50 combined pain studies underway, including three multi-centre studies with a focus on pediatric pain.



# **KEY ACHIEVEMENTS**

Federal Minister of Health, the Honourable Ginette Petitpas Taylor, announces the formation of the Canadian Pain Task Force. The Task Force consists of eight members, which include four members of the Chronic Pain Network's governance structure. The Pediatric Registry Working Group pilots the Canadian Pediatric Patient Pain Registry at the Hospital for Sick Children.

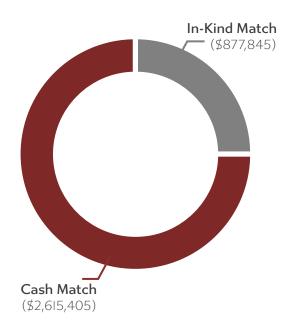
# **KEY ACHIEVEMENTS**

Network patient perspective partners publish paper Guidance on Authorship with and Acknowledgment of Patient Partners in Patient-Oriented Research. The Adult Registry Working Group pilots the questionnaire to be used as the main collection tool for the Canadian Adult Pain Patient Registry. The Clinical Research Network adds one new site in Quebec.

# **KEY ACHIEVEMENTS**

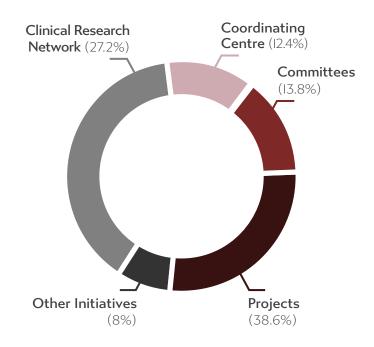
The Canadian Pain Task Force releases its final report. Three new sites join the Clinical Research Network. The CPN awards two grants in Knowledge Translation to support the dissemination of research evidence and facilitate effective uptake that has the potential to impact health, care or research. Application for the next iteration of the Chronic Pain Network is submitted to CIHR.

# **NETWORK FINANCIALS**



# **MATCH FUNDING**

As part of its initial application for the Strategy for Patient Oriented Research (SPOR) grant, the Chronic Pain Network iidentified \$20,767,855, over five years, in designated funds from partnering institutions. Securing I:I match funding from non-federal government partners was just one of the SPOR submission requirements. The Network has now received all pledged funds, with \$3,493,250 of the pledged cash and inkind match received in Year Five.



# **EXPENSES**

Year Five of the Chronic Pain Network saw project funding as the Network's largest expense, with 38.6% of the budget spent directly on pain research. The Clinical Research Network received 27.2% of the Network's budget, while committees accounted for I3.8% of Network spending. Other initiatives, such as Pain Management in Hemophilia training and Knowledge Translation awards, accounted for 8% of the budget.

# **SOCIAL MEDIA**

Since the Network created its social media channels in December of 2016, its reach has steadily grown. It continues to be the leader in social media activities amongst the five SPOR networks in chronic disease, and even boasts a larger reach than all SPOR SUPPORT units.

Each year, the Chronic Pain Network creates and implements several social media campaigns, such as those supporting National Pain Awareness Week (NPAW). The purpose of NPAW is to create awareness about chronic pain and those affected by it.

The 2020 NPAW campaign saw the CPN taking the opportunity to highlight different vulnerable groups impacted by chronic pain, bringing to light some of the challenges they face, and showed how CPN-supported projects and initiatives are working to create better treatments and access to care for those living with these conditions. Vulnerable groups included: Canadian Veterans, injured workers, senior citizens, children and Indigenous peoples.

The top tweet from the 2020 NPAW campaign was a Twitter post that looked at chronic pain in seniors and the work of Dr. Thomas Hadjistavropoulos and his team, who created the See Pain More Clearly initiative. The tweet received more than 3,000 unique impressions and 60 engagements.

The 202I NPAW campaign saw even more success, with I7.6K impressions on Twitter during its seven days. The top tweet, which featured a quick video that provided an overview of chronic pain in Canada, received I0,959 impressions, 6I likes and 49 retweets. The same post received more than 6,000 impressions and 7I5 ThruPlays on Facebook during the campaign.

The Network also took part in several social media campaigns run by other organizations, such as the PainBC led #PrioritizePain campaign and the United Nation's International Day of Women and Girls in Science.



**4,249** Twitter followers as of December 2021



**251** page likes on Facebook as of December 2021



**24K+** impressions on Twitter in November 202I alone, and **8K+** impressions on Facebook during the same period



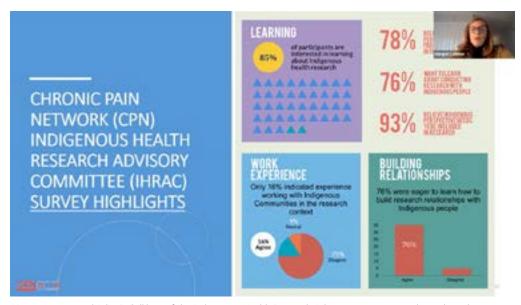
**1,500+** tweets since joining Twitter in December 2016

# **WEBINARS**

"Throw Imposter Syndrome out. Jump in and get to know patient partners," is the key piece of advice Melanie Noel had for trainees and researchers when co-presenting with Patient Perspective Partner Janice Sumpton at the second webinar in the Chronic Pain Network's Patient EngagEment in Research (PEER) webinar series.

During its six years, the Network hosted several webinar series, in addition to seeing its members take part in those held by other organizations, such as Healthcare Canada, the Canadian Pain Society, PainBC and SPOR SUPPORT Units.

The PEER series, a collaborative effort between the CPN's Patient Engagement, Knowledge Translation and Training and Mentoring committees, took a closer look at innovative ways in which patient engagement can take place at all levels of research, using case studies, panel discussions and personal experience to show the evolving role of patient engagement in health research. The series consisted of eight webinars and was aimed



Margot Latimer and John R. Sylliboy, of the Indigenous Health Research Advisory committee, co-hosted a webinar entitled Navigating Knowledge about Protocols and Conducting Indigenous Health Research.

at trainees and researchers.

In addition to Melanie and Janice, presenters included members of the Canadian Pain Task Force, CPN patient perspective partners and project leads from Network-funded projects, as well as members of the Solution for Kids in Pain team.

Webinars for the PEER series, cumulatively, saw more than 290 registrants, and have received several hundred additional views since being posted on the CPN's YouTube channel. They have also been used as a resource for the Advisory Council of Veterans for the Chronic Pain Centre of Excellence for Canadian Veterans.

# PAIN MANAGEMENT IN HEMOPHILIA

In 2017, the Chronic Pain Network united with patient partners, hematologists, pain experts, nurses, physiotherapist and other health care professionals and researchers from across the country to examine the role of pain in hemophilia and the ways in which quality of care and treatments could be improved for those living with the disease.

In order to achieve this, a working group was formed with the aim of identifying chronic pain and acute recurrent pain occurring in hemophilia patients; identifying research needs concerning chronic and acute recurring pain in hemophilia; identifying training and mentoring opportunities around the

study and treatment of chronic/recurring pain and acute pain in hemophilia; an identifying knowledge translation needs and training opportunities addressing chronic and recurring pain within the hemophilia community and beyond.

In 2019, the Michael G. DeGroote Pain Clinic hosted an in-person interdisciplinary Pain Management training day for two hemophilia clinic teams. Presenters included physicians, psychologists, pharmacists, and physiotherapists and occupational therapists. The training was well-received, with plans to hold sessions for more clinics in the future.

With restrictions arising from the COVID-19 pandemic, in-person training sessions evolved into an interactive virtual education series. Issues covered included appropriate assessment of patients with chronic pain, recognizing co-morbidities, creating interdisciplinary pain management treatment plans, and understanding how case management is implemented at the Pain Program - among others.

The series saw participation from across Canada, with the sessions receiving positive feedback from those in attendance. The sessions were recorded for repeat viewing and have been made available online. Plans are underway to examine opening up education sessions to a wider audience.

In addition to the webinars, the hemophilia working group also finalized a clinical pathway, piloted in hemophilia clinics, and engaged a software development group to implement the Pain Treatment Planning Questionnaire (PTPQ), developed by the hemophilia clinic in Saskatchewan and a team led by Susan Tupper CEO of SaskPain. This tool was programmed into the myCBDR app, as a resource for managing, tracking and engaging discussion on pain in hemophilia at patient annual appointments. The app has been tested and was piloted at clinics in Hamilton, Saskatoon and London.

# **IMPACT**

The vision of the Chronic Pain Network is to change the way pain is managed in Canada through improved assessment, prevention and provision of timely and optimal pain management. One of the key ways it has sought to do this is through the creation of a Canadian pain strategy to advise policy makers on the type, magnitude and direction of resource allocation. The creation of the CPN itself allowed the establishment of several elements identified as critical by other organizations, such as the Canadian Partnership Against Cancer, when embarking on the process of establishing a national strategy. Working with the Canadian Pain Care Forum and McMaster Health Policy Forum, deliberations with key audiences were held in order to identify short, medium and long term needs of an effective Strategy proposal.

Significant headway was made in 2019 when the Federal Minister of Health announced the formation of the Canadian Pain Task Force. The Task Force includes people with lived experience, researchers,

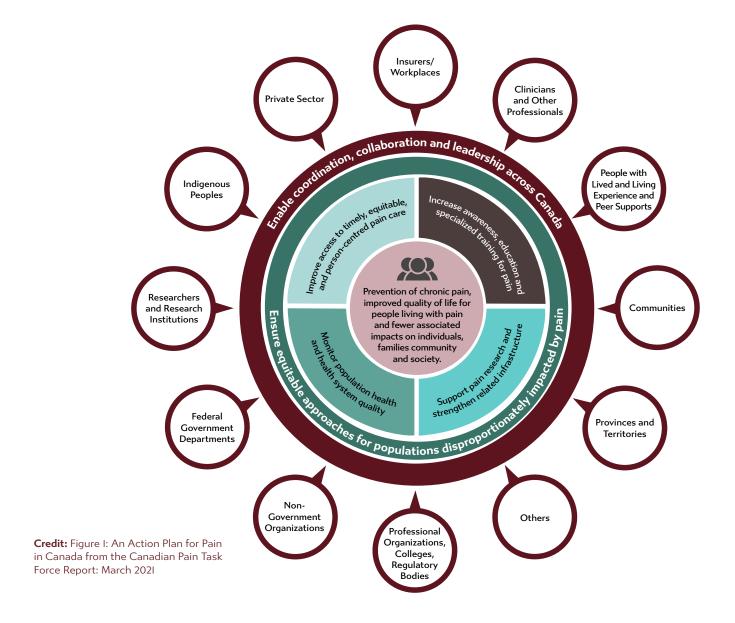
educators and health professionals. and incorporates advice and insights from an external advisory panel consisting of diverse experts in their fields. The CPN saw significant representation in this process, with Network patient perspective members Jacques Laliberté and Linda Wilhelm and Principal Applicants Manon Choinière and Maria Hudspith appointed to the Task Force, and other members of the Network's governance, such as the Network's Scientific Director, Norm Buckley, providing supporting roles on the external advisory panel.

The Task Force produced three reports that highlighted gaps in access to timely and appropriate multi-modal care, chronic pain surveillance and health system quality monitoring, education, training and awareness for individuals and health care providers, and research and related infrastructure; identified gaps, challenges and best practices; and concluded (An Action Plan for Pain in Canada) with recommendations on priority actions to ensure that people with pain are

recognized and supported and that pain is understood, prevented, and effectively treated throughout Canada.

The work of the Task Force has been congruent with the Network's mission to improve quality and delivery of pain prevention, assessment, management and research for all Canadians. In fact, many of the areas identified in the Task Force's Action Plan for Pain are actively being addressed through Network- supported initiatives and projects.

With the momentum and awareness gained over the life of the Network, the challenge now becomes channeling knowledge gained and utilizing newfound resources to create meaningful change at the policy level to eliminate the remaining barriers still faced by those living with chronic pain.



# COMMITTEE HIGHLIGHTS

As part of Network Knowledge Translation (KT) activities, a KT consultant was engaged to meet with project leads and assess the state and extent of their KT initiatives, using a tool developed by Melanie Barwick. The intention was to get project leads to think about KT in a broader sense, beyond publications, and earlier opportunities to disseminate key messages to their identified target audiences. After meeting with each project lead, the completed tool was shared with the Network's KT committee, which then reached out to project leads to determine next steps and identify ways the Network could provide additional support. The KT committee is now in the process of winding down activities in anticipation of the transition into the next iteration of the CPN. This work has been invaluable in identifying potential priority items to pursue during the hoped for Knowledge Mobilization network to come at the call from CIHRfor next steps in CPN.

In 2020, the Indigenous Health Research Advisory committee conducted a survey with CPN members about their knowledge and interest in conducting research with Indigenous Peoples. Nearly all respondents recognized the need for increased Indigenous representation and input in health research, though very few had experience engaging with Indigenous communities. Results were presented at the CPN-hosted PEER webinar, which also shared experiences from the Aboriginal Child Hurt & Healing Initiative (ACHH) and identified Indigenous research methodologies learned through the process.

The Patient Engagement (PE) committee identified a gap concerning authorship and acknowledgment of patient partners and wrote a guidance document, which was published in 2020. In addition to this, patient perspective partners also presented at the Canadian Pain Society Conference in a session entitled "people who Live with Chronic Pain - Efforts in Research and Beyond," which consisted of a panel of four patient partners. The committee has also been engaged with PainBC in the organization of a

conference geared towards people with lived experience planned tentatively for fall 2022.

Many of the initiatives supported through the Network's Training & Mentoring committee saw significant changes in terms of program delivery in 2020 and 2021 due to the appearance of COVID-19. While those originally scheduled to take place in the early days of the pandemic saw cancellation, a switch to virtual platforms saw Network-supported initiatives, like Pain In Child Health (PICH), still able to run much of their programming with some adaptations.

In addition to its support of external initiatives, the Training and Mentoring committee also worked with the Network's KT and PE committees to hold a webinar series, entitled the Patient EngagEment in Research (PEER) series, which was geared towards trainees with the aim of demonstrating innovative ways to include patient engagement at all levels of research.

# COMMITTEE MEMBERS - 2020/2021

#### **EXECUTIVE**

Norm Buckley, Jacques Laliberté. Manon Choinière, Nader Ghasemlou, lan Gilron, Maria Hudspith, Margot Latimer, Mike McGillion, Cyril Schneider & Karen Smith

#### **STEERING**

Norm Buckley, Linda Wilhelm, Susanne Benseler, Lynn Cooper, Manon Choinière, Karen Davis, Luda Diatchenko, Allen Finley, Nader Ghasemlou, Ian Gilron, Maria Hudspith, Alfonso Iorio, Margot Latimer, Mike McGillion, Joy MacDermid, Patricia Poulin, Cyril Schneider, Bonnie Stevens & Jennifer Stinson

#### CLINICAL RESEARCH NETWORK

Ian Gilron, Chris DeBow, Jennifer Anthonypillai, Krista Baerg, Amel Bagdhadli, Orlane Ballot, Jillian Banfield, Helene Beaudry, Etienne Bisson, Stephanie Blackman, Fiona Campbell, Caylin Chadwick, Bruce Dick, Tanya Di Renna, Jessie Dhillon, Scott Duggan, Renée El-Gabalawy, Allen Finley, Lauren Harris, Howard Intrater, Audrée Janelle-Montcalm, Keith Jarvi, James Khan, Susan Lau, Gabrielle Logan, Mary Lynch, Aaron MacInnes, Casey McMahon, Marylie Martel, Marco O. Martel, Melissa Milc, Kendra Mueri, Maliha Muneer, Nida Mustafa, Melanie Noel, Gabrielle Pagé, Anne Marie Pinard, Patricia Poulin, Nivez Rasic, Danielle Rice, Tiffany Rice, Rachel Roy, Yoram Shir, Jennifer Stinson, Sylvie Toupin, Yannick Tousignant-Laflamme, Elodie Traverse, Michelle Verrier, Marc White & Ramesh Zacharias

#### INDIGENOUS HEALTH RESEARCH ADVISORY

Margot Latimer, John Sylliboy, Sharon Rudderham, Maria Hudspith & Elder Margaret Lavallee

#### **KNOWLEDGE TRANSLATION**

Nader Ghasemlou, Lesley Singer, Mary Brachaniec, Katie Birnie, Jennifer Daly-Cyr, Alfonso Iorio, John Lavis, Jennifer Stinson & Karine Toupin-April

#### **PATIENT ENGAGEMENT**

Maria Hudspith, Therese Lane, Delane Linkiewich, Katie Birnie, Jennifer Daly-Cyr, Mario Di Carlo, Kathleen Eubanks, Janet Gunderson, Rebecca Lee, Patricia Poulin, Dawn Richards, Sandy Smeenk, Jennifer Stinson & Linda Wilhelm

#### **PATIENT-ORIENTED RESEARCH**

Cyril Schneider, Marc White, Jason Busse, Louis Gendron, Ian Gilron, Joy MacDermid, Tiffany Rice, Barry Sessle & Janice Sumptom

#### **REGISTRY WORKING GROUP**

Adult Sub-Committee: Manon Choinière, Richard Hovey, Sarah Ahmed, Nicolas Beaudet, Ian Gilron, Irina Kudrina, Curtis May, Dwight Moulin, Dave Walton, Mark Ware, Owen Williamsom & Ramesh Zacharias

Pediatric Sub-Committee: Jennifer Stinson, Carley Ouellette, Krista Baerg, Stephanie Blackman, Fiona Campbell, Bruce Dick, Alex Falcigno, Allen Finley, Lauren Harris, Pablo Ingelmo, Audrée Janelle-Montcalm, Kendra Mueri, Fareha Nishat, Melanie Noel & Tim Oberlander Ad-Hoc Pediatric Sub-Committee: Ardith Baerveldt, Susan Carter, Jennifer Crotogino, Marie-Joelle Doré-Bergeron, Sheri Findlay, Megan Greenough, Abi Kandasamy, Golda Milo-Manson & Fotini Zachariades

#### TRAINING AND MENTORING

Mike McGillion, Carley Ouellette, Christine Chambers, Manon Choinière, Renée El-Gabalawy, Alfonso Iorio, Margot Latimer, Jeff Mogil, Renata Musa, Lesley Singer & Judy Watt-Watson

# REGISTRY WORKING GROUP

The aim of the Networks Registry Working Group has been to put in place a Canadian registry of registries of chronic pain patients to harness existing patient registries, thereby allowing the sharing of data to conduct research on chronic pain.

In order to support the development of new patient registry initiatives using a cohesive national approach, the collection of a standard set of outcome measures amongst registries and use of servers/platforms was deemed necessary.

Having now reached a consensus on a minimum dataset that will constitute the Canadian Adult Pain Registry (CAPR), the Registry Working Group saw the online patient questionnaire containing the minimal dataset and its associated Patient Summary Form (PSF) programmed into the REDCap platform. With the CAPR finalized, ethics approval was granted at two CRN sites. Data is now being collected at intake into the pain clinics and

every three months thereafter. Data obtained will be used to generate reports of the evolution of the patient's condition (PSF). Discussions are ongoing with CPN CRN sites to adapt and integrate the CAPR to local infrastructures and logistics. The CAPR is also informing similar efforts undertaken by the Chronic Pain Centre for Excellence for Canadian veterans.

With the Pediatric Pain Patient
Registry completed its pilot of the
minimum dataset at SickKids, the final
version of the paper questionnaire
and patient summary form is now
complete, as well as the final
protocol submission.

# CLINICAL RESEARCH NETWORK

The Clinical Research Network (CRN) consists of I6 university-affiliated, adult and pediatric, pain treatment facilities across Canada – and continues to grow. As a pivotal component of the Chronic Pain Network, the CRN integrates knowledge, expertise and clinical experience of multi-disciplinary pain clinics to conduct clinical trials, establish and maintain the Canadian Pain Registry, and facilitate dozens of other research investigations to accelerate real-world pain research in Canada.

The shared infrastructure of the CRN, and its real-time integration with other elements of the Chronic Pain Network, allow for timely, relevant and cost effective research and knowledge mobilization from across Canada.

Since its inception in 2015, the CRN has served as the main pipeline for the Canadian Pain Registry. As of February 2021, the CRN has generated over I22 single-centre research projects and seven multi-centre

research projects and produced many journal publications, with several pending.

The iCanCope project, one of the 22 projects to receive funding through the CPN, is just one of the many projects to make use of the CRN. iCanCope is a smartphone and webbased program designed to support young people with chronic pain. iCanCope was rigorously evaluated through a randomized controlled trial supported by the CPN, utilizing CRN to recruit and enroll participants.

The last year has seen the addition of three new CRN sites, and interest continues to grow. A coordinated effort is currently underway to secure the resources necessary to ensure that the CRN will continue to thrive beyond CPN's initial funding.

#### **Adult Sites**

Centre hospitalier de l'Université de Montreal

Hamilton Health Sciences

Kingston Health Sciences Centre

Mount Sinai Hospital

Ottawa Health Research Institute

Research Institute of McGill University Health Centre

Toronto Academic Pain Medicine Institute

University of British Columbia

Université Laval

University of Manitoba

Université Sherbrooke

#### **Pediatric Sites**

Alberta Children's Health Research Institute

University of Saskatchewan

Sick Kids Hospital

# **Adult and Pediatric Sites**

Dalhousie University

University of Alberta

# PATIENT ENGAGEMENT

Patient Engagement is the foundation on which the Chronic Pain Network was built. Before Principal and Co-Applicants were finalized, or the governance structure defined, it was clear that people with lived experience needed to be included at all levels of Network activity. They needed to have significant roles that were more than just tokenistic in nature, where they were recognized for their unique viewpoints and the expertise they brought to the table.

In addition to their positions within the governance of the Network itself, as well as working with project leads as integrated members of research teams, CPN patient perspective partners have provided a voice for those with lived experience far beyond the reach of the Network. Presenting at conferences, authoring manuscripts, serving as reviewers for grant applications and lobbying for change, they are truly changing the way research is done in Canada.

One of the most notable accomplishments over the life of the Network has been the paper Network patient perspective partners and researchers wrote and published on authorship and acknowledgment in patient-oriented research. As of May 2021, this paper has been accessed more than 4,300 times and was presented at the Alberta SPOR Support Unit's Journal Club.

Two Network patient perspective partners were also called upon to serve as members of the Canadian Pain Task Force (CPTF). This has seen them engaged in its outreach efforts, and their work with the Task Force has supported three published reports. These publications will go on to help inform policy and influence decisions makers through the insight and input provided.

In addition to this, the Network collaborated on a study, led by a trainee (Kyle Vader), to understand trainee perceptions of and experiences with patient engagement in pain research in Canada. The bilingual survey had I28 respondents, and a poster was presented at the Canadian Pain Society 2021 Conference. An additional poster was presented at the International Association for the Study of Pain 2021 Conference. The paper is being prepared for submission for publication.

# **EVALUATION OF PATIENT ENGAGEMENT**

As part of the commitment of the Chronic Pain Network to patient engagement, an evaluation of the Network's patient engagement work was conducted by evaluators from the Public and Patient Engagement Collaborative at McMaster University. The objective of the evaluation was to evaluate the structures and processes for engaging patient perspective partners in the Network and to assess the impact of patient engagement on the Network's activities and outputs. A series of interviews and surveys with patient perspective partners, committee co-chairs and members, Network staff, and funded researchers were conducted during the Network's mandate. The Patient Engagement Committee provided ongoing consultation to the evaluation.

The evaluation results highlighted the value and success of the Network's approach to engagement. Including patient perspective partners as cochairs of all committees, having a

separate committee focused solely on patient engagement and engaging patient partners at the leadership level facilitated strong patient engagement throughout the Network. This approach successfully ensured patient engagement remained a priority, that patient perspectives were included in all work and allowed for ongoing adaptations to be made to engagement processes. While challenges were felt with the process of engaging patient perspective partners in the funded research projects, several successful partnerships were formed between researchers and patient perspective partners. The Network continuously adapted and sought innovative ways to connect funded researchers and patient perspective partners. The impact of patient engagement within the Network can be identified in many of the outputs of the Network and was identified by many as a key to its success.



Julia Abelson, whose team conducted the evaluation, speaking at the 2019 Chronic Pain Network Annual Meeting.

# RESEARCH HIGHLIGHTS

"It facilitated patient engagement in research and integrated knowledge translation. It also helped us connect with patient partners, clinicians and researchers from all over the country," said Karine Toupin-April when asked how being a part of the Chronic Pain Network (CPN) had an impact on her project. "The funding we received from the Chronic Pain Network will help young people with juvenile arthritis, and their families, make informed and personalized decisions to manage pain optimally, thus improving their quality of life."

Karine's project is a decision aid to help teens with Juvenile Idiopathic Arthritis (and their parents) become informed about pain management options, make decisions that match with what is important to them, and be engaged in their own care. This is just one of more than 20 projects funded through the CPN.

Thomas Hadjistavropoulos, whose Network-funded project looked at Pain in Older Adults, credits the CPN with establishing a process for working with patient perspective partners and ensuring that they will have key roles in pain research in Canada for years to come. Thomas's team launched the #SeePainMoreClearly social media campaign in October 2021. The aim of the campaign is to raise awareness and advocate for better pain assessment to improve the ability to manage pain in people with dementia. The campaign saw more than three million impressions in just five weeks and 30.000 views on YouTube.

The iCanCope project, led by Jennifer Stinson, employed a social media campaign to support recruitment for a version of the app tailored to those with Juvenile Idiopathic Arthritis (JIA) pain, and to spread knowledge about the study. The campaign included having patient perspective partners speak about their experience using the app on their Podcast, called Take a Pain Check. A one-minute video

("5 reasons why you need to try iCanCope") was created and shared on multiple social media channels (Instagram, Twitter and YouTube). Within four days, the video received over 230 views between Instagram and YouTube, and the tweet has been amplified to reach over 2,300 followers.

The Aboriginal Children's Hurt and Healing (ACHH) initiative also saw significant growth with the development of the Kids Hurt App (www.kidshurtapp.com) and created an introduction video for knowledge translation use. This app is currently being translated into Mi'kmaw and will have a narration option in both English and Mi'kmaw as well.

Although the appearance of COVID-19 resulted in delays for some Network projects, it presented unique opportunities for others, such as Network Principal Applicant Manon Choinière. Manon and her team undertook an online survey

examining the impact of the COVID-19 pandemic on Canadians living with chronic pain. Network Co-Applicant Renée El-Gabalawy conducted an online survey-based study to learn more about what factors may predict or prevent post-traumatic stress and growth following the pandemic so that we are better equipped to meet needs if faced with a similar situation in the future. Network Principal Applicant Jennifer Stinson, Co-Applicant Melanie Noel and Kathryn Birnie also began work on a study to examine stepped care solutions to reduce the impact of the COVID-19 pandemic on mental health, substance use and functioning in youth living with chronic pain.

Remaining Network-funded projects are anticipated to conclude by March 2021.

"The Chronic Pain Network has been an integral component of our pain research over the past five years. At the time of completion of our feasibility trial for iCanCope, the CPN enabled us to scale up the recruitment to 10 sites in Canada, leveraging the support of the CPNfunded SPOR coordinators across many of these sites. This leverage has led to improved national collaboration including patient partners, and increased diversity of the study sample."

> - Dr. Jennifer Stinson iCanCope

#### PATIENT PERSPECTIVE PARTNERS - 2020/2021

Kristy Barnaby Mary Brachaniec Carolynn Bulmer Lynn Cooper Jennifer Daly-Cyr Chris DeBow Mario Di Carlo Kathleen Eubanks Janet Gunderson Richard Hovey Jacques Laliberté Therese Lane

Rebecca Lee Delane Linkiewich Curtis May Nathalie Ouellet Carley Ouellette Lesley Singer Karen Smith Janice Sumpton Marc White Linda Wilhelm

#### **GOVERNANCE - 2020/2021**

Sara Ahmed Krista Baera\*\*\* Abaerveldt Baerveldt Jillian Banfield Nicolas Beaudet\*\*\* **Etienne Bisson** Jason Busse\*\*\* Joseph Caffazo Fiona Campbell Alina Carter Susan Carter Christine Chambers Manon Choinière\*\* Jill Chorney Adena Cox Kenneth Craig\*\*\*

Jennifer Crotogino

Karen Davis\*\*

Jessie Dhillon

PI Devereaux\*\*\*

Luda Diatchenko\*\* Bruce Dick Scott Duggan Renée El-Gabalawy\*\*\* Jean-Francois Ethier Linda Ferguson Sheri Findlay Allen Finley\*\* Louis Gendron\*\*\* Nader Ghasemlou\*\*\* Ian Gilron\*\* Megan Greenough Thomas Hadjistavropoulos\*\*\* Lauren Harris Maria Hudspith\*\* Pablo Ingelmo Howard Intrater Alfonso Iorio\*\* Audrée Janelle-Montcalm Keith Jarvi\*\*\*

Irina Kudrina Margot Latimer\*\* Susan Lau Elder Margaret Lavallee John Lavis Mary Lynch Mike McGillion\*\*\* Aaron McInnes Casev McMahon Meghan McMurty Allison McPeak Jov MacDermid\*\* Golda Milo-Manson Jeff Mogil Dwight Moulin\*\*\* Maliha Muneer Renata Musa Chris Musquash Richard Nahas Melanie Noel\*\*\*

Tim Oberlander Lisa Patterson Patricia Poulin\*\* Steve Prescott\*\*\* Garry Salisbury\*\* Cyril Schneider\*\* Saiffee Rashia Nivez Rasic Danielle Rice Tiffany Rice Dawn Richards Rachel Rov Sharon Rudderham Mike Salter\*\*\* Cyril Schneider\*\* Brent Scott Barry Sessle\*\*\* Yoram Shir Gurmit Sinah\*\*\* Bonnie Stevens\*\*

Jennifer Stinson\*\*
Frank Sullivan
John R. Sylliboy
Karine Toupin-April\*\*\*
Michelle Verrier
David Walton\*\*\*
Mark Ware\*\*\*
Judy Watt-Watson\*\*\*
Owen Williamson
Brent Young
Tuma Young
Ramesh Zacharias

# **COORDINATING CENTRE**

Kimberly Begley Norm Buckley\* Megan Groves Donna Marfisi

\*Nominated Principal Applicant

\*\*Principal Applicant

\*\*\*Co-Applicant

#### SUPPORTING INSTITUTIONS & ORGANIZATIONS

Alberta Children's Hospital

Research Institute

Department of Anesthesiology & Pain

Medicine, University of Alberta

The Arthritis Society

Association Québécoise de la Douleur Chronique

Bayer

Department of Anesthesiology, University of British Columbia

Canadian Anesthesiologists Society

Canadian Pain Society

Centre de recherche du CHUS

Centre de recherché du Centre hospitalier

de l'Université de Montreal

Children's Hospital of Eastern Ontario

Department of Anesthesia, Dalhousie University

Eli Lilly Canada Inc.

Hamilton Health Sciences

Health Information Research Unit,

McMaster University

Hospital for Sick Children (SickKids)

Research Institute

Hotel Dieu Chronic Pain Clinic,

Queen's University

The Improving the Lives of Children with Chronic Pain Charitable Foundation

**IWK Health Centre** 

Jim Pattison Children's Hospital Foundation

Faculty of Medicine, Laval Université

Department of Anesthesia, University of Manitoba

McGill University

Alan Edwards Pain Management,

McGill University

Michael G. DeGroote

Institute for Pain Research and Care

Department of Anesthesiology,

Université de Montreal

Wasser Pain Centre, Mount Sinai Hospital

Multiple Sclerosis Society

of Canada

The Ottawa Hospital Research Institute

Pain BC Pfizer

Purdue Pharma

Ouebec Pain Research Network

Queen's University University of Regina

College of Medicine,

University of Saskatchewan

Saskatchewan Health Research Foundation

Faculty of Medicine and Health Sciences, Université de Sherbrooke

University of Toronto Centre

for the Study of Pain Faculty of Music, University of Toronto

Department of Physical Therapy,

Western University

University Health Network Toronto

# **ADDITIONAL LINKS**

Canadian Pain Task Force

https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force.html

Gaga: Five Foot Two

https://www.netflix.com/ca/title/80196586



Strategy for Patient-Oriented Research



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