



# The Provincial Pain Summit

2011

## Acknowledgements

The inaugural Provincial Pain Summit could not have taken place without the commitment of the Specialist Services Committee (SSC). The Pain BC Board of Directors is very grateful for their support in hosting the Summit and their commitment to working together on recommendations for change.

The participation of people living with pain was crucial to the Summit goals and format. Pain BC was honoured to have so many patients share their stories and contribute their expertise to the dialogue.

Pain BC appreciates the health care providers and administrators who attended, listening openly and working collaboratively to develop suggestions for action. Health care providers provided their perspective and experience from the front-line, while leaders and policy makers contributed the systems-perspective necessary for developing solutions.

Together, people living with pain, health care providers and administrators will bring about change, and reduce the burden of pain on individuals, families and communities in BC. Pain BC is grateful for this commitment and collaboration.

## Summit Context and Goals

Pain BC is a non-profit organization made up of patients, health care providers, physicians and others with a passion for supporting people living with pain. Since 2009, Pain BC has been leading efforts to reduce the burden of pain on individuals, families, and communities in our province.

In the last few years, there has been increasing focus on the issue of chronic pain in BC. People living with pain are getting organized, educated and speaking out. Health care providers are seeking education and better ways to manage pain while health care systems are considering new options to achieve better health outcomes, reduce cost, and improve the experience of patients and providers.

Building on this momentum, Pain BC launched its first Strategic Plan in November 2010. The Plan outlines several objectives organized around six primary goals:

1. Encourage Prevention and Early Intervention
2. Facilitate Patient Engagement and Enhance Patient Education
3. Enhance Support and Education for Health Care Providers to Enable Best Practice
4. Advance System Responsiveness through Advocacy and Redesign
5. Broaden and Deepen Engagement of Pain Stakeholders
6. Build Pain BC Society's Organizational Capacity

While the Strategic Plan was informed by an environmental scan and interviews with key informants, Pain BC wanted to bring together key stakeholders to:

1. Foster further dialogue and action
2. Share promising practices, successes and innovations in pain management
3. Increase the knowledge and capacity of people living with pain and health care providers to reduce the burden of pain in BC

These goals were shared by the Specialist Services Committee (SSC), a joint Committee of the BC Ministry of Health and the BC Medical Association. The SSC provided sole sponsorship for the event, with the intention of working with Pain BC and other partners to implement recommendations coming forward from the Summit.

## Summit Program Overview

Pain BC is a unique organization, bringing together people living with pain, health care providers and systems (health care and others) to work together on shared goals. The Summit program reflected the four elements of Pain BC's mission:

- **Engagement** of people living with pain, health care providers, and community, government, and academic partners
- **Education** of people living with pain, health care providers and the general public
- **Advocacy** with decision-makers in health care and other systems supporting people living with pain
- **Knowledge translation** to bring evidence and research into practice

The Summit opened with two compelling keynote speakers. Physiotherapist and pain educator Neil Pearson fostered optimism and inspiration with cutting-edge thinking about pain and recovery. Professor Diane Gromala captivated participants with the promise of immersive virtual reality as a pain management tool. Both speakers illuminated the connection between mind and body in pain management, challenged myths, and offered hope.

The second day of the Summit was kicked off by Dr. Mary Lynch, Past President of the Canadian Pain Society. Dr. Lynch conveyed the national and international contexts, reinforcing the new conception of chronic pain as a disease in itself and sharing emergent thinking about adequate pain management as a fundamental human right. Dr. Brenda Lau, Regional Division Head of Pain Services for Fraser Health reported on innovative approaches to service delivery, all built on a foundation of activated patients, multidisciplinary teams and a stepped care model where the majority of people living with chronic pain are treated in the primary health care context.

Following the morning speakers, one hundred and eighty-five people participated in breakout sessions focused on four themes:

1. Strengthening the Continuum of Patient Self Management Support
2. Resources for Clinical Decision-making Across the Patient Journey
3. Practical Application of Opioid Prescribing Guidelines in a Primary Health Care Context
4. System Redesign: Fostering Innovation and Collaboration

All of the breakout sessions began with content experts setting the context for dialogue, providing background to inform the discussion or presenting specific examples to spark new ideas. After this, the participants worked in small groups, grappling with challenges, identifying opportunities and developing concrete suggestions for change. Breakout summaries and recommendations follow in this report.

The Summit provided health care providers and people living with pain with rich opportunities for learning. Providers learned about how to optimize care for people living with chronic pain, applying the complete toolkit to three patient cases: a man with low back pain, an elderly woman with multiple health issues, and a child with Complex Regional Pain Syndrome (CRPS). People living with pain participated in an interactive workshop with a team of experts, learning about the biology of pain and goal setting as well as experimenting with soothing touch, laughter yoga, and mindfulness meditation.

Pain BC's Annual General Meeting wrapped up the Summit, with the Board of Directors reporting on the last year's accomplishments and directions for the coming year. By-law amendments were passed and a new Board elected for 2011-2012.

To view presentations from any of the sessions or to learn more about Pain BC's newly elected Board, please refer to [www.painbc.ca](http://www.painbc.ca).

## **Breakout Sessions – Key Themes and Recommendations for Action**

### **Breakout # 1**

#### **Strengthening the Continuum of Patient Self Management Support**

The session on self management was very well attended, with registration capped several days prior to the Summit opening. The presentations generated a shared understanding of the definition of self management, how it can help people living with pain, and what self management programs are currently available in BC.

Patrick McGowan, PhD., Director of the University of Victoria Centre for Aging's Chronic Disease Self Management Program shared the goals, model and outcomes of their Chronic Pain Self Management module. Janice Muir, Clinical Nurse Specialist from the Pain Program at Providence Health Care and a Pain BC Board member, presented an environmental scan of chronic pain self management programs currently offered through hospitals or community-based health programs around the province.

Following the presentations, participants worked in small groups to discuss three questions:

1. What are the barriers to increasing self management supports?
2. What are the solutions to strengthening self management supports?
3. What role can I play in strengthening self management supports?

#### **Barriers**

**Lack of awareness and education** is a significant barrier to people living with pain being engaged in self management programs and practices. This lack of awareness was identified:

- Among Physicians – the existence of chronic pain as a problem, community programs that can help, lack of empathy and interest in referring patients to outside supports
- Among people living with pain – programs available, the need for education, where to go
- Among the public - cultural myths, stigma, lack of understanding that pain is real

Participants also identified the low profile of self management programs as an issue, feeling that they are not marketed well to their target audiences. Cultural and language barriers, as well as barriers related to age and gender were also identified. Lastly, the group noted that the language used in describing self management programs remains largely medical and that more holistic language would better resonate with people living with pain.

**Financial and structural barriers** were identified as preventing many people living with pain from taking part in self management programs. People living with pain experience:

- Lack of funding, both for fees and for transportation, to attend community programs
- Mobility challenges – just getting to a program can be difficult
- Low physical tolerance to participate in programs
- Waitlists for programs with no interim support while they wait
- Different learning styles that may not be accommodated through existing models
- Barriers to access given that referrals are dependent on having a knowledgeable family doctor

People living with pain articulated **emotional and personal challenges** that negatively impact the ability to participate in self management. These challenges included:

- Pride, resistance to labelling, and fear of stigma
- The isolation, depression, and “*downward spiral*” that can result from chronic pain
- The spiritual/emotional pain and loss of identity that often accompany persistent physical pain
- The challenge of articulating the symptoms, feelings, and experience of chronic pain

**Lack of communication** between health care providers, family caregivers and patients was also a barrier, furthered by “*outdated, paternalistic attitudes*” among some health care providers and by health care environments not yet integrated with technology (e.g, a shared electronic medical record).

While people familiar with the self management programs recognized their value, they also offered **critiques of the structures of the current programs**. These included:

- Lack of follow up coaching and support
- Lack of a psychologist or other mental health supports – identified as key given the depression and other mental health issues that can accompany chronic pain
- Not enough community-based programs for the need

- Family needs weren't adequately addressed in the programs, especially important given that chronic pain can have a devastating effect on one's loved ones
- Physicians as the gate-keepers – many felt that they could benefit from self-referring to community-based programs or having access to hospital-based programs with allied health staff while waiting to see a specialist

## **Solutions**

Participants identified many practical solutions to the barriers.

First, they felt that the people living with pain and health care providers would benefit from **better access to information** and that this could be accomplished through:

- Broad public education campaigns focusing on prevention and early intervention – through schools, churches, community centres
- Education to increase understanding and reduce stigma
- A centralized, web-based hub of information that is well publicized to patients and health care providers – the Pain BC website was suggested
- Ongoing professional education for health care providers and for third party payers
- Mandatory provision of self management info with all opioid prescriptions, as well as using pharmacists as educators for those using medications

A related theme emerged related to **marketing self management programs**, including suggestions to make the name of the program more appealing to participants, to publicize the programs through online, print and other media, and to offer food or other incentives such as tax breaks to participants.

Participants had several concrete suggestions for **improving the programs' structure**, including:

- Incorporating a broader coaching and mentoring approach, including options for home visits, case management and referral
- Incorporating more social aspects to bring in fun, hope and optimism
- Expanding the reach of the programs through targeted recruitment of volunteers representing linguistic and cultural diversity
- Incorporating help for family members, including options to meet with other family caregivers for support
- Enabling patients to self refer to the community-based programs

- Using allied health resources to offer self management programs to patients on waitlists for tertiary program

Lastly, the participants articulated a need to teach **self-advocacy** to people living with pain, as an essential component of self management.

Participants articulated several **roles they could play** in strengthening the continuum of self management support. These roles included:

**Advocating** – for more resources, for increased awareness among professional associations and other health care organizations, for pain to be included in existing resources (e.g., Healthlink hotline, curriculum for health science students)

**Communicating** – making information available through their various circles of influence, including social media

**Educating** – sharing information in their roles as peer support leaders, health care providers, insurers and health care administrators

## Breakout # 2

### Resources for Clinical Decision-Making Across the Patient Journey

The impetus for this breakout was a recognition that health care providers, across disciplines, are often struggling to adequately support people living with chronic pain: missing opportunities for early detection, lacking knowledge, time and tools for appropriate assessment, unaware of what works and how to apply it in their clinical practices, and unwittingly leaving people living with pain to languish on wait lists to see specialists.

David May, a family physician and pain expert from Powell River provided context, sharing his experience with best practice assessment tools and treatment approaches in a primary health care practice. Patrick McGowan, Director, University of Victoria Centre for Aging's Chronic Disease Self Management Program complemented Dr. May's review of clinical tools with a presentation highlighting the role clinicians can play in encouraging self management.

Participants then brainstormed a list of questions to work on, generating the following list in order of priority:

1. How can we get GPs more engaged in questions regarding chronic pain? (17 votes)
2. How do we better educate other health care practitioners regarding chronic pain management? (16 votes)
3. What works and how can we build on it? (16 votes)



4. What do we need to connect chronic pain patients with the full range of knowledgeable resources? (15 votes)
5. What tools are available to detect early onset of chronic pain? (14 votes)
6. How can we improve system navigation and empower patients with more information? (12 votes)
7. How do we improve coordination between self management programs and GPs? (12 votes)
8. How might we better address the mental health needs of chronic pain patients (stigma, etc...)(7 votes)
9. How can we get GPs to spend more time with chronic pain patients? (5 votes)
10. How do we allocate limited funds across the spectrum? (5 votes)

Once the list was generated, participants set to work developing suggestions for advancing action in each area.

**How can we get GPs more engaged in questions regarding chronic pain? and How can we get GPs to spend more time with chronic pain patients?**

- Develop a Practice Support Program module to educate GPs on chronic pain
- Use the Divisions of Family Practice to educate GPs and develop supports in primary health care
- Educate GPs on how they can use existing billing codes to allow for more time with chronic pain patients
- Make it realistic - lobby for new codes that will further enable GPs to manage the complexity of chronic pain, similar to those for other chronic diseases

**How do we better educate other health care practitioners regarding chronic pain management?**

- Focus on getting pain management curricula embedded in medical and health science programs
- Develop the value proposition to explain the benefits of adequately treating chronic pain
- Engage speakers (expert patients as well as health care providers and researchers) to present to practitioners in their practice environment
- Engage regional health authorities and deliver workshops to their front-line staff

**What works and how can we build on it?**

- Take best practice examples from other diseases to use as a prototype (e.g., cardiac care)
- Find a well known public figure to raise awareness (e.g., Michael J. Fox for Parkinson's)

**What do we need to connect chronic pain patients with the full range of knowledgeable resources? and How can we improve system navigation and empower patients with more information?**

- Develop comprehensive collection of resources and post to a central website
- Develop positive communications campaign to raise awareness and direct patients to the resource site
- Increase access to the system by enabling multiple points of access, not just through referral by a GP

**What tools are available to detect early onset of chronic pain?**

- Create a central, online reservoir of tools, including Brief Pain Inventory, CAGE questionnaire, PHQ-9 and other validated tools
- Convene multi-disciplinary dialogue to agree on consistent tools across disciplines
- Offer tools that can help objectify the subjective experience of chronic pain

### **Breakout Session # 3:**

#### **Practical Application of Opioid Prescribing Guidelines in a Primary Health Care Context**

One of the most challenging areas of chronic pain management is the prescription of opioid medications. Physicians are sometimes unaware of the complete pain toolkit and rely solely on medications for management. Others are unwilling to prescribe opioids, fearing surveillance or disciplinary action by the College of Physicians and Surgeon's Prescription Review Panel. Opioid prescribing also takes place in a larger social-political context where medications are diverted, through sale or theft, to the street-based drug trade, creating implications for the policing and justice systems. For people living with pain, opioids are often a double-edged sword: needed to manage pain but carrying stigma, the potential for addiction and a host of unwanted side-effects.

In 2010, the National Opioid Use Guideline (NOUG) was published, the culmination of a three year development process that involved a research group, a national advisory panel and a group of forty national faculty members working on implementation.

Pain BC opted to open this dialogue at the Summit in an attempt to foster a pragmatic discussion on the NOUG and found a willing collaborator in the BC College of Physicians and Surgeons. Dr. Galt Wilson, Deputy Registrar, opened the session with a review of the guideline, the reason for its development, how it is meant to be applied to various clinical situations, and how the College sees its role in supporting the guidelines' implementation. Following this, participants used a dialogue-based process to explore the barriers and solutions to guideline implementation, focusing on three questions:

1. What barriers exist to implementing the guideline in a primary health care context?
2. How might those barriers be mitigated?
3. Will the guideline have a positive impact on your provision of care (*for physicians*) or your care (*for patients*)?

**What barriers exist to implementing the guideline in a primary health care context?**

- Limited support and time for GPs – GPs are overloaded, which can create anxiety in dealing with complex patient needs
- Lack of multidisciplinary team or access to allied health supports - opioids should not stand alone but be part of a broader individualized care plan that includes multidisciplinary support
- Patients need education and support to understand that pain may persist and require long-term management, not a cure
- Misconceptions regarding opioids exist among health care providers (fear of prescribing) and patients (*“meds are dirty”*)
- Some medications are not covered by MSP
- Patients need more compassion, better understanding and advocacy support from their GPs

While the participants identified barriers to implementing the guidelines, they also articulated **the value of the guideline** in that it:

- Opens up the dialogue and provide a venue for the (sometimes difficult) conversation to occur
- Increases awareness and decrease misconceptions
- Facilitates vigilance in prescribing

**How might the barriers to implementation be mitigated?**

- The guideline can be used as a tool for change and education
  - For physicians– develop a PSP module on chronic pain and include a portion on the guideline and the realities of prescribing
  - For patients – develop clear and easy-to-understand materials to decrease fear and anxiety, dispel myths
- Treat each patient as an individual, recognizing that the guideline is just a starting point

- Best practice chronic pain treatment requires a multi-disciplinary approach; if GPs had access to multidisciplinary supports (or patients could have increased access to affordable allied health supports in the community), they could more easily implement the guideline as one aspect of the care plan – *“This needs to be part of the system redesign conversation.”*
- Collaboration between GPs and other disciplines and the patient themselves is key - start in one community to develop a prototype that can be studied and implemented in other areas
- GPs need support – chronic pain should be recognized as a chronic disease like any other with the appropriate codes for tracking and billing

Participants used a process called “the constellation” to answer the last question about the impact of the guideline on their provision of care/their care. In this exercise, participants took their places in a circle, literally standing in relation to the guideline – standing close to signify a positive impact on care, or standing far away to illustrate a negative impact. As participants discussed their stance in relation to the guidelines, a potent, and sometimes emotional, learning experience unfolded. Some felt that the guideline was very positive while others shared stories of the guidelines’ interpretation creating fear and anxiety for both patients and providers. Ultimately, the guidelines were viewed as being necessary in order to manage risk to the patient and the provider, with cautions on how they are implemented in a clinical context.

#### **Breakout Session # 4:** **System Redesign: Fostering Innovation and Collaboration**

The session on system redesign was well attended, with registration capped at sixty participants days before the Summit. Attendees were clearly interested in looking at systemic solutions to reduce the burden of pain and came together to brainstorm and prioritize areas for action.

The following were chosen as the first areas of focus, with barriers, opportunities and next steps identified for each:

1. Shortening the patient journey through the health care system
2. Providing education for health care providers to improve treatment of people living with chronic pain

3. Integration across the continuum between primary, secondary and tertiary services
4. Development of a pathway for transitions from tertiary services to the community
5. Developing a classification system for pain – striving for a diagnosis

### **1) Shortening the patient journey through the health care system**

Resoundingly, participants felt that system redesign efforts must reduce the length of the patient journey through the health care system. This was a recurrent theme throughout the Summit and was a subtheme in all of the breakout discussions. Currently, too many people living with pain wait unnecessarily on lists for tertiary centres, despite successes elsewhere in treating over 80% of chronic pain patients in primary health care setting and through supported self management. Participants felt that greater emphasis must be placed on early detection and intervention, preventing the progression from acute pain to chronic pain to disability.

Doing so would meet the triple aim of reducing health care costs, bettering outcomes for patients and improving health care provider and patient experience in the system.

There was a strong consensus that multidisciplinary primary health care teams, including Occupational Therapy, Physiotherapy, Nursing, and Psychology, must be developed, with appropriate funding for allied health supports. These teams would be able to screen early, offer the whole gamut of management, including self management programs, and enable multiple entry points to the system of care.

#### **What will enable this to happen?**

- Funding for allied health providers and/or funding for patients to spend on treatment
- Strengthening self management support and infrastructure across the system and starting all patients with self management programs/approaches while diagnostics or waiting for specialist consults continue
- Developing algorithms or flow sheets outlining protocols, screening tools, guidelines, resources and embedding these in the electronic medical record
- Enabling patient access to electronic medical records and a “patient passport”
- Developing specific codes for pain, providing incentives for care and making it possible to adequately track patient outcomes

### **2) Providing education for health care providers to improve treatment of people living with chronic pain**

The participants in the system redesign breakout echoed the comments in many of the other sessions, citing the need for provider education as a means to improving outcomes, and the health care experience, for people living with chronic pain. The **barriers** identified to increasing provider knowledge, skills and confidence were:

- Pain management not being part of the curriculum of most medical and health science programs
- Cultural barriers and stigma attached to chronic pain
- Lack of funding for education
- Caregiver fear of failure – sense that chronic pain can't be easily “fixed”
- Lack of evidence (especially in pediatrics) and sense that chronic pain is subjective
- Inertia
- Providers not understanding the impact of chronic pain on the lives of patients
- Uncertainty over who is responsible to make education happen

### **What concrete actions will enable further education for health care providers?**

- Continuing Education through all available channels – interdisciplinary education, PSP module for GPs, online courses for all health care disciplines, workshops by pharmaceutical companies on new medications, mentorship between GPs and specialists and across other disciplines
- Develop central, online hub for information and resources – use Pain BC website
- Certification for pain specialty in all disciplines
- Curriculum embedded into pre-licensure education
- Fostering a paradigm shift in the way we view pain – combating prejudices and stigma

### **3) Integration across the Continuum – between primary, secondary and tertiary services**

Participants identified the fragmentation between primary, secondary and tertiary services as a key problem for people living with chronic pain and for providers working with them. The following barriers to integration were identified:

- Limited resources – lack of funding for pain programs, for allied health in the community
- Organizational structures – health authorities, GPs and other physicians, community agencies are all separate and distinct, with their own funding envelopes and mandates
- Cultural and administrative barriers – trust, turf, planning/thinking in traditional silos, and unwillingness among stakeholders to look beyond their own priorities
- Lack of unifying website with services available – include patient supports, allied health, medical services
- Overarching nature of pain (cuts across diseases and programs) and the complexities of it (links with mental health, addictions and other program areas)

Given the climate of health care reform in BC, particularly in primary health care, participants saw **rich opportunities for integration, all building on existing infrastructure or initiatives:**

- Develop PSP modules to educate GPs
- Develop models of collaborative care (e.g., a rapid access phone line for clinical consultation, mentor/mentee networks where GPs could be mentored by pain specialists) with funding from the Specialist Services, Shared Care and General Practice Services Committees
- Building on the primary health care teams, home care, and Divisions of Family Practice
- Advocate with Healthlink BC to include pain information and resources
- Provide opportunities for learning through complex case rounds - through hospitals and new provincial network for GP pain experts organized through St. Paul's hospital in Vancouver
- Work with Regional Health Authorities to advance integration at the regional level – e.g., engage the community resources in the transfer of care, prior to discharge from hospital, develop regional pain programs such as those that exist in Fraser Health and Vancouver Island Health Authority
- Use CHARD, the provincial health resource directory for health care providers that now includes pain resources
- Shared electronic medical records - integrating medical records has potential to advance integration of other kinds and to put ownership of record into the hands of patients

#### **4) Develop a pathway for transitions from tertiary services to the community**

Participants took their focus on integration to a greater level of detail, prioritizing development of a clinical pathway to support the transition of patients from tertiary services to the community. They identified several **challenges** with the current journey from hospital to community-based care:

- Poor discharge planning
- Patient reluctance – will they get the same expert care in the community?
- Iatrogenic suffering – patients experiencing pain as a result of treatment may, quite rightly, distrust the system

- Expert, but vulnerable, patients
- Not enough education for community-based health care providers
- Lack of resources and skills in the community, especially for pediatrics and complex pain
- Variation in what is available in different Regional Health Authorities
- No one coordinating care as patients move from one setting to another, exacerbated by poor communication among health care providers in different settings
- Lack of info sharing and structural barriers to accessing information
- Currently unmapped, or inadequately-mapped, system and subsequent lack of awareness of current resources in the community

Similarly to the question on system redesign, participants felt that there were rich **opportunities for improvement**. While many of these action items could build on existing initiatives, some would require new, or expanded, funding and support.

- Rapid Access phone line or program for community providers to access specialist advice/services
- Complex case rounds – invite GP and patient to interdisciplinary tertiary centre case review
- myhealthportal.ca – patient-owned medical record pilot in Fraser Health Authority
- Identify GP Division Pain champions/leads/clinics to implement a prototype of community-based multidisciplinary care - could include self management program, rapid access line for specialist support, with tie into disability resources, vocational supports and others, as identified by the team of providers and patient advisors
- Leverage existing community resources such as recreation centres – build on partnerships emerging between municipalities and health authorities
- Utilize Clinical Nurse Specialists or Nurse Practitioners for case coordination
- Focus on the transition of care, with discharge info given to patient with a clear plan

#### **What needs to change in order for this to happen?**

- Develop cross-continuum, online algorithms for health care providers and patients, focusing on pre-discharge engagement of community resources, with documentation given to patients and transmitted to community-based providers
- Fund options for community-based multidisciplinary care teams, with a designated lead for case coordination
- Fund and implement a rapid access line for specialist consultation



- Fund and implement mentor/mentee networks to build linkages and expertise between GPs and specialists
- Develop standards of care across the continuum
- Have stakeholders recognize the importance of everyone's roles – set up compacts that are simple to put in place
- Fast-track the implementation of electronic medical records, shared across the continuum of care

## 5) Developing a classification system for pain – striving for a diagnosis

The last priority area was one not focused on system redesign per se, but on the complexities of chronic pain as an illness and the resulting challenges in diagnosing and treating people living with it. While this priority isn't directly focused on the design or delivery of health care services, it does have implications for redesign efforts.

Participants identified the current challenges in diagnosing chronic pain:

- Lack of education among health care providers
- Lack of methods to clinically detect pain mechanisms
- Differing views of whether chronic pain can be relieved: *"Some chronic pain is treatable while other chronic pain is not. The concept that everyone with chronic pain has to live with it needs rethinking. What is needed is identifying the patients whose pain, however longstanding, is treatable."*
- Lack of clarity in MSP codes – there currently isn't a way to bill for a chronic pain visit – and resulting lack of data about people living with chronic pain

While the group emphasized the importance of developing a classification system, they also cautioned against seeing diagnosis as a panacea. They recognized that classifying pain diagnoses won't mean a unifying pain pathway that will be appropriate for all and cautioned that *"sometimes searching for a diagnosis can impede moving forward with recovery."*

Despite identifying challenges and cautions, the participants also saw **opportunities** to move forward:

- Advance universal screening for chronic pain, using standardized screening tools supported by Pain BC
- Identification of biomarkers

- Work with partners such as the International Association for the Study of Pain to redo existing diagnostic criteria
- Advocate with the Ministry of Health to track chronic pain in order to capture relevant data. Track outcome measures and identify key indicators that are used across the province

Compilation of evidence, knowledge translation and further research to validate chronic pain as a chronic disease were all cited as necessary enablers.

## Summit Evaluation

The Summit, by all accounts, was a resounding success. The Summit model, combining educational sessions with solution-focused working sessions, was very well received by all participants. The dialogue between people living with pain, health care providers, administrators and representatives from the NGO sector and industry was enlightening for all and a highlight noted by many.

- ✓ *The opportunity to address the significant issues in pain management, especially barriers and brainstorm creative, constructive possibilities to take forward in a concrete solution based format. It was excellent that professionals and 'patients' were able to learn from one another.*
- ✓ *Education, support, networking; this summit made me feel like "I am still worth it." I feel empowered; I am so grateful to have been able to participate.*
- ✓ *It was all great - networking, connecting with other organizations; listening to brainstorming ideas; presenters were excellent; breakout sessions very good.*
- ✓ *This was a very respectful, informative, positive summit. I wish I could have attended all the breakout sessions.*
- ✓ *The highlight was learning what other programs are doing, learning the public and patients' perspective. Loved the format! Solution based.*
- ✓ *Thank you for organizing this summit and starting a model for the rest of Canada.*
- ✓ *Good to have the professionals at the tables with pain patients. I am a pain patient. This organization gives me HOPE there is something for pain patients. Thank you!*

Participants also provided some concrete suggestions for improvement. Suggestions focused primarily on the length/intensity of the Summit program, on the needs of people living with pain, on the mixing of the various stakeholders and on increasing multi-disciplinary representation/focus in Summit sessions.

- ❖ *Just too long sitting for pain people- I have made a suggestion for comfort option. People in pain take a lot of meds- a very small snack at coffee time would be much appreciated. (Purposefully) Place health care providers at tables with patients- not all with their own profession- patients like to talk to other doc's and RN's too.*
- ❖ *Very uncomfortable chairs- need more scheduled breaks and guided stretching. I am not a chronic pain patient so I wondered how uncomfortable they must have been. Room was a bit cold, especially for the patients.*
- ❖ *What you could have done differently would be less overly technical medical language that was difficult to understand.*
- ❖ *It would have been nice to have more non-physician experts as speakers. Would be nice to have a "patient expert" included as one of the speakers (not only experts who happen to have pain).*
- ❖ *Would love to see more representation from disciplines (more at teaching hospitals, more from insurance sources, etc.)*

## **Next Steps**

The Board of Pain BC, the SSC and several of Pain BC's partners are committed to taking forward recommendations for action from the Summit. The Pain BC Board will be meeting to review summaries of the breakout sessions over the summer. Working groups will be established or resources allocated to take forward specific actions by early fall. All presentations from the Summit, along with the final report, will be posted on the Pain BC website by mid-July, as well as being circulated to all participants and members. As actions move forward, milestones will be reported through the Pain BC newsletter.