



Community Engagement



Vancouver Coastal Health Regional Pain Strategy

Community Engagement Report January 2007

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Regional Pain Strategy

“FINANCES is a huge barrier to care, medication, and support, especially when one has to continually leave their community for the support. While I now have health care providers who do believe me about my pain it took seven years of people not believing me to find them, the same goes for respect. One of the biggest barriers has been going to specialists that look at only one part of the equation. I had doctors focusing strictly on my knee problems and not taking into account wrist, ankle, collarbones, elbows, fingers etc. Doctors need to look at the whole picture and this includes mind/body. A person who is depressed with pain does not have pain because he/she is depressed - there is a connection but they don't necessarily cause one another. Many people are depressed because they spend years dealing with doctors who put them down and tell them they are overreacting. Another barrier is overgeneralization. Many people in my support group have the same experience, if they are women under a certain age the reason they have pain is "personal problems at home" and if they are over a certain age it is "menopause". Do not over-generalize, take each patient as an individual and take them seriously. Many people in the support group give up on doctors because so many put down patients. The majority of those in the group, myself included, take people into appointments to act as witnesses because we have all been verbally attacked by doctors, and some end up just giving up on the medical professionals because all they feel is judgment and they are judging themselves enough already!”

Acknowledgements

We would like to acknowledge the contribution and insight of all of the participants of this engagement process, individuals who are living in chronic pain as well as caregivers of those in pain. Your stories and reflections, suggestions and analysis were both informative and moving.

We hope that this report accurately reflects what you told us.

We would also like to thank the staff of VCH and other community organizations for helping us connect with individual participants, facilitating our communications and helping with the logistics to make this engagement possible.

Executive summary

Disabling chronic pain is a major health care and social problem of epidemic proportions. It is the most frequent cause of suffering and disability that seriously impairs quality of life in Canada.¹ And, the financial burden of chronic pain is astronomical: according to the Chronic Pain Association of Canada, the annual cost of chronic pain, including medical expenses, lost income, and lost productivity (but not the social costs) is estimated to exceed \$10 billion.

Broadly, the Regional Pain Strategy Project aims to improve both the recognition of chronic pain as well as the treatment options that are available and accessible to clients within Vancouver Coastal Health (VCH). To this end, it is developing an extensive pain management strategy and recommending an optimal service model that spans both the course of an individual's life as well as the continuum of care, from acute care to community services.

The Regional Pain Strategy Project Steering Committee approached the Community Engagement team with the request to consult members of the public about their experiences of living with chronic persistent and episodic pain and to solicit their suggestions for changes to services and supports. The community engagement process took place from July to September 2006, gathering input from people living with pain and their caregivers. Information was collected through computer-based and paper based surveys, focus groups and individual interviews. Over 370 people responded via survey and an additional 236 individuals participated in either a focus group or interview (which were conducted in Farsi, Punjabi, Cantonese, Mandarin, Russian, Spanish and English). Concerns about broad involvement and representation were addressed by travelling to remote areas, conducting the survey over the phone when requested, conducting interviews with people in their homes, and holding focus groups in partnership with other organizations in community based locations.

Individuals who live with pain, who need to navigate the health system, make decisions and negotiate barriers are viewed here as experts of their own experience. Those who participated in this engagement process have reflected on gaps in the current system and the consequences of those gaps to both their health and to the broader health system. They identified the areas that negatively impacted their already complex lives and fragile health as well as suggested opportunities for change and possible collaboration. This report is a compilation of the stories that were heard, the insights that people offered and the reflections that they had about their journey with pain.

For most people, chronic pain impacts all aspects of their lives. They often struggle with co-morbidities, many of which have been aggravated as a consequence of struggling with pain (e.g. the difficulty of managing diabetes without being able to exercise). And, while people spoke about wanting to have greater access to a variety of treatment and pain management options, they most notably spoke about how the lack of compassion, understanding and simple listening had profoundly impacted their overall experience of pain. For many, their emotional and mental health was jeopardized by this continuous struggle and ultimately, impacted their ability to care for themselves. The majority of the participants felt isolated, marginalized, and not understood; if there was one clear message, it was that they did not feel listened to.

For those who live in pain, it is an individual and unique journey. Their access to economic resources, the extent of their social and familial support networks, their knowledge of and access to treatment and pain management options, their luck in finding a receptive and responsive health practitioner, and their experience navigating and responding to systemic barriers, all directly impact their ability to effectively manage their pain.

¹ Bonica's Management of Pain, 3rd Edition, Chapter 10, *Basic Considerations of Chronic Pain*, Lippincott, Williams & Wilkins, pg. 242.
Community Engagement, VCH

The challenges that were shared spanned across the physical, emotional, psychological, spiritual and financial realms. From this, the following key themes emerged:

1. The relationship with physicians and mainstream health care providers is typically, difficult and in many cases, a source of additional challenge for the patient
2. Clients are seen as their condition, not as a whole person
3. There are multiple barriers to access
4. There is a lack of information for people living with pain to navigate the system and to participate meaningfully in managing their own health
5. There is a lack of appropriate services, as well as a lack of financial and emotional supports for people living with pain

Recommendations for consideration

Individuals offered a wide range of suggestions from systemic, structural change to attitudinal and ethical shifts. However while there were many themes that emerged, the overwhelming message was that individuals wanted to be treated with more respect, to feel compassion and to be heard; they wanted to have people (namely health professionals) understand the numerous struggles they faced living with persistent pain. The recommendations that emerged included:

1. Change the way that clients receive care

- Support the development of more effective communication between health care providers and clients
- Support education that has a focus on dignity, empathy, respect, and compassion for the client situation
- Demonstrate an understanding of the broad factors that impact individual situations
- Address stigmas, in society and with health professionals, that negatively impact the health of those living with pain (stigmas such as being drug-seeking)
- Enable individuals to make choices that work for them
- Develop an approach to treating pain that addresses barriers to access and minimizes the difficulties in navigating the system

2. Foster and support a holistic approach to pain

- Increase the understanding of GPs and specialists around pain as it impacts ALL aspects of an individual's life
- Focus more attention on emotional and psychological support
- Develop more integrated care team approaches to pain treatment
- Expand care options to include those provided by alternative care practitioners
- Enhance ways for clients/ caregivers to manage their pain more effectively and increase their quality of life

3. Enhance access to a wide range of services and supports

- Increase access to alternative therapies and approaches
- Increase access to narcotics or drugs that work for the individual
- Shorten wait lists and ensure appropriate and timely access to pain services
- Ensure services are available in the client's own language
- Address societal stigma related to living with disabilities
- Enhance transportation options
- Provide more home support for those in pain
- Publicize services more effectively in order to raise awareness and enable greater access
- Expand the number of pain clinics available

4. Provide adequate and appropriate information

- Improve diagnosis process and make it more timely
- Ensure medical follow-up and more seamless transitions between various health care providers
- Ensure time in each healthcare encounter to ask questions and receive frank and truthful answers
- Educate healthcare providers about chronic pain and working with pain sufferers
- Educate employers about the needs of employees living with pain and work with them to support employees living with pain

5. Enhance a variety of supports for people living with pain

- Develop self-management and education programs
- Fund support groups for people with pain
- Provide support for caregivers
- Provide funding for assistive devices
- Enhance financial assistance (for Long Term Disability and welfare)

Introduction

The Pain Strategy project aims to improve both the recognition of chronic pain as well as the treatment options that are available and accessible to clients within VCH. To this end, it is developing a quality pain management strategy and recommending an optimal service model that spans both an individual's life span and the continuum of care.

The steering committee for the Regional Pain Strategy Project approached the community Engagement team to consult members of the public about their experiences of living with chronic persistent and episodic pain and to solicit their suggestions for changes to services and supports. Between July and September, 2006 information was collected through surveys, focus groups and individual interviews.

This report is a compilation of the stories that we heard, the insights that people offered and the reflections that they shared about their journey with pain. It captures the web of experiences common to the pain sufferers to whom we spoke, the choices they made (or that were made for them) regarding their treatment and care, and the challenges and successes that they experienced along their journey. Finally, it documents the suggestions that they offered as ways to both improve the recognition of chronic pain and the treatment and management options that are available to clients within VCH.

For those who live in pain, it is a unique journey. An individual's access to economic resources, the extent of their social and familial support networks, their knowledge of and access to treatment and pain management options, their luck in finding a receptive and responsive health practitioner, and their experience navigating and responding to systemic barriers, combined with a multitude of other factors, contribute to their ability to manage their pain.

While people spoke about wanting to have greater access to a variety of treatment and pain management options, they emphasized the lack of compassion, understanding and simple listening they experienced in their interactions with health care providers, and the impact of this on their overall experience of pain. This broad range of participant input and reflection formed and informed the recommendations that are generated in this report.

Methodology

Given the scope of the project and the limitations of reaching the numbers of people who needed to be heard from, 3 methods were used.

An online survey was launched and an invitation to participate (including location and instructions) fanned out through internal mechanisms and external networks. In addition, the survey was available on the websites of Vancouver Coastal Health (CE site), the Arthritis society of BC and the BC Cancer Agency. The online survey was launched in the middle of July and stayed live for just under 2 months. During that time 374 people either answered online, completed the survey over the phone with our assistance, or completed a paper based version and submitted it through the mail. These last two options of submission were in recognition that those living in pain might not be physically able to participate or have access to a computer.

Focus groups: Recognizing both the limitations of reaching people through the internet as well as the barriers to involvement that are inherent in computer-based surveying, certain population groups and people living with particular categories of pain were identified and specifically asked to participate in either focus groups or interviews.

Interviews: Individual interviews were set up for those individuals who were either unable to get to locations, were uncomfortable in a group setting; we met with people in their homes and over the phone when more appropriate.

Alongside an extensive email fan-out within VCH and to hundreds of community-based organizations, VCH Community Health Advisory Committee Members took the invitation to participate into their respective communities. Posters were put up in hospitals, community centers and neighbourhood houses; surveys were dropped off with program coordinators and organizations were asked to host the survey on their websites. The objective was to ensure that we located participants whose experience spanned a wide range of pain conditions, various locations across the continuum of care, ages, cultural and linguistic backgrounds, geographic locations as well as socio-economic realities.

We spoke with teenagers** and seniors**, with those living with pain and those caring for those living in pain**. Interpreted sessions were conducted in Punjabi**, Cantonese**, Mandarin**, Russian**, Spanish** and Farsi**. Outreach was done to remote communities in the Coastal area as well as into the Downtown Eastside of Vancouver.

Interviews and or focus groups were conducted with individuals who experienced pain associated with one or more of the following: (note: those marked with ** were specifically targeted)

- Cancer **
- Traumatic injury (car accidents, motorcycle accidents, injury with heavy machinery...)**
- Addiction and mental health **
- HIV/ AIDS**
- Fibromyalgia **
- Living with a with disability**
- Pre-surgical or post-surgical**
- Arthritis/ osteoarthritis/ rheumatoid arthritis
- Musculo-skeletal (soft tissue damage, scoliosis, stenosis of the spine, degenerative discs...)**
- Multiple Sclerosis
- Headaches/ migraines**
- Gastrointestinal, Crohn's disease
- CRPS/RSD
- Neuropathic pain
- Abdominal pain-endometriosis
- Palliative condition**

The questions that were asked fell into the following themes:

- The ways that quality of life is affected by chronic pain
- Support and treatment options that individuals have accessed
- Difficulties that people had experienced trying to access supports and services
- Specific discussions regarding particular experiences or populations
- Recommendations to improve supports and services for people living with chronic pain

The survey is attached as Appendix 1.

The numbers

Total surveys:	374
Total interviews:	56
Focus groups:	19
Total Participants:	610

Limitations

Even with the extensive distribution of invitations and information about the project, there was a relatively low response. The reasons included:

- The time of year was particularly difficult. Summer found staff out of their offices, and some of the potential participants away from their homes and out of their routines. In addition, some staff were unable to assist with recruitment due to workload issues.
- Accessing participants was very challenging, often directly attributable to their relative isolation and sometimes tenuous/ strained connection with health care providers.
- The scope of the project was broad and expansive. This required relationships to be built with a vast array of organizations and individuals. Some staff initially acted as gate-keepers for their clients, cautious about the CE process being an intrusion into their clients' lives.
- This was a difficult project for many to participate in; many sessions were booked and later cancelled. It was physically and emotionally challenging for people to attend a session; sometimes after the session had begun, they were in too much pain to tolerate the conversation physically or emotionally. There were many individuals who refused to participate due to the consequences it would take on their frail health.
- Within the First Nations community in particular, a history of bad experiences (such as being labeled as drug-seeking and addicted) with health care providers translated into lack of trust in the intentions and integrity of the process and a correspondingly low participation.
- Time and financial constraints limited participation. Most notable was limited participation by those who speak a language other than English. Finding participants was difficult given the language divide, the absence of services in other languages resulting in a lack of established professional relationships through which to access individuals. This was compounded by the fact that these individuals, like others, were living in relative isolation.

Key Findings

For most people, chronic pain impacts all aspects of their lives. They often struggle with co-morbidities, and many of these conditions have been aggravated as a consequence of struggling with pain (e.g. difficult to manage diabetes without being able to exercise).

Individuals spoke about wanting greater access to a variety of treatment and pain management options (including both alternative and complementary care as well as traditional medicines). And they recounted how often, in the mainstream services, they had, by and large, experienced a lack of compassion, understanding and simple listening and reflected on what role they thought these things played in the overall experience of their pain.

For many, their emotional and mental health was seriously jeopardized by their ongoing struggle and ultimately impacted the way that they could take care of themselves. The majority of the participants felt isolated, marginalized, and not understood; if there was one loud message, it was that they did not feel listened to.

The ways that quality of life is affected by chronic pain

- a) Work and income
- b) Emotional impact
- c) Family relationships
- d) Social relationships
- e) Recreational and leisure activities
- f) General health and well-being

Work and income

Employment and individual financial situations played a dominant role in the discussions. The vast majority of respondents said that their pain negatively affected or restricted employment (in the paid workforce or work in the home) and most had had to leave work due to chronic pain, paid jobs that had played a central role in their lives. There was not only a devastating financial loss but a loss of identity and sense of meaning and worth. The loss of adequate income meant that they had lost financial independence to make broader decisions for themselves around their own care.

Some of those we spoke to were struggling to retain their jobs. Most needed the income and they wanted to work; their challenge was workplaces where they were not able to modify their jobs or their workload or were not granted the flexibility that would allow them to manage their pain condition while continuing to work.

Once people were out of work and their savings exhausted, living on a Long Term Disability (LTD) or welfare income profoundly limited what they could access for treatment or pain management. In the survey, 40.5% of respondents listed finances as being seriously impacted by their pain. Individuals who had worked unpaid within the home or who had been self employed made mention of the lack of financial assistance but in many cases, had also been without the benefit of long term disability payments through work, or, if they had sustained an injury while working, were without compensation from Worksafe.

Many had to rely on their families to make ends meet, whether as children, youth or adults. This put an enormous economic and relational strain on the family.

"I am always broke because I can't work as much to make money, so Mom has to spend money to get me by."

For those who had worked in the home, the loss of the ability to care for that home was an equal loss of identity. This was echoed by individuals who could no longer physically clean their homes or complete household tasks and this directly connected to an individual's sense of self, their overall sense of health, and of the desire to have anyone in their home.

"I had to learn to let go of control, let other people help. This was extremely hard for me- e.g. letting go of the standard of cleanliness in my home. Not being able to do chores – you wouldn't think people would grieve that, but it was one more loss, one more thing that I couldn't do."

As well, individuals who had provided ongoing care for another member of the family now lost or had that provision of care threatened, due to their level of pain. In some cases, an individual had actually developed the cause of their pain as a result of caring for someone else and it was not uncommon that they had put their own health on hold in order to not jeopardize the care they provided.

For those enrolled in educational institutions, most of them felt no form of real support and many had been forced to leave, citing a lack of flexibility and compassion in both the teaching staff and registrar's office to recognize the limitations of their disability. The experience of students (and their parents) in elementary or high school settings was of massive bureaucratic red tape and an absence of support.

Emotional impact

"I have become agrophobic – afraid of leaving the house because I may begin to feel ill. Hypersensitivity to problems and complications. Basically it feels as if the pain uses up all of my capacity to cope so that if one additional thing is added it can push me over the edge."

"I have felt suicidal. If I compare my life before to my life now, I don't want to live long. I mourn my losses, the mobility, my colourful life. When the pain is really severe, you want to die. No one can fully understand your pain, or help, even if they want to."

"Fear, frustration, grief, numbness, short-temperedness, anger. All of this in a rotating soup including anxiety, depression, and suicidal thoughts. Occasionally there is joy, happiness, peace and clam. But don't ask me when last any of that happened. It was like a book I once read."

"I HAVE NO HOPE."

In the surveys as well as the interviews and focus groups, the negative emotional impact of pain was prominent and persistent. People described their emotional state as including combinations of:

- depressed
- sadness from loss (of what I used to have/ of who I used to be)
- angry
- thoughts of violence
- lonely
- frustrated
- a grinding hopelessness, especially during a flare-up
- panic/ panic attacks
- stressed
- feelings of being useless
- fatigued
- disinterested
- poor self-esteem
- self-blame
- inability to concentrate
- irritable
- suicidal

These negative emotions were often compounded by the lack of sleep that seems to dominate people's lives. Most experienced a lack of sleep which they linked to general irritability, lack of clarity, flare-ups in their condition and as a contributor to their overall emotional exhaustion. It reduced their ability to manage their emotions or to cope with the pain overall.

Family relationships

"My family is still trying to recover from the loss of income while I was unable to work. When a family member lives with chronic pain, the entire family dynamic changes. Uncertainty, anxiety, irritability, depression, lack of sleep, inability to make and keep plans, limited activity, loss of income, and feeling like a burden severely affect relationships and family life."

"I don't know how many times my ex-wife kicked me out. Now I look back and realize that it was me acting out because of my pain. I understand it now, I wish that I could have said it then."

"My kids and my husband have lived with my pain, my irritability, my heightened anxiety when I am in pain. My son felt angry and upset by the pain I suffered for the five years after the auto crash. He was a teenager and had his own stuff to deal with other than having two disabled parents on welfare. My depression and anger put real strain on our marriage. A lesser couple would not have made it through. My son got married while I was in depression. The family knows that plans have to be made around some of my needs: I can't sit or stand comfortably for any period of time. I can no longer drive my husband, and I guide him less which means that he has less opportunity to exercise and get out into the world. I can't pick up my grandson or offer to babysit."

"My marriage broke up after 15 years because of my chronic pain--e.g. pressure of being my sole support/caregiver, inability to keep social plans. I was then sole caregiver for two grade-school-aged children. I had been a teacher for almost 20 years at that point, while coping constantly with the pain. I had to go on several periods of short-term disability, and now have been on long-term disability continuously for about 9 years. I could not attend a lot of my children's activities, or play as active a role as I would have liked to play. I lost my career and my depression/anxiety/social anxiety/panic attacks have made me unable to leave my home very much. I have been unable to maintain friendships and so my now-grown children, who are just in college and starting their own careers bear the burden of worrying about me."

Family relationships, while predominantly supportive, were strained. By and large, family members are experienced as very helpful and they offer care in many ways. They step in to take care of physical needs around the house as well as physical and emotional needs for the individual living with pain. This sometimes shifts the dynamic and as one woman said, *"my partner is stressed out and cautious about my actions... and so I am often treated like a child."*

The burden of care puts a strain on the family; this, as well as financial pressure, was mentioned as an underlying factor in the disintegration of marriages and relationships. These tangible pressures were often exacerbated by a lack of understanding or compassion within the family about the struggle of living with pain. This had a devastating emotional impact on the individual with pain, but also manifested itself in the family as a lack of trust and lack of respect, ultimately damaging the relationships.

"My family does not want to deal with me anymore, because my condition is too depressing."

"My family do not acknowledge my pain or chronic condition because they cannot see anything wrong they don't believe there is anything wrong; they are too busy with their lives to take time to find out they. Probably do not believe I could possibly be in the pain that I am in"

"[I want the] acknowledgement of those around me that I am trying my hardest to survive "

"My family does not understand the nature of my pain and prefer not to hear about any of my medical problems at all."

"Profoundly. Financially! Physically, as my children struggle to learn that they cannot use me as their role model for what a healthy person does in their day. Emotionally, as we all cope with the endless compromises and adjustments we need to make. It's not all bad, though. My family has learned the value of moving calmly and slowly through the world, and of making careful choices about how we will use our time and energy."

In many cases, parents felt like they had abandoned their children, life partners felt estranged from their spouses, and adults felt like they had been forced back to being treated as a child.

"My husband has had to shoulder all cost obligations. My children cannot rely on me for help or as a babysitter. My house is a mess, I cannot care for my father as I would like to. My grandchildren hear" not now I'm in pain", more than I would like to have to say. My youngest child had to grow up quickly because of my pain. My moods affect/worry everyone around me."

"My daughter lost her father (at least the one she grew up knowing) and my wife is married to a stranger."

Social relationships

"People who have never experienced another's crucifying pain themselves will eventually get impatient with the disruption it causes to their plans or surroundings, that's only natural; it gets to be a real drag for them."

"To look at me, I look fit enough to do anything, but when I try and I fail, or when I don't try at all, people laugh at me and say that I'm weak... and I walk away humiliated and embarrassed. I've lost of friends this way."

While some individuals spoke of a committed network of social relationships, by and large most spoke of the loss of friendships and a disintegration of the social fabric of their lives. Their pain was very isolating and their impaired mobility had a huge impact on social connections – making it very hard to be a part of any community or get any help. With this loss of friends and social interactions was the loss of interaction and distraction that many felt had previously played a role in managing their pain.

For some, being out in public had become embarrassing given their physical limitations. Constantly having to navigate spaces that hampered mobility, requiring consideration around timing and fluctuating fatigue levels, dealing with others' watching their laboured movement often became another reason to not socialize.

Recreational and leisure activities

The vast majority of respondents referenced recreational and leisure activities as the major area of their life that had been impacted. The inability to be involved in previously held interests and activities was attached to a loss of self and the lack of exercise to negative impacts on mood, strength and stamina. Many people mentioned how the lack of the ability to exercise added to their physical discomfort.

"It is important that I keep moving and keep as active as possible. I cannot even get the cost of my rehab specialist as a tax deduction, yet she is the main reason that I am still able to function and to contribute to my family and my community."

"IT SUCKS!! I want to be able to exercise without pain! I want to sleep without pain. I want to move without pain."

Language barriers profoundly impacted our inquiry into the impact of the living with pain on people's connection to their culture; while the numbers of participants from linguistic minorities was relatively low, culture was described as playing a dominant role in their lives, and isolation from it (because they could no longer eat the food or their needs fell outside of acceptable norms or the understanding of chronic pain was non-existent or not-acknowledged, etc.) was extremely emotionally painful.

Included in this theme are the difficulties that clients faced with general mobility. The lack of an ability to get around independently or with ease, meant that individuals felt like they spent a lot of time waiting, whether for family or friends, or for handi-dart (public transit operated). Managing appointments or attending to personal needs was difficult due to long waits and often spread out appointments. The felt

it was “a waste of time, a waste of life”. And for those who were from remote and rural locations the experience was even more frustrating. There was not only the physical time involved but also the discomfort of waiting in ferry line-ups, airport waiting rooms or enduring long drives for care.

General health and wellbeing

Many participants felt that activities of daily living were compromised, and their physical constraints meant that keeping homes clean, doing dishes, laundry or cooking were often impossibilities. Because of this, many spoke of living in conditions that they were uncomfortable with and sometimes ashamed of; of rarely inviting people into their homes; of eating less often and not as healthily as they would have liked. Most spoke about exhaustion and fatigue and how this was exacerbated by a lack of sleep due to their consuming discomfort. And this lack of sleep coupled together with the stresses listed above, meant that their ability to manage emotional was compromised along side of their physical compromised bodies.

“For the most part, I've had to do alot of my own pain 'management' because of how I feel about the subject and how I have come to know beyond a doubt that illness and disease goes beyond just treating pain with drugs. I feel fortunate that there are more people who are gaining an understanding and acceptance of this and thus have others to talk to and work with now.”

Support and treatment options used by participants

The treatment and management options participants used were impacted by: the knowledge of and responsiveness to wide-ranging modalities by their GP; their own struggles with different options; financial constraints; negative experiences that had denied them access to certain options. Overall, responses fell into one of 4 categories:

1. Those who had/were using medications.
2. Those who had used/ were using a combination of medications and alternative therapies and modalities.
3. Those who chose to use options other than medication.
4. Those who had limited or no access to effective medications or alternative therapies.

Treatment/ management options that participants had used/were using, included:

- Prescription medication
- Prescription narcotics
- Drugstore pain medication
- Care from a family doctor
- Specialist: condition specific
- Specialist: pain specific
- Pain clinic
- Care from a psychologist, psychiatrist or counselor
- Physiotherapy
- Acupuncture
- Chiropractic care
- Massage therapy
- Meditation
- Traditional medicine or treatments (e.g. First Nations, Chinese or other options)
- Compassion Club (medical marijuana)
- Alcohol or illicit drugs for self-medication

- Support group or other social support
- Other community-based supports
- Occupational therapy
- Eating properly/ nutrition
- Naturopathy
- Exercise
- Going to church
- Home care, home help and meals

In the survey, certain trends emerged. Most things that people had tried were only somewhat helpful (out of a 4 point scale of not helpful, somewhat helpful, mostly helpful and very helpful). The top three answers included: Prescription pain medication (41%, 108 of 263), over the counter pain medication (49%, 133 of 272), and care from a family doctor (43%, 117 of 270). Among those who had access to care from a pain clinic where 34 out of 104 individuals (33%) felt that it was very helpful.

Reflecting on the narrative responses, what had been the most helpful was linked to access: access to the right drugs in the right amounts and in a timely fashion; access to effective narcotic drugs; access to a GP or pain specialist who is knowledgeable, understanding, open and supportive. In addition, many who had tried complementary and alternative care had experienced a notable amount of success; however, an inability to pay for it (because of reduced or limited income) on an ongoing basis meant that it was not a sustainable management option.

Alternative or complementary care provided by physios, acupuncturists, massage therapists were named as 3 modalities that was widely tried (with or without consent from their doctor), that often had moderate to above average results, but was financially out of reach of most of the respondents over the long term. Exercise (most notably modified or pool-based options) was mentioned as a good option for many people, but again, the cost was prohibitive when they were working with limited funds.

Emotional support from friends, family, and medical professionals was critical, although for most, was noticeably absent. Often in discussion, individuals mentioned the link between their social connections and the management of their pain; social connections and healthy relationships were helpful and for many these connections were through a support group.

“I have improved my quality of life by moving to a place where meals are provided and many of the usual daily chores are done for you. Though my hands are a bit numb (from the MS) they have lots of people to help you along i.e. exercise programs, supervised outings, supervised games) I attend MS Group things, hard-of-hearing group activities and being with others in the same problems are very beneficial.”

“Aspects that are important to individuals as they manage their pain”

Participants articulated clearly what mattered to them as they tried to manage their pain. Not surprisingly, the list of what was important to them included:

- Being treated as a whole person
- Not being looked down upon by society because I cannot do as much as I would like to do.
- People recognizing that it is emotionally exhausting to manage this level of pain.
- Others to recognize that I’m still able to do basic daily task and needs
- Support in listening to what I say rather than care providers assuming that they know more about how I feel in this body than I do.
- Having professionals listen to me and take me seriously and understand my financial difficulties in accessing appropriate care.
- Support from my employer

- Flexibility and understanding are very important to me as I try and manage my pain
- “Acknowledgement of those around me that I am trying my hardest to survive “
- Having control over my options
- Being listened to
- Having my daily needs met
- To know that I can contribute to society, continue building, growing and learning
- Respect for my choices
- Being listened to.
- Being believed
- My dignity
- Avoiding depression
- Freedom to choose different modalities to increase quality of life
- The ability to try and to afford new treatments until I find what works for me
- To maintain my present level of independence
- To have a reasonable quality of life
- Empathy
- Comprehensive approach to pain management
- Patience
- Support
- Understanding
- Caring
- Compassion
- That I have the right diagnosis.
- For people to believe and to have it properly investigated
- Knowing that access to care providers is available, within reasonable period of time, when symptoms worsen.
- I don't want to become dependant on meds

“(It's important for me to have) enough money to pay the gas bill to heat my home this winter.”

“I want to avoid embarrassment, avoid pain, don't show pain, don't let my family suffer due to pain, try to find comfortable sitting, standing and sleeping positions. I detest that I am gaining weight exponentially. When I exercise I feel great, for a while. Then it suddenly begins to hurt and doesn't stop for weeks. As my adhesions become worse with movement, they become inflamed, (and) then start pulling on my bladder and bowels. IT SUCKS! I want to be able to exercise without pain! I want to sleep without pain. I want to move without pain.”

“It is important for me to stay focused on the fact that if I am ever able to manage my pain I may be able to reclaim a bit of the old life I had. I may be able to stop staring at the four walls of my home, relying on the help of others and live somewhat independently. It is important that medical professionals treat me with the respect I afford them and that they look at me as a whole person who wants to get back to a life I worked hard to have. Don't look at me as a broken person who will never be put back together and don't let their poor perceptions come out in a medical appointment. It is important that I be seen as a productive part of society even though I am unable to have children, work, or do many of the other things people take for granted. My body may be broken but my mind and mouth have never stopped working.”

Experiences of trying to access supports and services

The participants in this engagement process said that nearly all aspects of their lives were impacted by their pain. They spoke of the tiresome process of getting a diagnosis, finding treatment options and negotiating emotional and physical fatigue. The few successes that were mentioned, included having a caring, helpful and knowledgeable GP; integrated teams in pain clinics; working with pain specialists; and various alternative care options, most often notably: massage, acupuncture and chiropractor. Woven into many of the stories were strong threads of hope and optimism, of self-efficacy and determination.

However, the vast majority of stories were about the struggle that individuals faced: physically, emotionally, psychologically, spiritually and financially. From this, the following themes emerged:

1. The relationship with physicians and mainstream health care providers is typically unsupportive
2. Clients are seen as their condition or pain, not as a whole person
3. There are barriers to access
4. There is a lack of information
5. There is a lack of services, financial or emotional support

Individuals were also asked what would make a difference to their ability to manage their pain; what was most important to address if we were to look at changes to the system that would offer real support to those who lived with chronic pain. These recommendations have been merged into the narrative below.

1. The relationship with physicians and mainstream health care providers is typically unsupportive

"I feel everyone is tired of dealing with me as they cannot FIX the problems. They have not come to a concrete conclusion. They just fill me full of pills and want me to go away. They say they have taken all the tests and they cannot put a finger on it. Also, it is very difficult to go to the Doctors office and there is no one there that wants to make house calls. I feel brushed over and the pain never stops, year after year."

"Many doctors do not understand the impact of chronic pain on your entire life. Many do not appreciate the severity of pain that people live with. And the majority of doctors are not willing to prescribe narcotics to manage chronic pain--even when they know that you have explored many other options. Frequently doctors (perhaps unintentionally) imply that chronic pain is somehow something that you are responsible for or that you have brought on yourself. Like people with depression, people with chronic pain are too often treated like "just pull up your socks and get on with life!" It can be extremely difficult to find a new physician -- my long-time physician left her practice and it took me a long time to find one who was willing to take me on with fibromyalgia, arthritis and the use of narcotic pain medication to manage my pain--despite the fact that I am fully functioning, work full-time, and have been on the same dose of pain medication for many years. Before I began taking this pain medication I had been on disability for nearly two years, completely unable to work or participate in life in any meaningful way."

The challenges faced by those with chronic pain are numerous. But by and large they were impacted most dramatically by the nature of the relationship with medical care providers, particularly GPs and specialists. Struggling to communicate about their debilitating, yet "invisible illness", they spoke of battling with health care providers who don't believe them about their pain and receiving disrespectful and unsupportive treatment when they are seeking support, guidance and assistance.

“My general physician is a caring, supportive and well-informed practitioner. Unfortunately, I cannot say the same about my experiences with medical 'specialists'. In addition to the lengthy timeframe involved to get in to see a 'specialist, I find that they are often rushed, impatient, rude and quick to jump to conclusions-- (e.g. the pain is in my head). Their solution-- a prescription for a sedative. Such encounters are dehumanizing and frustrating. I understand, that as a natural science conventional medicine bond to the tenets of objectivity, but isn't 'listening' a part of the formula?”

- Health care providers don't believe me when I tell them about my pain

Repeatedly, people said that they want and need to be listened to; that they know their bodies best. However, participants said that many care providers don't believe them when they describe their pain and there is a marked absence of empathy and compassion.

“My perceptions of how I will be treated keep me from seeking treatment”

“When I went to VGH Emergency, the Triage nurse was not going to let me be seen. I had the feeling that because I was not visibly wounded that I was seen as not really acutely ill or in need of emergency, high level medical assessment.”

“My family doctor seemed unable to understand the severity of the pain I was experiencing and was very angry when I was confused about the medications I was taking, and spoke to me in a totally unprofessional manner, causing me to look for another doctor at a difficult time in my life.”

“Before I was diagnosed with RSD in 1999 medical people in BC treated me disrespect! and informed me that I was an attention-seeking person. This treatment encouraged long-term negative effects on my life.”

In stark contrast was the experience of the relatively few individuals who were in the care of a professional that respected them and included them in their care.

“My current doctor knows that I am a sensible person and works with me as a partner to decide treatments; this is such a gift to someone living in chronic pain.”

“The pain specialist at St. Pauls, _____, is top notch. Ask any patient; they want to see _____. Extremely knowledgeable, very consultative, empowering- gives me all the info – fields all questions, remains open to discussion, re-explains things, lets me make decisions, and tells me that I know my body best.”

- The treatment by professionals is not supportive

Participants felt that there was a lack of understanding or compassion about their pain, and how the isolation they experience with this condition as well as their embarrassment to talk about it, impacted their interactions. This was one of the areas that they felt contributed to why they didn't have as much involvement/control as they would like, regarding decisions about treatment of their pain

“Doctors don't seem to care. If it isn't something they can name a cause for in their field, it must be in your head. This by far is the most frustrating factor of my pain. I'm astounded at the lack of compassion and limited awareness they all seem to have for pain and how it affects one's entire life.”

“I am an articulate, confident and English fluent. However, I still experience challenging and difficult health care providers who do not have the time, skills, information or bedside manner to listen and help manage my chronic pain.”

"I've found some doctors BLAME me for my meds. Yell at me. Some do NOT understand the nature of pain/chronic pain, nor solutions."

"I would like more druggists behind the counter to treat me as a person with a disability (that I did not ask for), rather than some guy whom they look at like a pathetic welfare bum. P.S., I am not on welfare but I do experience this degrading experience about 40% of the time. I am financially hard shipped by my reduced ability to be able to work, thus, I do not pay for medications after I have paid up to the \$2,000 a year mark. When the (some) druggists give me my prescriptions and the amount due is zero, they look at me like I am taking advantage of the system somehow; like I am purposely injecting an expensive, and painful medication as a way of abusing the medical system?. The worst part of my month is when I have to go and pick up my medication. I refuse to let my wife do it as I feel it is my cross to bear."

"I am a butch lesbian and fear discrimination from most medical services."

"Maybe not so much that they don't believe me or respect me, but more that I have difficulty explaining myself to them. My despair, my pain, my fears, my depression. I have been covering for so long that I don't drop my mask even with my doctors. Both of them are new to me. But I feel that I'm just shuffled thru, given my refills and sent on my way."

"My family physician often seems too rushed for me to pursue new options of pain treatment"

"I recently had to stop going to my long time GP because he became disrespectful, brash and he seemed to give up wanting to help me. There's more but the main problem is finding a new doctor who will take me."

"In my case it is access to strong pain medications when needed (that is important to me) and I have this. I do fear when my Dr. retires I may not be so lucky. That really is my biggest fear."

An overwhelming theme that emerged was the desire to be able to mobilize their agency. Enabled with information and dignity and flexibility, people spoke about wanting to have REAL control in their treatment and management options. Most of the respondents wanted a high level of involvement in their own care but perceived that this was inhibited by the discomfort of GPs to address pain in a meaningful way, as well as their perceived lack of knowledge about pain. They felt that it was critical that doctors listen and provide options instead of solely prescribing what the client should do to do.

"That my personal decisions to manage pain (such as medicinal cannabis use) not be criminalized, but rather, regulated."

"I feel that by taking responsibility for myself, my health etc as much as I feel I can, in turn, it enables me to feel more in control and for that, I feel stronger."

"In some ways, the doctor's expectations of their role needs to change: maybe they can't cure my pain, but we can have a conversation about how to minimize or reduce the pain (or any other health problem, like cancer), and we can talk about options and make those decisions together."

- There is a lack of confidence in health care providers' knowledge of pain

There was a general lack of confidence in the knowledge of the medical providers about pain conditions and effective and appropriate treatment options. Individuals, while aware of many of the legal implications, expressed concerns that doctors were scared to deal with the government around access to prescription narcotics.

“When I began, the first physio, she made me visualize myself running and I couldn’t even walk at the time. So I just burst into tears. She was also too rough for my condition and didn’t believe that children could get RSD.”

“Did I get pain treatment early enough? I finally saw the pain specialist in January ’06. I had to call the specialist myself; the referral did not come from my cancer doctor. I had severe pain for a year before and could only use Tylenol. But my cancer doctor never mentioned anything else. When I was in hospital for chemo one time, I told her I was in great pain and she just said “use Tylenol”. This is just last Christmas. And when my brother brought it up with her, she said: “I’m not a pain specialist. I don’t know this area.” But couldn’t she have found me a pain specialist?”

- Social stigma and ostracization related to treatment/management options

Overwhelmingly people spoke about the loss of friends and disintegration of their social networks. Most were very isolated, often because others either did not believe or understand their pain, they had been shown in some way that they were a burden, or because they felt discrimination and stigma.

This was compounded by the fact that for many, being on medications physically alienated them from others or they felt that others alienated them due to their medication use. For others, they were resistant to try certain pain management options because of the stigma:

“The biggest barrier is poverty and living in the DTES and going to clinics where they automatically brand you an addict.”

“I would like medical marijuana but do not want to be treated like a pothead.”

“People make light of what it is like to live life on narcotics.”

The Success: When I didn’t live in poverty my doctor treated my pain and he didn’t call me an addict and he believed me and we had such a great relationship.

The Challenge: When I moved to the DTES because of divorce and found myself in poverty without my regular doctor (it was too expensive to continue seeing him) I was denied access to pain medication simply because of where I lived. It was then that I truly suffered. Nobody listened to me, nobody helped me. After 9 months of being bedridden I finally realized that the only person who knew what it felt like was ME and that if I didn’t do something about it nobody would. So I went to the street and got some of my regular pain medication. It put me in worse poverty. I wasn’t able to eat anymore, no funds. I wasted away and then all the doctors who wouldn’t help me said ‘See, you ARE and Addict.’ They made me an addict because that’s the lens in which they see people from that part of town. And I thought it was quite ridiculous that the doctors all agreed I had a permanent disability of Fibromyalgia, among other things, and signed off my disability forms that way but yet, they still wouldn’t treat my pain. How crazy is that?”

- Communication between professionals not always efficient or timely

Participants felt that having to navigate the disjointed and disconnected system of pain management options inhibited the timely, appropriate and effective management of their pain condition. Many told stories of information not being passed along between referring health professionals, a lack of coordination in their care, of falling through the cracks. Given the challenges faced by participants in accessing care at all, the additional challenges posed by the lack of communication or collaboration between providers exacerbated an already difficult situation.

- Lack of belief amongst physicians in alternative modalities

For many who had exhausted their conventional options, having a GP or a specialist who either knew about or was at least supportive of the idea of exploring alternative care or traditional made a huge difference both physically and emotionally. The struggle with professionals who did not support this exploration was often spoken about as exhausting, degrading and resulted in a power struggle.

“My GP takes direction from me as far as monitoring the known underlying causes (e.g. bone density, x-rays) but discourages referrals to specialists for pain that is still under investigation (i.e. whose cause remains unknown, and not effectively controlled by conventional treatments)”

“My cardiologist saw how much pain I was in; he helped me find a surgeon; I went for corrective surgery in 2003 but it made it worse. The surgeons couldn’t explain why. This is the problem with doctors: a person with a degree in medicine had a certain way of looking at things: with pride, egotism; when I told a surgeon I was in pain he said, “I have done the surgery, your pain is not connected” ... end of conversation! I knew he was not right but he has the power; I have none, and no authority. I know the pain is connected because now I have great pain in my legs – extremely painful every day – to the point of crying.”

Recommendation: Change the way that clients receive care

- Support the development of more effective communication between health care providers and clients
- Support education that makes central: dignity, empathy, respect, compassion for the client situation
- Demonstrate an understanding of individual circumstance
- Address negative stigmas (in society and with health professionals)
- Enable individuals to make choices that work for them
- Develop an approach to treating pain that addresses barriers to access and minimizes the difficulties in navigating the system

“Better care for chronic pain from physicians--I didn't ask to have chronic pain and why should I be treated as suspect and a drug-seeking/addict when I have to see my physician's associate because my family physician is on vacation? People who live with chronic pain have enough to deal with without the suspicion and negative stereotypes that I have observed in well over 80% of the physicians I have had to interact with. Chronic pain is an unacknowledged epidemic that has enormous impacts on our society--at home, at work and beyond.”

2. Clients are seen as their condition or pain, not as a whole person

Individuals spoke about feeling fragmented in the mainstream medical system; often only their physical condition was ever acknowledged. Nearly all had been offered medications as a response to their pain, most often in the absence of any other options. A sense of urgency or desperation had forced many to be very active and vocal in their pursuit of options but the burden of exhaustion, frustration meant many had limited capacity to do this long term. Without a sense of being respected or believed, it was difficult for participants to think that their provider really valued their involvement in their own care.

Being fatigued, feeling isolated, and a lack of seeing any positive progress in their pain condition, was disheartening and de-motivating. Most spoke of being emotionally distraught, psychologically distressed and for some, spiritually strained. For the most part, they found that doing anything when they were depressed or consumed by their pain, unmanageable. When faced with doctors and specialists who dealt with them in fragments, who only acknowledged their physical pain without a

recognition of the emotional and psychological stress, they experienced additional struggles due to the disconnect.

“Providers get paid for a Sickness Based model compared to Wellness Based models”

“One of the biggest barriers has been going to specialists that look at only one part of the equation. I had doctors focusing strictly on my knee problems and not taking into account wrist, ankle, collarbones, elbows, fingers etc. Doctors need to look at the whole picture and this includes mind/body. A person who is depressed with pain does not have pain because he/she is depressed - there is a connection but they don't necessarily cause one another. Many people are depressed because they spend years dealing with doctors who put them down and tell them they are overreacting.”

“I am unable to adequately describe where and how the pain appears in order to get the proper diagnosis and assistance.”

“I feel frustrated with trying to convey the level of pain that I am in, getting the time with my doctor (always feeling rushed), getting a plan in place for my pain.”

Pain emerged as a unique manifestation in each individual, a combination of individual capacities and understanding, cultural contexts, available resources, physiological reactions to medications, interplays with co-existing conditions and many other personal and social realities. Often the treatment options presented were not culturally relevant or were not discussed with the knowledge or acknowledgement of the social and cultural contexts of the clients, and in such became undoable or inappropriate.

Recommendation: Foster and support a holistic approach to pain

- Increase the understanding of GPs and specialists around pain as it impacts ALL aspects of an individual's life
- Focus more attention on emotional and psychological support
- Develop more integrated care team approaches to pain treatment
- Expand care options to include those provided by alternative care practitioners
- Enhance ways for clients/ caregivers to take better care of themselves

3. There are barriers to access

Respondents vocalized how difficult it was for them to access appropriate and effective treatment or management options for their pain. For some it was a challenge to get medications that actually substantially impacted their pain levels; while for others it was the fact that they were looking for non-medication options all together. For most however, they felt that they needed but had not been offered, a menu of options that would have helped them to make choices that were most appropriate and effective for their situation.

- Long wait lists for specialized services

“You wait weeks, months to see a physician. Day of the appointment big thing – physician gives you three minutes and walks out leaving you feeling totally deflated and depressed.”

“Timely surgical care has been my greatest barrier.”

“[The] availability of specialists [is low], [and they have] mixed opinions. I want the pins in my hip taken out and hip replacement, I am told every year to wait. I am 37 now and it is becoming unbearable the last 3years. I have not slept in years; I am always told to wait for services.”

- Inability to access to appropriate medication or non-medication options

Across the board, individuals had been offered medication in response to their pain. The defining feature however, was not IF they would be prescribed medication, but WHAT. The bulk of individuals had been offered Tylenol 3 or other over the counter pain relief suggestions, which was largely ineffective. Some had been able to secure stronger prescription drugs and for those with a supportive physician had been able to access narcotics. Being in a remote area sometimes meant that over the counter pain relief was not even available; for others, it was getting relief when they needed it, when they were experiencing the most pain. And for many, it was about not being treated as an addict because they were simply asking for effective medication.

Two issues emerged. First, for most, they had or continued to struggle with a prescription that did not meet their needs either in quantity (they had been rationed) or in strength. Either way, they were without enough relief to make a difference to the suffering in their lives.

"I know what's best for my body. I know what it feels like and I've lived over 8 years with this disability. So when I ask for pain medication I'm not asking for this to become an addict. I am asking this because after 8 years I know what works and what doesn't."

"I try to tell the doc's "when I'm on my T3s you never see me. It's when you try to cut me off my meds, that's when we have a fight. I've got nothing to lose."

The second issue was that many would like to be medication free. For some, in the absence of any other option, they accepted prescriptions; for others, they struggled to find alternative treatments. But the costs associated with options other than medication, and for some the medication options themselves, were restrictive and so not an option without financial assistance.

"This is why I don't take opiates as well: I don't want to feel stoned/ spacey; I've kept my body clean, and my mind is all I have left: this is important to me."

"I do take the medications, but find their side effects almost as wretched as the illness and pain."

"Due to allergies or severe side effects, an alternative medication can cause severe side effects as well. If my kidney's malfunction again, there is no medication that will work anymore except one that hasn't been authorized."

- Services are not available in my area

There was an extra cost associated with being ill in remote and rural locations. Here individuals questioned whether their location jeopardized timely diagnosis, treatment, and consistent access to care providers. This includes access to alternative therapy care providers.

For those who traveled to appointments, expenses included: airfare, hotel accommodations, extended child care, unpaid leave from work, and the cost burden of treatments themselves, etc. Travel for services throughout the Lower Mainland was further compounded logistically, physically and financially for those living in remote areas of the region. Waiting in lineups for ferries or flights; miscommunication about, or last minute cancellations of, appointments all added to the stress of the situation and directly impacted on the level of pain being experienced

For many, the only option was to move out of their home community to get services they needed.

- Lack of transportation to appointments / pick-up of medication impacts access

Participants talked about the difficulties with transportation, both to get to appointments and to pick up medication and supplies. This took a toll on many who felt "I spend my whole life waiting..." or "I have

to rely on friends and family to shuttle me around... I don't like to be dependent and it adds to the strain on my relationship."

"I am borrowing a 3 wheel scooter for short trips to the store. At least 6 to 8 months ago I tried to get a walker subsidized and still haven't heard anything about that. In the near future I will most likely need a wheel chair; how long will that take or will I get help to buy one?"

"Even though I am in pain, it is not enough to qualify for HandyDart. If my condition is unmanageable, sometimes I avoid seeking professional help due to the transportation difficulty."

Recommendation: Enhance access to a wide range of services and supports

- Increase access to "alternative" therapies/ approaches
- Increase access to narcotics or drugs that work for the individual
- Shorten wait lists and ensure appropriate and timely access to pain services
- Ensure services are available in the client's own language
- Address societal stigma related to living with disabilities
- Enhance transportation options
- Provide more home support for those in pain
- Publicize services more effectively in order to make them more easily accessible
- Expand the number of pain clinics

4. There is a lack of information about the different kinds of services and treatments

Individuals felt that they were operating in the absence of adequate information; information that was readily available from the care provider or more generally. This included information about their condition, treatment and management options.

"I don't know much about other supports/groups in community and don't know where to get this info."

"Often I'm too busy surviving (making ends meet) to source out new treatments I could try (my family doctor isn't helpful in finding them for me)."

"I have some information, but not enough."

"Although medications help the pain, I do not like the fact that I have to take them, but I am not prepared to stop until another alternative that works is found."

"For the most part, I've had to do alot of my own pain 'management' because of how I feel about the subject and how I have come to know beyond a doubt that illness and disease goes beyond just treating pain with drugs. I feel fortunate that there are more people who are gaining an understanding and acceptance of this and thus have others to talk to and work with now. "

Recommendation: Provide adequate and appropriate information

- Improve diagnosis process and make it more timely
- Ensure medical follow up and more seamless hand offs between different health care providers
- Ensure time in the health care encounter to ask questions and receive frank and truthful answers

- Educate health care providers about chronic pain and working with pain sufferers
- Educate employers about the needs of employees living with pain and work with them to support employees living with pain

5. There is a lack of services, financial or emotional support

- The cost of medications, treatments, assistive devices, necessary assistances is prohibitive

Being strained economically, directly impacts an individual's ability to make healthy and appropriate choices; whether it is paying for medications that are not covered, paying upfront for complementary care options, or needing to purchase in-home or other assistance. For some, this meant that they compromised what they felt were appropriate and effective choices. For others, this resulted in them needing to search out pain relief from street-based sources.

"The cost is more than I can afford. For example, I had wisdom teeth removed and was given a prescription for pain meds. I couldn't afford them so I just didn't get them - this was very painful! My other pain meds are covered (Placquanyl, gabapentin), but the phentanyl patches weren't originally covered at my usual pharmacy. I would never have been able to afford that. I went to the Downtown Health Clinic, they made one phone call to Victoria and got it covered for me, at any pharmacy. How did they do that? And why couldn't my regular pharmacy have done that?"

"I want to do more than just taking pain medications but do not have the resources."

"I'm self-employed, so (there is) no (paid) medical leave – and I can't afford to stop working so that hands etc can recover."

- Poor living environments do not foster self-care

Individuals who had experienced a decline in their home environments noticed a worsening of their condition and those who were in marginal housing or not housed at all found it nearly impossible to manage their pain. Sleeping in the cold or on bad beds, having to walk and stand and wait all day, or not being able to modify their environments to mitigate their pain, all contributed to high levels of stress and frustration.

"The message is that we're not worth the care, and that we're not given the same treatment, that we're not valued, that our pain doesn't matter."

"[I need] to have as calm an environment as possible. I find dealing with problems uses energy I need to fight pain. Also, quiet and space when I need it. I find it very difficult to be around people or have a lot of noise around me when the pain is high."

- Limits on available support contribute to ineffective pain management

"Massage therapy has been reduced from 12 visits a year to 10. At least you could have gone once a month for some relief, now you have to live longer with the pain, and I think that is actually more costly for the government because you have to see the doctors more, and use other treatments. Because I also need to see the Podiatrist, and I have to pick and choose and try to spread the 10 visits between the 2 types of treatment"

"I have been in consultation with doctors in Germany for a Ketamine treatment however it will cost about \$20,000.00. This treatment is not available in Canada."

Recommendation: Enhance a variety of supports for people living with pain

- Develop self-management and education programs
- Fund support groups for people with pain
- Provide support for caregivers
- Provide funding for assistive devices
- Enhance financial assistance (Long term disability and welfare)

Extended discussions

From the engagement with clients and caregivers, strong themes emerged that connected the individual experiences of those living with pain. These have been discussed above. In addition to these, however, were issues that were central and critical to further understanding particular experiences. In some situations the information we gathered provided greater context and important historical considerations; in some situations it identified additional systemic barriers and individual constraints. These conversations are explored below.

People living with mental health issues

Those with a mental health condition that they are managing with medications experienced difficulties with interactions between the medications for pain and for their mental health condition, including lessening the effectiveness of their pain medications. In addition, the emotional and psychological impacts of living with pain often exacerbated and impacted their ability to manage their mental health condition.

“I am bi-polar, however, I would have had a great deal more success dealing with my mood disorder had my pain level not been high and ongoing.”

Some made a connection between their mental health and not having had their pain dealt with in a timely fashion; they spoke of how they had become a mental health client BECAUSE of their pain.

In addition to those who manage complex mental health issues, many people mentioned their mental health being jeopardized. Dealing with relentless stigma, misunderstanding, lack of compassion and isolation had a serious toll on their mental well-being.

People living with addictions

“I used to be a person who is injured and needed pain medication, now I’m a junkie.”

“So here is the cycle that so many people talk about: I’m self-employed; I have a bad accident; I need to buy my own pain meds (morphine) because I don’t get medical paid for by an employer; I use up all my savings paying for morphine, while I am out of work. Once the savings are gone I cannot afford a decent place to live and must go on welfare... and must still find pain control, so I start using illegal drugs – or go to a doctor who offers me methadone. There are no alternatives offered! I am then labeled an addict, living in this neighbourhood (Downtown East Side), and start using other drugs because there is so much trauma here.”

“It makes me feel outside of society because people who don’t have chronic pain don’t understand. I’ve even had to go to the street to find relief for my pain when the doctors wouldn’t help me. I was in bed for 9 months before I decided to go to the street.”

Those battling current addictions were often denied narcotics or adequate amounts of prescribed medication. Having been verbal berated by health care providers was common and some felt threatened, with their GPs giving them an ultimatum that if they abused the prescription that they would be cut off. Battling fluctuating pain levels and an inability to access adequate medication, left some participants little option but self-medication, often in the form of street drugs.

"I can't get pills. You don't get prescriptions [in the Downtown], so you have to buy it on the street. There are not even sleeping pills or anti-depressants prescribed."

"My doctor says "you're an addict" so no pain meds, "Just cope with it". So I smoke crack because it "warms the bones" and alleviates the pain."

Some mentioned that because they had an addiction, doctors refused to prescribe medications. Or if they were prescribed they were not privy to the full menu of options, many being offered only methadone to treat their pain. Clients raised concerns not only about the lack of effectiveness of methadone in treating their pain, but also the economic motivation behind prescribing it, given that there is a different funding arrangement around methadone.

"Patients are often put on opiate medication, only to have the doctor try and exchange that prescription for a methadone prescription. So the patient says "No, I need pain medication", but the doctor says "methadone or nothing". The person is forced to go on methadone or to street for stuff."

"I'm on methadone now, but I have so much resistance that it doesn't even touch the pain. That's why people are sometimes overdosing in great pain; they just take too much."

Participants spoke about having to turn to illegal drugs (heroin) or go on methadone, which holds off the pain longer than opiates, but was perceived to be MUCH harder for withdrawal. According to participants, there is little incentive for doctors to continue with prescribing opiates over methadone because for the former they are scrutinized and sometimes their license jeopardized.

"Dispensing methadone is known to be fairly lucrative for both pharmacies who dispense it and doctors who prescribe it as the fee-for service structure supports it in a different way. And for those who refuse methadone there is little else."

What is available for these clients is other types of medication, such as T3s, which for almost all of the individuals we spoke with was ineffective and did not impact their pain. These prescription drugs became a source of income for participants to get the "medication" that they needed from the street.

The conversation about addictions includes those who do not live with an addiction. Lots of people had had practitioners judge them, accusing them of being "drug-seeking" or an "addict". This unfounded accusation impeded people's ability to gain access to appropriate medications, made them not seek care, created negative self-esteem and encouraged self-doubt and often impeded them from being prescribed stronger narcotics as their condition worsened.

"But there is stigma when using methadone. I got labeled as a 'junkie' instead of 'a person with pain issues'."

"Doctor offered me medical marijuana but I didn't want to be "on the list"; didn't want to be labeled."

"The specialist was condescending and didn't believe that I had any medical condition & said I looked like a 40 year old street junkie (I was in my early 20's and had lost weight & was in extreme pain daily for years with out pain medication)."

First Nations peoples

“Once you say that you live in the DTES and they find out that you are Native, then their attitudes REALLY change!”

First Nations peoples have a long history of facing discrimination and stigma in institutions and health care facilities and as such often won't go to see a care provider until much later in the process, when their condition has progressed, their care more compromised.

“Our people won't even talk to providers; therefore can't ever get into a place, let alone get treatment. If you are soft-spoken, they yell speak up and therefore shut down. Need to educate them about how to talk to us.”

Within the conversations with First Nations peoples, there was extensive mention of the need to have a broader definition of pain, one that not only recognized the emotional, mental and physical, but also encompassed spiritual grief and pain. It was important that links between pain and the Residential School experience be acknowledged; in particular, the denial of pain, a sense of inadequacy and how they felt silenced and unable to talk about their pain experience.

“[from the] Residential School Experience: we need to educate our people that it is okay to see someone; we need to open up the doors slowly.”

“People don't pay attention to pain because they are emotionally drained; they just keep going to the Emergency Room when it gets bad.”

“(I) got arthritis because pain and shame is stuck in my joints.”

For many First Nations peoples, theirs is a history and that is wrapped up in fighting with addiction, its issues and its stigma, and as a result a lot of people don't want to use medications, in particular, narcotics. For others they don't want to ask because they fear encountering judgment and stigma about them being drug-seeking; and for others they believe that they are not offered an appropriate prescription because of that same stigma. For those who do access medication and potentially, narcotics, there are a lot of emotional challenges with taking medications sometimes to a community kickback about now not being “clean” or having fallen off the wagon.

“I never drank before I had pain, but I started; I used alcohol to self medicate.”

“I spent years of healing and being drug free... there is great internal and social pressure to not be on opiates; not to take narcotics. It is important to me that I have control of the process; that my status as a recovering addict is respected.”

For many of the individuals we spoke with, cultural practices and approaches had had the greatest impact on their pain. There was an expressed desire to see the role and recognition of traditional medicine reflected in the medical system along with acknowledging spiritual practices and cultural activities as legitimate pain management options.

Some of the other emergent themes that ran through the discussions included: the role of poverty; systemic racism; the pervasiveness of depression; funding difficulties associated with their status; and their location of being on or off reserve.

“How we are treated is DISRESPECTFUL; it compounds the pain.”

People living in remote or rural locations

For people living in rural and remote areas, accessing supports and managing life with pain is particularly challenging. Participants talked about the lack of services in their communities and the corresponding burden of scheduling appointments, traveling to get services, and the financial burden that this entails, from long distance calls to plane, ferry, bus or car travel to the costs of staying in hotels. The logistical challenges were compounded by inclement weather.

Some felt that they had no option but to leave their communities and move to the city in order to receive adequate treatment and manage their pain. However, participants noted that moving meant leaving family and established support networks, often resulting in increased isolation and the challenges associated with that. For First Nations people from remote areas, leaving a home community often meant moving to the Downtown Eastside in order to find affordable housing and to live amongst other Aboriginal people.

Youth

“My health care provider(s) don’t believe me when I tell them about the pain that I’m in, especially when I was younger. I felt hurt and annoyed. They didn’t believe that children could get RSD. Overall, I haven’t had as much input that I would like in decisions about my treatment. And often I’m explained things like an idiot. I’m a child, not an idiot. I just need to be explained things on a kid level; talk to ME.”

“I find the worst thing is the non-believers: the emergency staff, our GP, they don’t believe her. They don’t treat pain in children and young adults aggressively enough. It is ignorance that keeps us from the proper supports. There needs to be more awareness. (Daughter) the first doctor even kicked me out of the room, saying that I was faking it.”

For children and youth social isolation is compounded by their inability to participate in the usual activities of life as a young person, namely school. Teachers lack an understanding of pain and there are few supports within the school system for those students who will have constant integration/reintegration needs. Parents need to become their child’s advocate within the school setting, looking out for their treatment as well as their progression through the curriculum. There is a constant need to explain to school staff the many ways in which chronic pain impacts their child and his/her learning.

“Most people don’t understand the pain. Relationships die out because of that and school suffers. I can’t really take part in things. They didn’t understand it either; they assume that it gets better when I take time off, that suddenly I will be cured. People often think that they have the answers for me and they don’t. It affects all aspects of my life. I used to be an active person and now I always have to take breaks. It’s difficult to balance my life from day-to-day, hour-to-hour. It’s depressing. Dealing with the pain is exhausting.”

“Getting her through school has been a major chore. For 3 of the years she required 24-hour care. And since her illness I have had to home-school her. So that meant that I was her mum, teacher, friend, nurse, as well as a wife, a mother to another daughter and the daughter of an aging parent.”

For children and teens, constantly focusing on surviving and meeting immediate and emerging need means that there is little consistency in their days that would help them facilitate friendships and to get their lives “set-up”.

“I’ve dealt with stuff that [my friends] have never even thought of.”

There are limited child-specific options for children who live with pain. Those who were lucky enough to work with the pain clinic at Children’s Hospital found its child-focus critical, its involvement of the family
Community Engagement, VCH

integral to their survival and the integrated team care approach an excellent model. The difficulties were trying to get into the clinic and what you needed to face once you needed to leave at age 18.

“When I was 18 I had to move from Children’s Pain Clinic to St Paul’s where I was with old people. A was a horrid transition. At 18 I was just told “OK, now you’re done”.

Elders and Seniors

In the discussions with seniors, many spoke of age related biases, where they felt that they had received a different level of care or attention because of their older age. This, coupled with and internalized belief that they should be grateful for what they got, that they didn’t want to become the bother that old people become, meant that they suffered in relative silence.

Being told that their pain was merely a part of growing old, whether by their health provider or those in their family, many seniors had dismissed the pain that they were experiencing. However, seniors having had a lifetime of knowing their body felt they knew that it is a degenerating condition not merely a declining age.

One of the key concerns was the access to transportation. No longer able to drive, they were reliant on the erratic HandiDart or on their family members. Using HandiDart meant that they would need a whole day of waiting to make an appointment

But many seniors are also primary caregivers to an aging partner and sometimes, parent. Their overall health directly impacts both them and those they care for.

“Life is burdensome for me. It’s hard for me to take care of my husband now. Pulling him out of his wheelchair or helping him out of his bed can make my back pain severe. I feel helpless and desperate a lot of times.... My husband really dislikes the idea of going to a senior’s home. I am afraid of forcing him to live in a senior’s home because it may cause him dismay and shorten his life. However, it’s very hard for me to be taking care of him now”.

Caregivers

Whether it be a parent caring for a young adult, an partner caring for their spouse or an adult child caring for an aging parent, caring for individuals living with chronic had profound impacts on caregivers. Families were stressed physically, emotionally and financially as priorities shifted to accommodate the increased needs of those in pain; relationships were strained, marriages broke apart. Some caregivers had abandoned their own emotional and physical needs in the wake of caretaking only to have these present in much more acute and severe ways later on.

“I got pretty sick in the first few years. I lost substantial weight and then after 6 years of dealing [with it] I needed to go on meds. I just couldn’t cope, and I couldn’t cope now without them. But I’m scared of telling people about it. People make judgments about [needing to use medications], about my ability to cope. But it’s never ending. Every day, every day, every day there is something that she needs.”

“Because I am a young caregiver, everyone thinks that I am fine and professionals focus on my handicapped sisters needs; they don’t consider my own pain needs. Since they assume I am fine, they are actually creating a problem for themselves because I can see I am not going to be able to care for her long-term and will need to stop working sooner than the average person because of my own needs”

"I'd love it if she was able to be doing what kids do, leave the house, venture out for themselves to school or work. Then my life would begin. But she won't be able to work. She will always live with us, and a lot of that time she will be sick. She doesn't have the physical ability to cook, clean, shop for groceries, get meds, bathe."

"I'm no longer an I. I have become a WE. We both say "we" as we are tied at the hip."

People who speak other languages or are from various cultural groups

Different experiences emerged in different cultural communities that reflected both a wide variation in perceptions of illness, pain and medical intervention as well as differing histories in the Canadian context.

Common among the respondents who mentioned culture, was the articulation of the integral role that it played in their lives; that the tension that existed between their cultural context and their pain was a key element in their decisions around the management of that pain. There was a lot of discussion about the profound sense of isolation that individuals felt when they were no longer able to comfortably and easily attend functions or social gatherings, or in some cases even attend at all. Challenges included such things as a non-acceptance of their condition, an inability to eat the food provided and a profound discomfort with the tension that a lack of their full-participation caused. For many, this compounded the already existing difficulties of getting to gathering spaces and then physical challenges of staying there.

"Also I have a huge family here in Vancouver and every now and then we have to attend family functions, parties etc. which means oily foods, lots of junk food like pop and chips. It is always hard for me to refuse food in those social gatherings because your relatives tease you and you don't want to be rude and you have to try every food which is offered."

In some cases, the additional financial and physical burden of caring for an individual living in pain, exacerbated difficult family situations.

"The client is sponsored by her daughter (10 years sponsorship) so she or her daughter needs to pay for the fee if she wants to be admitted to a hospice care home. But they can't afford it so she lives at home. And living at home is a problem because her burnt-out daughter needs to take care of two young children and she is pregnant with marital difficulty. The daughter may ignore the needs of her mother. The daughter has admitted to sometimes verbally abusing her mother when she is mad at her. That affects her mother's well-being and indirectly affects the way the client deals with pain. Without the support at home, her mother feels she is a burden to the family."

There was a lot of discussion about how language presented a huge barrier to accessing appropriate care; this was evident from initial diagnosis and referrals, to accessing pain management options and locating important information.

"I almost don't speak any English. Now without Cross-cultural health brokers, I won't be able to see the Chiropractor I was seeing; can't see specialists who don't speak Chinese. Our family doctor is very mean, but since there are only a few choices for Chinese speaking doctors, he is not afraid of losing clients and we don't have much choice. I can't make medical appointment, or get services in the community if it's offered in English."

"The problem that I encountered in Vancouver General Hospital was that there was no interpreter available and sometimes I had problems to explain my condition or to get a proper explanation from the medical staff. This was very stressful."

"I haven't tried other methods then my pain-killers, my language is very limited and I don't know how to get access to other methods if there are others. I have some ointments I brought from my country and I used them more at night as they relieve the pain so that I can sleep. But her I don't know where to go or how I can access them."

"I wish I would have a doctor that would speak my language so I would get better knowledge of what is available for me. If I go to the doctor by myself it is very difficult for me to understand them or to ask all what is concerning me."

Difficulty arises for those who are in the Chinese community and needing and choosing to take opiates. It may be in secret and it is certainly not without shame and without conflict

"Success staff: "there needs to be more education for those in hospice care, about use of painkillers; they don't have many months to live but wont take painkillers, because older Chinese people respect hardship and endurance. This proves they have willpower, so they wont take drugs. But people need to be educated on the usefulness of painkillers."

"People here have not tried illegal drugs. According to Chinese, opiates are dangerous drugs; we have a low opinion of this kind of self-help."

"My doctor told me to take morphine for my pain, but I said no; this is a dangerous drug and it is for drug addicts".

Conclusion

The community engagement process was successful in reaching significant numbers of clients and caregivers to participate in a process that captured their experience of living with chronic and persistent pain. Their suggestions form an important contribution to the development of the Regional Pain Strategy.

The engagement explored the barriers, challenges and successes individuals had encountered along their journey. It inquired into the treatment and support that they had chosen as well as what they felt they lacked access to or would choose as management and treatment if they had the option. Participants were also asked for their suggestions and recommendations about changes that they thought would make a difference to their quality of life and to their pain experience or condition.

The overarching themes included: difficult and often disrespectful relationships with mainstream health providers, a lack of provider understanding of the broader impacts and needs associated with an individuals pain, an absence of adequate information and an inability to access the needed services and supports, dominated the discussions. In response, participants offered constructive and thoughtful suggestions and recommendations

There was generous participation in the engagement process from a diverse range of people, living complex lives, who wanted to contribute to the outcome of this process. Their investment in telling their "full story" has produced this rich information for the Pain Strategy project. In this vein, it is strongly recommended that consultation with members of the public be incorporated into ongoing planning and design so that we might continue to hear and incorporate this knowledge and insight.

Appendix 1:



Vancouver Coastal Health Pain Survey: **We Want to Hear from You!**

About VCH and the Regional Pain Strategy

This survey is being conducted by Vancouver Coastal Health (VCH). VCH is conducting this survey to help design a comprehensive strategy to improve the recognition of, and treatment available for, pain.

Our health services range from the first point of contact with a health care professional, such as a family doctor; to care in our hospitals; to community based residential, home health, mental health, and public health services. VCH also provides care to patients from other parts of the province who require highly specialized services.

VCH is trying to improve services and quality of life for people living with pain within our region (Richmond, Vancouver, North Shore, Sea to Sky, Sunshine Coast, Powell River and Central Coast) and we would like your feedback.

The purpose of this survey is to learn more from you about

- what you experience living with pain
- how you currently manage your pain
- how we could improve our services to meet your needs

Your participation will help us to focus our efforts.

About the Survey

- ✓ This survey is designed to collect information from those who experience pain. If you are a caregiver for someone experiencing pain, we also welcome your participation; if the individual you are caring for is unable to fill out the survey, please fill out the survey on their behalf.

Your answers will remain anonymous. No one reading your answers or comments will know who you are.

This survey is designed to take about 30 minutes to complete. There are 6 pages of questions.

If you have difficulty or have questions related to the survey please contact:
Kaye McMahon at 604.714.3763 or emailing kaye.mcmahon@vch.ca.
Thank you again for your participation!

- Ongoing (constant or chronic)
- Both: I have pain that is ongoing with times when the pain is more intense

Do you know the cause of your main pain problem?

Do you experience health problems other than the one that causes your main pain problem? If so, please list.

Which areas of your life are negatively affected or restricted because of your pain? Please check all that apply.

- Activities of daily living (personal care, general household chores, etc.)
- Employment or your major daily responsibilities
- Sleep
- Social or family relationships
- Caring for family members
- Cultural activities
- Recreational or leisure activities
- Emotional well-being/mood
- Enjoyment of life/quality of life
- Finances
- Other _____

Does your pain affect the way you feel emotionally?

- Yes
- No

If yes, in what ways does it affect you emotionally? Please check all that apply.

- Depression
- Anxiety
- Irritability
- Thoughts of suicide
- Other _____

About Your Experience with Supports and Assistance for Treating and Managing Pain

What supports or assistance have you used to deal with your pain? Please check all that apply and rank their helpfulness.

	Not helpful	Somewhat helpful	Mostly helpful	Very helpful
Prescription pain medication				

Over the counter pain medication				
Care from a family doctor				
Care from a specialist				
Care from a Pain Clinic				
Care from a psychiatrist or psychologist				
Advice from a pharmacist				
Physiotherapy				
Occupational therapy				
Acupuncture				
Traditional medicine or treatments				
Chiropractic care				
Massage therapy				
Personal coping skills (e.g., meditation)				
Attend Compassion Club				
Use of alcohol or illicit drugs for self-medication				
Support group or other social support				
Other community-based supports (please list)				

Do you have any other comments about supports or assistance that you have or have not used?

How much involvement do you have in decisions made about the treatment and management of your pain?

- Very involved
- Somewhat involved
- Not very involved
- I am not involved
- I don't know

How much involvement would you like to have in decisions made about the treatment and management of your pain?

- Very involved
- Somewhat involved
- Not very involved
- I am not involved
- I don't know

Who else is involved in decisions about the treatment or management of your pain? Please check all that apply.

- My children

- My partner or spouse
- My parents
- Elders
- Other _____

**How satisfied are you with your current pain treatment and management?
Please check one.**

- Very satisfied
- Somewhat satisfied
- Not very satisfied
- Not at all satisfied
- I don't know

**What barriers are you experiencing in accessing supports to deal with pain?
Please check all that apply.**

- The supports I need are not available in my area
- The supports I need are not in my language
- The supports I need are not culturally relevant to me
- There are long wait lists for the supports/assistance that I need
- I can't or don't want to take medications because of side effects
- I would rather not take medications for reasons not related to side effects
- I can't get access to the medications I need
- My health care provider(s) don't believe me when I tell them about my pain
- I don't feel respected by my health provider(s)
- I do not have family or friends who can help me get what I need or to get to my appointments
- I don't have information about the different kinds of services or treatments that might help with my pain
- The cost of treatments is more than I can afford
- Nothing I've tried has been able to stop/reduce my pain
- Other _____

Have you had to wait to get treatment or support for your pain?

- Yes
- No

If yes, how long have you had to wait?

- 3 to 6 months
- 6 months to 1 year
- 1 year to 18 months
- 18 months to 2 years
- More than 2 years

OPEN QUESTIONS

We're interested in what people living with pain go through as they seek care. What would you like to tell us about the challenges and successes that you have experienced?

What is important to you as you try to manage your pain?

At this point in time, what two things would improve your quality of life?

How has your family been affected by the pain you experience?

What would improve the supports and services for people living with pain?

Is there anything else you would like to share with us?

Thank you for your participation!!

Please send your completed survey by **AUGUST 13th** to:

VCH Community Engagement
200-520 West 6th Avenue
Vancouver, BC
V5Z 4H5

Information provided in the surveys will be analyzed and a report presented to the Regional Pain Strategy Project Advisory Team. This final report will also be posted on the VCH website at www.vch.ca/ce. If you would like to receive a copy of the final report, please request one by contacting Kaye McMahon at 604.714.3763 or emailing kaye.mcmahon@vch.ca.

This Regional Pain Strategy Project Advisory Team is made up of physicians, other health care providers, and representatives from partners such as educational institutions and other health care organizations. This team will review the final report on the survey results, as well as looking at other information (e.g., literature on the best models for pain management etc.), and will use this information to develop a region-wide strategy for improving diagnosis, treatment and management of pain.

This strategy will go forward to the VCH's Senior Executive Team in late fall 2006.