Canadians and Pain:
A National Survey on Personal Experience, Treatment Approaches and Policy Perspectives

-- Angus Reid Institute in partnership with Pain BC and the Mindset Foundation --

Final Questionnaire (May 31st)

Introduction

Today’s survey tries to better understand people’s different experiences in life. As always, there are no right or wrong answers – we just want your honest perspective.

Please be assured of the complete confidentiality of all our surveys; responses are pooled with all others and only analyzed on a combined basis.

Part A. Pain: Experience and exposure

QA1 To start off, we want to get an idea of people’s general sense of well-being and the different conditions some people are living with. We know this is personal, but again, your answers are confidential. Would you please indicate if you’ve had personal experience with each of the following:

[Conditions:]
- Insomnia – often not being able to sleep for several nights
- Serious Weight issues – the kind you’ve talked to a health professional about
- Mobility issues – that is, trouble moving around
- Anxiety and/or depression
- Noticeable pain that lasts or recurs for more than three months

[Responses]
- No personal experience with that
- Yes, have experienced

QA2 Does anyone close to you (family members or close friends) currently experience any of these things (as far as you know)?

[Same list of conditions]

[Responses]
- Yes, family/friend experience
- No, no one close to me

QA3 We’d like to focus on the subject of pain – specifically, noticeable pain that lasts or recurs for more than three months. Often referred to as “chronic pain”, this might or might not be severe pain, it could be constant or intermittent, and it could be due to many possible causes (including an injury, surgery, a health problem, or some undiagnosed cause).
To confirm, have you yourself experienced this kind of ongoing pain?

Yes, currently
Have in the past, but not currently
No, have not

QA4a Do you currently spend time with, help out or provide care for someone else who lives with this type of on-going pain? (This might be a spouse, parent, other relative, or friend.) (Select all that apply)

No, do not
Yes, spend time with
Yes, help/provide care for

[If Yes at A4a:]
QA4b And what is your relationship to that person living with on-going pain? Please select all that apply if there is more than one person:

A spouse or partner
A parent
A parent-in-law
A child
Another family member
A friend
A neighbor
A co-worker
Someone else (specify:_____

[If selected more than one at A4b]
QA4c And which of these people’s pain condition would you say you are most familiar with? (Since we have some follow-up questions on that.)

[List options chosen by respondent in QA4b, to choose from below] [One only]

Part B. The pain experience – personal

[To be asked of those with personal experience with pain – Yes, currently or In the past at QA3]

You’ve indicated you have (or had) personal experience with pain lasting or recurring for longer than three months. We’d like to understand that experience better.

QB1a How long have you had this pain? [Past: Or how long did you have it?]

Less than a year
1 to 2 years
3 to 5 Years
QB1b And how long has it been since you had this ongoing pain – when did it end?

Ended just this past year
1 to 2 years ago
3 to 5 Years
6 to 10 years
10 to 20 years
20+ years ago
(Hard to say/Not entirely ended/Changed)

QB2 As far as you know, what were the factors that contributed to the development of this pain? (Select all that apply from the list below.)

[This order]
Injury – motor vehicle/sports/workplace etc
Posture or repetitive movements
Surgery
Cancer treatment (other than surgery)
Treatment for another illness (not cancer)
Age-related condition/illness (osteoarthritis etc)
Inflammatory or auto-immune disease (rheumatoid arthritis etc)
Chronic disease (such as diabetes/Chrohns/colitis)
Following a stressful/traumatic event
No precise cause/Undiagnosed/Don’t know
Some other cause (Specify:_____)

QB3a. Thinking about that pain that you experience(d), how would you describe it at its worst?

Barely noticeable
Minor
Moderate
Severe
Pain as bad as you can imagine

QB3b. And how would you describe the pain on average?

Barely noticeable
Minor
Moderate
Severe
Pain as bad as you can imagine
QB4 How would you describe your own pain experience on the following dimensions? Is it: [Past: (or was it):]

[Slider scale -- 5 pts]

Constant or intermittent (comes and goes)?

Predictable or unpredictable?

Well managed or out of control?

QB5 We’re interested in what kind of impact ongoing pain has on different people. Please indicate the extent to which -- if at all -- your pain interferes [Past: (or did when you had it)] with each of the following:

[Rows. Randomize]

Your general activity (getting dressed, in and out of vehicles, meal prep etc)

Your mood

Walking ability

Normal work (outside the home and/or housework and/or school)

Relationships with other people

Sleep

Your enjoyment of life [Anchor]

[Columns]

Does not/Did not interfere

A bit

To some degree

A lot

Completely interferes(d)

QB6 Has your own experience with on-going pain led you to any of the following? (We realize these are personal questions – please be assured of complete confidentiality. And if you’d rather not answer just select that response.)

(Select any that apply.)

[This order]

Depression

Feeling that life isn’t worth living

Stress and anxiety
Loneliness
Isolation/Cut off from others
Avoid activities/doing things
Drinking too much alcohol
Using non-prescribed drugs
Using too much prescription medicine
Smoking too much
Other (Specify:)
No, none of the above [Anchor – Exclusive]
Rather not answer [Anchor – Exclusive]

QB7 We’d like to get a better understanding of different personal experiences with ongoing pain. Generally speaking (and realizing everyone has their ups and downs), how would you describe your own feelings about your pain.

Use the slider to show how you feel about your pain [Past experience: (or felt at the time you had ongoing pain)] on each of these dimensions.
[Slider scales]
[Randomize dimensions]

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<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3-Neutral</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>Pessimistic that it will ever be okay</td>
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<td>Optimistic that pain will not keep you from living a good life</td>
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<tr>
<td>Feeling hopeless about managing with this</td>
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<td>Feeling hopeful</td>
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<td>Alone in your struggle</td>
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<td>Supported by others</td>
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<td>Frustrated</td>
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<td>At peace</td>
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<td>Doubted</td>
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<td>Ashamed and embarrassed talking about your pain</td>
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<td>Open and confident talking about it</td>
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<td>Me and my pain are being judged by others</td>
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<td>Me and my pain are accepted by others</td>
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</table>

QB8 We’re also interested in how other people in your life react or deal with your pain – if they are involved at all. To what extent would you say each of the following is: [Past: -- or was, when you were experiencing it --] supportive or not supportive of your pain? (If they are not at all involved or unaware, please indicate that.) (And just select “not applicable” if that’s the case for any of these – ie no spouse or employer etc.)

[Randomize Rows]
Your GP -- family doctor
Your specialist
Your spouse
Your children
Other close family  
Your friends  
Your employer  

[Columns]  
Very supportive of your pain  
Supportive  
Not supportive  
Very unsupportive of your pain  
Not at all involved  
They are not aware  
Not applicable/Don’t have  

**Part C. The pain experience – loved ones**

[To be asked of those who have NOT personally experienced chronic pain themselves at QA3 but spend time or help care for someone living with pain at QA4a.]

You’ve indicated you spend time with or help care for someone who lives with chronic pain – your [pipe-in response from QA4b or c]. We’d like to understand this condition better so we have a few questions for you about that person’s pain experience.

Please answer based on whatever you may have discussed or observed with that person or on your own impressions, and if you feel you really can’t say on a specific question then just indicate that.

**QC1 How long has this person had this ongoing pain?**

Ended just this past year  
1 to 2 years  
3 to 5 Years  
6 to 10 years  
10 to 20 years ago  
20+ years ago  
(Can’t say/Don’t know)

**QC2 As far as you know, what were the factors that contributed to the development of their pain?**  
(Select all that apply from the list below.)

[This order]  
Injury – motor vehicle/sports/workplace etc  
Posture or repetitive movements  
Surgery  
Cancer treatment (other than surgery)  
Treatment for another illness (not cancer)  
Age-related condition/illness (osteoarthritis etc)  
Inflammatory or auto-immune disease (rheumatoid arthritis etc)
Chronic disease (such as diabetes/Chrohns/colitis)
Following a stressful/traumatic event
No precise cause/Undiagnosed/Don’t know
Some other cause (Specify:_____)
(Can’t say/Don’t know)

QC3a Thinking about that pain that this person experiences, how would you describe it at its worst?

Barely noticeable
Minor
Moderate
Severe
Pain as bad as you can imagine
(Can’t say/Don’t know)

QC3b And how would you describe their pain on average?

Barely noticeable
Minor
Moderate
Severe
Pain as bad as you can imagine
(Can’t say/Dont know)

QC4 How would you describe their pain experience on the following dimensions?

[Slider scale -- 5 pts. Include “Can’t say/Don’t know” option]

Constant or intermittent (comes and goes)?

Predictable or unpredictable?

Well managed or out of control?

QCS We’re interested in what kind of impact ongoing pain has on different people. From whatever you’ve discussed or observed and on your own impressions of their situation, to what extent -- if at all -- would you say that person’s pain interferes with each of the following:

[Rows]
Their general activity (getting dressed, in and out of vehicles, meal prep etc)

Their relationships with other people

Their enjoyment of life
[Columns]
Does not interfere
A bit
To some degree
A lot
Completely interferes
(Can’t say/Don’t know)

QC6 And, as far as you are aware, has their experience with on-going pain led them to any of the following? (We realize these are personal questions – please be assured of complete confidentiality. And if you’d rather not answer just select that response.)
(Select any that apply.)

[This order]
Depression
Feeling that life isn’t worth living
Stress and anxiety
Loneliness
Isolation/Cut off from others
Avoid activities/doing things
Drinking too much alcohol
Using/abusing other non-prescribed drugs
Using too much prescription medicine
Smoking too much
Other (Specify:)
No, none of the above [Exclusive]
Rather not answer [Exclusive]
Really can’t say/Don’t know [Exclusive]

C7. How would you describe that person’s overall feelings about their pain -- optimistic or pessimistic?
Use the slider to show your best sense of how they feel.

[Slider scale -- 5 pts. Plus “Can’t say/Don’t know”]

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<th></th>
<th>1</th>
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<th>3-N</th>
<th>4</th>
<th>5</th>
<th>(Can’t say/Don’t know)</th>
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QC8 From your perspective, do you think that person living with on-going pain generally feels the following are supportive or unsupportive of them? (Some of these people in their life are perhaps not at all involved or unaware, so you can indicate that. And just select “not applicable” if that’s the case for any of these – ie they have no spouse or employer etc.)

[Randomize]
Their GP/family doctor
Their family

[Responses]
Very supportive
Supportive
Not supportive
Very unsupportive
Not at all involved
They are not aware
Not applicable/Don’t have
Can’t say/Don’t know

Chronic Pain “segments” for analysis:

Person currently living with severe persistent pain

Person living with moderate persistent pain – more intermittent/managed

Past experience with chronic pain

Proximous – someone close/provide care for a person living with pain

Not personally exposed

Another key dimension for analysis:

Well-managed versus not managed at all – what does this continuum look like?
In what ways do these groups differ: demo-wise, socio-economically, and outlook etc.

Part D. Pain Treatments – usage and accessibility (Personal experience)

[To be asked of those with personal experience with pain – Yes, currently or In the past at QA3]

We want to learn more about what kinds of different treatment people might use to address their on-going pain. The range of treatments fall into four broad categories: pharmaceutical or drug treatments, medical and other physical treatments and psychological treatments.

QD1 Considering each of these four broad treatment categories...

a) Please indicate which of the more specific types of treatments you have ever used (or even just tried) for your on-going pain.
(Select all that apply)

[Currently living with pain:]

b) And which, if any, are you currently using to treat your on-going pain?
(Select all that apply)
<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Ever Used/Tried</th>
<th>Currently using</th>
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<tr>
<td><strong>Pharmaceutical</strong></td>
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<td>Prescribed pain medications</td>
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<td>Over-the-counter pain medications</td>
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<td>Cannabis (prescribed or not)</td>
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<td><strong>Medical treatments</strong></td>
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<td>Surgery</td>
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<td>Other medical interventions (deep brain/spinal cord stimulation, shock wave therapy, prolotherapy, nerve block, etc.)</td>
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<td>Medical devices (implantable nerve stimulator, splints, etc.)</td>
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<td><strong>Other physical treatments</strong></td>
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<td>Exercise/Therapeutic movement/Yoga</td>
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<td><strong>Non-physical or psychological treatments</strong></td>
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<td>Other psychological treatment(s) (biofeedback/virtual reality, etc)</td>
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<tr>
<td>None of these – Anchor, Exclusive</td>
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[Currently living with pain:]
QD2 Have we missed any chronic pain treatments that you think are important?

No, can’t think of any others
Yes, (Please specify: __________)

QD3 Thinking about the types of treatment you have used for your chronic pain, based on your own personal experience, how effective is/was each of these for your own pain management?

[List each treatment ever used/attempted from QD1a]

[Responses]
Very effective
Quite effective
Not very effective
Not effective at all
Really can’t say/Don’t know

[Currently living with pain:]
QD4. Are there any of these treatments you are currently using that you consider to be absolutely critical to your pain management – you would not go without? (Select all that apply)

No, consider none of these as critical [Anchor, Exclusive]
Yes, consider one/some critical: Select all that apply:
[List of those currently used from QD1b]

QD5 Turning now to the issue of costs and affordability...

Thinking about all of the various types of treatments you use for pain [Past: (or did use when you had on-going pain)] – including all those treatment approaches we just looked at – overall, roughly how much of the total costs are [Past: or were] paid for by you and your household and how much are [Past: or were] covered by your provincial health care plan or a private/employee insurance plan? (If you do have some kind of plan, please consider the re-imbursements you received, and your usage of any treatments beyond a deductible or maximum number of covered visits, that kind of thing.)

Overall, would you say your total costs for any and all pain treatments has been:

Always paid by you with no insurance/government coverage
Mostly paid by you with some insurance/government coverage
About 50:50 (you pay roughly half)
Mostly paid by insurance/government with some paid by your household
Always paid by insurance/government with nothing paid by your household in the end
Not sure/Can’t say

[Currently living with pain:]
QD6 Getting back to the specific treatments you indicated you are currently using, are any of these a financial struggle or hardship for you to afford? (Select all that apply)

No, none pose a financial hardship
Yes, some do: Select all that apply:
[Treatment List – those currently used from QD1b]

QD7 And thinking again of the whole range of possible pain treatments we just looked at, are there any of these pain treatments that you would use or would use more but don’t because they cost too much money? [Past: (or would have used or used more when you were experiencing on-going pain)]?

No, None I would use/use more
Yes, some I would: Select all that apply from our list of treatments:
[Full Treatment List from QD1a]
QD8 Setting aside financial considerations for a moment, and focusing on geography, as far as you are aware, are any of these possible pain treatments unavailable where you live (let’s say, NOT within an hour’s drive from where you live).

No, all of these exist within an hour’s drive of me
Yes, some are further than that – Select all that apply:
[Full Treatment List from QD1a]

QD9 And what about wait times for these various pain treatments? Based on your own experience and on whatever you’ve seen or heard about it, do any of these treatments have long wait times in your area – let’s say, you would have to wait six months or more to get in?

No, not aware of any wait times of six months or more
Yes, some long wait times – Select all that apply:
[Full Treatment List from QD1a]

Part E. Pain Treatments – usage and accessibility (Loved one)

[To be asked of those who have NOT personally experienced chronic pain themselves at QA3 but spend time or help care for someone living with pain at QA4a.]

We want to learn more about what kinds of different treatment people use to address their on-going pain. So we have some additional questions about your [Pipe-in from QA4b or c] who is living with on-going pain. Again, please just answer based on what you’ve discussed or observed with that person, and if you can’t say on a specific question then just indicate that.

QE1 The range of pain treatments fall into four broad categories: pharmaceutical or drug treatments, medical and other physical treatments and psychological treatments.
<table>
<thead>
<tr>
<th>Medical devices (implantable nerve stimulator, splints, etc.)</th>
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**Other physical treatments**

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**Non-physical or psychological treatments**

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<tr>
<th>None of these [Anchor/Exclusive]</th>
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<tr>
<td>Can’t say/Don’t know [Anchor/Exclusive]</td>
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</table>

QE2 As far as you know, are there any of these treatments they are currently using that they consider to be absolutely critical to their pain management – they would not go without? (Select all that apply)

No, consider none of these as critical
Can’t say/Don’t know
Yes, consider these treatments critical: (Select all that apply)
[List of those currently used from QE1]

QE3 Turning now to the issue of costs and affordability...

Thinking about all of the various types of treatments they use for pain – including all those treatment approaches we just looked at – overall, roughly how much of the total costs would they pay for themselves/as a household and how much is covered by their provincial health care plan or a private/employee insurance plan?

Overall, would you say their total costs for any and all pain treatments has been:

Always paid by them with no insurance/government coverage
Mostly paid by them with some insurance/government coverage
About 50:50
Mostly paid by insurance/government with some paid by their household
Always paid by insurance/government with nothing paid by their household in the end
(Can’t say/Don’t know)
QE4 Getting back to the specific treatments you indicated that this person is currently using, are any of these a financial struggle or hardship for them to afford?

No, none pose financial hardship
Can’t say/Don’t know
Yes, some pose financial hardship: Select all that apply:
[List of treatments being taken in QE1]

QE5 And thinking again of the whole range of possible pain treatments we just looked at, as far as you are aware, are there any of these pain treatments that they would use or would use more but don’t because they cost too much money?

No, None they would use/use more
Can’t say/Don’t know
Yes, some they would use/use more – Select all that apply from our list of treatments:
[Full Treatment List from QE1]

QE6 Setting aside financial considerations for a moment, and focusing on geography, as far as you are aware, are any of these possible pain treatments unavailable where this person lives (let’s say, NOT within an hour’s drive of their home)?

No, all exist within an hour’s drive of them
Yes, some are further than that – Select all that apply:
[Full Treatment List from QE1]

QE7 And what about wait times for these various pain treatments? As far as you are aware, do any of these treatments have long wait times in their area – let’s say, they would have to wait six months or more to get in?

No, not aware of any wait times of six months or more
Yes, some long wait times – Select all that apply:
[Full Treatment List from QE1]

Part F1. Attitudes

[Ask all those with no personal experience with pain currently or in the past at QA3]

QF1.1. You’ve indicated that you personally have not had any ongoing pain issues, which is great! We do have a few questions about how you feel about this issue from a personal point of view.

Suppose you did encounter a situation where, for whatever reason, you were dealing with some long-term pain, lasting more than three months. How confident are you that you would be able to…

Afford the pain medications that you need, whether prescription or over the counter
Afford physical pain treatments like physiotherapy, massage, chiropractor etc.
Be able to see a good quality doctor
Access care in a timely fashion – the wait times won’t be unreasonable

Very confident
Confident
Not that confident
Not confident at all
Can’t say/Don’t know

QF1.2 And do you generally worry about developing long-term pain, or is this not something you ever think about?

Worry about it often
Worry about it once in a while
Don’t really worry about it
Never worry about it

[Ask everyone in the survey:] QF1.1 Here are a few statements that people have made about the subject of pain treatment. For each one, please indicate whether you agree or disagree.

[Randomize]

Every Canadian – regardless of income – should have access to pain treatment that works for them
It’s simply not right that some Canadians have to struggle to pay for medicine they need
I don’t know very much about a lot of the new types of pain treatments
If pain treatments were widely available at no or low cost, a lot of people would be living in less pain
People shouldn’t have to wait for months and months for pain treatment
The stigma surrounding chronic pain prevents people from seeking treatment
If Canadians had better access to other kinds of pain treatment, it would reduce reliance on opioids

[If currently living with pain at QA3 only:] If I could afford to pay for more of the available treatments, I would be living with less pain today

Strongly agree
Agree
Disagree
Strongly Disagree
Not sure/Can’t say

Part F2. Drugs for pain

[Ask Everyone]

QF1 A few questions about prescription medicines used to treat chronic pain – in particular, opioids such as morphine, codeine, oxycodone, oxycontin and others.
a. To what extent are you concerned about the following risks when people use these types of pharmaceuticals for persistent pain?

[Rows. This order]
People over-using these drugs – that is, using more than the recommended dosage
The risk of becoming addicted to one of these drugs
Risk of overdose

[Columns]
Very concerned
Somewhat concerned
Not very concerned
Not concerned at all
Can’t say/Don’t know

[Those currently living with pain:] b. Does concern about these potential problems with prescription pain medication affect your own use of these medications for your pain?

Yes, don’t use because of these concerns
Yes, curtail my use because of concern
No, would not use anyhow
No, does not affect my usage

[If Yes, don’t use or Yes, curtail:] c. And how would you describe the impact of not using or limiting your use of prescription pain medications? Would you say:

It means a lot more pain/less activity for you
OR
You’ve found other ways to deal with the pain

[Those living with pain:] d. Have you had any problems getting prescription medicines that you needed or the dosage or length of prescription you needed because of your doctor’s or the system’s concerns about people becoming addicted to these drugs?
(Select any that apply)

No, no issues [Exclusive]
Some issues – needed to convince that drugs were needed
Yes, MD insisted on lower dose
Yes, MD would not renew prescription
Yes, MD would not prescribe at all
Yes, other (specify: _____)
Part G. The HC system and pain

[Ask everyone]

Let’s put our focus now on the public health care system in your province. For our purposes, your province’s public health care system mainly includes doctors and specialists (as well as nurses and technicians and other health care workers) in a doctor’s office, clinic or hospital setting.

[Display for those with pain experience/loved one: This would not include many of the treatments we were just considering (such as massage therapy and chiropractors, for example, or treatments like acupuncture or physiotherapy, etc) which are outside the public system.]

QG1 Overall, what kind of a job do you think the health care system in your province does when it comes to the problem of pain and how to help people living with it?

Very good
Good
Poor
Very poor
Not sure/Can’t say

[QG2 series is for those with pain experience -- current or past:]
QG2a Overall, how has the public health care system in this province treated your own issues with pain?

Very good
Good
Poor
Very poor

QG2b And what about your main doctor -- the one you discuss(ed) your pain issues with the most? How would you rate that doctor for each of the following:

[Randomize Rows]

Being up-to-date on the latest pain treatments
Informing you about alternatives for treatment
Open to new treatment ideas and options
Interested in your pain
Knowledgeable about chronic pain
Sympathetic and caring about your pain

[Anchor] The overall job they are doing {Past: or did} dealing with you and your pain

[Columns]

Very good
Good
Poor
Very poor
(NA -- do/did not discuss with MD)

[QG3 series is for those spending time/caring for loved one in pain:]
QG3a Overall, how would you say the public health care system in this province has treated your [Pipe-in from QA4b or c] and their pain issues?

Very good
Good
Poor
Very poor
(Can’t say/don’t know)

QG3b And what about their main doctor? Overall, what kind of job would you say they are doing in dealing with this person’s pain?

Very good
Good
Poor
Very poor
(NA – no MD involved)
(Can’t say/don’t know)

Part H: Policy Proposals/Remedies

QH1. A number of different proposals have been made with respect to the treatment of chronic pain here in Canada. Let’s keep in mind that lots of things cost money and new approaches and programs in one area can mean cuts elsewhere or higher taxes or deficits. Please consider each of the following proposals and indicate how worthwhile, or not, you think each would be.

[Randomize Proposals]

Providing more publicly funded pain clinics with a team of experts (specialists, pharmacists, psychologists, occupational and physical therapy etc) available at one central location

Subsidizing people who can’t afford pain treatments that work for them

Educating the public to better understand chronic pain and the challenges for those living with it

Providing more support for those living with pain such as support groups, education programs, patient advocacy organizations etc

Providing more funding for expanded research into new pain treatment therapies

Increasing coverage for pharmaceutical/medicinal pain treatments
Increasing coverage for medical cannabis

Covering the costs of more pain treatments as part of public health care [Anchor]

[Responses:]

Definitely worthwhile
Probably
Probably not
Definitely not worthwhile

QH2 Just a more specific question as we wrap-up....
There are a number of different pain treatment options in Canada for people dealing with long-term pain. Some of them are covered by the public health care system, while others are not and the person with pain has to pay for them themselves or via private insurance.

Please have a look at our list of pain treatments below and tell us which ones, if any, you think your province’s public health system should cover the costs of.
Select all that apply:

[Full Treatment List from QD/E1]

QH3. All things considered, based on your own experience and on whatever you may have seen or heard, when it comes to the overall amount of focus and resources given to treat and assist those living with chronic pain, would you say the public health care system in your province:

Does too much already
Gives the appropriate amount of attention
Should be doing more
Don’t know/can’t say

Socio-Demographics

Comprehensive series of socio-demographics to be captured for population sub-group analysis.