



albertapatients
Your Voice Matters

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Specialist Referral and Care Experiences

November 2018

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>> Research methodology

- Online survey was fielded via the albertapatient's online research panel
 - Field dates: October 18 – 28, 2018
 - Sample size: n=2,451
- Results reflect a representative sample of patients in Alberta
- Data was weighted to reflect gender, age and region of Albertans who have used the health care system within the past year
- This online survey utilizes a non-random sample; therefore, the margin of error is not applicable. However, for interpretation purposes, a probability sample of this size would yield a margin of error of +/- 2.0 percentage points 19 times out of 20 at a 95% confidence interval
 - Accuracy of sub-samples of the data decline based on sample size
- NOTE: Additional profiling variables were included in this study (e.g., medical cannabis users)

>> Who responded?

Region	%
Calgary	35%
Edmonton	32%
North	12%
Central	11%
South	10%
Gender	%
Male	50%
Female	50%
Age	%
< 45 years	51%
45-54 years	17%
55-64 years	16%
65+ years	16%

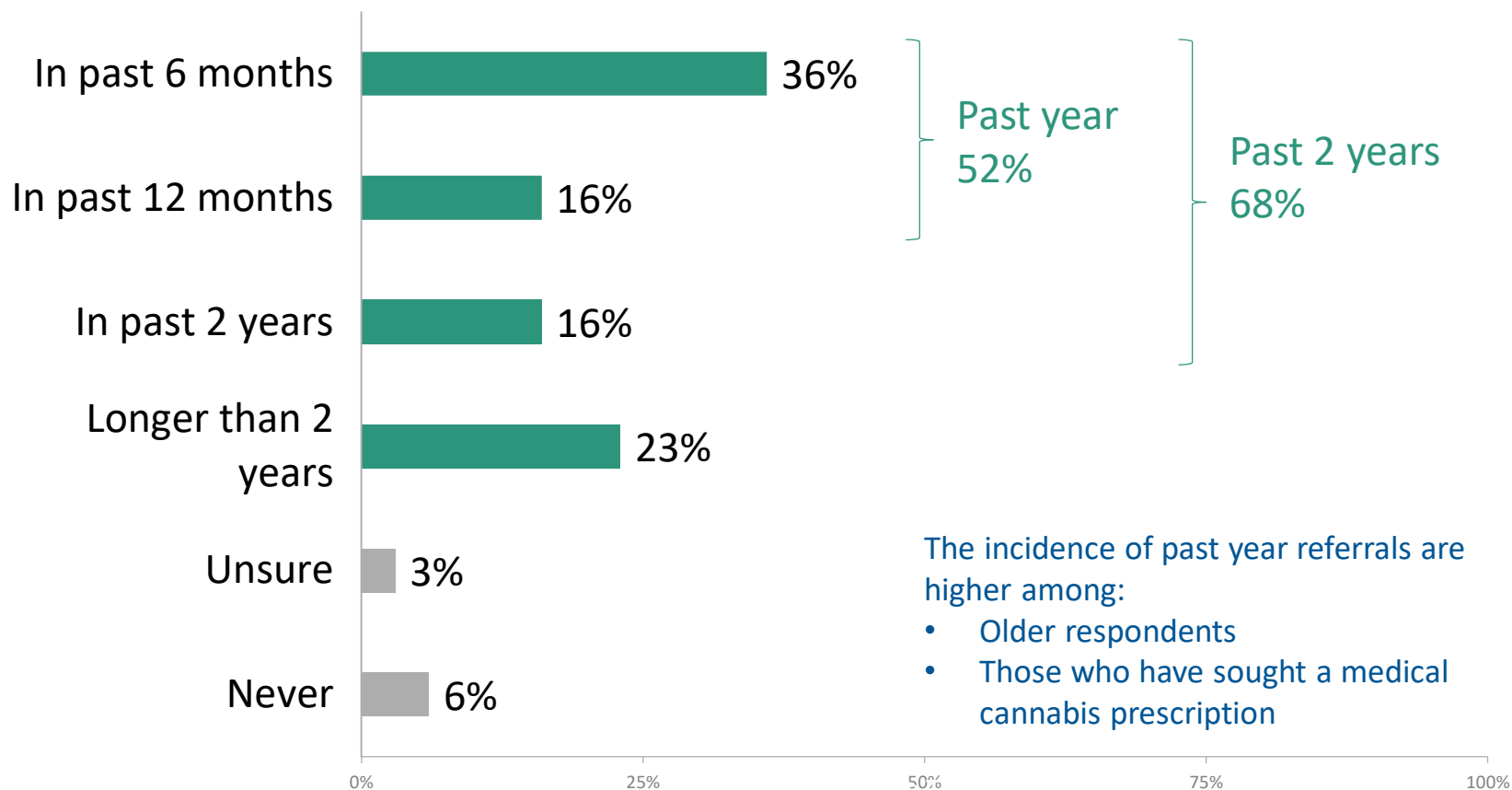
Education	%
High school	10%
College	36%
University	46%
Refused	8%
HH Income	%
<\$40K	15%
\$40K-<\$99K	27%
\$100K+	34%
Refused	24%
Kids at Home	%
Yes	32%
Caregiver	%
Yes	15%

Employment	%
Full/part/self	54%
Job seeker	4%
Student	2%
Not working	30%
Refused	10%
Has Family Dr.	%
Yes	89%
Uses walk-in	6%
No	5%
Chronic Condition	%
Self has	47%
One in care has	25%

Seeing a Specialist

>> Most have been referred to a specialist

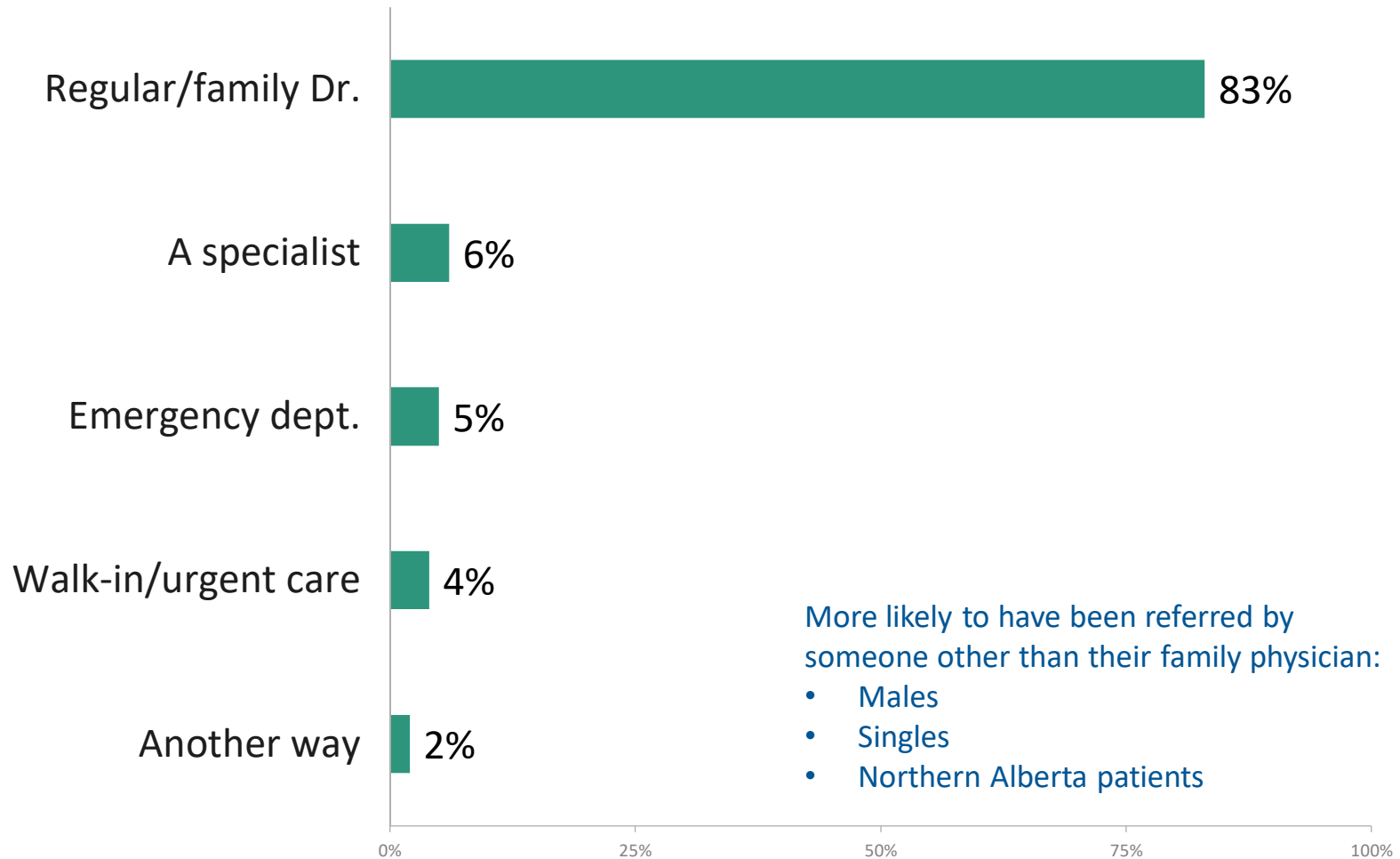
“When was the last time you personally received a referral from a family physician/doctor in Alberta, to see a specialist?”



Base: All respondents (n=2,451)

>> The majority are being referred by their family physician

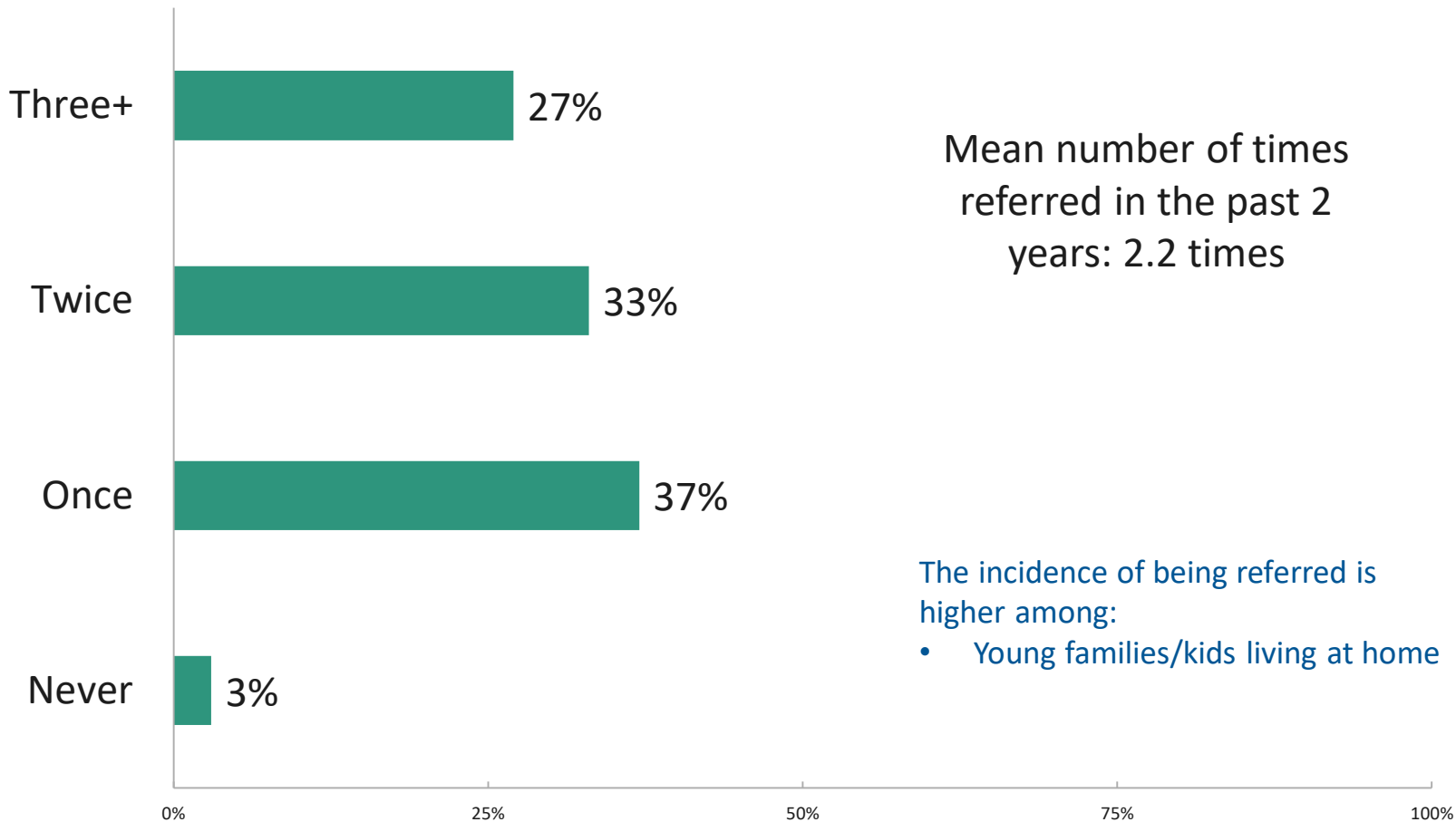
“Which of the following best describes the family physician/doctor that referred to you the specialist?”



Base: Referred to specialist in past 2 years (n=1,666)

Members report being referred to see a Specialist just over two times in the past two years

“How many times have you been referred to a specialist in the past two (2) years?”



Mean number of times referred in the past 2 years: 2.2 times

The incidence of being referred is higher among:

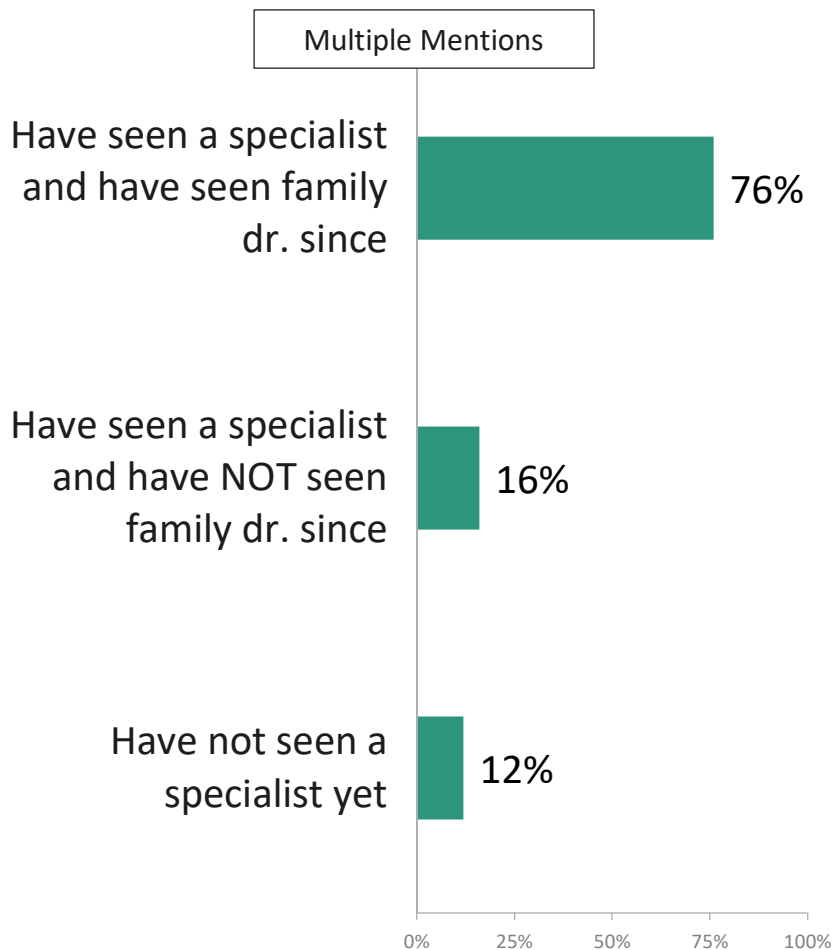
- Young families/kids living at home

Base: Referred to specialist in past 2 years (n=1,666)



Most who saw a specialist in the past 2 years have seen their family physician since the specialist appointment

“Which of the following describes your situation?”

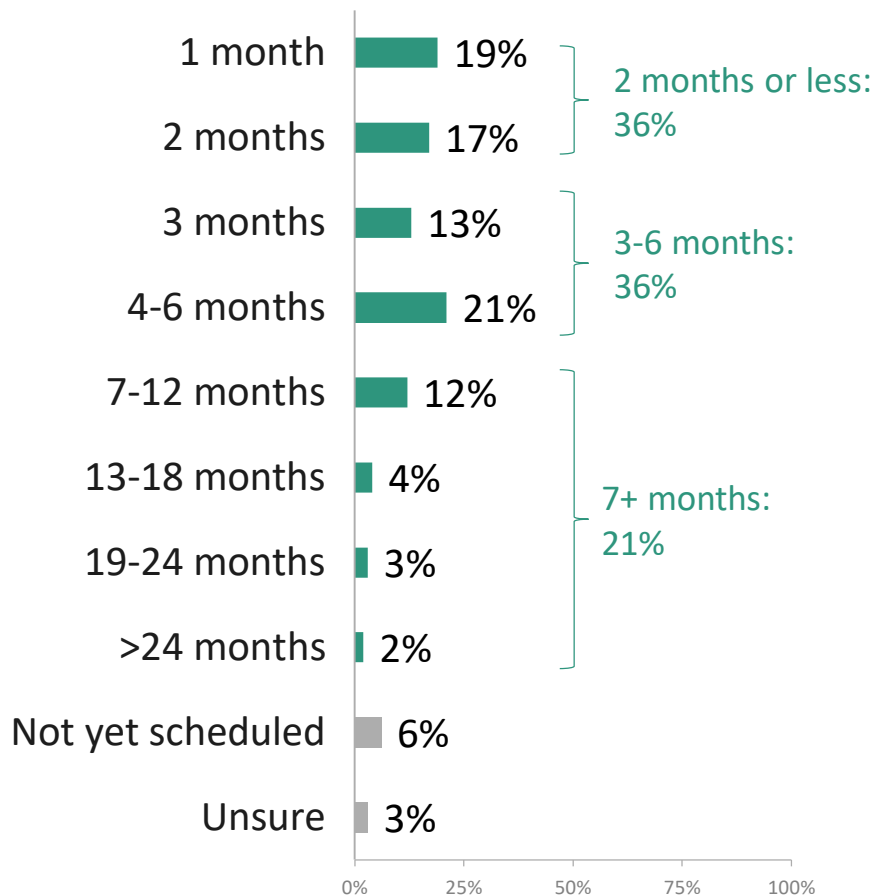


Base: Referred to specialist in past 2 years (n=1,610)

- Those more likely to have not yet seen the specialist, or to have seen a specialist but not yet seen their family doctor include:
 - Single respondents
 - Patients residing in Northern Alberta
 - Those who report their wait to see a specialist was 7+ months

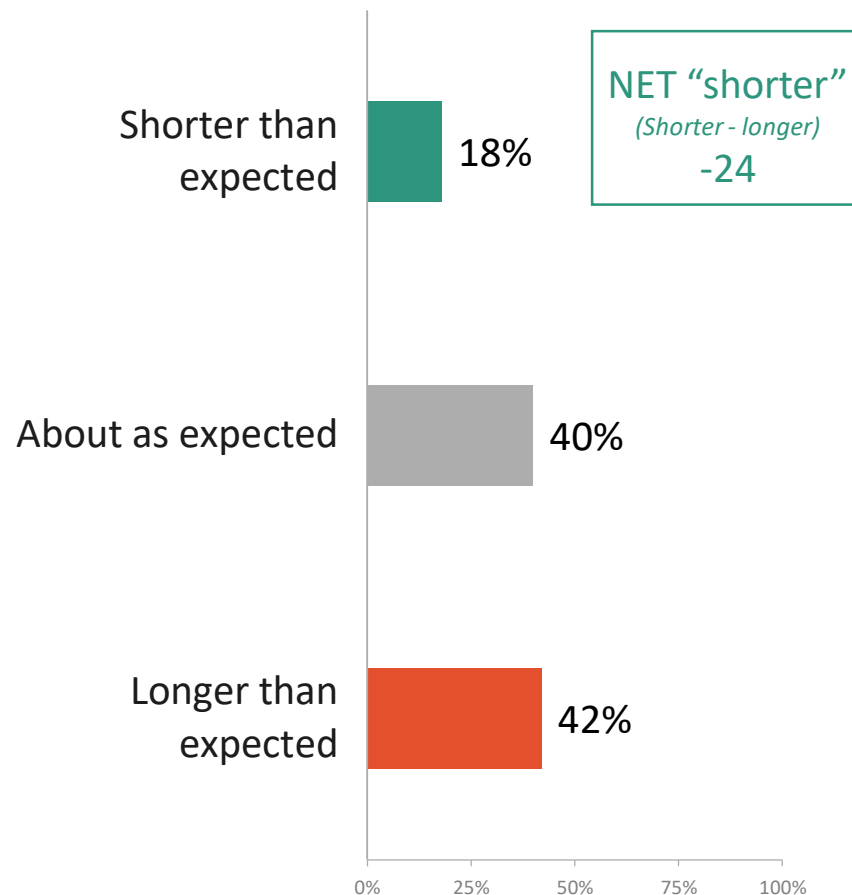
➤ Many find the wait to be longer than expected

“How long was/is the total estimated wait for you to see the specialist?”



Base: Referred to specialist in past 2 years (n=1,609)

“In your opinion, the wait (or waits) to see the specialist was/is...”



Base: Referred to specialist in past 2 years (n=1,609)



Wait experienced varies by city, gender and family composition

	TOTAL	Calgary	Edmonton
	(n=1,609)	(n=583)	(n=505)
2 months or less	36%	36%	43% ↑
3-6 months	34%	35%	29%
6+ months	21%	23% ↑	17%
	TOTAL	Males	Females
	(n=1,609)	(n=754)	(n=856)
2 months or less	36%	40% ↑	32%
3-6 months	34%	34%	35%
6+ months	21%	16%	25% ↑

	TOTAL	Young families	Kids at home	No kids at home
	(n=1,609)	(n=339)	(n=524)	(n=1,085)
Longer than expected	42%	49% ↑	46% ↑	40%
What I expected	40%	45%	41%	39%
Shorter than expected	18%	6%	13%	20% ↑
NET shorter	-24	-43 ↑	-33 ↑	-20

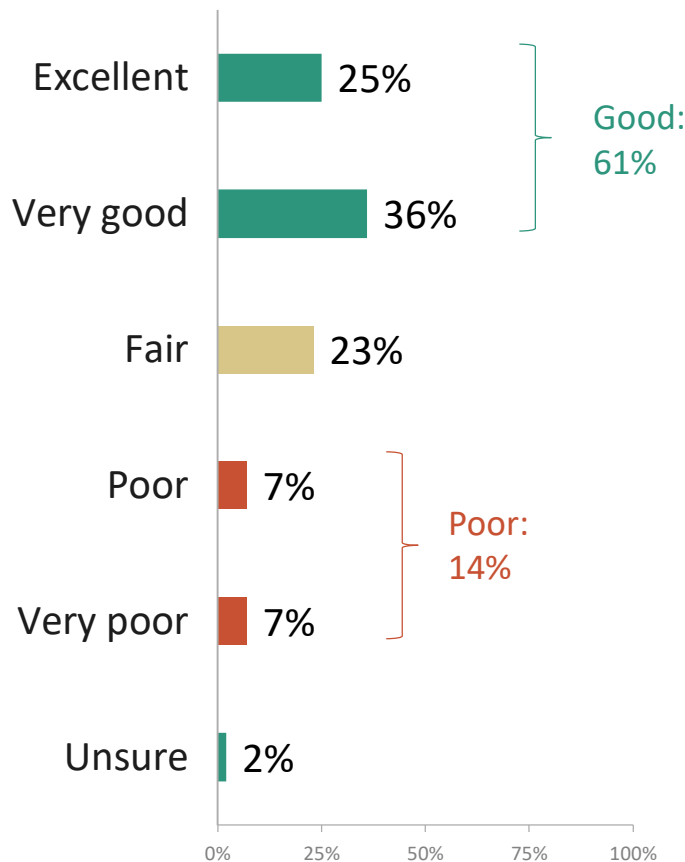
↑ indicates significantly higher

Base: Referred to specialist in past 2 years (n=1,609)



Those who were referred give moderately positive ratings to the overall referral experience

“How would you rate your overall referral experience between the family physician and the specialist’s office?”



Base: Referred to specialist in past 2 years (n=1,610)

- Those more likely to rate the experience positively:
 - Edmonton patients (vs. Calgary)
 - Males (vs. females)
 - Patients without kids at home
 - Older respondents (ratings improve with age)
 - Least educated (ratings decline as education levels increase)
 - Least affluent (ratings decline as household income rises)
- Referral experience ratings directly correlate with wait times to see a specialist:
 - <3 months: 85% excellent/very good
 - 3-6 months: 60% excellent/very good
 - 7+ months: 39%

Base: Referred to specialist in past 2 years (n=1,610)

>> The referral process - What went well

“Given you rated the experience/experiences as excellent/very good, please tell us what went well.”

Most comments related to **process** and **wait times**:

- Many respondents say they felt the referral process was timely, efficient, and straight forward, and were pleased with their overall experience
- While some of these respondents feel their wait time to see the specialist was reasonable (or even shorter than expected), many commented they were unhappy with the lengthy wait
- Even though many experienced a lengthy wait to see the specialist ...
 - Most were still pleased with the smoothness and ease of the overall process, and feel their specialist visit was worth the wait
 - Some of these respondents also mentioned that their family doctor’s timeliness and efficiency or their positive interaction with the specialist caused them to look favourably on their overall experience
- Many also commented that they felt the flow of communication between their family doctor and specialist was good, and some credit their family doctor’s timeliness in facilitating the referral to a better than expected wait time

Base: Specialist experience was excellent/very good

» Sentiment: The referral process - What went well

"Given you rated the experience/experiences as excellent/very good, please tell us what went well."

"Waiting time was unacceptable. 18 months to see a gastroenterologist. Family dr. was very good at continuing to try and get an appt and keeping me updated..."

"My doctor seems to get good results from her referral colleagues. I have not had to wait longer than a month and a half to see the specialist. I have been pleased with the care I received from the specialist."

"I was told it would be 3-6 months but was only 5 weeks to see specialist. I was very happy with the whole process and got results quickly from family physician also."

"I am grateful to have an excellent family physician who will refer if beyond their scope of expertise; one who listens well and is genuinely concerned."

"My family Dr. sent the referral the same day I saw him. I was able to see the specialists within 6 mons. My family Dr. is very efficient and always follows through when he refers to a specialist."

Base: Specialist experience was excellent/very good

» Sentiment: The referral process - What went well

“Given you rated the experience/experiences as excellent/very good, please tell us what went well.”

“The specialist I was referred to was very capable and knowledgeable. However, I did not get into the specialist in what I consider to be a timely manner. I had to wait way too long...”

“Despite a long wait list, the specialist office was helpful and courteous through their intake process.”

“My doctor diagnosed my condition early in an annual check up. She referred me to a highly respected specialist dermatologist. Both physicians are meticulous in their care. I am fortunate to have such an excellent family Dr.”

“Good communication between my family Dr. and the specialist with follow up report and treatment. It was completed in a timely fashion.”

“Considerable wait time but the appt. was fast and efficient and the staff at the specialist were knowledgeable.”

“The specialist and my family doctor consult/ share results on a regular basis. They keep up to date with my health concerns.”

“Well I had to wait a long time, almost one year... I suppose it would have been better to get in faster...”

“My doctor is above average is providing help and getting help if there is a good chance there is something serious. I usually get to see the specialist within a decent amount of time.”

“I received a letter from the specialist after about a month with an appointment date about 6 weeks later. My issue is not urgent so I am reasonably happy with the timing, although I wish it was somewhat faster.”

“Pretty strait forward process - had a complex health issue that warranted more in depth investigation, family dr. set it up, all was easy other than the wait time.”

Base: Specialist experience was excellent/very good

>> The referral process - What didn't go well

"Given you rated the experience/experiences as poor/very poor, please tell us what didn't go well."

Lengthy wait times were the main reason these respondents rated their overall referral experience as negative.

- Many respondents were unhappy with:
 - The length of time they waited to see the specialist
 - The length of time to be notified of their appointment time and date
 - Waiting room delays (up-to 2 hours for some)
 - Impacts of rescheduling appointments (some experienced significant delays if, for example, they were unable to see the specialist on their assigned date or time)
- Other frustrations shared:
 - Poor communication between their family doctor and specialist
 - Poor patient service (rude staff, unanswered phone calls, etc.)
 - Forgotten or lost referrals
 - Having their concerns 'dismissed' by their family doctor

Base: Specialist experience was poor/very poor

>> Sentiment: The referral process - What didn't go well

"Given you rated the experience/experiences as poor/very poor, please tell us what didn't go well."

"Wait time to see the specialist was intolerably long, especially since I was dealing with an issue that was causing excruciating pain. In the time that I waited to see a specialist, my pain went unchecked and untreated, often leading to ER visits when I mentally and emotionally couldn't tolerate the pain anymore."

"They forgot that I needed an appointment. I was told that the specialist's office would call me and I had to call them myself because they 'forgot' about my referral."

"Referral was completed and it seemed like there was a series of hoops to jump through in order to see the specialist.... every stop along the way: no one knew how long for a referral or when."

"It takes so long to get in to see a specialist. A person could die before they get to you."

"Being referred is not the issue. It's like making a restaurant reservation. The issue is that they are booked up and it takes a long time to get the appointment."

Base: Specialist experience was poor/very poor

» Sentiment: The referral process - What didn't go well

“Given you rated the experience/experiences as poor/very poor, please tell us what didn't go well.”

“The wait time to see a specialist is unrealistic. By the time you get in your issue has become way worse.”

“The process is cumbersome and onerous. Waits to see the specialist(s) are often long. If you and that specialist do not see eye to eye, you are often left being re-referred and waiting even longer.”

“Referral was refused by back clinic for second opinion on multiple occasions. There is never any communication to the patient once the referral is submitted and it takes up to a year to see specialists.”

“I had to remind my doctor to send the referral as I waited 12 months before booking an appointment and then waited another 12 months for the appointment.”

“My family doctor has been excellent, as has the surgeon. The problem is the wait time between the two.”

“Lack of communication either between clinic and specialist, patient and clinic, patient and specialist.”

“The specialist office lost my referral. Then the specific specialist moved and did not let me know. I had to track their new office down on my own. Then she canceled my day of my appointment.”

“GP didn't take my concerns seriously.”

“Just seems like there is a lack of communication between my GP and specialists. I always feel lost about what to do or who to talk to next. I wish my GP took more of a role in managing my case and helping guide me through the system.”

“It takes months and I still hear nothing. Sometimes when I complain to my family doctor, his office calls again. Sometimes it makes a difference. Often times it does not.”

Base: Specialist experience was poor/very poor

>> Suggestions: Improving the referral experience

“Based on your experiences in the past two years, how could the referral experience be improved?”

Comments focused on improving **communication** and **wait times** during the referral process:

- Many said their experience could have been improved with quicker notification of their appointment date and time, and a shorter wait to see the specialist
- Others desired increased communication and more information (e.g. letting them know their referral was received, approximate wait times, etc.)
- Better communication between their doctor and the specialist was also mentioned by some
- Some commented that missed or lost referrals are an issue, that their waits were delayed further by doctors or their staff forgetting to submit their referral or the referral being misplaced by the specialist’s office
- A few suggested they would like an online system where they could see the status of their referrals and other relevant information
- A few mentioned they would like a say in which specialist they get referred to (e.g. a preferred specialist or practice, one closer to home, etc.)
- As well, some shared that their experience was positive or that they couldn’t think of any improvements

Base: Referred to specialist in past 2 years

>> Sentiment: Improving the referral experience

“Based on your experiences in the past two years, how could the referral experience be improved?”

“...If electronic communication for referrals was available for me to see, along with the medical professionals, mistakes or delays could be prevented, or at least understood and remedied when possible.”

“Referrals can be dictated by the physician, however there is no guarantee that staff actually sends it on. I have made a point of checking with specialist myself if there is no contact within 2 weeks, and in every case, specialist had not received the requisition.”

“I wish there was a letter or email sent to notify you that the specialist has received your referral. I have had problems in the past where the wait time was up to a year and after the year had passed I followed up and they had lost the referral and I had to wait an additional 6 months to get in. This really effected my health in a negative way...”

Base: Referred to specialist in past 2 years

» Sentiment: Improving the referral experience

“Based on your experiences in the past two years, how could the referral experience be improved?”

“I could not request any more from my experience. Unless it came with wine and appies!”

“More communication between GP and specialist so that I didn't have to repeat tests.”

“I had to wait a long time for my appointments. In the meantime, pain increasingly limited my activities. I had to go on addictive painkillers. Then another long wait for surgeries.”

“Waiting 5-8 months for a referral doctor to reply when I'm ill and in pain enough to see a specialist is unacceptable and cruel punishment. Then waiting 3-5 more months for the actual appointment is literally inhumane.”

“Make it policy that an error made by the referring office must be repaired, not glossed over and ignored...”

“Quicker response time from specialists. Easier access to mental support for those of us suffering from chronic disease while we wait for specialist care.”

“Follow up with pending appointments via online so that a person could see that the referral has been made and a rough time period for the wait.”

“More rapid communication regarding referral appointments and confirmation thereof would be beneficial.”

“Specialists do not consistently keep family doctors informed with consult feed back.”

“I am impressed and think everyone involved did everything possible with their best. I am proud and feel safe with our medical system in Alberta.”

Base: Referred to specialist in past 2 years

Transition of Care

>> Transition of care: Introductory information

Respondents were shown the following description and were asked follow-up questions:

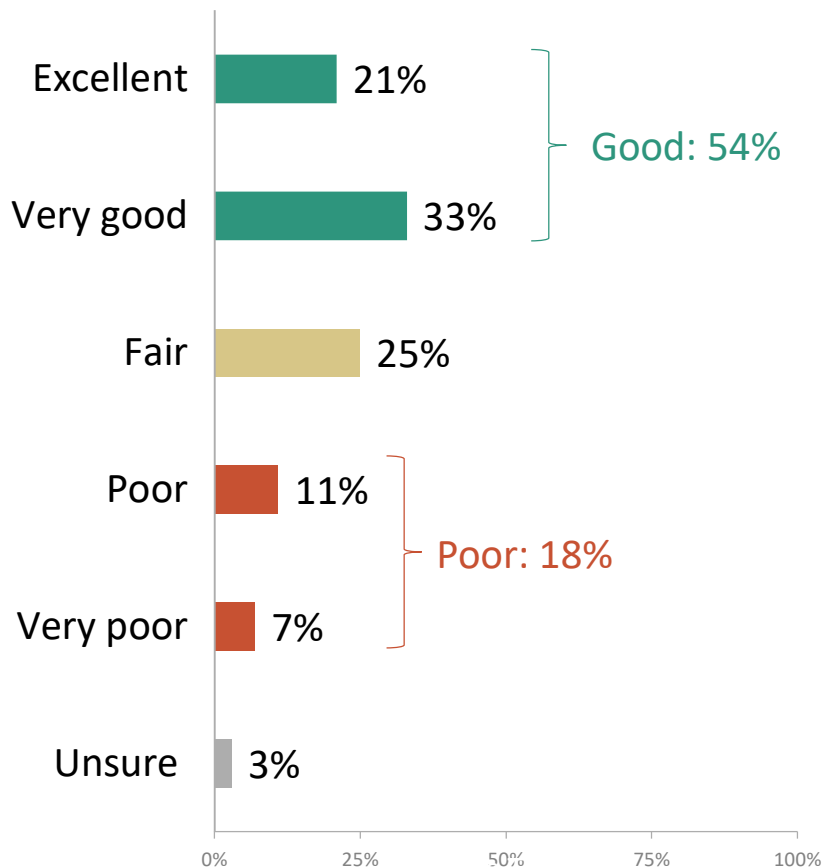
Given that you mentioned earlier that you've seen a specialist in the past two (2) years, we're interested in your impressions and experiences with the process.

Specifically, we want to hear your thoughts about the "Transition of care"

"Transition of care" refers to the coordination and continuity of health care during a movement from one healthcare setting to another healthcare setting, or from a healthcare setting to one's home. This includes the transition of the patient but also the coordination of information between healthcare practitioners and settings. Think of it as the handshake between doctors and specialists.

Transition of care receives moderately positive ratings

“How would you rate your most recent experience - transition of care back and forth between your family physician and the specialist you have been referred to?”



Base: Saw a specialist in past 2 years (n=1,456)

- Ratings tend to be higher among:
 - Males (vs. females)
 - Older respondents (ratings increase with age)
 - Least affluent (ratings decline as household income rises)
- Ratings are lower among:
 - Families with kids at home
 - Those who reported longer waits to see the specialist

>> Transition of care: What went well

“Given you rated the experience as excellent/very good, please tell us what went well.”

- Those who provided a positive rating to their transition of care shared that they feel their transition of care process was **smooth, efficient**, and resulted in **prompt treatment** and care
- Some indicated that even though they experienced a lengthy wait to see the specialist, they were still pleased with their overall transition of care
- Many felt their **family doctor and specialist worked well together**, noting there was good communication with good/timely flow of information back and forth (background, diagnostics, test results, care recommendations, etc.), and that results and care plans were shared back to them in a timely manner
- A few added that **improved communication** (either between the doctors, or the relay of information back to them) or **shorter wait times** could still have improved the experience

Base: Transition of care experience was excellent/very good

>> Transition of care: What went well

“Given you rated the experience as excellent/very good, please tell us what went well.”

“There was great communication between me, my Dr. and the Specialists I saw. All of them had good advice, told me the results of the tests they had ordered, made suggestions and best of all my own Dr. had all the information from these visits and his office called to make an appointment to talk about all the results. So I got not only individual results but my own physician looking at all the pieces of the puzzle and putting together the results for me and for himself.”

Base: Transition of care experience was excellent/very good

» Transition of care: What went well

“Given you rated the experience as excellent/very good, please tell us what went well.”

“There were no problems or hiccups in the process. As far as I could tell, things went as they were intended.”

“They communicated on my condition and together advanced my care.”

“My family Dr. is fully engaged with my care so I am not left hanging. Specialists seem to be pretty good at including him.”

“It was a smooth transition, and my only criticism was the wait.”

“Both my surgeon and the family doctor had the information needed and shared as necessary. There were no delays.”

“My family doctor received the report from the surgeon very quickly. Both doctors were able to explain the treatment plan clearly to me.”

“The specialist was very prompt in replies to my family doctor in keeping him informed as to what was happening.”

“The transition was very good, but the wait times are horrible!”

“My family doctor has been informed from day one. Every test, action and result has been copied to my family doctor.”

“I would rate it as good, not very good. It would nice to see better communication between doctor and specialist.”

“Both doctors shared their findings and talk about a way to move forward with my care.”

“Things were dealt with quickly and smoothly.”

“I did not notice any gaps in my care.”

Base: Transition of care experience was excellent/very good

>> Transition of care: What didn't go well

"Given you rated the experience as poor/very poor, please tell us what didn't go so well."

- Top complaints among those who provided a poor rating for their transition of care included poor communication between doctors, and/or poor communication back to them as a patient
 - **Poor communications:** Specialists not having complete information at their appointment, facing delays in information being sent back to their doctor, or family doctors not following up or discussing their care plan
 - **Lost referrals:** Incorrect paperwork or errors, feeling dismissed by doctors and long wait times

Base: Transition of care experience was poor/very poor

➤➤ Transition of care: What didn't go well

"Given you rated the experience as poor/very poor, please tell us what didn't go so well."

"Communication was non-existent from the specialist to the family physician. The family physician made numerous attempts to contact the specialist to no avail. The specialist did not communicate the medical tests that were required for him to see me and thus a longer wait was incurred! Let's just say there was not transition of care."

"I find the wait time too long, especially when the matter needs resolving, before further damage is done or hospitalization is needed. The methods of communication are not good enough. A phone call or a letter should be backed up with an email or text. I often find that the information that is supposed to be relayed back to my doctor isn't. The information is in the system of in my chart but the doctor is not actually alerted to the results all the time."

Base: Transition of care experience was poor/very poor

» Transition of care: What didn't go well

"Given you rated the experience as poor/very poor, please tell us what didn't go so well."

"To my knowledge the specialist never confirmed or reported back to my family doctor..."

"The wait time, told nothing could be done for pain and family doctor offers nothing to help - time to get medical marijuana for the pain cause no one else has any help."

"The specialist did not share the information with the family doctor. He had to request it after I saw him and requested it. It leads to incomplete discussions in the family physician's office."

"The family doctor makes a referral and then does not follow up. It takes a l-o-n-g time to get in with a specialist and, in the interim, one is simply sitting in limbo, getting worse and worse typically. There is little, if any, interim care."

"They don't talk to one another, they have no idea what the other is doing/thinking when it comes to treatment."

"The specialist did not send a thorough report to my family physician. My issue continues without improvement."

"The specialists office staff do not communicate with other doctors well. Sometimes, not at all."

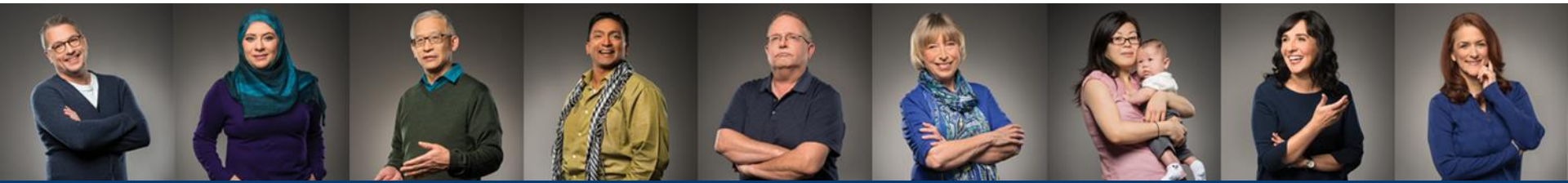
"There is little to no communication and I end up having to make sure each doctor has all necessary info. I start over with every single doctor. There is zero attention to detail."

"The drs. don't care and don't look at the client as a package..... but more by 'parts'. They only care about the 'part' they know about. Our doctors need to be a team.... need to consider holistic health of the patient. All the interconnected parts."

Base: Transition of care experience was poor/very poor

»» Last Word – transition of care

“I just want to share that I am happy this topic is being investigated. I've had a lot of time in the health care system due to a number of serious chronic diseases, and can say I feel this issue of navigating the pathway to specialist care and follow through to be the most difficult. Waiting time for tests etc. is understandable, but waiting for care and answers is very difficult when you are significantly ill with something affecting your quality of life, ability to work, etc....”



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www.albertapatients.ca

For more information, contact:
Marc Henry, President
ThinkHQ Public Affairs Inc.
MLH@THINKHQ.CA

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