



# **REVIEW AND ASSESSMENT BRITISH COLUMBIA NEUROFIBROMATOSIS CLINIC**

PREPARED BY:



## Review and Assessment British Columbia Neurofibromatosis Clinic

### Executive Summary

Sometimes, even in the most trying of circumstances, an extraordinary opportunity can materialize. In October 2021, despite the challenges presented by the COVID-19 pandemic and the shortage of medical services around the world, the Tumour Foundation of BC launched a pilot project to address the medical needs of adult patients living with neurofibromatosis (NF) in BC. Working with physicians in the Elisabeth Raab Neurofibromatosis Clinic based at the Toronto Western Hospital, the Foundation is organizing online consultations with Canada's most highly regarded experts in NF. As a result of the pilot project, adult NF patients in BC have been, many for the first time, accessing specialized care.

The launch marked a significant milestone in the Foundation's 12-year fight for a clinic dedicated to the care of the more than 1700 people in BC living with NF. With the overwhelmingly positive results of the pilot project in hand, the Tumour Foundation of BC is now looking for opportunities to offer a permanent NF clinic for adults in BC.

### Background

The Tumour Foundation of BC (TFBC) is on a mission to improve the medical care received by those affected by neurofibromatosis (NF). The Foundation has been advocating for an NF clinic in BC for more than 12 years with the aim of ensuring that all patients in BC have access to high-quality, coordinated medical care and have the opportunity to participate in the research trials that are so critical to finding a cure for NF. TFBC launched a pilot program in October 2021 to test the demand for a dedicated NF clinic for adults. Working with Dr. Gelareh Zadeh, co-director of the Elisabeth Raab Neurofibromatosis Clinic at the Toronto Western Hospital, the pilot program has offered online consultations for a select number of adult patients in BC. In one year, the Foundation's clinic has served 31 patients with NF1 and NF2 from all five health regions in British Columbia through a series of six virtual consultations.

#### *What is Neurofibromatosis?*

Neurofibromatosis encompasses a set of three distinct genetic disorders (NF1, NF2, and Schwannomatosis) that share the manifestation of tumour growth. In NF1, which is the most common form of NF, tumours develop along nerves throughout the body, and can affect the development of non-nervous tissues such as bones and skin. NF1 can cause additional complications such as disfigurement, bone deformities, learning disabilities, and cancer. NF2 is characterized by the development of benign tumours on the nerve that carries sound and balance information from the inner ear to the brain. These tumours affect both ears, often leading to partial or complete hearing loss. People with NF2 may also develop other types of benign brain or spinal tumours. Finally, schwannomatosis causes the development of benign tumours — called schwannomas — usually on spinal and peripheral nerves. These tumours develop when Schwann cells, which form the insulating cover around nerve fibers, grow abnormally.

NF1 is considered a rare genetic disorder with an incidence of one in 2,500 to 3,000 births. (NF2 has an incidence rate of 1 in 25,000 and the rate for Schwannomatosis is 1 in 40,000). However, rare is a relative term — there are more than 1700 people in BC, over 12,000 in Canada and two million worldwide affected with this disorder. NF is more common than cystic fibrosis, Duchenne's muscular dystrophy and Huntington's disease combined. Knowledge of NF within the community and the medical profession, however, falls well below that of less common disorders. As a result, the quality of healthcare available to adult NF patients in BC is severely lacking, highly inconsistent and dependent on the engagement of referring family doctors. There are no NF specialists serving adult patients in BC.

#### *The Tumour Foundation of BC*

As a non-profit organization, the TFBC has been offering essential information and support services for individuals with NF for 38 years. Encompassing dedicated staff [1+ FTE], dozens of volunteers including a highly committed volunteer Board, TFBC operates with an annual budget of less than \$200,000 raised through individual donations, a community gaming grant, and various fundraising events. These funds are used to fulfill the provincial mandate of the foundation through programs and services, which include: one-to-one support, community events, educational scholarships, vital resource publications, and an annual symposium that attracts specialists and attendees from around the world.

In a 2020 Health Care Survey, TFBC asked its members to report on the biggest challenges related to living with NF. **Lack of professionals who understand the disorder (59.2%)** and **Lack of coordinated care (49.0%)** were cited as the two most significant challenges.

The need for improved care was clear but determining what improvements could be implemented by a 1.0 FTE staffed foundation during the COVID-19 pandemic, required further investigation. In the same survey, members were asked: If an NF clinic offered online appointments with specialists, what might prevent you from using this clinic? The results

were surprising. More than **71.4% of respondents** advised that **nothing would prevent them from accessing online services offered by an NF clinic**. Where members had previously expressed reservations about online medical care, the survey results indicated that attitudes toward online care were changing.

*If an NF clinic offered online appointments with specialists, what might prevent you from using this clinic?*

Answer Choices	Responses	Ratio
I don't have access to a computer or smart phone	0	0%
I get overwhelmed learning new technology	3	6.1%
I have security concerns of being online with my personal information	2	4.1%
I prefer the personal connection of face to face with my doctor	14	28.6%
Nothing would prevent me from accessing online services offered by an NF clinic	35	71.4%
Other – please list	5	10.2%

*\*Health Care Survey Results of Patients with NF in British Columbia, May 2020*

This change represented an opportunity for TFBC to reach out to specialists, who are only available for adult patients outside of BC, to help bring the vision of a clinic to reality.

### *NF Clinics in Canada*

Three NF clinics are currently operating in Ontario – two for pediatric patients and one for adults (the Elisabeth Raab Neurofibromatosis Clinic). The clinics offer diagnostic services and aim to give patients access to the wide array of specialists needed to manage the symptoms of NF – neurosurgeons, oncologists, neurologists, medical geneticists, genetics counsellors, plastic surgeons, orthopaedists, neuro-ophthalmologists, endocrinologists and dermatologists. A 2017 review of the Elisabeth Raab Neurofibromatosis Clinic, published in The Canadian Journal of Neurological Sciences<sup>1</sup> offers valuable information on the structure of the clinic and identifies shortfalls in the services they are able to offer. The clinic is managed by a multidisciplinary team, which is considered critical when addressing NF due to the diverse spectrum of clinical manifestations.

### **The BC Neurofibromatosis Clinic Pilot Project**

In October 2021, the TFBC launched a pilot project to address the medical needs of the adult BC NF community. Working with the physicians based in the Elisabeth Raab Neurofibromatosis Clinic, BC participants have been, for the first time, accessing specialized care with Canada's most highly regarded experts in neurofibromatosis in adults. The launch marked a milestone in the Foundation's 12-year campaign for a clinic dedicated to the care of the more than 1700 people in BC living with NF.

### **Clinic Structure**

#### *Staff*

TFBC funds one BC-based nurse position to support the operation of the clinic. While the position was initially filled with an FTE of 0.2, the FTE increased to 0.4 at times during the pilot project in order to meet the demands of working with patients and doctors during a pandemic, within a provincial medical system that has been stretched to the limit.

The Executive Director of the TFBC contributed an additional 0.4 FTE to the initiation of the clinic pilot project and continues to contribute 0.2 FTE to its delivery. Responsibilities include the hiring and supervision of the TFBC-funded nurse and managing the subscription to the medical records database.

#### *Clinic Delivery*

To date, the clinic has offered consultations to **31 patients over 6 clinic dates**. During each clinic date, the consulting physician at the Elisabeth Raab Neurofibromatosis Clinic determines the number of patients that can be accommodated. The consultation is delivered via Zoom.

A typical consultation involves the following steps:

1. The TFBC funded nurse manages a waitlist of all prospective patients for the clinic dates. The nurse contacts the patients directly, guiding and supporting them through the process of obtaining a referral, documenting their consent to participate, and meeting all clinic requirements.
2. Once a clinic date is determined, the nurse contacts patients on the waitlist to notify them of the date and reviews the availability of pre-requisite information (see Prerequisites for Patient Care below).

<sup>1</sup> Mansouri, A., Ghadakzadeh, S., Maqbool, T., Barnett, C., Au, K., Kongkham, P., Bril, V., Zadeh, G. (2017). Neurofibromatosis Clinic: A Report on Patient Demographics and Evaluation of the Clinic. Canadian Journal of Neurological Sciences, 44, 577-588.

3. The nurse works with each patient, general physician, and any other specialists and technicians involved in the patient's care to collect and forward the following information to the consulting physician at the Elisabeth Raab Neurofibromatosis Clinic:
  - a. MRI images transferred to CDs;
  - b. Genetic testing records;
  - c. Notes from previous specialist consults; and
  - d. Whether closed captioning services are required (often needed for patients diagnosed with NF2 who have auditory deficits).
4. The nurse provides information to both the patients and the family physicians about the role of the clinic and the relevance of recommended diagnostics from the consulting physician.
5. On the day of the consultation, the nurse confirms attendance by each patient and joins the online consultation to take notes, confirm the recommendations of the physician, and to support the patient.
6. Following the consultations, the nurse reviews the patient consultation notes, uploads them to the record-keeping software and sends copies to healthcare providers for each patient in BC. If the consulting physician's recommendations include requests for imaging, referrals to specialists, or the prescription of medications, the expectation is that the patient's general physician will receive the recommendations from the patient and will follow them. In several cases, the nurse has contacted general physicians and specialists, often repeatedly to ensure the recommendations are implemented.
7. The nurse books any future consultations for the patient as space allows on the waitlist.
8. The nurse follows up with individual patients to encourage the patients to discuss clinic recommendations with the family physician and to encourage compliance with the recommendations of the consulting physician. Once the recommendations are implemented, the nurse requests test reports, reviews any new information and facilitates the sharing of these records with the Elisabeth Raab Neurofibromatosis Clinic.

During the pilot project, TFBC implemented the medical record-keeping software called Jane, to store confidential records, manage patient consultations and record consultation outcomes including physician recommendations.

#### *Referral of Patients*

Leading up to and during the pilot project, TFBC has employed minimal external advertising of the clinic. Despite limiting the communications to a small number of postings on TFBC social media accounts (Facebook, Instagram, and Twitter) and references in the annual mailed letter to members, the waitlist quickly grew. **Currently, the waitlist includes 19 prospective patients waiting for a first consultation** with the practitioners at the Elisabeth Raab Neurofibromatosis Clinic.

Of the patients receiving consultations to date, all but two were self referred. All patients were required to seek a referral letter from a general physician prior to the clinic consultation. To date, only one patient was initially referred by a family physician. One additional patient was referred to the clinic by a physician employed through Telus Health.

#### *Prerequisites for Patient Care*

Prior to their consultation, the nurse works with patients to gather the following information and documentation:

- A referral from a general physician (many patients do not have a family physician);
- A completed patient consent form to participate in the clinic;
- The results of genetic testing (if completed);
- Electronic copies of any imaging (MRIs, CT scans, ultrasounds, etc.) the patient has undertaken in the last 5-10 years;
- A completed *Impact of NF on Quality of Life Questionnaire* (voluntary) regarding status of health, perceptions about quality of current medical care (Attachment B).

#### *Collection of Data*

With the permission of patients involved in the pilot project, the TFBC nurse collects the following information regarding each patient:

- Responses to *Impact of NF on Quality of Life Questionnaire* (if completed);
- Consulting physician's recommendations; and
- Outcomes of physician's recommendations (eg. confirmation that genetic testing was completed or an MRI was scheduled).

This information is shared in the attachments and summarized below.

### **Pilot Project Outcomes**

#### ***Patient Demographics***

31 patients have attended the clinic since the launch in October 2021. Of that number:

- 29 were diagnosed with NF1 and two were diagnosed with NF2

- 12 had undertaken genetic testing to confirm their diagnosis/identify specific genetic variations
- 26 had undertaken MRI evaluation at some point prior to attending the clinic, some relatively recently

Following the consultations, of the 30 participants:

- 30 (97%) received recommendations for updated MRI evaluation
- 15 (48%) received recommendations for specialist referrals (eg. neurologist, oncologist, plastic surgeon, otorhinolaryngologist (ENT), pain clinic, psychiatrist, dermatologist)
- 9 (29%) received recommendations for genetic testing
- 27 (87%) require follow up consultations with physicians at Elisabeth Raab Neurofibromatosis Clinic

A full summary of the clinic outcomes can be found in Attachment A.

### **Patient Experiences**

Prior to attending their consultation, patients were asked to complete a quality of life survey. The results of the survey (Attachment C) reflect what has been demonstrated in the literature: NF is impacting every part of these patients' lives – vision, mobility, bone health, muscle strength, learning, breathing, sleeping, relationships, self-esteem, and mental health. When asked to describe the impact, patients reflected on their fears about the future, the difficulties of living with incredible uncertainty, the frustrations of accessing knowledgeable care, and the ongoing need to advocate for their own care.

For many of the patients, their consultation through the clinic marked their first meeting with an expert in their own disorder. Within the first month of the pilot project, the feedback regarding the clinic and the online consultations were already overwhelmingly positive. Patients were immediately experiencing the impact of the clinic, with many of them claiming to feel hopeful about their future with NF for the very first time.

*“I would encourage everyone to make an appointment with the virtual clinic. I learned a lot about my NF that I was not aware of. It will benefit everyone in some way.” Clinic patient, Northern BC*

*“I am looking forward to my family doctor having ‘guided care’ from the recommendations that the clinic doctor made during my appointment.” Clinic patient, Vancouver Island*

In an NF Clinic Patient Experience Survey completed in July 2022, nine of the early participants in the pilot project provided feedback on their experience with the clinic (see Attachment C for complete results). The results were very encouraging:

- 77.8% of the participants were very happy (5/5) with the care that they received in the clinic. The remaining 22.2% were happy (4/5)
- When asked about the biggest impacts experienced from their appointments, the participants overwhelmingly stated that the clinic is addressing two critical needs in their care:
  - Increased access to specialized care (MRIs, genetic testing, mammogram, mental health support, etc.) (88.9%)
  - Being able to ask questions of a knowledgeable NF specialist (77.8%)

Although fewer respondents selected the following options, the results remain significant:

- Increased understanding of my diagnosis (33.3%)
  - Increased knowledge about worrisome symptoms that I can self-monitor (33%)
  - Increased capacity to cope with my diagnosis (33.3%)
  - Decrease in feelings of anxiety and depression (33.3%)
  - Access to a clinical trial (22.2%)
  - 88.9% of participants agreed that they would strongly recommend the clinic to other patients (5/5)
  - Participants were hopeful that their participation in the clinic would improve their overall medical care.
- Comments included:

*“Having a specialist to review and synthesize information is valuable. There’s no one to tie all the pieces together otherwise. Trying to jigsaw all the various specialists / care needs is a challenge. A combined approach to all medical avenues is very helpful.”*

*“The clinic was a long time coming. Having a specialist in the field of NF guide the patient’s journey will improve the overall approach to their health. Hopefully one day there will be a physical clinic within reach.”*

### **Pilot Project Limitations**



The Elisabeth Raab Neurofibromatosis Clinic is managed by a multi-disciplinary team that includes neurosurgeons, oncologists, neurologists, medical geneticists, genetics counselors, plastic surgeons, orthopaedists, neuro-ophthalmologists, endocrinologists and dermatologists.

As noted in the review published in the Canadian Journal of Neurological Sciences:

There is currently a comparative dearth of comprehensive adult NF clinics, which ultimately leads to fragmented care of NF1 patients upon reaching adulthood. Though the biological consequences of NF1 are most prominently recognized and studied, the psychosocial aspects of this disorder cannot be understated. The underappreciated intellectual impact of NF1 results in significant disability, psychological suffering, decreased quality of life, limitation in societal integration and increased healthcare costs. Thus, improving access to comprehensive multidisciplinary care for adults with NF1 can have numerous positive consequences for the patients, their caregivers, public health and, ultimately, society in general.

To date, the BC clinic has been limited to online consultations with neurosurgeons, Dr. Gelareh Zadeh, Dr. Sungath Suppiah, and Dr. Ruth Lau. Access to other specialists must be organized through referrals within BC, which means that BC patients are not receiving the full benefit of care provided by a multi-disciplinary team with experience supporting patients with NF. In the future, it would be incredibly helpful to have a team of specialists in BC who develop this expertise and are available to work with patients referred from the clinic.

It would also be beneficial for patients to have access to in-person consultations that allow for the physical assessment of plexiform fibromas, subcutaneous neurofibromas, and the many NF symptoms including scoliosis, skin conditions, and bone deformities.

### **Moving Forward: A Permanent NF Clinic in BC**

TFBC has worked incredibly hard to change the lives of people in BC living with NF. The costs of self-funding the pilot project, including hiring a nurse, purchasing software to manage medical records, and diverting staff time away from fundraising and other activities, have been significant. TFBC consciously launched this pilot project knowing that it would likely consume all of the resources of the Foundation and possibly result in the financial collapse of the organization. When the opportunity arose, the decision by the Board of Directors was clear and unanimous: this small organization would prove that an NF Clinic is not only desperately needed in BC but it is, in fact, within reach.

Reconsider one very important statistic included in this report:

**Of the 31 patients who have received consultations to date, 29 were self referred. Twenty-nine patients experiencing some of the most frightening, painful, disfiguring, debilitating, and life-threatening consequences of NF were forced to seek out and request specialist medical care on their own.**

This is not a new phenomenon for BC's NF community. TFBC regularly hears from members that doctors turn to them for guidance on their own care. One member advised:

*"I have struggled to get a diagnosis and doctors seem unclear. I had to go on a 2 year genetic test waitlist which was triggered by my pushing my doctor. Doctors need to be educated better, re: NF diagnosis steps."*

A clinic participant echoed the need to push for their own medical care:

*"I found the clinic to [sic] really beneficial to help me advocate and receive medical services for things that I need to monitor with my NF (MRI) and to be taken more seriously for a tumour removal. I really appreciate that."*

This pilot project is no small testament to the overwhelming need within the NF community, a community that understands all too well what it means to live without adequate medical care. As one clinic patient recently wrote after attending his consultation:

*"I am too late to save, but others are not I hope."*

### **The need for a permanent NF clinic in BC is clear and urgent**

With the pilot project completed, TFBC is seeking partners, advocates and champions who will help to make a permanent clinic a reality. We cannot do this work alone. Please consider how you can help.

## Summary of Clinic Outcomes

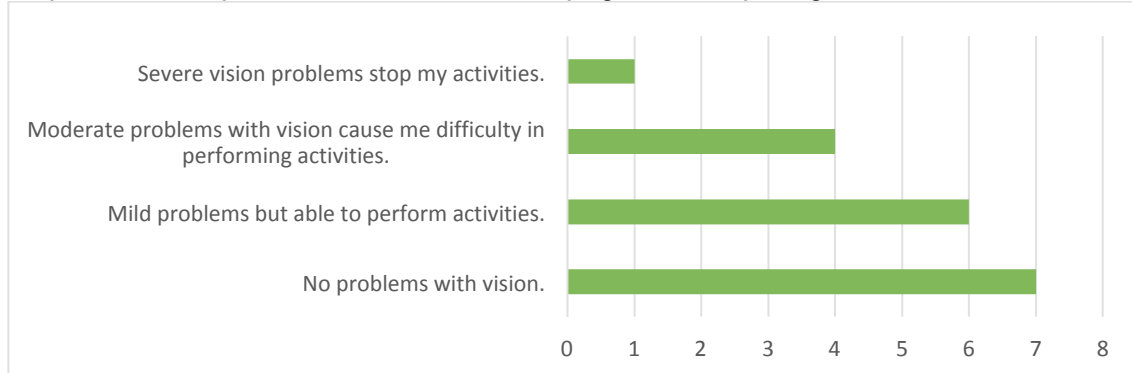
Tracked Outcomes	Number
Total # of patients assessed	31
Total # of patients assessed with NF1	29
Total # of patients assessed with NF 2	2
Geographical areas represented by patients	100 Mile House, Baldonnel, Baynes Lake, Burnaby, Coquitlam, Courtenay, Fort St. John, Grand Forks, Kamloops, Langley, Lillooet, Richmond, Surrey, Trail, Vancouver, Vernon, Victoria, Whistler
# of patients who had MRI prior to attending clinic (some outdated, some recent)	26
# of patients with follow up MRI recommendations from clinic	30
# of patients who completed/awaiting testing dates for recommended MRI or major tests	18
# of patients who received recommendations for specialist referrals	<ul style="list-style-type: none"> <li>– 1 patient referred to Plastic Surgeon</li> <li>– 1 patient referred to Otorhinolaryngologist (ENT) after abnormal MRI results post NF Clinic</li> <li>– 1 patient referred to Dermatologist</li> <li>– 1 patient referred to Oncologist</li> <li>– 3 patients referred to Pain Clinic</li> <li>– 1 patient referred to Psychiatrist</li> <li>– 3 patients referred to Neurologist, including referrals to Toronto Western Hospital for electrodelessication (1) and electrocautery (1)</li> <li>– 1 patient referred to clinical trial (MEK inhibitor): determining eligibility</li> <li>– 1 patient referred to Ophthalmologist</li> <li>– 12 patients waiting for consultation notes and possible referrals from consulting physician</li> </ul>
# of patients who achieved specialist referrals	<ul style="list-style-type: none"> <li>– 1 patient achieved referral to Plastic Surgeon</li> <li>– 1 patient achieved referral to Otorhinolaryngologist (ENT)</li> <li>– 3 patients have referrals outstanding (patients considering options, Oncologist referral denied by BC Cancer Agency)</li> </ul>
# of patients who require additional clinic consultations (follow up or ongoing)	27
# of patients who had genetic testing prior to clinic consultation	12
# of patients who received recommendation for genetic testing from clinic consultation	9
# of patients who achieved recommended genetic testing	<ul style="list-style-type: none"> <li>– 1 patient referral denied by genetics clinic</li> <li>– 2 patients referred and waiting for approval</li> <li>– 1 patient approved for genetic testing, test ordered.</li> </ul>



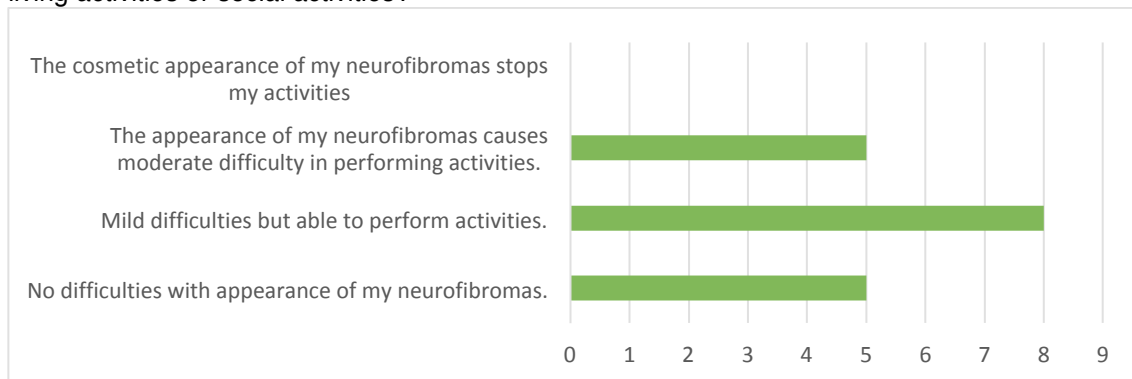
### Impact of NF on Quality of Life Questionnaire - Summary of Responses

Patients were asked to complete the *Impact of NF of Quality of Life Questionnaire* prior to their clinic consultation. For each of the questions, patients were asked to mark one box that best describes how they felt in the last month.

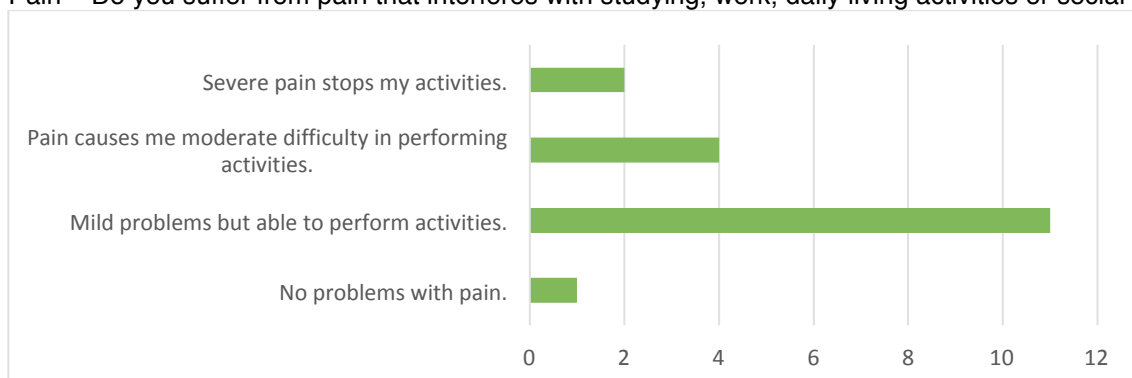
1. Do problems with your vision interfere with studying, work, daily living activities, or social activities?



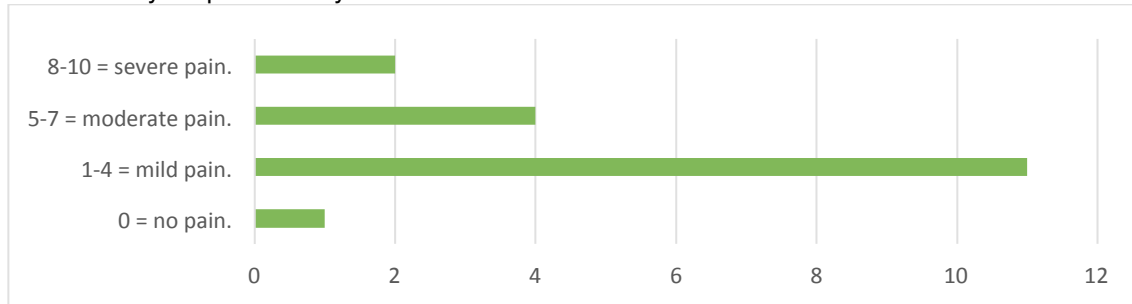
2. Does the cosmetic appearance of your neurofibromas (the way they look) interfere with studying, work, daily living activities or social activities?



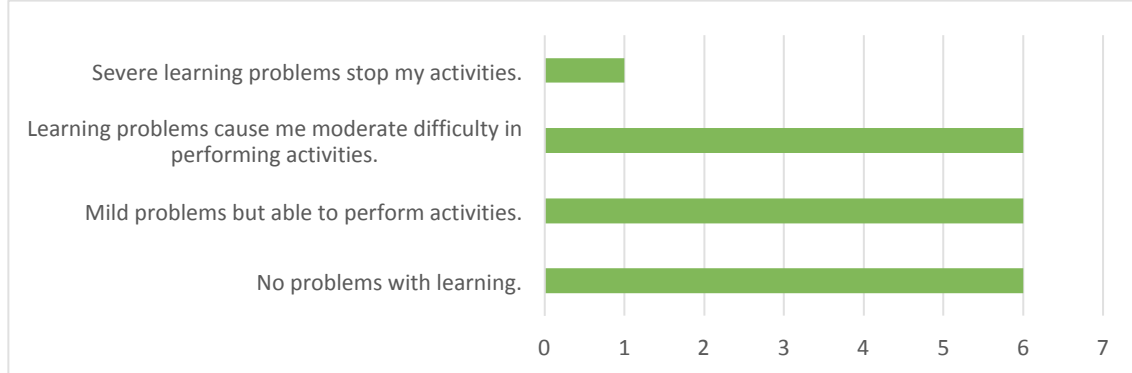
3. Pain – Do you suffer from pain that interferes with studying, work, daily living activities or social activities?



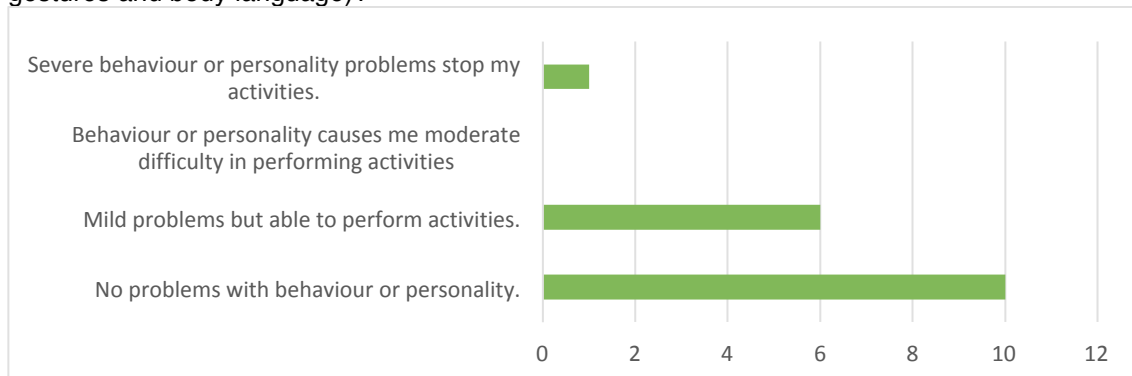
4. How bad is your pain usually?



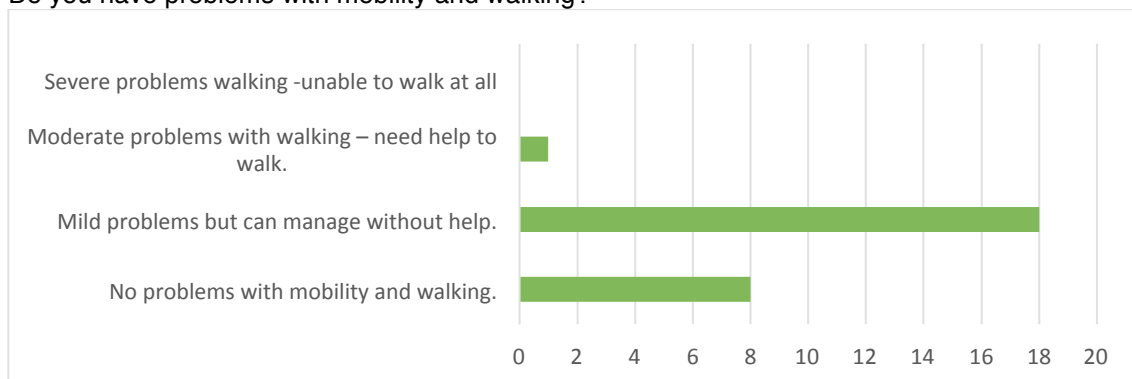
5. Do you have learning problems? (e.g. problems with reading, writing, spelling, maths, concentration, coordination, organization) interfere with studying, work, daily living activities or social activities?



6. Do you have problems with your behaviour or personality that interfere with your studies, work daily living activities or social activities? (e.g. difficulty in making friends, autism, difficulty in understanding jokes, gestures and body language)?



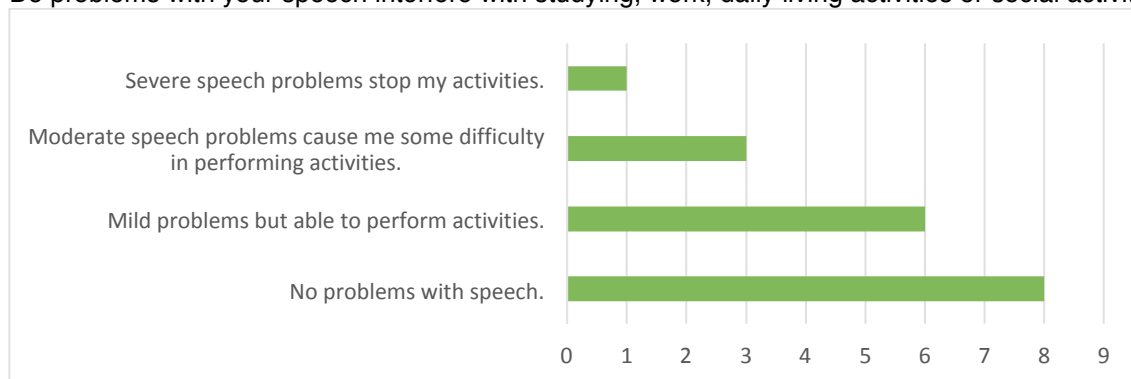
7. Do you have problems with mobility and walking?



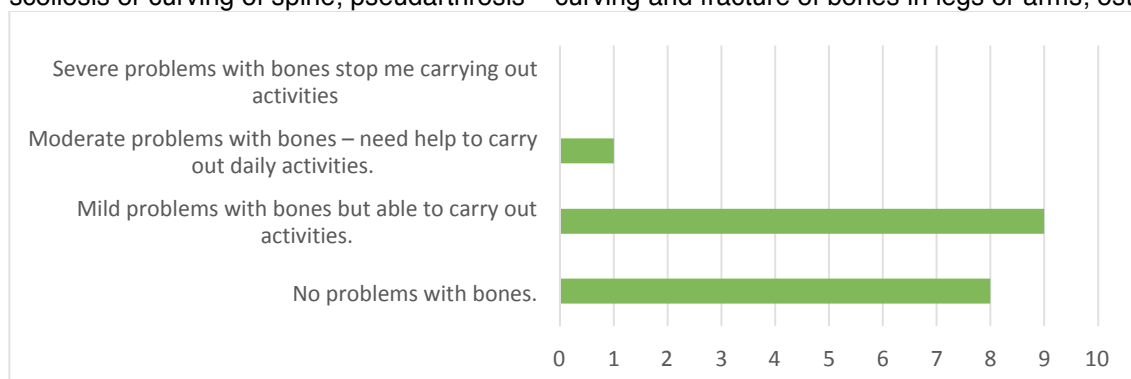
8. Do you have problems with weakness, numbness or clumsiness of your hands that interfere with studying, work, daily living activities or social activities? (e.g. using a knife and fork, writing, doing up buttons, doing the cooking, brushing your hair)



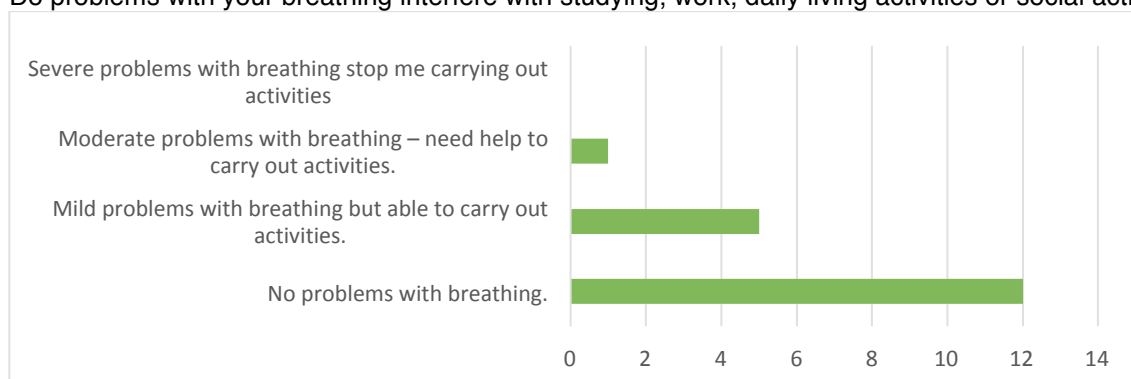
9. Do problems with your speech interfere with studying, work, daily living activities or social activities?



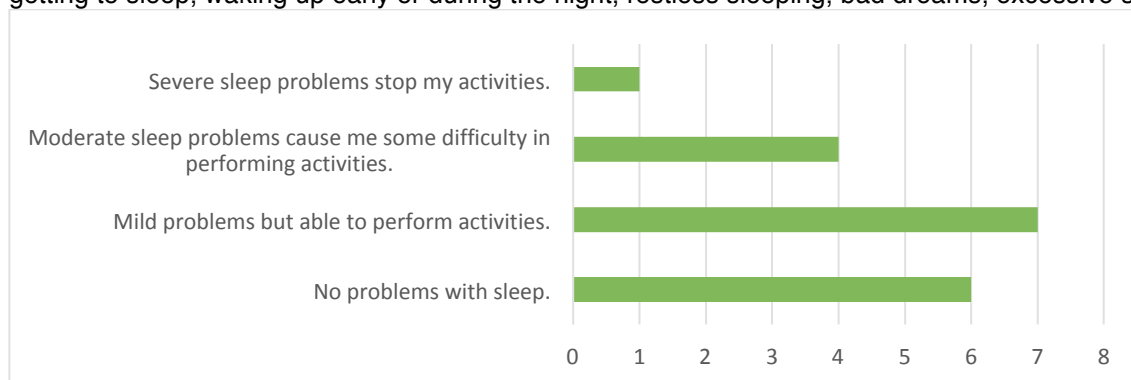
10. Do problems with your bones interfere with studying, work, daily living activities or social activities? (e.g. scoliosis or curving of spine; pseudarthrosis – curving and fracture of bones in legs or arms; osteoporosis)



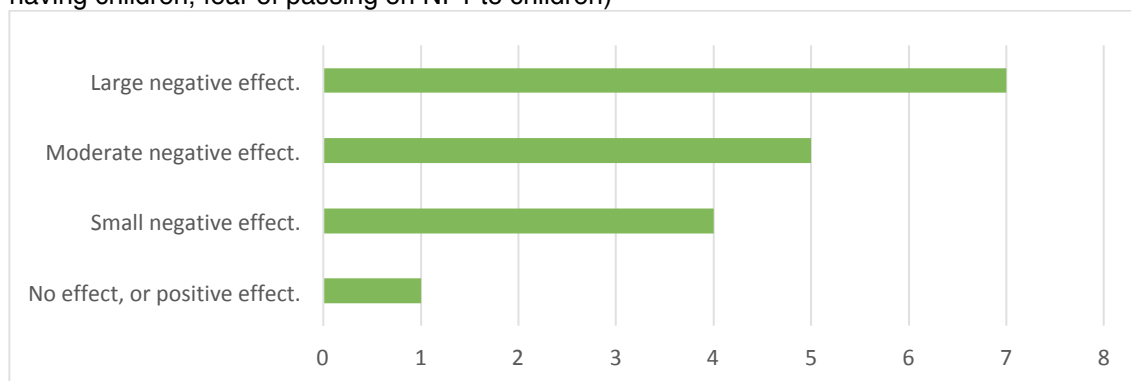
11. Do problems with your breathing interfere with studying, work, daily living activities or social activities?



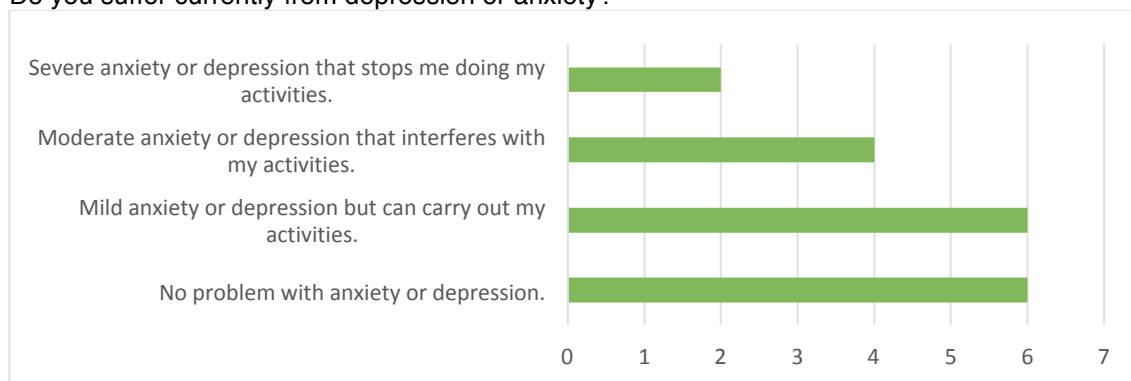
12. Do problems with sleeping interfere with studying, work, daily living activities or social activities? (e.g. difficulty getting to sleep, waking up early or during the night, restless sleeping, bad dreams, excessive sleepiness)



13. Has NF1 affected your role and outlook on life? (e.g. career, confidence, relationships, caring for family, having children, fear of passing on NF1 to children)



14. Do you suffer currently from depression or anxiety?



15. If there is anything else you would like to add about the impact of NF1 on your quality of life please write down your comments below.

- Not sure how to answer that would make sense I know I have continued to have operations on the tumour on my eye but really can't put anything into words I usually do not like to talk about it.
- Mostly just physical appearance and low self esteem.
- I have NF2 but your questions above are similar to what I have to deal with. Thanks for asking them all. Things are getting very bad due to my age 56 years old. You should have asked your age but hopefully you will get to find it out when people who join give you there DOB in a reply email. Thanks again for asking all the above and your help [removed to protect privacy].
- Being a senior, I find it's sometimes frustrating to get answers, and explain symptoms to drs.

- I don't know if I have internal tumours as I have never had a full body MRI
- People don't seem to understand the impact of NF1. They question your pain as you make look healthy. Frustration...would just like to feel normal .. be pain free ...
- I am 45 years old, I could not attend regular school and was in a special need class in primary and high school. After high school i attended [removed to protect privacy] for a few years. Now I was allotted Independent Living under RSCL . I live with my room mate and some others individuals at a building named [removed to protect privacy]. I was allotted 1 to 2 or 2 1/2 hour a day of help from Monday to Friday. mainly cooking, cleaning and grocery shopping. My parents still involve a lot to help me, like doctors, dentist, hair dressing, nail cutting appointments because i don't understand what the doctor or dentist convey to me. I can not cook because i am only one handed and I don't see well.
- The above questions cover all areas.
- I have a lack of understanding from others. NF is so misunderstood from many physicians
- Plexiform nerve sheath tumour on my ankle (which has been waiting for surgery in Vancouver for yea now). Shaking and tremors in my hands Migraines. Temporal lobe seizures (focal impaired) causing emotion swings, memory loss and odd behaviours
- Major anxiety and sleep problems, migraines. Diagnosed with Fibromyalgia and ADHD
- Being the only one in the family affects me greatly. Lately there is major weakness in my legs and bad back pain near the bottom of my spine.
- Wish people would understand NF
- The biggest impact of my neurofibromatosis is cosmetic and mild pain from neurofibromas. As I get older I continue to get more neurofibromas which makes me fearful of what they will look like in the future. I have had some removed but those are all considered cosmetic and our out-of- pocket payments which when you have multiple neurofibromas will add up quickly. I have also had several mammograms and an MRI mammogram and I do worry about the high risk of breast cancer in patients with neurofibromatosis. I worry that the risk might be greater than what doctors believe because neurofibromatosis isn't commonly known. Another thing I would love to have is a list of doctors/surgeons that you can be referred to in the Vancouver area when you do find challenges arising with your NF. Otherwise I find there is a lot of trial and error and you might go to one doctor and they can't help you or they don't want to help you. As long as you are good to advocate for your own health and push for yourself you can get a referral to another doctor but that does take a lot of time and waiting periods. Other patients might not have the ability to push and advocate for their own health.

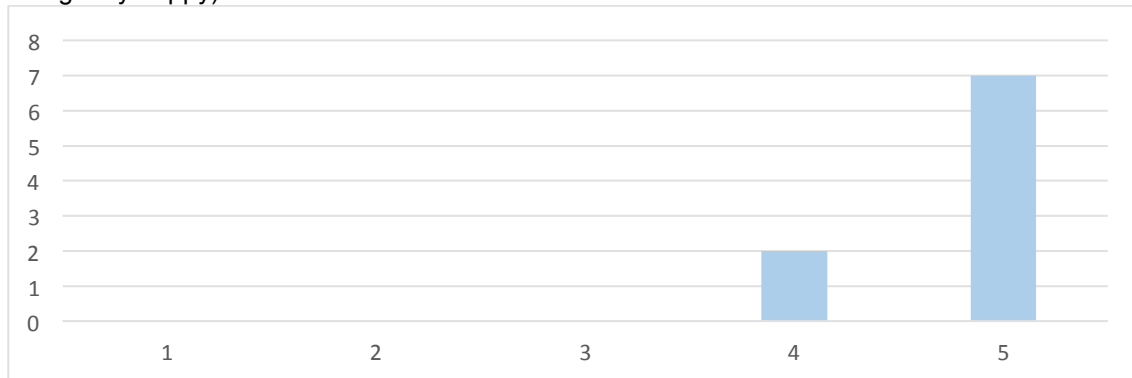
### NF Clinic Patient Experience Survey

You are being invited to take part in this survey because you were part of the virtual NF Medical Clinic pilot project.

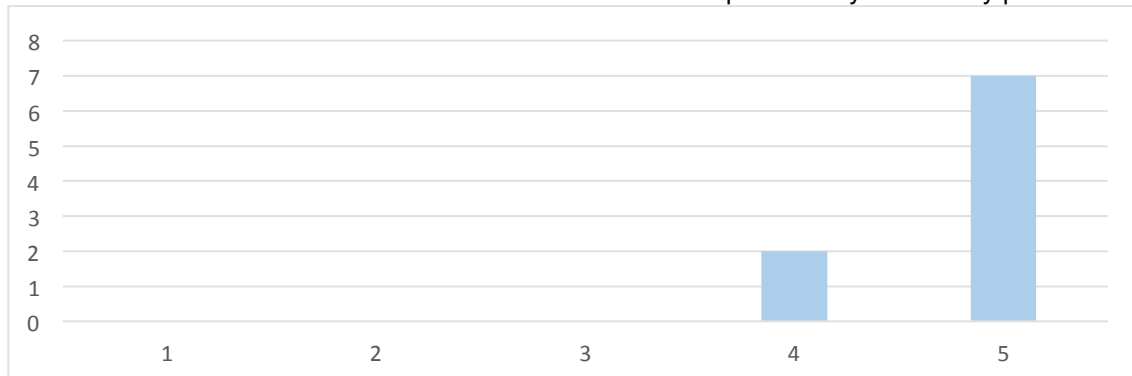
Your responses to the questions on this survey will help us improve the care we provide patients with neurofibromatosis and help us access ongoing operational funding. The survey will take approximately 3-5 minutes to complete.

Participation in the survey is completely voluntary and all your responses to the survey questions will be kept confidential.

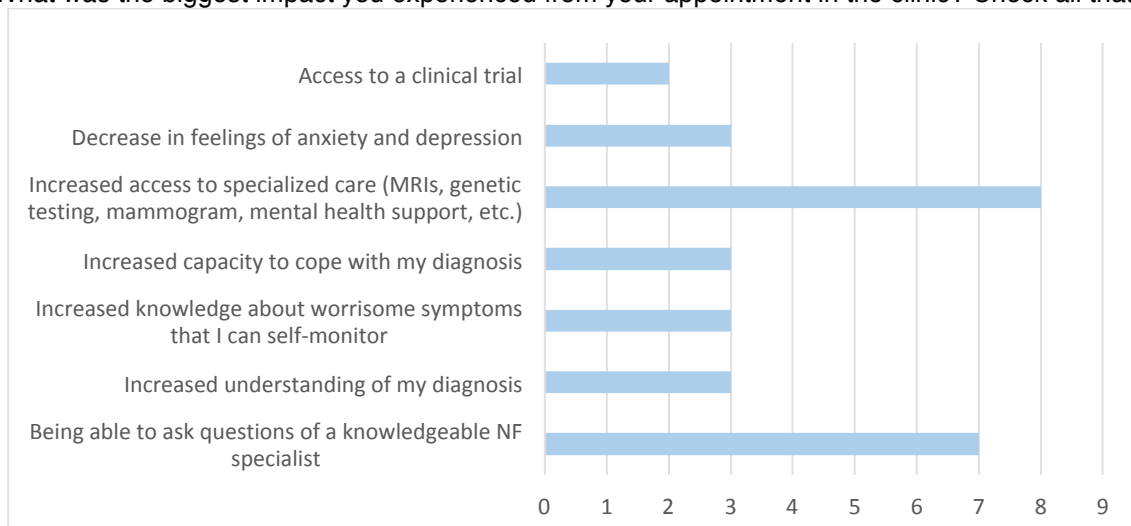
1. On a scale of 1-5 how happy were you with the care you received in the NF clinic? (1 being very unhappy and 5 being very happy).



2. How well were the evaluation and clinic recommendations explained to you? 1- very poor- 5 outstanding).



3. What was the biggest impact you experienced from your appointment in the clinic? Check all that apply.

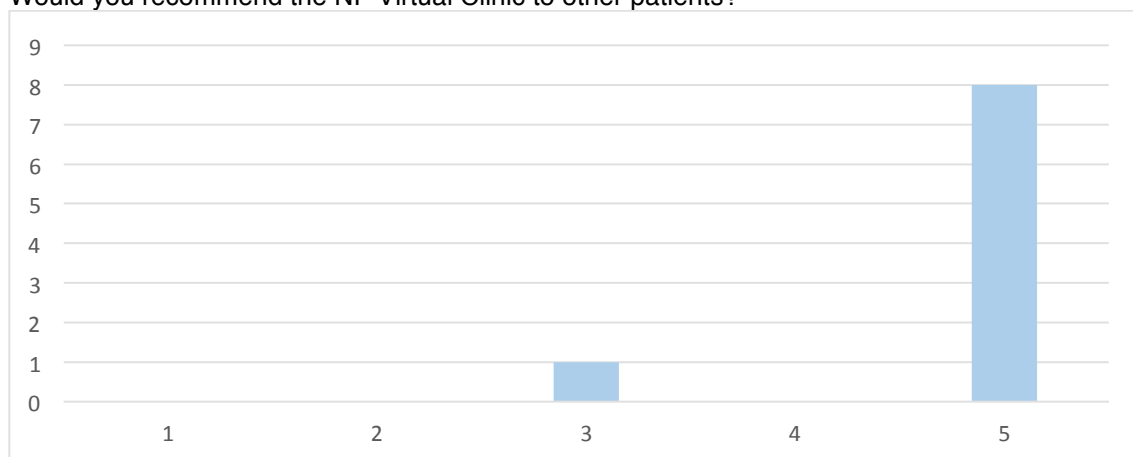




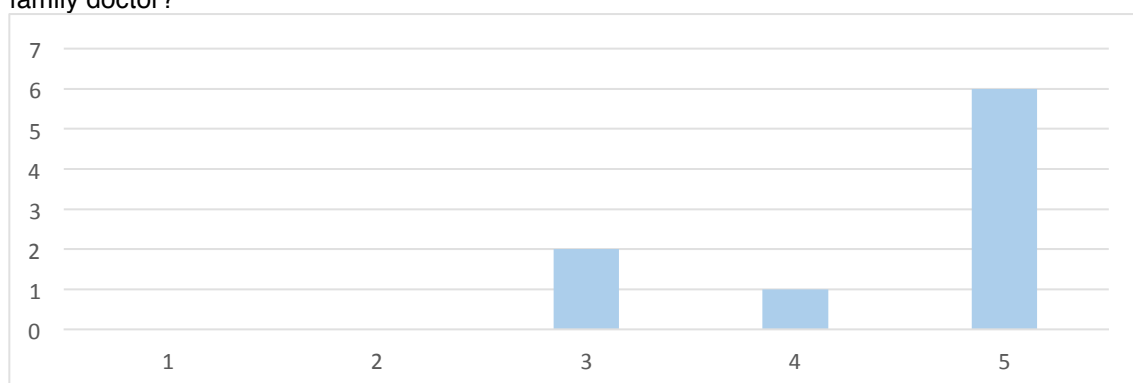
4. Thinking of your overall experience with our clinic, what is...? One thing done particularly well: One thing that could be improved upon?

- Answered my questions, and followed up
- To improve on, more understanding of provincial wait times for MRI, monogram, etc. and being able to refer me, instead of going through my GP
- Answers to questions
- I can't think of anything, right now
- Letting me know what types of scans I should have and letting them know I should have them
- Gathering my history of NF was done well. More time for the patient to talk would be nice.
- Accommodate me based on my availability.
- Improve - Nothing at this time.
- I'm grateful for this opportunity, I just wish it were in BC!
- I found the clinic to really beneficial to help me advocate and receive medical services for things that I need to monitor with my NF (MRI) and to be taken more seriously for a tumour removal. I really appreciate that.

5. Would you recommend the NF Virtual Clinic to other patients?



6. Do you believe that your medical care will be improved as a result of the clinic consult report being sent to your family doctor?



7. How do you feel your medical care will improve as a result of being a part of the clinic?

- Hopefully a lot, hopefully get to partake in clinical trials
- Not sure
- My doctor was all for it
- I hope it will improve, not many doctors know
- I am hoping more will be done as medical problems coming up
- MRI was recommended. I have never had one in relation to my NF.
- Having a specialist guide my family doctor.

- Having a specialist to review and synthesize information is valuable. There's no one to tie all the pieces together otherwise. Trying to jigsaw all the various specialists / care needs is a challenge. A combined approach to all medical avenues is very helpful.
- I find that it's great to have the recommendations of a specialist to help me better advocate for my care and for me to be taken more seriously to do that.

8. Do you have any additional feedback that you would like to share about your experience in the NF virtual clinic? Your words may be shared anonymously in our funding requests to donors and grant sources.

- I just going over with my niece who is in Toronto and goes to the clinic
- Can't think of anything
- not now
- The clinic was a long time coming. Having a specialist in the field of NF guide the patient's journey will improve the overall approach to their health. Hopefully one day there will be a physical clinic within reach.
- I think this clinic is great. It offers medical support and advice that is much needed. It helps to better advocate for our healthcare and monitor ourselves for issues that can be affected by NF.

9. Would you like someone from the clinic to follow-up with you about your experience at the clinic?

