



Health Care for Patients with NF



General

	Survey name	Health Care for Patients with NF
	Author	Tumour Foundation of BC
	Survey language	 en
	Survey URL	https://www.surveio.com/survey/d/F1E4X4H9J5V4B0A4H
	First response	06/10/2020
	Last response	07/16/2020
	Duration	37 days

Survey visits

134

Total visits

52

Total completed

0

Total unfinished

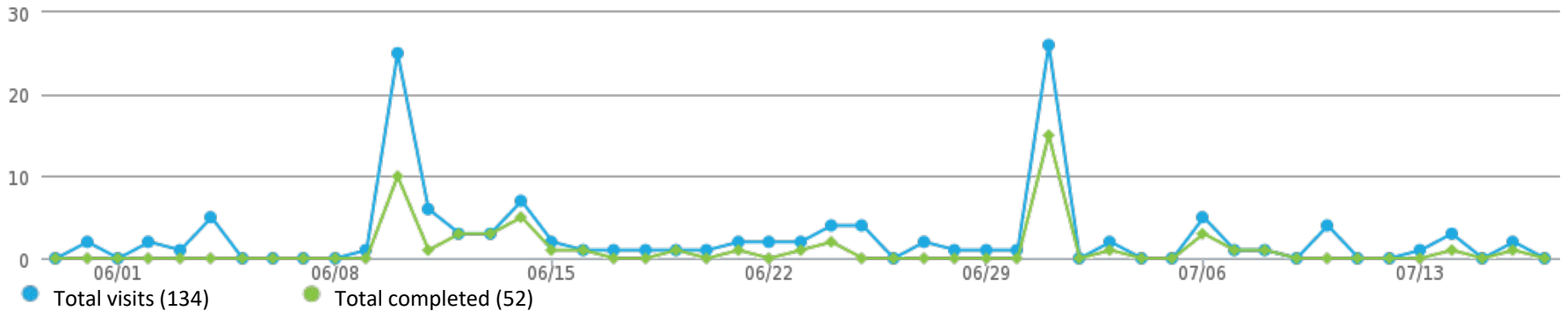
74

Displayed only

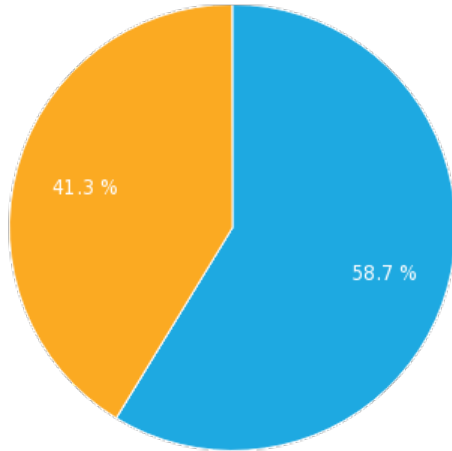
38.8%

Overall completion
rate

Visit History (06/10/2020 - 07/16/2020)

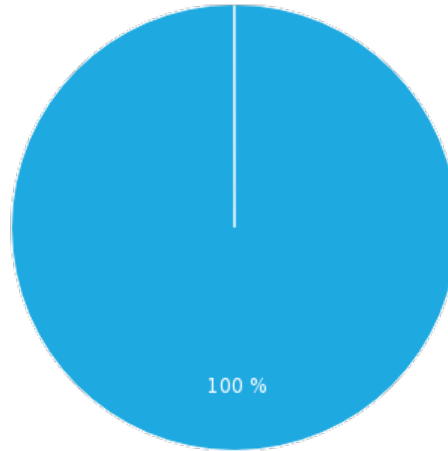


Total Hits



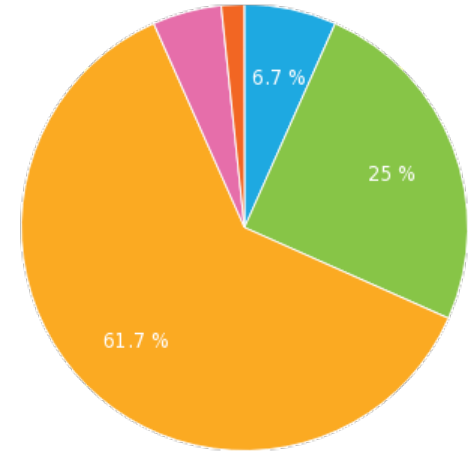
- Displayed only (58.7 %)
- Unfinished (0 %)
- Completed (41.3 %)

Visit Sources



- Direct link (100 %)

Average Time of Completion



- 2-5 min. (6.7 %)
- 5-10 min. (25 %)
- 10-30 min. (61.7 %)
- 30-60 min. (5 %)
- >60 min. (1.7 %)

Where do you currently live in BC? Please enter your postal code.

Text answer, answers 49x, unanswered 3x

How many people in your household have NF?

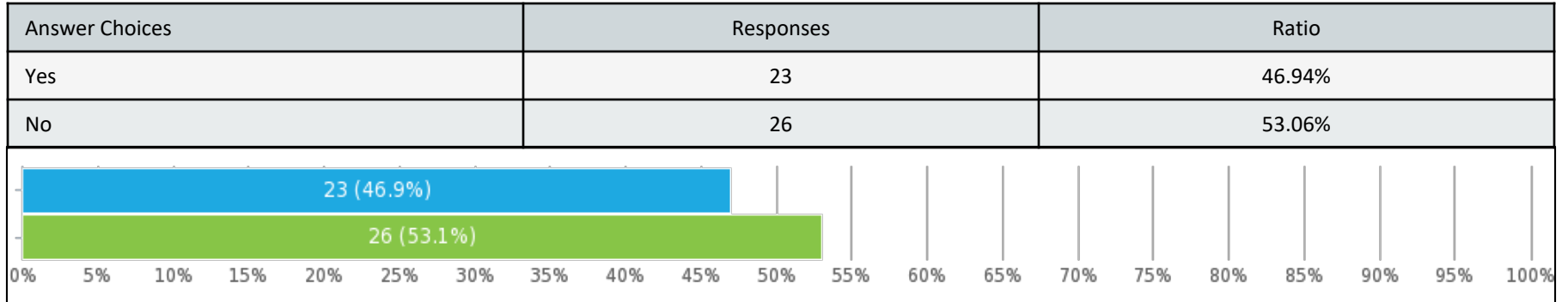
Text answer, answers 49x, unanswered 3x

What are the ages of each person in your household with NF?

Text answer, answers 49x, unanswered 3x

Are you completing this survey on behalf of another person?

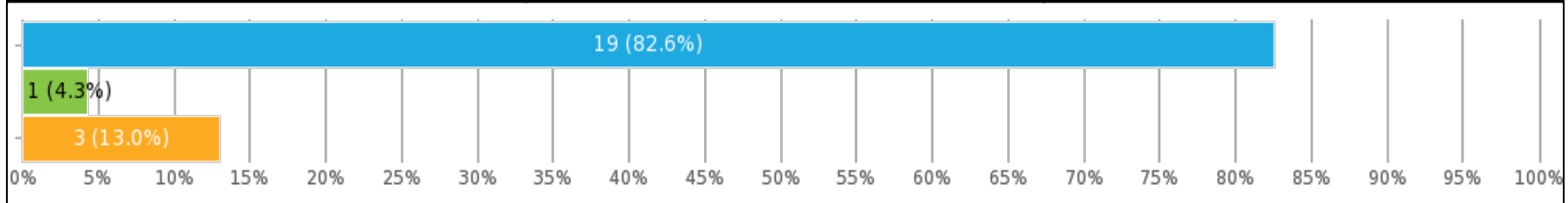
Single choice, answers 49x, unanswered 3x



Are you completing this survey on behalf of:

Single choice, answers 23x, unanswered 29x

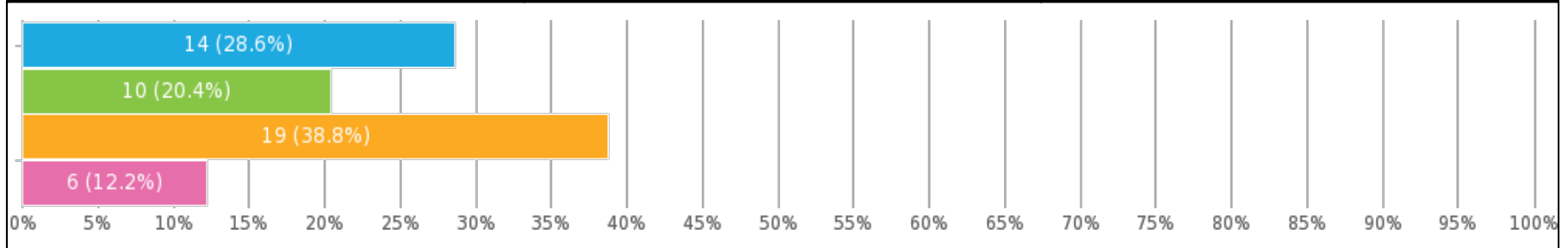
Answer Choices	Responses	Ratio
Child	19	82.61%
Dependent	1	4.35%
Other...	3	13.04%



Who diagnosed your NF?

Single choice, answers 49x, unanswered 3x

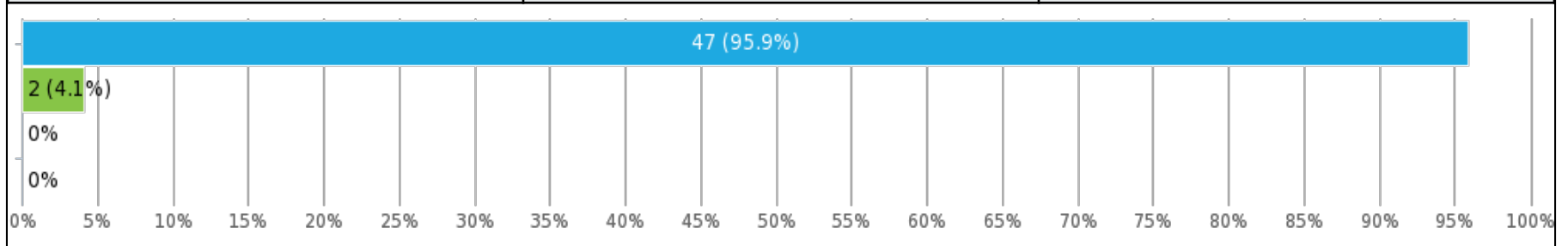
Answer Choices	Responses	Ratio
Family Doctor	14	28.57%
Paediatrician	10	20.41%
Genetic Specialist	19	38.78%
Other Specialist(s) - please list	6	12.24%



What type of NF do you have?

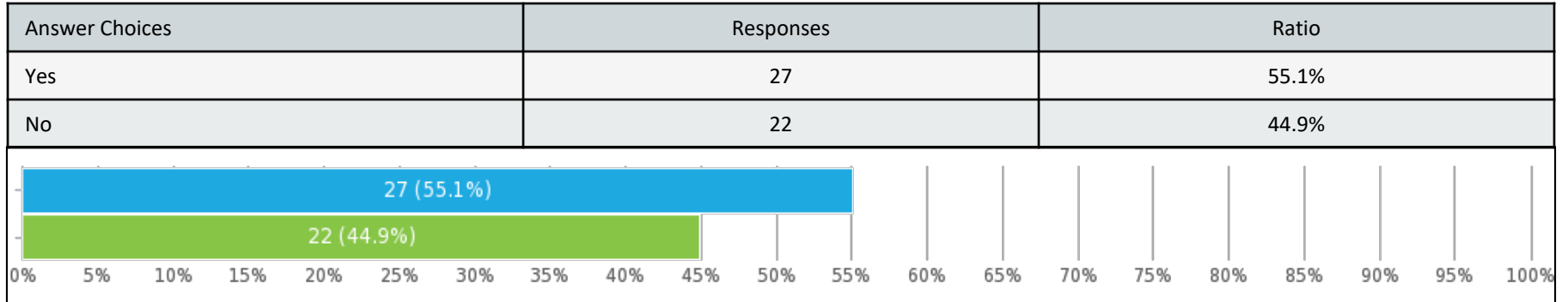
Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
NF1	47	95.92%
NF2	2	4.08%
Schwannomatosis		0%
I don't know		0%



Have you received genetic testing?

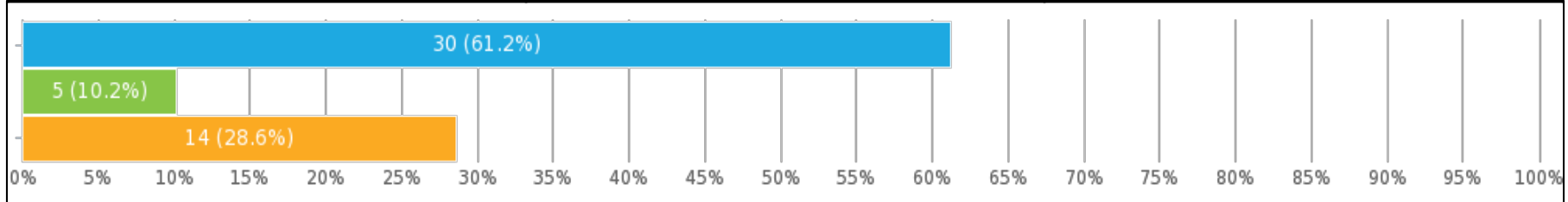
Single choice, answers 49x, unanswered 3x



Do you believe that genetic testing is an important consideration when diagnosing and managing NF?

Single choice, answers 49x, unanswered 3x

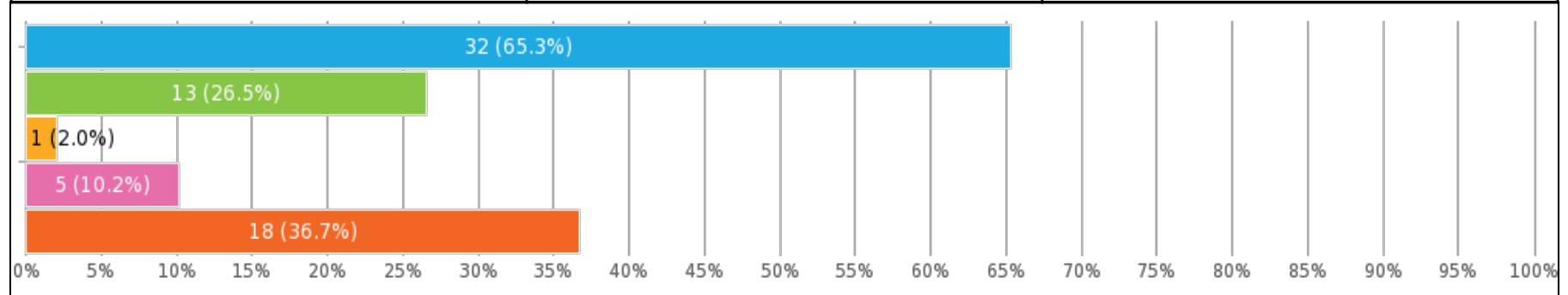
Answer Choices	Responses	Ratio
Yes	30	61.22%
No	5	10.2%
Undecided	14	28.57%



Who currently provides your primary medical care (eg. provides day-to-day healthcare and overseeing continuing care)?

Multiple choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Family Doctor	32	65.31%
Paediatrician	13	26.53%
Neighbourhood Medical Clinic	1	2.04%
Genetic Specialist	5	10.2%
Other Specialists - please list	18	36.73%



Which specialists have you consulted for NF care? 1/3

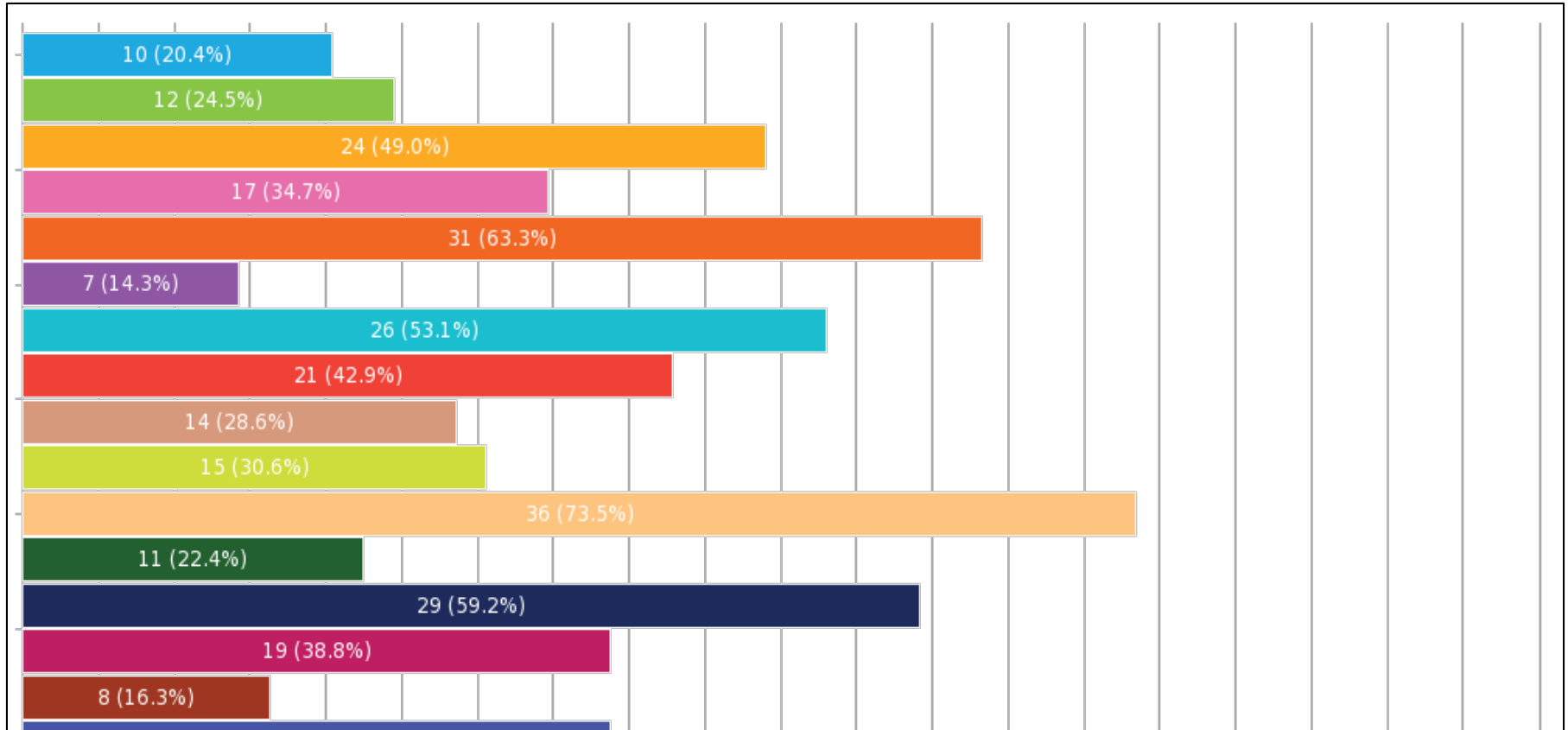
Multiple choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Cardiologist	10	20.41%
Counsellor/Social Worker	12	24.49%
Dermatologist	24	48.98%
Ear, Nose and Throat (ENT) Specialist	17	34.69%
Geneticist	31	63.27%
Infant Development Specialist	7	14.29%
Neurologist	26	53.06%
Neurosurgeon	21	42.86%
Oncologist	14	28.57%
Occupational/Physical Therapist	15	30.61%
Ophthalmologist	36	73.47%
Orthopedist	11	22.45%

Which specialists have you consulted for NF care? 2/3

Paediatrician	29	59.18%
Plastic Surgeon	19	38.78%
Psychiatrist/Psychologist	8	16.33%
Speech Therapist	19	38.78%
Radiologist	5	10.2%
Other Specialists - please list	9	18.37%
I haven't received any specialized care for my NF	1	2.04%

Which specialists have you consulted for NF care? 3/3

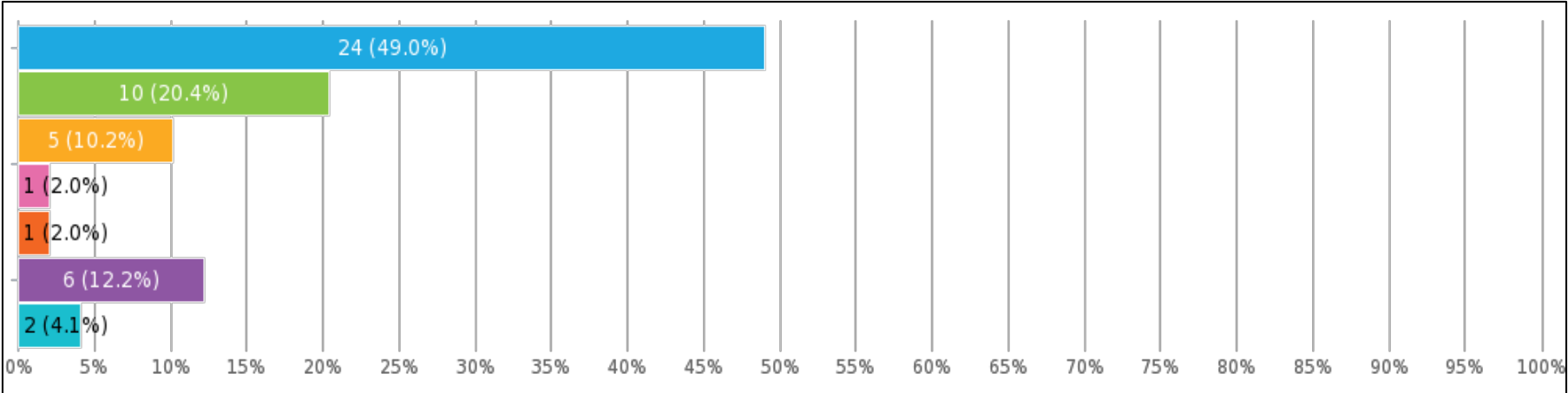


Who coordinates your NF medical care if multiple specialists are required? 1/2

Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
No one, I manage my/my child(ren's) NF medical care.	24	48.98%
Family Doctor	10	20.41%
Paediatrician	5	10.2%
Neighbourhood Medical Clinic	1	2.04%
Genetic Specialist	1	2.04%
Other Specialists - please list	6	12.24%
I haven't received any specialized care for my NF	2	4.08%

Who coordinates your NF medical care if multiple specialists are required? 2/2

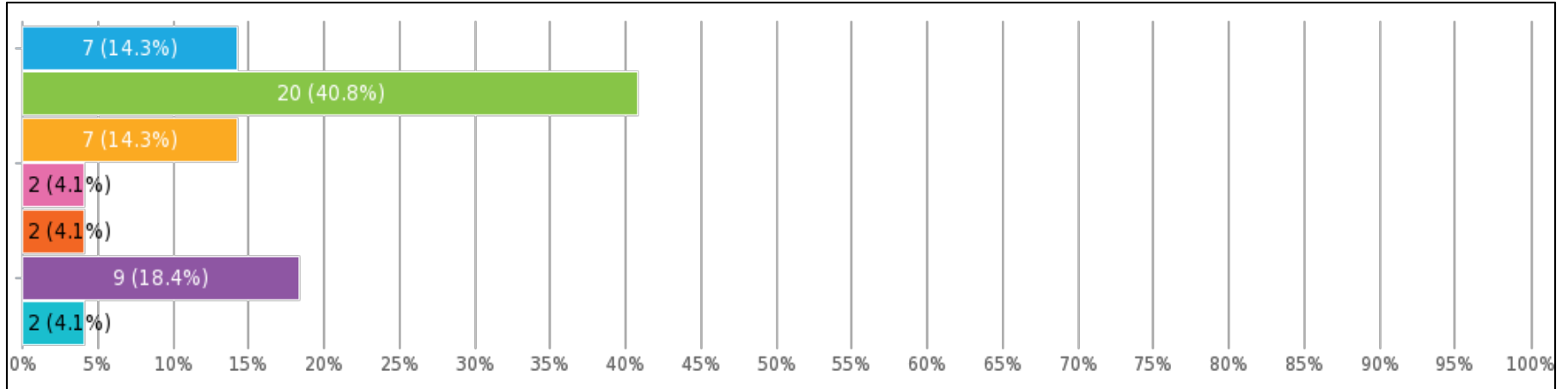


How often do you see a medical practitioner about NF? 1/2

Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Once per month or more frequently	7	14.29%
Several times per year	20	40.82%
About once per year	7	14.29%
Less than once or twice every five years	2	4.08%
Not in the past five years	2	4.08%
Rarely	9	18.37%
Never	2	4.08%

How often do you see a medical practitioner about NF? 2/2

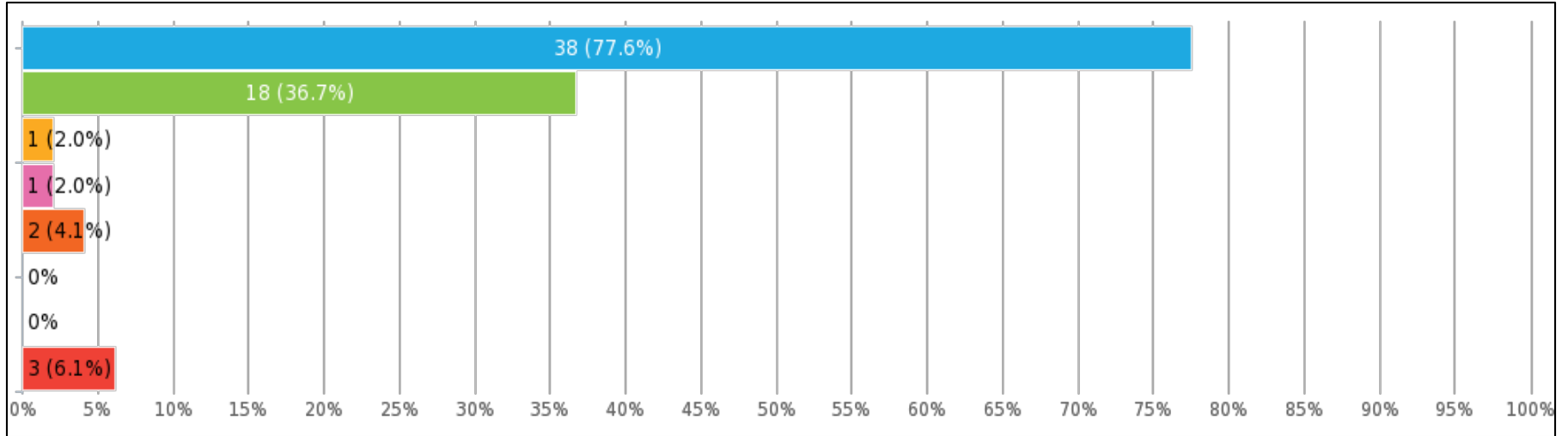


Where do you receive your medical care? 1/2

Multiple choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
In my own community	38	77.55%
Travel to major centre	18	36.73%
Travel outside province	1	2.04%
Travel outside Canada	1	2.04%
Access online medical care within province	2	4.08%
Access online medical care outside province		0%
Access online medical care outside Canada		0%
I do not receive medical care	3	6.12%

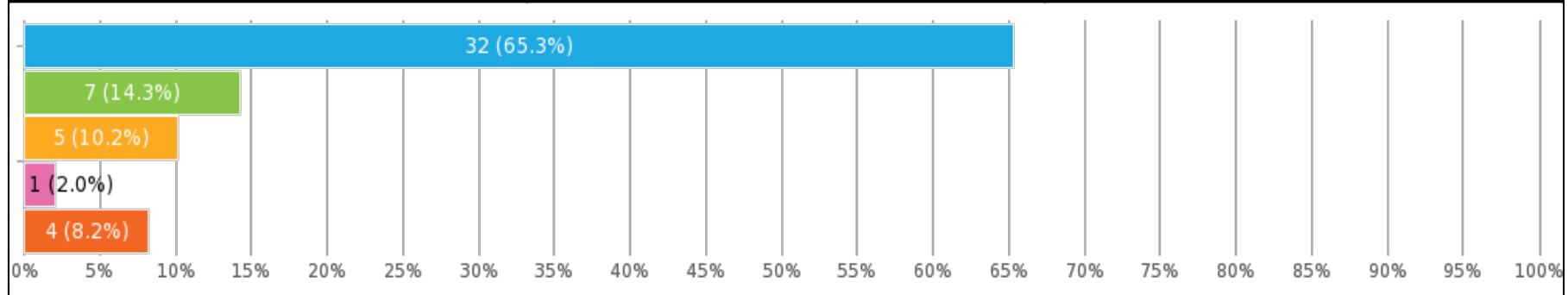
Where do you receive your medical care? 2/2



On average, approximately how many hours per month do you spend managing NF care (including travel to and from appointments, speaking with specialists about medical and education issues related to NF, undertaking personal research)?

Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Less than 2 hours/month	32	65.31%
Less than 6 hours/month	7	14.29%
Less than 10 hours/month	5	10.2%
Less than 15 hours/month	1	2.04%
More than 16 hours/month	4	8.16%



How do you believe your health is most affected by NF? 1/3

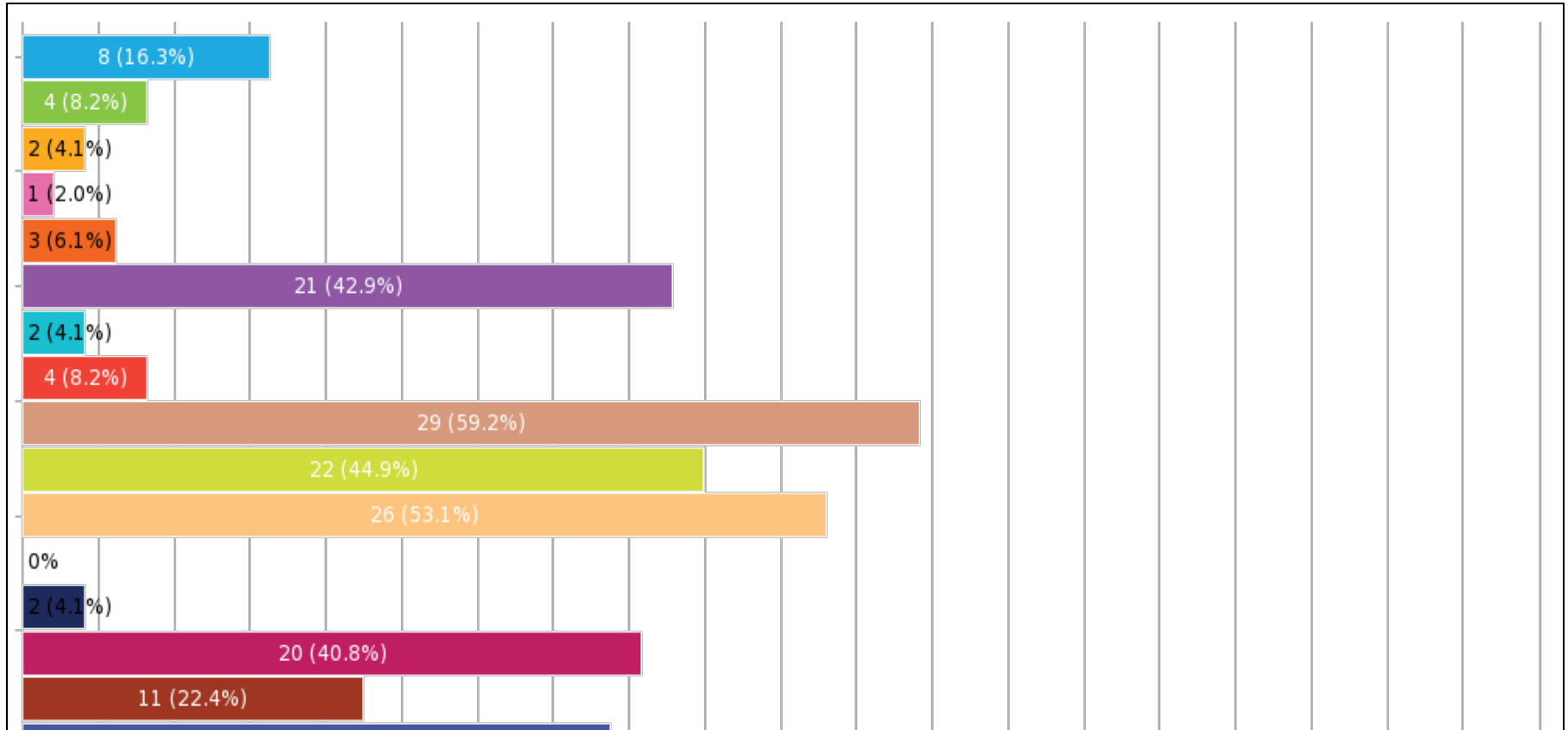
Multiple choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Bone Deformities	8	16.33%
Bone Fragility	4	8.16%
Deafness	2	4.08%
Ependymoma	1	2.04%
Facial Paralysis	3	6.12%
Headaches	21	42.86%
Hearing Loss	2	4.08%
Hypertension	4	8.16%
Internal Tumours	29	59.18%
Itching	22	44.9%
Learning Differences	26	53.06%
Limb Loss		0%

How do you believe your health is most affected by NF? 2/3

Meningiomas	2	4.08%
Pain	20	40.82%
Peripheral Nerve Tumour	11	22.45%
Plexiform Tumours	19	38.78%
Problems with Balance	16	32.65%
Scoliosis	12	24.49%
Seizures	7	14.29%
Skin Tumours	25	51.02%
Speech Difficulties	18	36.73%
Spinal Core Compression	6	12.24%
Schwannoma Tumours	4	8.16%
Vision Loss	12	24.49%
Other - please list	7	14.29%

How do you believe your health is most affected by NF? 3/3

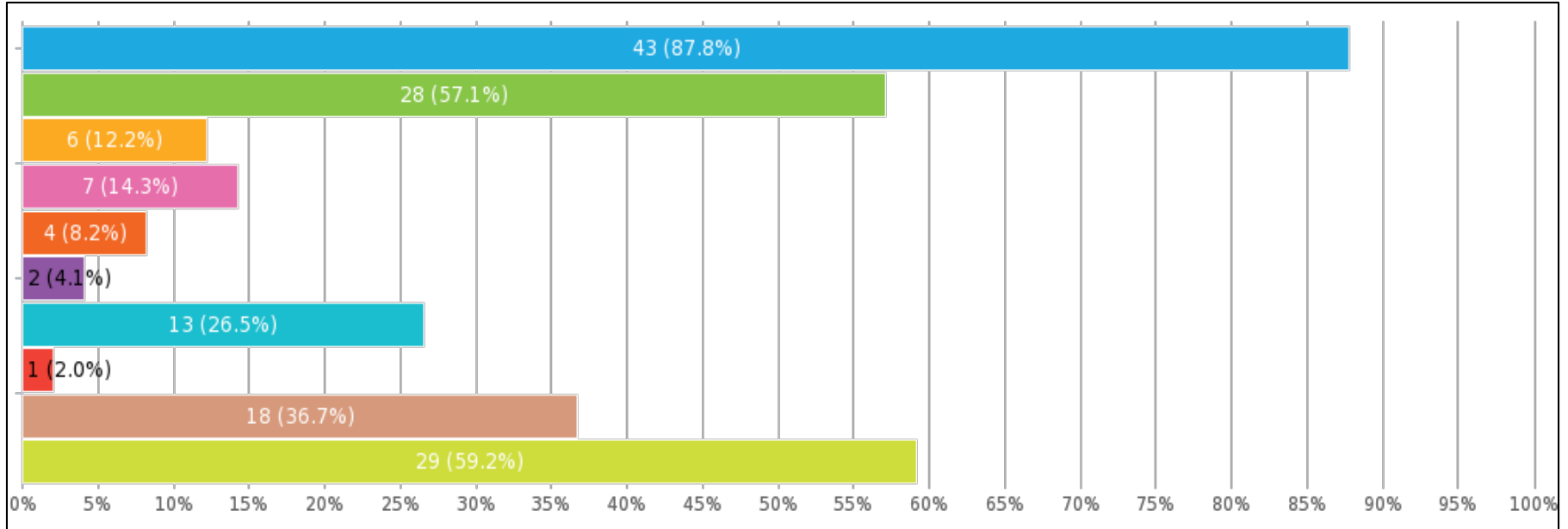


What types of care have you accessed in order to treat or manage your NF symptoms? 1/2

Multiple choice, answers 49x, unanswered 3x

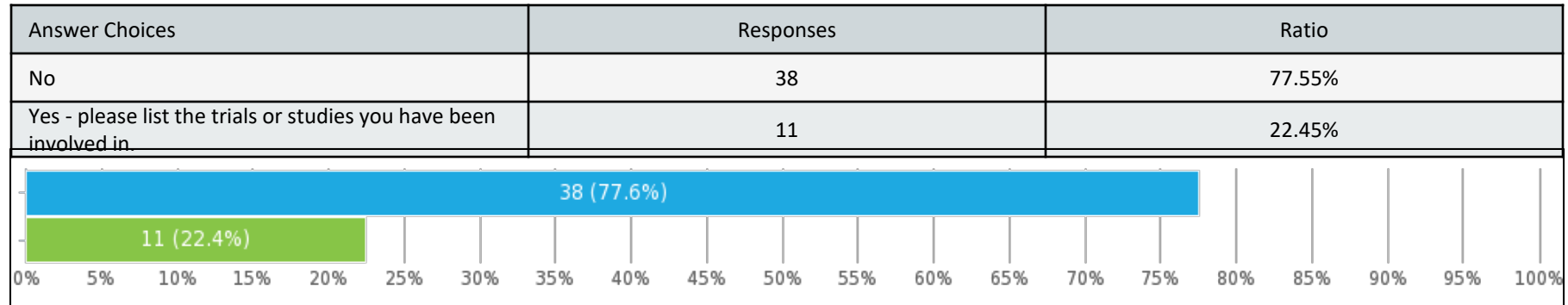
Answer Choices	Responses	Ratio
Imaging (MRI, xray, etc.)	43	87.76%
Surgery (please indicate for which symptoms in the "Other" answer)	28	57.14%
Chemotherapy	6	12.24%
Pharmaceuticals intended for pain management	7	14.29%
Pharmaceuticals intended for management of NF symptoms	4	8.16%
Pharmaceuticals intended to reduce tumour growth	2	4.08%
Physical Therapy	13	26.53%
Radiation Therapy	1	2.04%
Speech Therapy	18	36.73%
Other - please list	29	59.18%

What types of care have you accessed in order to treat or manage your NF symptoms? 2/2



Have you participated in clinical trials or research studies for NF?

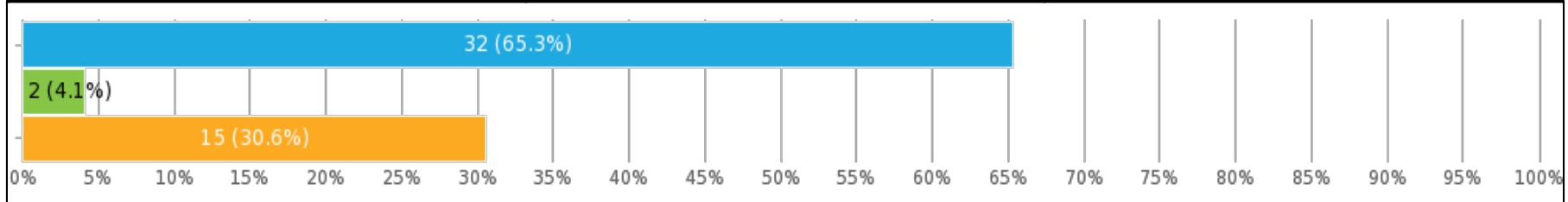
Single choice, answers 49x, unanswered 3x



Would you participate in a clinical trial if one was available to you?

Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Yes	32	65.31%
No	2	4.08%
Maybe - add text to explain	15	30.61%



What are your biggest challenges related to living with NF? 1/3

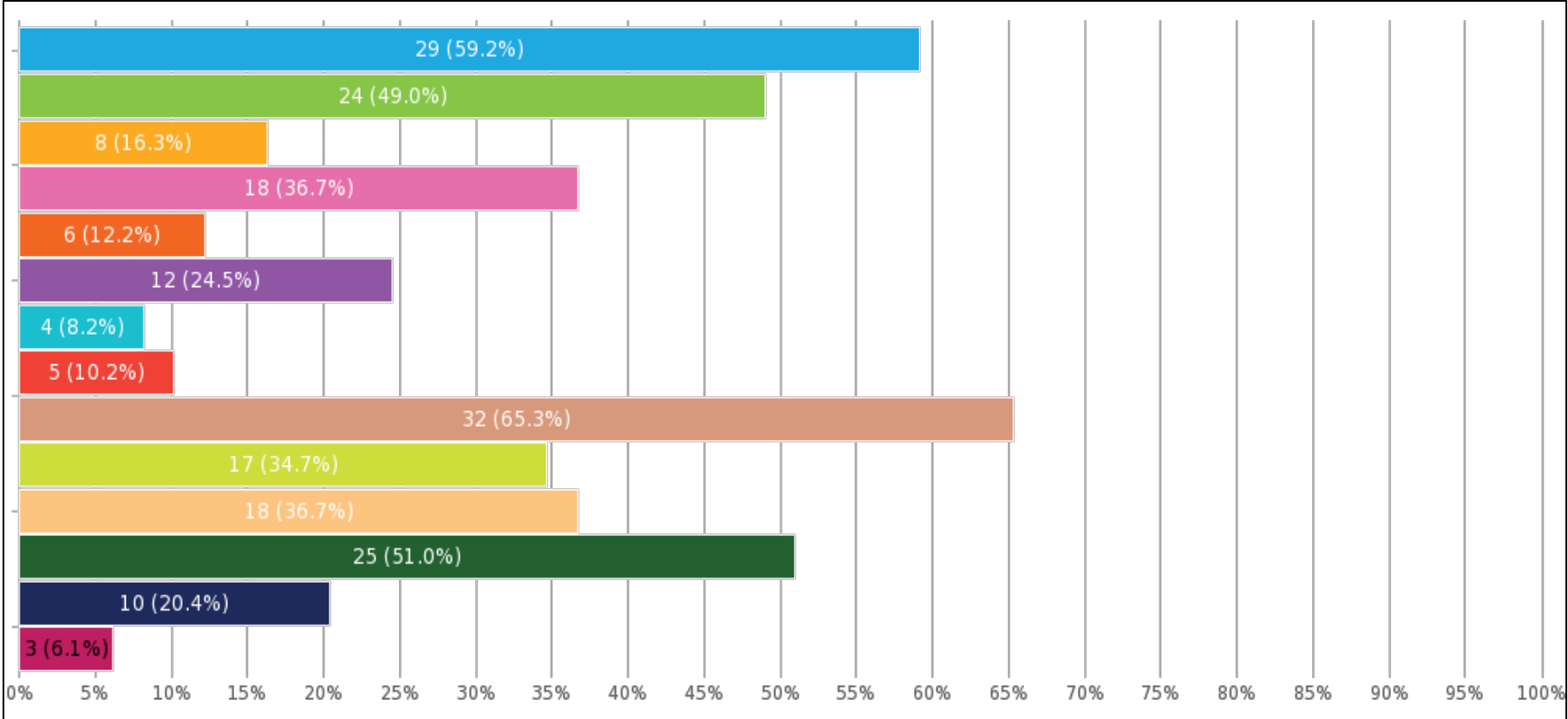
Multiple choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
Lack of professionals who understand the disorder	29	59.18%
Lack of coordinated care	24	48.98%
Lack of access to psychologist or counsellor	8	16.33%
Lack of education supports for learning differences	18	36.73%
Difficulties getting a job	6	12.24%
Lack of information	12	24.49%
Lack of family support	4	8.16%
Lack of support from friends	5	10.2%
Lack of public awareness	32	65.31%
Social isolation/stigma	17	34.69%
Depression	18	36.73%
Anxiety of living with uncertainty	25	51.02%

What are your biggest challenges related to living with NF? 2/3

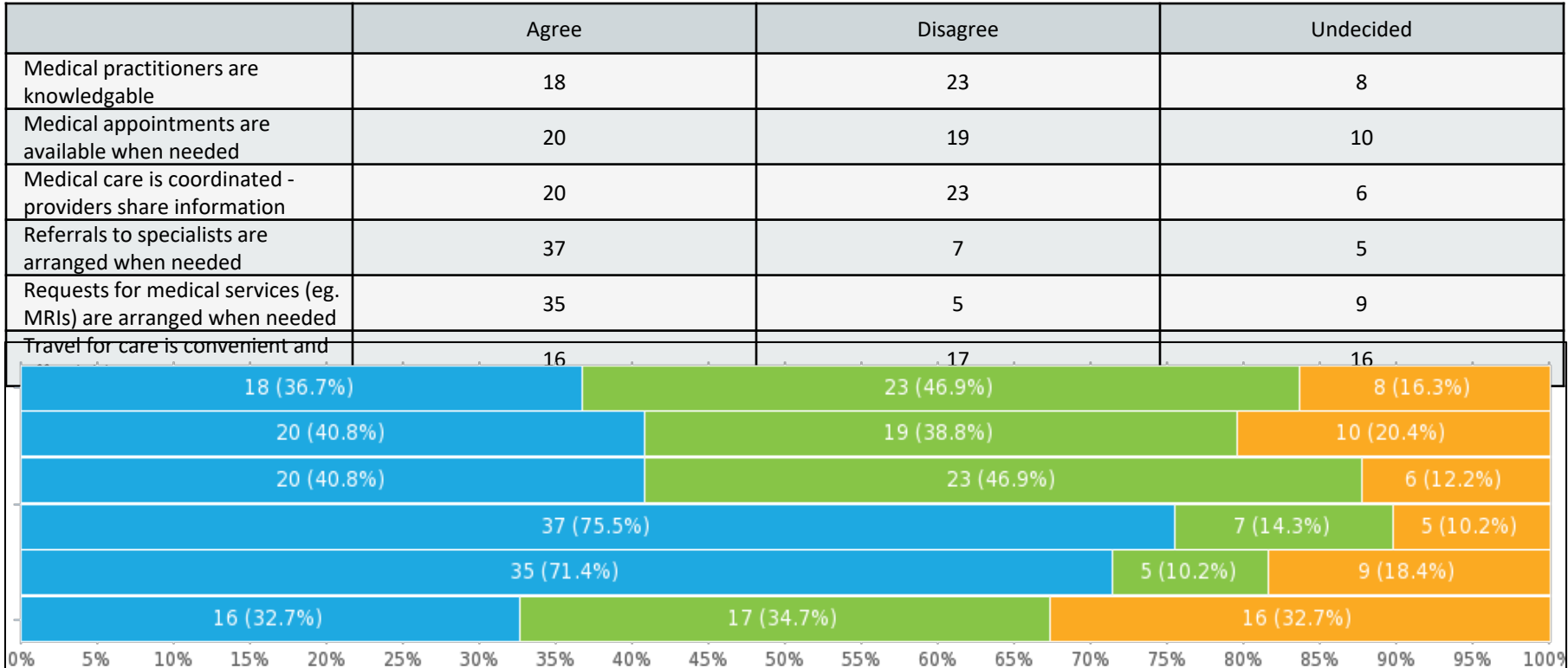
Other - please describe	10	20.41%
I don't have any challenges related to living with NF	3	6.12%

What are your biggest challenges related to living with NF? 3/3



How would you rate the medical care that you receive for NF related issues?

Matrix of single choices, answers 49x, unanswered 3x



In what ways do you feel that you do not receive adequate medical care?

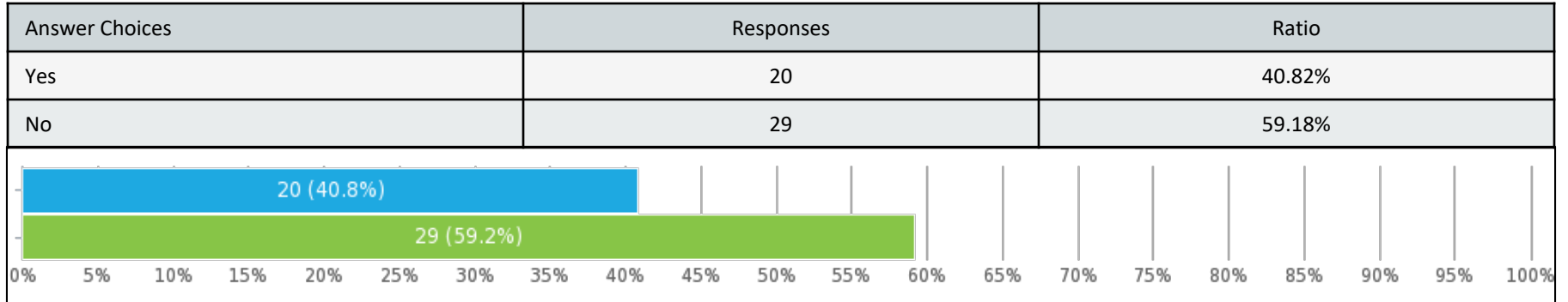
Text answer, answers 49x, unanswered 3x

How could your medical care be improved?

Text answer, answers 49x, unanswered 3x

Have you transitioned from paediatric care to adult care?

Single choice, answers 49x, unanswered 3x

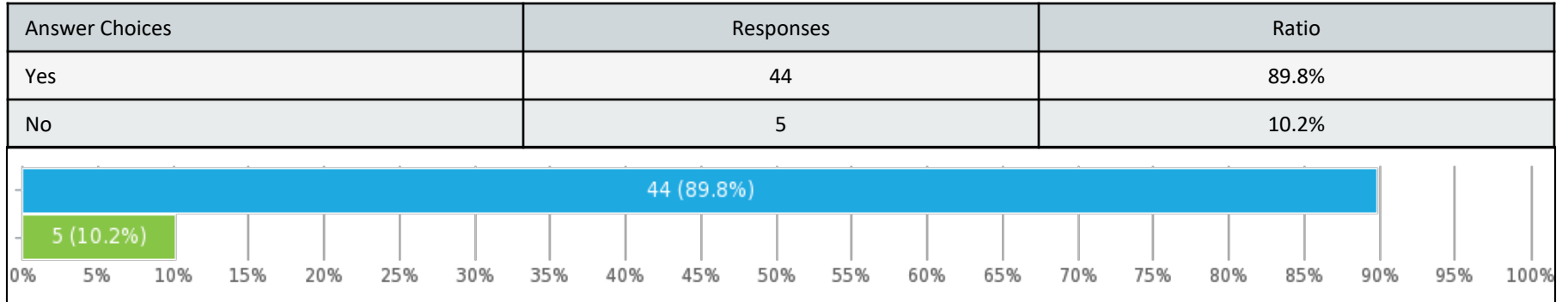


How would you describe the impact of the transition from paediatric care to adult care on the quality of your care?

Text answer, answers 20x, unanswered 32x

If a Vancouver-based NF clinic existed, would you use the clinic?

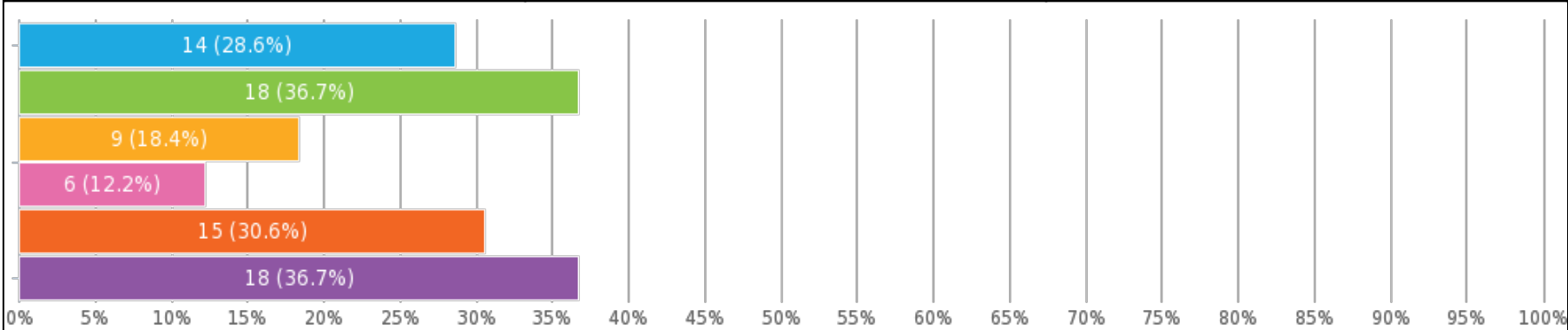
Single choice, answers 49x, unanswered 3x



What might prevent you from using a Vancouver-based clinic?

Multiple choice, answers 49x, unanswered 3x

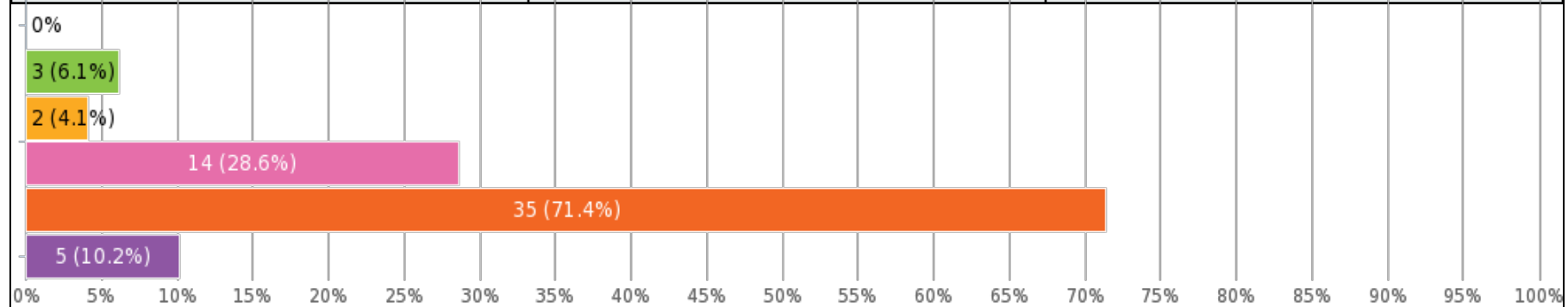
Answer Choices	Responses	Ratio
Cost of travel	14	28.57%
Inconvenience of travel	18	36.73%
Cost for accommodation	9	18.37%
My doctor would not be there	6	12.24%
Time off work	15	30.61%
Other - please describe	18	36.73%



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

Multiple choice, answers 49x, unanswered 3x

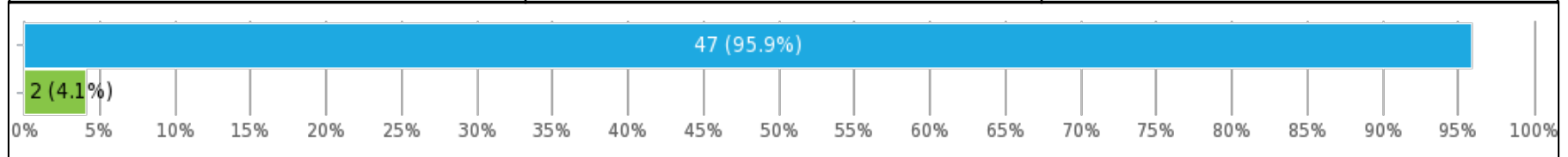
Answer Choices	Responses	Ratio
I don't have access to a computer or smart phone		0%
I get overwhelmed learning new technology	3	6.12%
I have security concerns of being online with my personal information	2	4.08%
I prefer the personal connection of face to face with my doctor	14	28.57%
Nothing would prevent me from accessing online services offerd by an NF clinic	35	71.43%
Other - please list	5	10.2%



***I accept the conditions of the contest and I confirm that I am aged 18 years or over.**

Single choice, answers 49x, unanswered 3x

Answer Choices	Responses	Ratio
I accept	47	95.92%
I do not accept	2	4.08%



Full Name

Text answer, answers 50x, unanswered 2x

Email Address

Text answer, answers 52x, unanswered 0x

Phone Number

Text answer, answers 52x, unanswered 0x

Can we contact you to ask additional questions?

Single choice, answers 52x, unanswered 0x

Answer Choices	Responses	Ratio
Yes	51	98.08%
No	1	1.92%

