

Neuromuscular clinic Telehealth survey

Please complete the survey below.

Thank you!

Participant Information and Consent

The Neuromuscular team at the Royal Children's Hospital is interested in your experience of the neuromuscular clinic's conversion to Telehealth during the COVID-19 period and views on how you want to access healthcare for your child in the future.

Your views will help us understand family preferences for how your child receives care (e.g. Telehealth versus face-to-face), costs and savings to families, and will help us improve care for your child.

What are we asking you to do?

We are asking families to fill out a one-off survey. This survey will take about 8-10 minutes to complete, and asks about your experience during your most recent Neuromuscular clinic appointment as well as some questions about you and your child. Please try to answer all the questions as best you can.

There will be no direct benefit to you or your child by participating in this research, however we will use the outcomes of this study to inform future access to Telehealth and improve the use of Telehealth for patients.

Participation in this study is voluntary and unpaid. You may withdraw from the study at any time. If you do not take part, or choose to withdraw, it will not affect your access to the best available treatment options from your health care providers.

All survey responses are anonymous. This means that no one, including the research team, will know who has completed the survey. Any information collected as part of this project will be treated as confidential and can only be accessed by the project research team and The Royal Children's Hospital Human Research Ethics Committee.

At the end of the project, we will send a summary of what we find to your health care provider, as well as use the results to inform advocacy for the provision of care via Telehealth. You and your child will not be identifiable in any results.

The patient completing this survey needs to be over 18 years old OR have their parent or guardian consent to them completing this survey?

Are you over 18 years old

OR

the parent or guardian of a patient attending the RCH Neuromuscular Clinic?

Yes No

You will need your parent to consent you in order to continue.

Please refer to the previous question when your parent is present.

Thank you

Do you consent to participating in this survey?

Yes No

TELEHEALTH DEFINITION

to be completed

What role did you play in the neuromuscular clinic appointment you attended?

- Parent or guardian
- Patient
- Clinician
- Administrator

What is your child's age in years?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21

Do you consent to your child answering a few questions at the end of this survey?

- Yes
- No

Demographics/background

To the best of your knowledge, what is your child's diagnoses?

- BMD
- CMT
- Congenital myopathy
- Collagen VI
- DMD
- FSHD
- Myotonic dystrophy
- SMA
- Unsure
- Other

Comment

To determine whether you would be eligible for medicare-funded Telehealth under the pre-COVID-19 scheme, we are seeking your postcode.
You do not have to provide this information if you don't want to.

Postcode:

At RCH Neuromuscular Clinic, have you had both face-to-face and Telehealth/video appointments? (not limited to COVID-19 period)

- Yes
- No

How long (in hours) does it generally take to travel to clinic at RCH?

- Less than 1 hour
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8+

What was the purpose of your neuromuscular clinic appointment during the COVID-19 period?

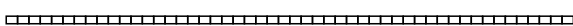
- Routine clinical care
- Research
- Requested appointment outside routine schedule of care
- Unsure

Did you receive a Telehealth/video appointment or a phone call?

- Telehealth/video
- Phone call by choice
- Phone call when Telehealth/video did not work
- Both video and phone call

What was it like to access the technology for your Telehealth/video appointment?
(slide the scale)

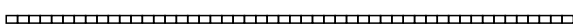
Very difficult Neutral Very easy



(Place a mark on the scale above)

Rate the quality of the connection during your appointment.

Very bad Neutral Very good



(Place a mark on the scale above)

Thinking about the Telehealth/video appointment:

what issues (if any) did you experience with the connection?
(select all that apply)

- Internet connection dropped out Poor sound Poor video (visuals) No issues
 Other

Comment

Thinking about the phone call, what issues if any did you experience with the connection?
(select all that apply)

- Poor sound Phonecall dropped out Incorrect phone number Poor phone service
 Other No issues

Telehealth experience

How many different clinicians did you see on your child's neuromuscular clinic day?

unsure 2 3 4 5 6 7

Which clinicians did you see?
(select all that apply)

Neurologist Respiratory doctor Orthopaedic doctor Physiotherapist Occupational
Therapist Dietitian Psychiatrist Genetics counsellor Social Work Nurse
 Unsure

Approximately how long on average were each of your
appointments?

Less than 20 mins 20 mins
 30 mins 40 mins
 50 mins More than 60 mins

Did all your booked appointments go ahead as planned?

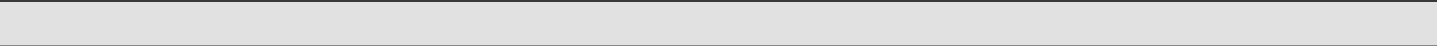
yes no unsure

If no, how many were you NOT able to connect with?

1 2 3 4
 5 6 7

Why were you unable to connect?

Technical issues Waiting too long
 The clinician was not there
 We had to leave Other

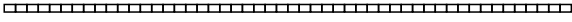


Was your child in the room for the neuromuscular clinic appointments?

Yes No

How would you describe your child's interaction with doctors and therapists during the Telehealth appointment?

Did not interact Neutral Able to fully interact



(Place a mark on the scale above)

Often hospital appointments are stressful.**We would like to know if Telehealth makes this better or worse for you.**

Describe your stress-level when attending neuromuscular clinic via TELEHEALTH

Very stressful Neutral No stress

(Place a mark on the scale above)

Were there any specific factors that added stress to your TELEHEALTH appointments?
(select all that apply)

- The Telehealth technology
- I was stressed related to COVID-19
- I always find neuromuscular clinic stressful
- I didn't find the appointment stressful
- Managing child wellbeing or behaviour
- Talking to someone through a screen
- Unsure
- Other

Please specify

Describe your stress-level when attending neuromuscular clinic via FACE-TO-FACE appointments

Very stressful Neutral No stress

(Place a mark on the scale above)

Are there any specific factors that add stress to your face-to-face appointments?
(select all that apply)

- hospital parking cost
- transport to hospital
- waiting
- the hospital environment
- moving your child from room to room
- leaving home
- talking to someone in person
- infection concerns
- child wellbeing or behaviour
- I always find neuromuscular clinic stressful
- I never find neuromuscular clinic stressful
- Other

Please specify

We understand that often RCH clinic appointments are stressful for kids as well.

We would like to get your thoughts on how your child responds to different clinic settings.

Based on what you saw and to the best of your knowledge:

Please rate your child's level of stress when attending a neuromuscular clinic appointment via TELEHEALTH

Very stressed Neutral No stress

(Place a mark on the scale above)

Based on what you see and to the best of your knowledge:

Please rate your child's level of stress when attending a neuromuscular clinic appointment FACE-TO-FACE

Very stressed Neutral No stress

(Place a mark on the scale above)

In your opinion, which RCH clinical appointment method does your child engage best with?

- Face-to-face Telehealth
- Both, equally Neither
- Unsure

Nearly there! Thank you for continuing.

Was your child asked to do anything active during the Telehealth session?

For example: perform a movement of activity

Yes No

Can you provide an example?

In which clinical appointment/s was your child asked to demonstrate an activity or movement?
(select most relevant)

- Neurology
- Respiratory
- Orthopaedics
- Dietetics
- Physiotherapy
- Occupational Therapy
- Psychiatry
- Genetic counselling
- Social Work
- Nurse

Considering your experience with Telehealth:

Would you choose to engage in a Telehealth appointment INSTEAD of face-to-face at any stage in the future?

No Neutral Yes

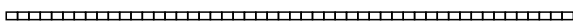
For which clinicians do you think you would you choose Telehealth appointments over face-to-face?

(select relevant boxes)

- Neurologist
- Respiratory specialist
- Orthopaedic specialist
- Dietitian
- Physiotherapist
- Occupational Therapist
- Psychiatrist
- Genetic counsellor
- Social Worker
- Nurse
- None

Overall, how would you rate the value of your Telehealth neuromuscular clinic appointment to your child's healthcare management?

No value Neutral Very valuable



(Place a mark on the scale above)

Were there advantages of a Telehealth appointment?

Yes No

Please select all that apply

- No travel time
- I didn't have to pay for parking
- I didn't have to organise childcare for other children
- A better way to engage with health professional
- Not having to wait in waiting room
- I preferred being in my environment
- I was more comfortable
- Improved wellbeing
- Easier communication
- Easier scheduling
- Other

Comment

For future neuromuscular clinic appointments, which would you prefer?

(select one)

- 100% face-to-face appointments
- 50/50 Telehealth and face-to-face
- Both but more face-to-face than Telehealth
- Both but more Telehealth than face-to-face

Regarding our shift to Telehealth during the COVID-19 period, are there any further considerations you would like to share?

Please comment

Welcome to the kid and adolescents's survey!
Depending on your age and reading level you may need your parents to help you.
There is no wrong answer to these questions, just choose what fits you the best.
There are 7 questions.
The questions are for kids aged 8 years-21 years old

Please note: most of the questions are supported by pictures. For our older adolescents, these may seem childish.
We apologise for this, but needed to make sure we could reach a wide range of ages.

Were you in the room for you Telehealth appointments?

Yes No

How old are you?

- 8 9 10 11 12 13 14 15 16 17 18 19
 20 21

Please choose the face that best shows:

How you felt during your Telehealth appointment (□□□□)

- 1 2 3 4 5 6 7

Please choose the face that best shows:

How you feel when you come to the hospital to have your appointments face-to-face? (□□□□)

- 1 2 3 4 5 6 7

Please choose the face that best shows:

How hard it is to talk to people from the hospital over Telehealth (□□□□)

- 1 2 3 4 5 6 7

Please choose the face that shows:

How hard it is to talk to the people at the hospital face-to-face

- 1 2 3 4 5 6 7

Which type of appointment would you choose next time?

- Face-to-face [] [] [] []
- Telehealth [] [] [] []
- Some face-to-face and some Telehealth [] [] [] [] + [] [] [] []

Is there anything else you would like to say? ☐☐

Clinician Survey

Which discipline do you represent in the neuromuscular clinic?

- Neurologist
- Respiratory specialist
- Orthopaedic doctor
- Psychiatrist
- Physiotherapist
- Occupational Therapist
- Dietitian
- Nurse
- Social worker
- Genetic counsellor
- Other

Details

Where were you situated for your Telehealth consultations?

- At RCH
- At my private residence
- A mix of RCH/home depending on the week and circumstances
- Other

Please specify

When considering most of you appointments over this period, how did you conduct your sessions?

- Telehealth/video
- Phone call by parent choice
- Phone call when Telehealth/video did not work
- Both Telehealth/video and phone call
- Neither, I was not able to make contact

The video calls were predominantly conducted via:

- RCH Telehealth/video
- Webex
- Zoom
- FaceTime
- Other

Please detail

Technology functionality

How easy was it to access the technology?

Very difficult neutral Very easy

=====

(Place a mark on the scale above)

Rate the quality of the Telehealth connection

Very poor Neutral Very good

=====

(Place a mark on the scale above)

What, if any, issues did you experience with the Telehealth connection?

(select all that apply)

- Internet connection dropped out
- Poor sound
- Poor visuals via camera
- No issues
- Other

Other, please comment

Scheduling

Generally speaking, how many patients have you typically been scheduled to see through Telehealth for NM clinic each week?

- 1-3 4-7 8-11 12-15 16+

Which diagnoses did you see via Telehealth?

(select all that apply)

- BMD
 CMT
 Congenital myopathy
 Collagen VI
 DMD
 FSHD
 Myotonic dystrophy
 SMA
 Other

Please specify

Approximately; how long on average were your Telehealth appointments?

- < 20 mins
 20 mins
 30 mins
 40 mins
 50 mins
 60 mins
 >60 mins

Did all your scheduled Telehealth appointments go ahead as planned?

- Yes
 No

If no, how many were you unable to connect with?

- 1
 2
 3
 4
 >5

Why were you not able to connect?

(select all that apply)

- Technical issues
 Waiting too long for patient availability
 Families not online eg: FTA
 Other

Please detail

Clinician and family engagement with Telehealth platform

Overall, how well did the parents/caregivers family engage with the medical/allied health staff during the Telehealth/phone appointments?

Disengaged Neutral Fully engaged

=====

(Place a mark on the scale above)

Overall, how well did the child engage with the medical/allied health staff during the Telehealth/phone appointments?

Disengaged Neutral Fully engaged

=====

(Place a mark on the scale above)

Describe your level of stress in engaging with Telehealth as a health professional

No stress at all Neutral Very stressful

=====

(Place a mark on the scale above)

Are there any particular reasons that you can identify, that add stress to NM clinic (or part there of) being provided through Telehealth?

- Telehealth software
- Logging on, eg: passwords
- Worry about the connection
- Scheduling of appointment times
- Amount of appointments to get through
- Provision of good clinical service
- Extra workload
- Discomfort from looking at screen for extended periods
- I was stressed because of COVID-19
- Others

Please comment

Thinking about your level of stress with Telehealth, how does this compare to face-to-face?

- Telehealth was more stressful than face-to-face Face-to-face is more stressful than Telehealth
- Both produced a similar stress-level whether Telehealth or face-to-face Unsure

Clinician satisfaction and preferences

How satisfied were you with the Telehealth NM clinic?

Dissatisfied Neutral Satisfied

(Place a mark on the scale above)

Please rate, to what degree were you:

Able to address the patient's issues during your Telehealth appointment?

None of the issues were address Neutral All of the issues were address

(Place a mark on the scale above)

Please rate, to what degree were you:

Limited by the Telehealth platform to address patient issues during the appointment?

Not limited at all Neutral Completely limited

(Place a mark on the scale above)

Were you able to undertake any physical or functional assessments with your patients over Telehealth?

- Yes, with all that required it Yes, with some that required it No, not with any Not Applicable

If yes, to what degree was this effective?

Ineffective Neutral Effective

(Place a mark on the scale above)

How likely is it that you would choose to engage in a Telehealth appointment instead of face-to-face?

Very unlikely Neutral Very likely

(Place a mark on the scale above)

Overall, how would you rate the value of your Telehealth appointment to your patient's healthcare management?

Not valuable at all Neutral Very valuable

(Place a mark on the scale above)

Were there any benefits to a Telehealth appointment over face-to-face?

- Yes No

If yes, what were they?

Please select all that apply

- Time management Access to patient Flexible working arrangements Patient attendance Others

Please comment

In the future, what would you prefer?

- 100% face-to-face
- 50/50 Telehealth and face-to-face
- Both, but more face-to-face than Telehealth
- Both, but more Telehealth than face-to-face
- Unsure

Is there anything more you would like to include about your experience with converting our neuromuscular clinic service to Telehealth/phone contact during the COVID-19 pandemic?
Please comment

Did the change from face-to-face consults to Telehealth for NM clinic affect your role?

- Yes
- No

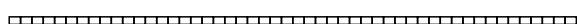
In what way did it impact on you?

- Increased workload
- Needed to upskill
- Increased contact with families
- Increased time supporting patients to access platform
- Time spent troubleshooting issues with Telehealth
- Time spent supporting clinicians with change
- New scheduling pressures
- Increased administrative demands
- Others

Please detail

Describe your level of stress in the first month when converting the clinic from face-to-face to a Telehealth platform

Very stressfull Neutral No stress



(Place a mark on the scale above)

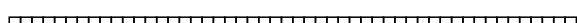
Which items (if any) increased your level of stress when converting NM clinic to Telehealth?

- Learning new processes
- Learning the Telehealth platform
- Contacting families
- Communicating the change to families
- Communicating the change to clinicians
- Scheduling
- I was stressed about COVID-19
- Working remotely
- Connecting to hospital software (eg: intranet, neuro drive etc)
- Unsure
- Others
- I did not experience stress with converting the clinic to Telehealth

Please detail

Describe the stress-level you experience when the clinic is conducted over Telehealth week-to-week currently

Very stressful Neutral No stress



(Place a mark on the scale above)

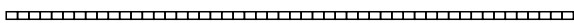
Which items (if any) increase your level of stress when conducting the weekly NM clinic via Telehealth ongoing?

- Remote coordination on the clinic day
- The Telehealth platform
- Contacting families
- Communicating about Telehealth with families
- Communicating about Telehealth with clinicians
- Scheduling
- I am stressed about COVID-19
- Unsure
- Other
- I do not experience stress with Telehealth clinics

Please detail

Describe your stress level when clinic is conducted face-to-face

Very stressful Neutral No stress



(Place a mark on the scale above)

Which (if any) increase your stress level when you are conducting NM clinic face-to-face?

- Scheduling clinicians
- Scheduling families
- Finding families in waiting room
- Finding clinicians
- Coordinating clinicians
- Communication with families
- Communication with clinicians
- Resource limitations of A5 clinic area
- Unsure
- Other
- I do not experience stress with face to face NMC

Please detail

Which format would you prefer?

- All face to face All telehealth
- Both, but with more face to face
- Both, but with more telehealth
- Unsure

Is there anything else you would like to tell us about your experience with converting the NM clinic to Telehealth over the COVID-19 period