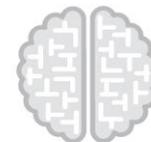


Charting our course in a changed world

NHCC Members' Meeting
June 16, 2020



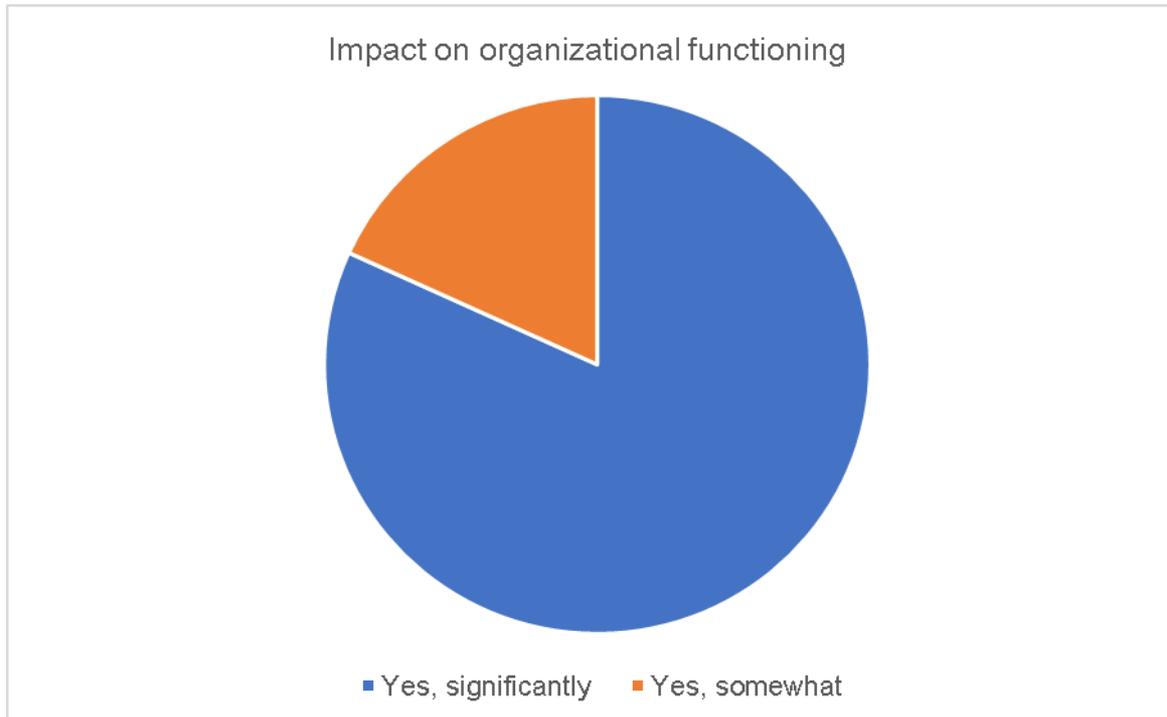
NHCC
NEUROLOGICAL HEALTH
CHARITIES CANADA

Conducted two surveys of members

- April 2020, NHCC surveyed member organizations about the impact of the COVID-19 pandemic in terms of serving clients and members and how they have adapted programs & services.
- Early June, NHCC surveyed member organizations about how the COVID-19 pandemic has directly impacted clients and members.

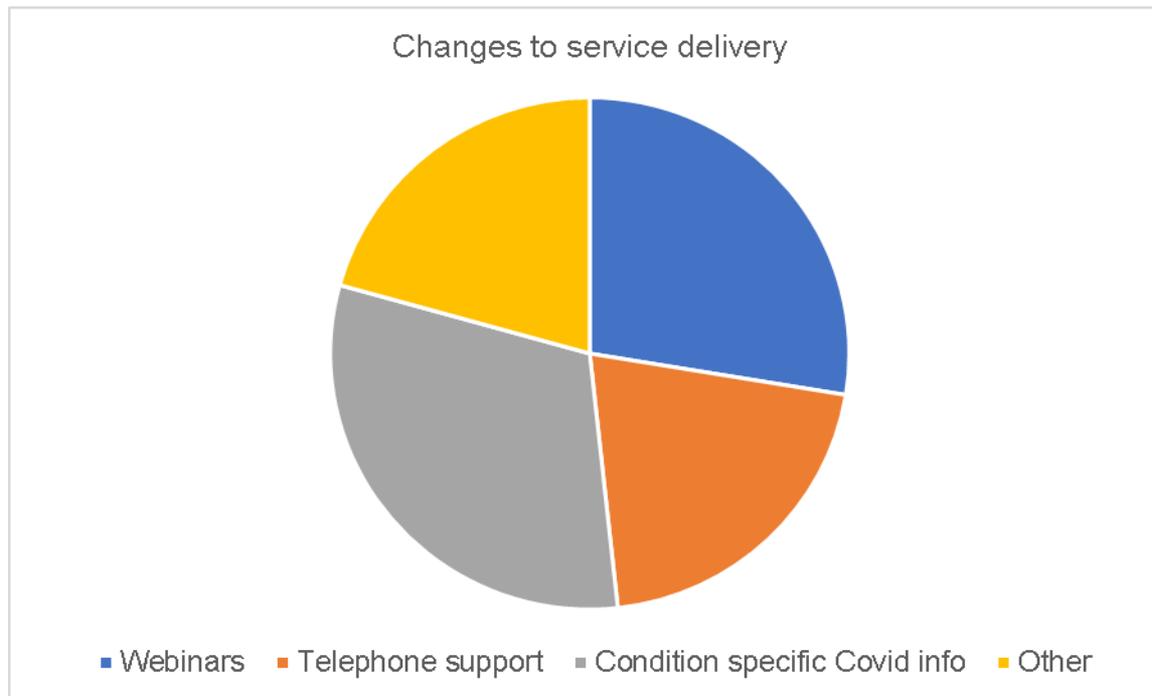
Results survey one

- **Q1 -Has the COVID-19 pandemic and the need for physical distancing changed the way your organization functions**
 - Yes, significantly - 81.82% (9 respondents)
 - Yes, somewhat - 18.18% (2 respondents)
 - No - 0.00% (0 respondents)



Q2 - How has your organization changed the way it is serving clients and members during the COVID-19 pandemic?

- We are offering programs by webinars - 72.73%
- We are offering one-to-one support sessions by telephone - 54.55%
- We are providing condition-specific information about COVID-19 on organization website, Facebook, Instagram, etc. - 81.82%
- Other - 54.55%



Q-3 Recognizing that it is still early, how successful have you been in carrying out the changed way of serving clients and members?

- It has gone well overall - 63.64%
- We had some glitches, but overcame them - 0.00%
- Still working to make programs and services available - 36.36%

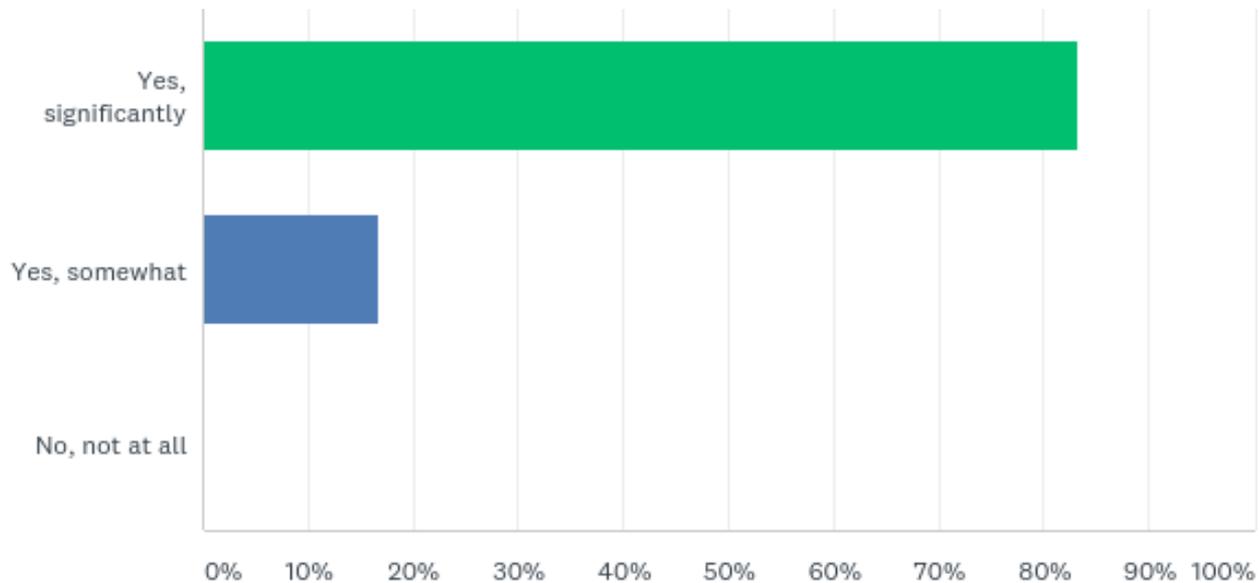


Best practices and successes

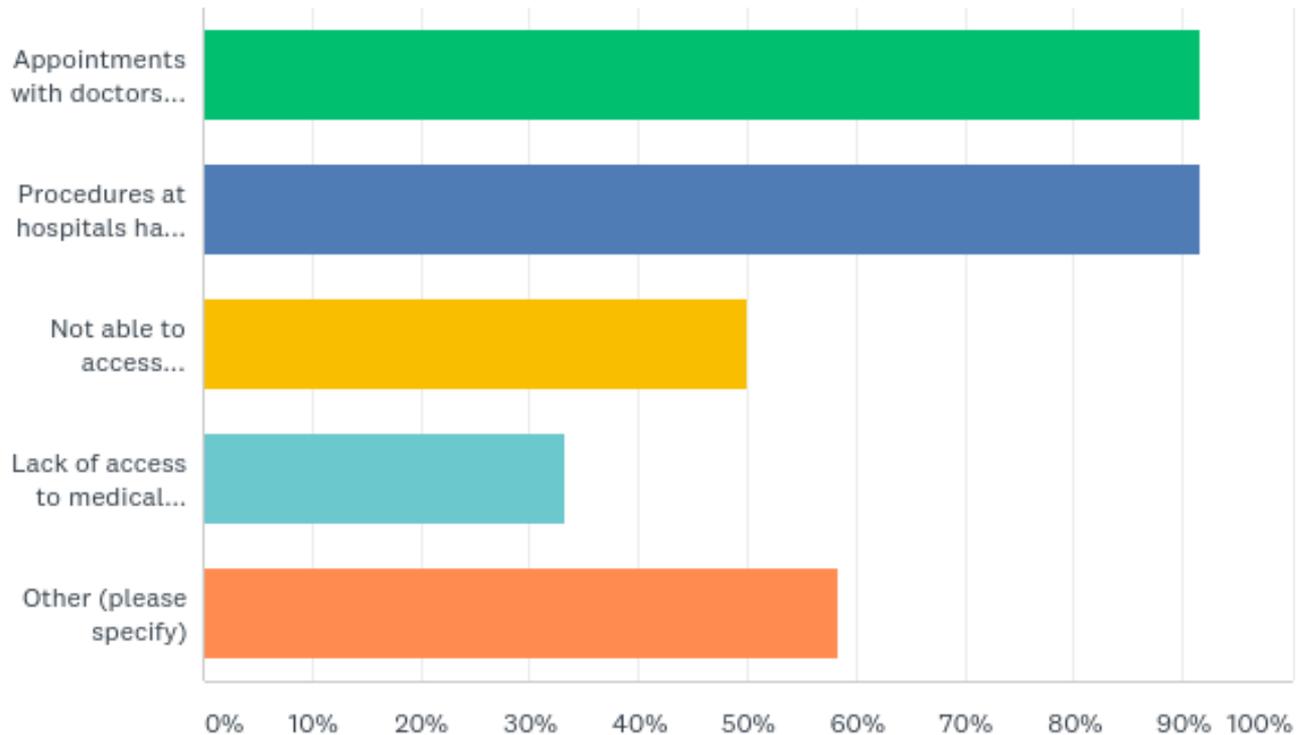
- ... offering exercise programs via facebook live twice a week and Mindfulness Mondays (most Mondays) via webinar. It has worked well.
- ...very successful in establishing new emergency funding programs in a very short period of time.
- Those living with neurological conditions, illness and injury are often already socially isolated, so we could all actually learn best practices from them.
- ... have provided family education using zoom but clinics are seeing less patients so it is manageable

Results survey two

- **Q4-** Have your clients/members been negatively impacted by the pandemic and the shutdown and/or reduction of health care delivered by doctors and hospitals?



Q5 - How have your clients/members been negatively impacted by the shutdown and/or reduction of health care services **delivered by doctors and/or hospitals.**

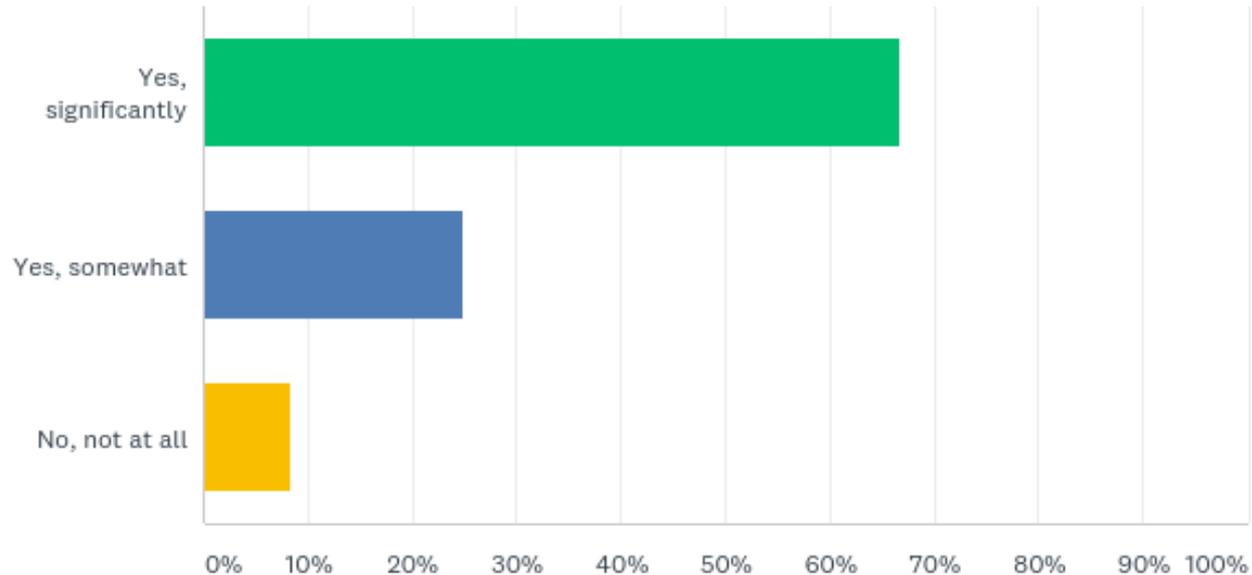


Q5 - details

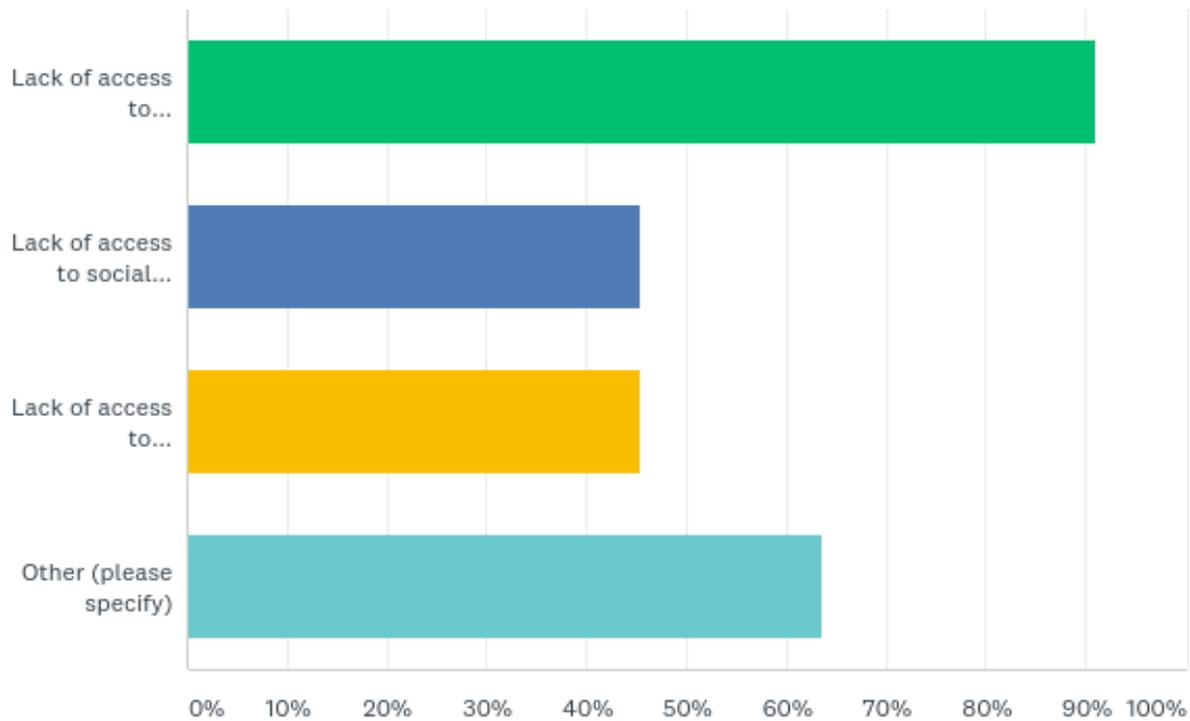
ANSWER CHOICES	RESPONSES	
Appointments with doctors have been cancelled	91.67%	11
Procedures at hospitals have been cancelled	91.67%	11
Not able to access emergency services	50.00%	6
Lack of access to medical supplies, e.g., face masks, catheters	33.33%	4
Other (please specify)	58.33%	7
Total Respondents: 12		

- Other comments (selected)
 - appointments with doctors and other healthcare team members by phone or video.
 - anxiety re COVID restrictions
 - social isolation
 - care partners unable to visit long-term care homes or hospitals, anxiety/depression, isolation
 - afraid to have psws enter their homes

Q6: Have your clients/members been negatively impacted by the shutdown and/or reduction of health care services in the community?



Q7: How have your clients/members been impacted by the shutdown and/or reduction of health care services in the community?

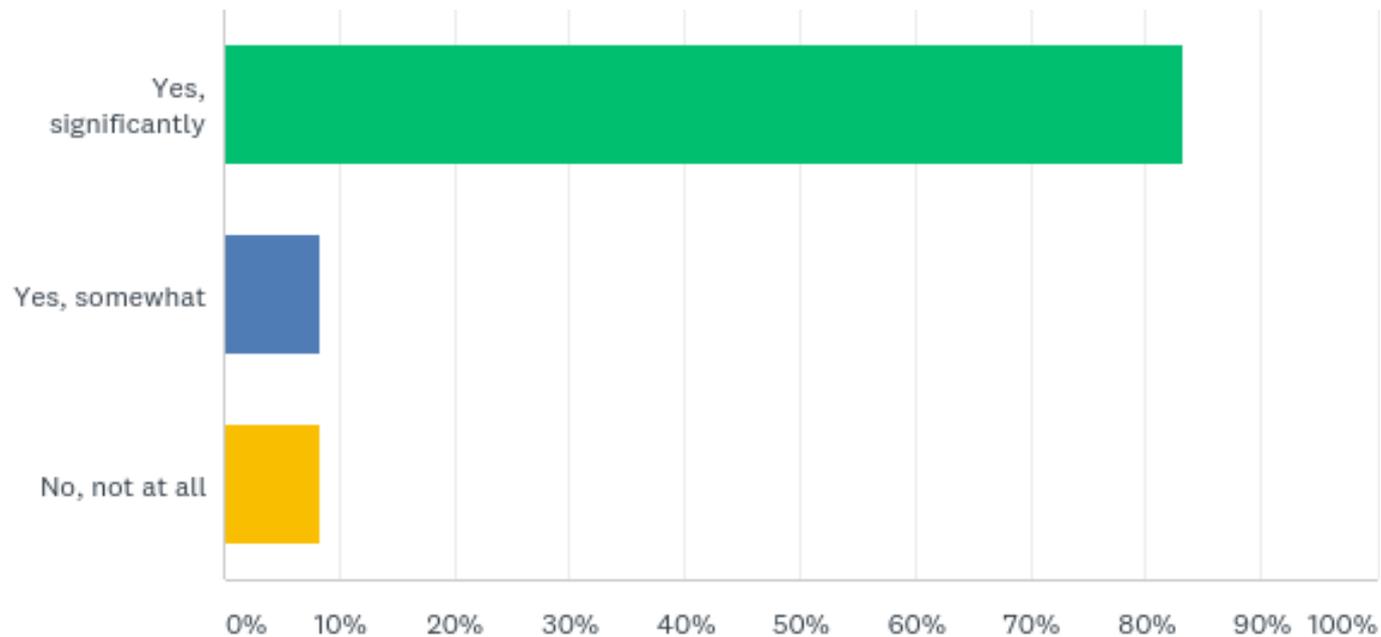


Q7 - details

ANSWER CHOICES	RESPONSES
Lack of access to rehabilitation services such as physiotherapists and occupational therapists	90.91% 10
Lack of access to social workers	45.45% 5
Lack of access to psychologists	45.45% 5
Other (please specify)	63.64% 7
Total Respondents: 11	

- Other comments (selected)
 - Some access...through tele-health but that is difficult for...individuals who have communication challenges.
 - ...shift in community programming to virtual does not benefit many... who are seniors and do not have access or knowledge to use technology ...
 - No access to recreation, mindfulness, camp, speech and language pathology, exercise programs, community pools, massage, acupuncture
 - children are not receiving education supports

Q8: Looking at your organization, have your revenues been impacted by the COVID-19 pandemic?

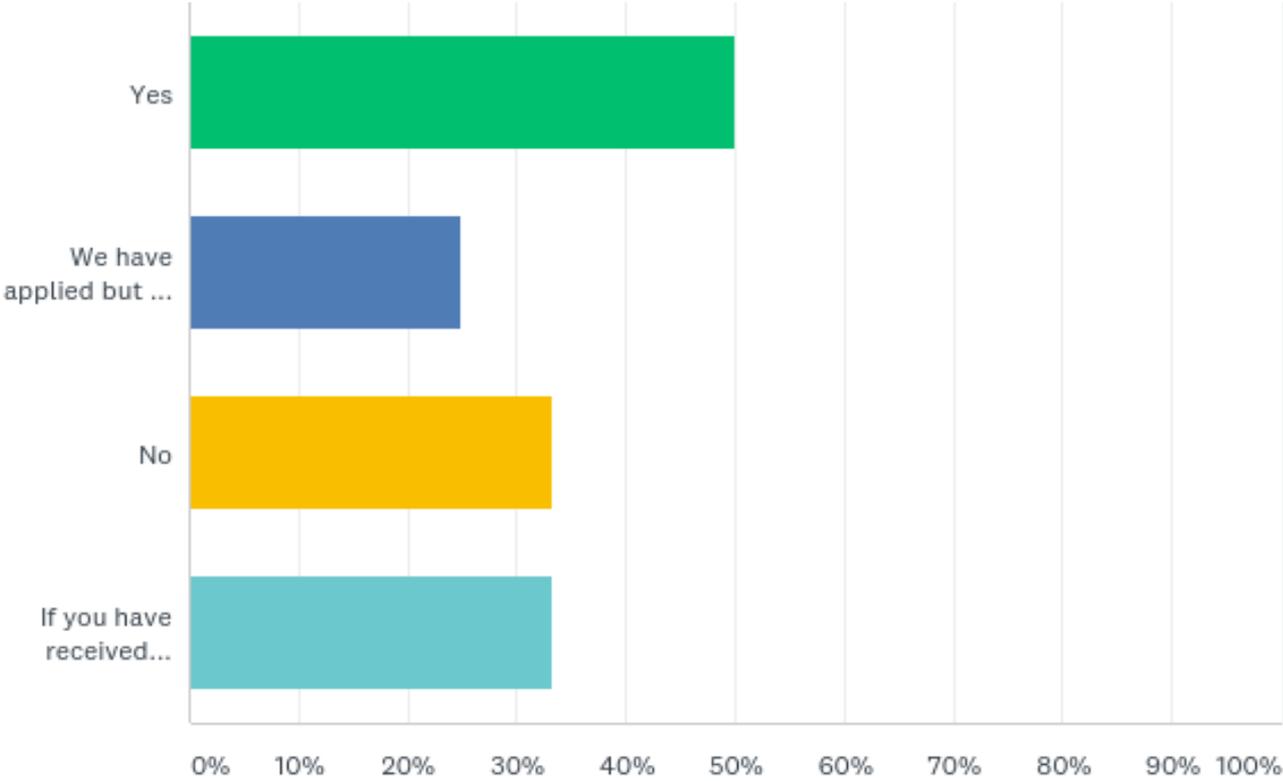


Q9: How has the impact on revenues affected your organization's activities?

ANSWER CHOICES	RESPONSES	
We have had to reduce/stop services for clients/members.	41.67%	5
We have had to reduce/stop funding research.	25.00%	3
We have had to reduce/stop advocacy activities.	33.33%	4
We have had to lay off staff.	25.00%	3
Other (please specify)	75.00%	9
Total Respondents: 12		

- Other comments (selected)
 - Let contract staff go and implemented hiring freeze
 - ...had to cancel our congress at a loss of \$850,000 in revenue
 - ...had to postpone conference and other revenue generating activities
 - Fundraising events cancelled
 - None... as we are solely funded by the provincial government

Q10: Has your organization been able to secure any government subsidies or supports?



Q10 - details

ANSWER CHOICES	RESPONSES	
Yes	50.00%	6
We have applied but are still waiting to find out if we are eligible.	25.00%	3
No	33.33%	4
If you have received government subsidies or supports, please provide brief details of what they are.	33.33%	4
Total Respondents: 12		

- Other comments (selected)
 - [received] CERB and a 10% payroll subsidy...looking into the rental subsidy with our property management and the charity subsidy.
 - have applied, and received our first month of payment subsidies for the 2 staff who are on payroll (approx \$4500/month)

Final thoughts by two members

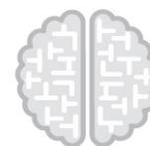
- COVID 19 has created angst and volatility in families that were already at risk. HD families are a low priority in the system and the added burden to help is put on the shoulders of HSC...Charitable nfps like ours seem to be misunderstood by a federal gov't that chooses to address small local charities rather than small-medium national charities impacting more families. If we do not survive the families will be left to their own and researchers will not be attracted to HD research.
- The charity subsidy looks to be quite difficult to access. It is being administered through the Red Cross and United Way.



Reaction?

Additional
thoughts?

- Visit www.mybrainmatters.ca
 - Register to receive regular updates
- ‘Like’ us on Facebook:
www.facebook.com/MyBrainMatters
- Follow us on Twitter: @MyBrainMatters



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