

## APPENDIX I: SURVEY OF CLINICIAN USE OF ADJUNCT THERAPIES FOLLOWING BOTULINUM TOXIN ADMINISTRATION FOR LIMB SPASTICITY

Dear Clinician,

Do you use botulinum toxin (BoNT) injections for management of spasticity in your practice? If yes, then you probably know that questions such as “what adjunct therapy(s) could I use in addition to the BoNT injection to maximize the outcomes of my patient?” still remain unanswered in the absence of sufficient research and national practice guidelines.

We need your expertise to help answer this question. We invite you to complete an anonymized survey about physician preferences and perceptions on the use of adjunct therapies following BoNT injection at ([https://ubc.ca1.qualtrics.com/jfe/form/SV\\_7TBdIcjPgBqQyih](https://ubc.ca1.qualtrics.com/jfe/form/SV_7TBdIcjPgBqQyih)).

Our goal is to better determine physician practice internationally, and to publish it in an international publication. We will be surveying various countries from around the world. If you participate in the survey we will send you a copy of the survey results.

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If the questionnaire is completed, it will be assumed that consent has been given.

Our apologies if you have received this invitation more than once, which may occur as we are attempting to contact as many physicians as possible through different access points.

**PRIVACY STATEMENT:** This survey and its results are hosted electronically on the University of British Columbia (UBC) Survey Tool website, with the server located in Canada and complying with relevant privacy legislation. The research data will be kept for 5 years after this study is published or presented. *Your de-identified research data may be published or deposited into a publicly accessible location at the time of publication. This enhances the transparency of the research, but also allows others to access the data. This should not increase risks to you, but it does mean that other researchers may analyze the data for different reasons other than those described in this consent form. Once data is made publicly available, you will not be able to withdraw your data. The extent of the risk of you being identified through public data is unknown, but currently appears to be low.* If you have any questions or concerns, please contact the Principal Investigator Dr. Patricia Mills via e-mail [patricia.mills@vch.ca](mailto:patricia.mills@vch.ca) or phone (778) 233-6222.

**ETHICS:** The UBC Clinical Research Ethics Board has issued certificate H18-01840 for this study. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

We thank you in advance for your voluntary completion of this research survey! Don't hesitate to send the survey to your colleagues.

Sincerely,

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*Survey Of Adjunct Therapies Following Botulinum Neurotoxin (BoNT) Injection*

**Q1 Country of practice**

\_\_\_\_\_

\_\_\_\_\_

**Q2 Province / state of practice (if applicable)**

\_\_\_\_\_

\_\_\_\_\_

**Q3 City of practice**

\_\_\_\_\_

\_\_\_\_\_

**Q4 Gender**

- Male (1)
- Female (2)

\_\_\_\_\_



**Q5 Age**

\_\_\_\_\_

**Q6 Specialty**

- Physical Medicine and Rehabilitation (1)
- Neurology (2)
- Anesthesia (3)
- Family Medicine (4)
- Dermatology (5)
- Orthopedic Surgery (6)
- Plastic Surgery (7)
- Physiotherapy (8)
- Other (9) \_\_\_\_\_

\_\_\_\_\_



**Q7 How many years have you been practicing as a clinician?**

\_\_\_\_\_

\_\_\_\_\_



**Q8 How many years have you used botulinum neurotoxin (BoNT) for limb spasticity management?**

\_\_\_\_\_

\_\_\_\_\_

**Q9 In what setting do you use BoNT for limb spasticity management? Select all that apply.**

- Academic hospital or medical centre (1)
- Non-academic hospital or medical centre (2)
- Community/Private Practice (3)
- Adult spasticity management (4)
- Pediatric spasticity management (5)
- Other (6) \_\_\_\_\_

\_\_\_\_\_

**Q10 What spasticity population do you service? Select all that apply.**

- Stroke (1)
- Traumatic Brain Injury (2)
- Cerebral Palsy (3)
- Multiple Sclerosis (4)
- Spinal cord injury (5)
- Other (e.g. hereditary spastic paraparesis) (6)

\_\_\_\_\_

**Q11 What type(s) of botulinum toxin do you use to treat spasticity? Select all that apply.**

- Botox (1)
- Xeomin (2)
- Dysport (3)
- Myobloc (4)
- Other (5) \_\_\_\_\_

\_\_\_\_\_

**Q12 How is the cost of BoNT covered in your practice? Select all that apply.**

- Provincial/national insurance (1)
- Private insurance (2)
- Patient (out of pocket) (3)
- Other (4) \_\_\_\_\_

\_\_\_\_\_

**Q13 How is the cost of adjunct therapies following BoNT injections covered in your practice? Select all that apply.**

- Provincial/national insurance (1)
- Private insurance (2)
- Patient (out of pocket) (3)
- Other (4) \_\_\_\_\_

\_\_\_\_\_

**Q14 Is the use of adjunct therapies standardized in your clinic or does it differ from clinician to clinician?**

- I am the only clinician practicing in my clinic (1)
- Standardized (2)
- Differs (3)

**Q15 Is this a multi- or inter-disciplinary clinic where you work with other healthcare professionals?**

- Yes (1)
- No (2)

**Q16 Which healthcare professionals do you work with in your clinic?**

- Nurse (1)
- Occupational therapist (2)
- Physiotherapist (3)
- Kinesiologist (4)
- Orthotist (5)
- Other (6) \_\_\_\_\_

**Q17 Please indicate how often you use these adjunct therapies *WITHIN 60 MINUTES* of BoNT injection in your practice.**

- X-axis = Frequency of use
  - Never use
  - Occasional use
  - Moderate to frequent use
  - Used in the past but stopped using
- Y-axis = Adjunct therapies *WITHIN 60 MINUTES*
  - Passive stretching of injected muscles
  - Active movement of injected muscles (e.g. get patient to walk right after leg injection)
  - Electrical stimulation (EStim) of injected muscles
  - Extracorporeal Shock Wave Therapy (ESWT)
  - Other: (textbox)

**Q18 What are the barriers, if any, to using these adjunct therapies *WITHIN 60 MINUTES* of BoNT injection in your practice? Select all that apply.**

- X-axis = Barriers to use
  - Financial – physician/clinic resources
  - Financial – patient resources
  - Adjunct therapy time constraints (e.g. takes too long to perform in clinic)
  - Clinician time constraints (e.g. clinical practice too busy)
  - Distance of patients to clinic – patients have to travel long distances
  - Risk of adverse events
  - Lack of evidence
  - Lack of effectiveness from clinical experience
  - Patient does not want to
  - No barriers
  - Other: (text box option)

- Y-axis = Adjunct therapies *WITHIN 60 MINUTES*
  - Passive stretching of injected muscles
  - Active movement of injected muscles (e.g. get patient to walk right after leg injection)
  - Electrical stimulation (EStim) of injected muscles
  - Extracorporeal Shock Wave Therapy (ESWT)
  - Other: (textbox)

**Q19 Please indicate how often you use these adjunct therapies *BEYOND 60 MINUTES* of BoNT injection in your practice.**

- X-axis = Frequency of use
  - Never use
  - Occasional use
  - Moderate to frequent use
  - Used in the past but stopped using
- Y-axis = Adjunct therapies beyond 60 minutes of BoNT injection
  - Stretching programme
  - Active exercise programme
  - Active exercise
  - Taping
  - Casting of upper extremity
  - Casting of lower extremity
  - Splinting (e.g. wrist hand orthosis, night time splints, dynamic splints)
  - EStim of agonist/antagonist muscles - no production of functional movement
  - Functional EStim (FES) of muscles - produces/assists functional movement
  - Extracorporeal Shock Wave Therapy (ESWT)
  - Transcutaneous electrical nerve stimulation (TENS)
  - Segmental muscle vibration
  - Constraint induced movement therapy
  - Motorized arm ergometer
  - Zinc supplementation
  - Magnesium supplementation
  - Other nutrient supplementation: (text box)
  - Dietary change recommendations (e.g. reducing sugar intake to optimize blood sugar control)
  - Other: (text box)

**Q20 What are the barriers, if any, to using these adjunct therapies *BEYOND 60 MINUTES* of BoNT injection in your practice? Select all that apply.**

- X-axis = Barriers to use
  - Financial – physician/clinic resources
  - Financial – patient resources

- Adjunct therapy time constraints (e.g. takes too long to perform in clinic)
  - Clinician time constraints (e.g. clinical practice too busy)
  - Distance of patients to clinic – patients have to travel long distances
  - Risk of adverse events
  - Lack of evidence
  - Lack of effectiveness from clinical experience
  - Patient does not want to
  - No barriers
  - Other: (text box option)
  - Y-axis = Adjunct therapies beyond 60 minutes of BoNT injection
    - Stretching programme
    - Active exercise programme
    - Active exercise
    - Taping
    - Casting of upper extremity
    - Casting of lower extremity
    - Splinting (e.g. wrist hand orthosis, night time splints, dynamic splints)
    - EStim of agonist/antagonist muscles - no production of functional movement
    - Functional EStim (FES) of muscles - produces/assists functional movement
    - Extracorporeal Shock Wave Therapy (ESWT)
    - Transcutaneous electrical nerve stimulation (TENS)
    - Segmental muscle vibration
    - Constraint induced movement therapy
    - Motorized arm ergometer
    - Zinc supplementation
    - Magnesium supplementation
    - Other nutrient supplementation: (text box)
    - Dietary change recommendations (e.g. reducing sugar intake to optimize blood sugar control)
    - Other: (text box)
- Q21 Which adjunct therapies would you most like to see further research in for determining effectiveness? Select all that apply.**
- IMMEDIATE passive stretching of injected muscles (1)
  - IMMEDIATE active movement of injected muscles (e.g. get patient to walk right after leg injection) (2)
  - IMMEDIATE Electrical stimulation (EStim) of injected muscles (3)
  - DELAYED EStim of agonist/antagonist muscles - no production of functional movement (4)
  - Functional EStim (FES) of muscles - produces/assists functional movement (5)
  - IMMEDIATE Extracorporeal Shock Wave Therapy (ESWT) (6)
  - DELAYED ESWT (7)
  - Stretching programme (8)
  - Active exercise programme (9)
  - Casting of upper extremity (10)
  - Casting of lower extremity (11)
  - Taping (12)
  - Splinting (e.g. wrist hand orthosis, night time splints, dynamic splints) (13)
  - Transcutaneous electrical nerve stimulation (TENS) (14)
  - Segmental muscle vibration (15)
  - Constraint induced movement therapy (16)
  - Motorized arm ergometer (17)
  - Zinc supplementation (18)
  - Magnesium supplementation (19)
  - Dietary change recommendations (e.g. reducing sugar intake to optimize blood sugar control) (20)
  - Other (21) \_\_\_\_\_

**APPENDIX 2: CHECKLIST FOR REPORTING RESULTS OF INTERNET E-SURVEYS (CHERRIES)**

Item Category	Checklist Item	Explanation
<b>Design</b>	Describe survey design	<b>Describe target population, sample frame. Is the sample a convenience sample? (In "open" surveys this is most likely.)</b> The target population was physicians (medical doctor and physical therapist) practicing BoNT injections for spasticity worldwide
<b>IRB (Institutional Review Board) approval and informed consent process</b>		
	IRB approval	<b>Mention whether the study has been approved by an IRB.</b> The survey was conducted in compliance with relevant codes of conduct and data protection legislation. An Ethics Committee approval was obtained in author and co-authors countries.
	Informed consent	<b>Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?</b> Participants were not informed about the length of the survey (approximately 10 minutes long). Their voluntary participation was taken as consent. Data were stored on an institutional survey tool website from UBC. This was clearly stated. The names of the investigators were mentioned and the purpose of the study explained in the introduction of the survey.
	Data protection	<b>If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.</b> No personal information was collected, nor stored. The survey was anonymized. Only demographic informations (country, age, specialty ...) were collected
<b>Development and pre-testing</b>		
	Development and testing	<b>State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.</b> The questionnaire was initially elaborated by a Canadian author who made external reviewing process by three clinicians experienced in the field. The questionnaire was used for a Canadian survey and published in 2020 (Ip et al. PM&R 2020).
<b>Recruitment process and description of the sample having access to the questionnaire</b>		
	Open survey versus closed survey	<b>An "open survey" is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).</b> This study was an open survey.
	Contact mode	<b>Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)</b> Participants have received an online link to the survey via e-mail. When clicking on the link sent, it directly connected to the survey. On request of the authors, an e-mail with explanation and link was sent by the national and international societies (see the list in the acknowledgements) to their members.
	Advertising the survey	<b>How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.</b> On request of the authors, an e-mail with explanation and link was sent by the national and international societies (see the list in the acknowledgements) to their members. The announcement is in Appendix 1
<b>Survey administration</b>		
	Web/E-mail	<b>State the type of e-survey (e.g. one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?</b> The e-survey was connected to a link sent by email. The responses were automatically collected on the secure online data collector.
	Context	<b>Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site.</b> The survey was posted on the University of British Columbia (UBC) Survey Tool. The survey was sent via e-mail to the national and international societies.
	Mandatory/voluntary	<b>Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?</b> It was a voluntary survey
	Incentives	<b>Were any incentives offered (e.g. monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?</b> No incentives were offered to provide the survey results.
	Time/Date	<b>In what timeframe were the data collected?</b> The data were collected from November 2019 to April 2020.
	Randomization of items or questionnaires	<b>To prevent biases items can be randomized or alternated.</b> Items weren't randomized or alternated.
	Adaptive questioning	<b>Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.</b> No adaptative questioning was used
	Number of Items	<b>What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.</b> The average of items per page was 3

(contd.)

Item Category	Checklist Item	Explanation
<b>Survey administration (contd.)</b>		
	Number of screens (pages)	<b>Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.</b> The questionnaire was carried out on 8 pages.
	Completeness check	<b>It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if "yes", how (usually JavaScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as "not applicable" or "rather not say", and selection of one response option should be enforced.</b> No consistency or completeness checks before the survey submission was done. The completeness check was done by the investigators, after the questionnaire has been submitted by participants.
	Review step	<b>All items had a non-response option if needed.</b> <b>State whether respondents were able to review and change their answers (e.g. through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).</b> The participants to the survey could change their answers, until they fully completed the questionnaire by clicking on a "completion button". Until this, they had the possibility to go back to each item on each page, whenever they wanted.
<b>Response rates</b>		
	Unique site visitor	<b>If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.</b> We determined a unique visitor based on IP addresses.
	View rate (Ratio of unique survey visitors/ unique site visitors)	<b>Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.</b> We were unable to determine the survey view rate because the survey hosting website (UBC Survey Tool) does not provide data on the number of site visitors.
	Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	<b>Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called "recruitment" rate.</b> The participation rate was 99.4%. There were 524 participants who filled in the first survey page, divided by 527 total participants who visited the survey.
	Completion rate (Ratio of users who finished the survey/ users who agreed to participate)	<b>The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate "informed consent" page or if the survey goes over several pages. This is a measure for attrition. Note that "completion" can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word "completeness rate".)</b> The completion rate was 75.5%. There were 398 completed surveys, divided by 527 total participants.
<b>Preventing multiple entries from the same individual</b>		
	Cookies used	<b>Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (e.g. the first entry or the most recent)?</b> No cookies were used. There were no duplicate entries observed based on unique IP addresses in the dataset.
	IP check	<b>Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (e.g. 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (e.g. the first entry or the most recent)?</b> Yes, IP addresses were used to prevent duplicate entries. There were no duplicate entries observed based on unique IP addresses in the dataset.
	Log file analysis	<b>Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.</b> Other than recording IP addresses, no other techniques were used for identification of multiple entries.
	Registration	<b>In "closed" (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (e.g. the first entry or the most recent)?</b> Our study was an open survey.
<b>Analysis</b>		
	Handling of incomplete questionnaires	<b>Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?</b> Questionnaires which were terminated early were also analyzed. Due to the design of the questionnaire not all questions required a response (different branches of questions) therefore all responses were taken into account.
	Questionnaires submitted with an atypical timestamp	<b>Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point and describe how this point was determined.</b> No cut-off point was used to exclude questionnaires.
	Statistical correction	<b>Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.</b> No statistical correction was used to adjust the non-representative sample.