INFORMATION and CONSENT

We are conducting this survey to describe current practices related to monitoring cough effectiveness, clinician prescription, and clinician recommendations for use of airway clearance strategies.

This project is funded by Muscular Dystrophy Canada.

Principal Investigator: Dr. Louise Rose, Associate Professor, University of Toronto.

Importance of the study: The overall goal of this research program is to improve uptake of recommendations for airway clearance strategies from the 2011 Canadian Thoracic Society Home Mechanical Ventilation Guidelines into the current practice of clinicians providing care to ventilator assisted individuals (VAI) with NMD living at home as well as to those individuals at risk for mechanical ventilation. This survey will enable us to understand current practice and where there is a need to target interventions to improve guideline uptake in the future.

We are asking you to take part because you are a healthcare professional working in a clinic or centre providing care to individuals with neuromuscular disease (NMD). We anticipate approximately 100 healthcare professionals will participate.

You will be asked more detailed questions on the use of these techniques. We have pilot tested the survey and it should take less than 15 minutes.

There are no known risks or direct benefits to participating in this study.

Your confidentiality will be respected. No information that reveals your identity will be released or published without consent unless required by law and no questions about individual patients will be asked.

The research study may be reviewed for quality assurance to make sure that the required laws and guidelines are followed. If chosen, (a) representative(s) of the Human Research Ethics Program (HREP) may access study-related data and/or consent materials as part of the review. All information accessed by the HREP will be upheld to the same level of confidentiality that has been stated by the research team.

Participation in this study is voluntary. You may refuse to participate, skip questions or completely discontinue participation in the study prior to submission of your response to the survey with no negative consequences. However once you submit your responses to the survey via the online survey platform we will be unable to withdraw these data. If you would like to find out more information about this study before participating, please contact the principal investigator, Dr. Louise Rose at louise.rose@utoronto.ca OR 647 267 3492

Before CONSENTING to participate in this study please make sure that you have read the

information provided to you in this document.

You understand
The potential harms and benefits of participating in this research study.
That you have the right not to participate.
That you have not waived your legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional responsibilities.
That data related to you will be kept confidential and that no personal information will be disclosed without your permission unless required by law
That you may contact the principal investigator now, or in the future, to ask any questions you have about the study.

Your signature is not required for participation. Your consent is implied if you submit your responses to the survey by answering survey questions and saving your progress or clicking Submit at the end of the survey.If you have any questions regarding your rights as a research participant, you may contact the Office of Research Ethics at ethics.review@utoronto.ca or 4169463273 during business hours

Please note that once you commence the survey you will not be able to return to complete it at a later date and will have to commence again. Therefore please ensure you have 15 minutes available.

1. Hospital/Institution in which your clinic is based/affiliated

* 2. Province in which your clinic is based

- ◯ Alberta
- ◯ British Columbia
- ◯ Manitoba
- ◯ New Brunswick
- ◯ Newfoundland
- ◯ Nova Scotia
- ◯ Ontario
- ◯ PEI
- ◯ Quebec
- ◯ Saskatchewan

3. Please confirm your current practice (i.e. the practice within your clinic/programme) involves assessment, monitoring, teaching or management of patients with neuromuscular disease (e.g. muscular dystrophy, ALS). These patients may be at risk of respiratory compromise or currently requiring non-invasive or invasive ventilation at home

4. Please identify your primary specialty or profession

5. How many years have you been working with patients with neuromuscular disease at risk of respiratory compromise or using ventilation in the home?

6. How many patients do you currently have in your clinic/program?

7. How many patients does your clinic/program commence on mechanical insufflation-exsufflation (MI-E) each year?

8. How many patients does your clinic/program commence on non-invasive ventilation (NIV) each year?

9. Are you aware of the Canadian Thoracic Society (CTS) Home Mechanical Ventilation (HMV) guideline recommendations related to airway clearance techniques?
(airway clearance techniques refer to lung volume recruitment (LVR), manually assisted cough (MAC) and mechanical insufflation-exsufflation (MI-E))

10. What tests are recommended by the CTS HMV guidelines to monitor cough adequacy? (tick all that apply)

- [ ] Maximal inspiratory pressure/Maximal expiratory pressure (MIP/MEP)
- [ ] Sniff nasal pressure (SNP)
- [ ] Peak expiratory flow (PEF)
- [ ] Peak cough flow (PCF)
- [ ] Maximal inspiratory capacity (MIC)
- [ ] Forced vital capacity (FVC)
- [ ] Slow vital capacity (SVC)
- [ ] Supine spirometry
- [ ] Standard spirometry
- [ ] Evaluation of swallow
- [ ] Other (please specify)

11. At which PCF (L/min) do the CTS HMV guidelines recommend airway clearance techniques are first commenced?

12. In your current practice (i.e. the practice within your clinic/organization), is adequacy of cough strength determined routinely?

13. Who determines adequacy of cough strength? (tick all that apply)

- [ ] Neurologist
- [ ] Respirologist
- [ ] Respiratory therapist
- [ ] Physiotherapist
- [ ] Nurse
- [ ] Physiatrist
- [ ] Other (please specify)

14. How is adequacy of cough strength determined routinely? (tick all that apply)

- [ ] Maximal inspiratory pressure/Maximal expiratory pressure (MIP/MEP)
- [ ] Sniff nasal pressure (SNP)
- [ ] Peak expiratory flow (PEF)
- [ ] Peak cough flow (PCF)
- [ ] Maximal inspiratory capacity (MIC)
- [ ] Forced vital capacity (FVC)
- [ ] Slow vital capacity (SVC)
- [ ] Supine spirometry
- [ ] Qualitative evaluation of cough strength
- [ ] Standard spirometry
- [ ] Evaluation of swallow
- [ ] Unsure
- [ ] Other (please specify)

15. In your current practice (i.e. the practice within your clinic/program) do you currently recommend/prescribe/teach/monitor airway clearance techniques including any of the following: lung volume recruitment (LVR), manually assisted cough (MAC), and mechanical insufflation-exsufflation (MI-E) when appropriate?

16. Please provide reasons why airway clearance techniques are only recommended or prescribed sometimes (tick all that apply)

- [ ] Patients are sometimes referred to a respirologist or other specialist outside of the clinic
- [ ] Not all patients have access to airway clearance equipment
- [ ] Not all patients and/or their caregivers are able to access education to use this equipment
- [ ] Not all patients and/or their caregivers are able to access ongoing support to use this equipment
- [ ] Impaired bulbar function in some patients
- [ ] I perceive these techniques to be ineffective for some patients
- [ ] Not all patients are able to adhere to airway clearance prescription/recommendations
- [ ] There is insufficient evidence is some patient groups related to the effectiveness of these techniques
- [ ] Other (please specify)

17. Please provide reasons why airway clearance techniques are<u>never</u> recommended or prescribed In your current practice (i.e. the practice within your clinic/programme) (tick all that apply)

- [ ] Patients are referred to a respiratory doctor or other specialist outside of the clinic
- [ ] Patients do not have access to airway clearance equipment
- [ ] Patients and/or their caregivers do not have access to education to use this equipment
- [ ] Patients and/or their caregivers do not have access to ongoing support to use this equipment
- [ ] I perceive these techniques to be ineffective
- [ ] Patients do not adhere to airway clearance prescription/recommendations
- [ ] There is insufficient evidence related to the effectiveness of these techniques
- [ ] Other (please specify)

18. In your current practice, which airway clearance techniques are routinely used on initiation?

- ◯ Lung volume recruitment (LVR) only
- ◯ Manually assisted cough (MAC) only
- ◯ Mechanical insufflation-exsufflation (MI-E) only
- ◯ LVR + MAC
- ◯ LVR +/- MAC + MI-E if PCF <270 L/min
- ◯ LVR +/- MAC + MI-E regardless of PCF
- ◯ LVR + MI-E
- ◯ Other (please specify)

19. Is PCF measured before initiation of airway clearance techniques?

20. At what PCF (L/min) are airway clearance techniques recommended/prescribed?

21. Please provide the reasons you do not measure PCF before initiation of airway clearance techniques (tick all that apply)

- [ ] No access to PCF monitoring equipment
- [ ] Unfamiliar with PCF measurement
- [ ] Use other measures to guide therapy
- [ ] Do not perceive PCF useful in guiding therapy
- [ ] Other (please specify)

22. Is PCF measured after therapy initiation to ensure technique adequacy?

23. If PCF is never measured after therapy initiation to ensure technique adequacy, please provide the reasons why (tick all that apply)

- [ ] Insufficient time
- [ ] Use other measures to assess technique
- [ ] Insufficient personnel
- [ ] Do not perceive PCF useful to assess technique
- [ ] Other (please specify)

24. Are PCF results shown and explained to the patient to provide feedback on their technique?

25. What is the minimum frequency recommended for patients to use airway clearance strategies on a routine basis (i.e. standard prescription)?

26. If your clinic routinely initiates airway clearance with LVR, MAC or both, do you transition to MI-E?

27. What criteria is used to transition to MI-E? (tick all that apply)

- [ ] Unable to maintain PCF >270 L/min with other airway clearance techniques
- [ ] Unable to maintain PCF >160 L/min with other airway clearance techniques
- [ ] Unable to maintain FVC with other airway clearance techniques
- [ ] Worsening clinical symptoms irrespective of PCF
- [ ] Repeated respiratory infections irrespective of PCF
- [ ] ED presentation/hospitalization for life threatening respiratory infection
- [ ] Poor tolerance of LVR/MAC
- [ ] Improved tolerance and ease of use with MI-E
- [ ] Lack of subjective/clinical benefit with LVR/MAC
- [ ] Other (please specify)

28. Please identify the reasons why you never transition to MI-E (tick all that apply)

- [ ] Inability to provide MI-E equipment
- [ ] Inability to provide patient/caregiver education
- [ ] Inability to provide patient/caregiver ongoing support
- [ ] Lack of evidence of effectiveness over other airway clearance techniques
- [ ] Other (please specify)

29. Does your clinic/program have a standardized plan/guideline for monitoring of cough strength and initiation of airway clearance techniques?

30. Does the standardized plan/guideline follow recommendations for airway clearance outlined in the CTS HMV guidelines?

31. Are patients provided with an emergency care plan that includes instruction on management of their airway clearance device?

32. Does your clinic/program provide initial teaching on airway clearance techniques?

33. Who in your clinic provides initial teaching for LVR and MAC? (tick all that apply)

- [ ] Physician
- [ ] Respiratory therapist
- [ ] Physiotherapist
- [ ] Nurse
- [ ] Physiatrist
- [ ] Other (please specify)

34. Where does this initial teaching occur?

35. Who provides initial teaching for MI-E to patients and families? (tick all that apply)

- [ ] Physicians
- [ ] Respiratory therapist
- [ ] Physiotherapist
- [ ] Nurse
- [ ] Physiatrist
- [ ] Other (please specify)

36. Where does this initial teaching occur?

37. How are airway clearance strategies taught? (tick all that apply)

- [ ] Demonstration
- [ ] Video
- [ ] Lecture
- [ ] Hardcopy materials
- [ ] Electronic (digital) materials
- [ ] Unsure
- [ ] Other (please specify)

38. On average, how much time is spent with patients and families on initial teaching?

39. If you don't provide initial teaching for airway clearance strategies, who does?

- [ ] Respirology clinic
- [ ] External HMV program
- [ ] Private provider
- [ ] Please provide the name of the private provider or if 'other' please describe

40. How is competency (in terms of skill/technique) of patients and families assessed? (tick all that apply)

- [ ] Not assessed
- [ ] Observation
- [ ] Teach back (pt/family demonstrates knowledge by teaching back to healthcare provider)
- [ ] Written test
- [ ] Unsure
- [ ] Other (please specify)

41. Is support available through your clinic/program to patients and families for education and troubleshooting after the initiation phase?

42. Who in your clinic/programme provides ongoing support related to airway clearance techniques for patients and families? (tick all that apply)

- [ ] Physician
- [ ] Respiratory therapist
- [ ] Physiotherapist
- [ ] Nurse
- [ ] Physiatrist
- [ ] Other (please specify)

43. Does your clinic/program provide support in the patient's home?

44. If your clinic/program does not provide ongoing support, who does?

- ◯ Respirology clinic
- ◯ HMV clinic
- ◯ Private provider
- ◯ Please provide the name of the private provider or if 'other', please describe

45. What are the criteria to have a MI-E device prescribed? (tick all that apply)

- [ ] Unable to maintain PCF >270 L/min
- [ ] Unable to maintain PCF >160 L/min
- [ ] Unable to maintain FVC
- [ ] Worsening clinical symptoms irrespective of PCF
- [ ] Repeated respiratory infections irrespective of PCF
- [ ] ED presentation/hospitalization for life threatening respiratory infection
- [ ] Other (please specify)

46. Have any of the patients in your clinic/program self-funded the purchase of their MI-E device?

47. In your opinion, what are the major constraints to provision of your ideal airway clearance strategy? (tick all that apply)

- [ ] There are no constraints
- [ ] Insufficient time to provide initial training to patients and caregivers
- [ ] Insufficient public funding for equipment
- [ ] Insufficient private funding for equipment
- [ ] Lack of funding for healthcare providers to provide initial training
- [ ] Lack of funding for healthcare providers to provide follow-up and ongoing support
- [ ] Insufficient knowledge/familiarity of community healthcare providers to provide training and follow up
- [ ] Inability to provide follow-up and support in the home
- [ ] Access to equipment in a timely manner
- [ ] User/family language barriers and lack of teaching materials in another language
- [ ] Other (please specify)

You have now completed the survey.

THANK YOU very much for your participation in this survey, we greatly appreciate it