Study Title: BIND Study: Assessing the Indirect Socio-Economic Burden of Inherited Neuromuscular Diseases

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Introduction:

For those that are answering questions for a person with NMD's behalf (i.e. proxy, child, or caregiver for NMD person), please note that all questions refer "you" as the person with the NMD, unless otherwise specified.

You are invited to participate in a web-based online survey on the impact of a neuromuscular disorder (NMD). This survey will assess costs associated with living with a NMD or caring for someone with a NMD and the impacts on quality of life. The purpose of this survey is to better understand the social and cost impact of NMDs on patients and their caregivers in Canada.

This is a research project being conducted by the research team at the Ottawa Hospital Research Institute (OHRI) in collaboration with partner organizations including Muscular Dystrophy Canada (MDC), the Neuromuscular Disease Network for Canada (NMD4C), and the Canadian Neuromuscular Disease Registry (CNDR).

This consent form asks you to allow the members of the study team to view your responses and your comments as data in this study.

Are there any conflict of interest?

The Canadian Institutes of Health Research are providing the researchers with financial support to cover the cost of conducting this study. The research team members do not have any perceived, actual or potential conflict of interest regarding this research.

What will happen during this study?

Your participation in this study will require the completion of a survey. The survey asks questions about indirect social and economic burden, as well as its determinants among patients and caregivers with genetic NMD disease. In addition, questions about costs associated with living with a NMD or caring for someone with a NMD and the impacts on quality of life will be asked. We will focus on the impact of genetic NMDs on schooling, education attainment, labour force participation, quality-adjusted life expectancy (QALE), and indirect costs (lost earnings and productivity by the patient or caregivers related to genetic NMDs). Surveys are available in English and French. Completion of all surveys should take approximately 60 minutes (1 hour) of your time. You do not have to complete the survey all at one time, you will have the option to close the survey and restart at a later time without losing progress. If you would like help completing the survey, research staff are available and can provide assistance.

The information you provide is for research purposes only. Some of the questions are personal. You can choose not to answer questions if you wish.

Voluntary participation and withdrawal

You do not have to be in this study if you do not want to be. You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. The decision will not affect your employment or any healthcare services you are entitled to at the Ottawa Hospital or any care associated with your neuromuscular disorder.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

Benefits

Your responses may help us learn more about the factors associated with quality of life for individuals impacted by NMDs, as well as factors impacting social and economic burden on individuals impacted by NMDs. The information we get from this study may help us influence positive change, that is, public policy efforts and advocate for better treatments and services to the meet the needs of patients with NMDs and their caregivers in the future.

Risks

The possible risks or discomforts of the study are minimal.

This study focuses on the burden and impact of neuromuscular disorders on patients and caregivers in Canada. As such, some of the survey questions ask about your day-to-day life as it relates to your health condition, or that of those you care for. Reflecting on your/their health and thinking about your experiences could be upsetting and distressing for some individuals. You may feel a little uncomfortable, sad, tired from answering personal, sensitive and many survey questions.

Confidentiality

You will be asked to provide personal identifying information in this survey, including your name and email address.

Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your original research records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Hospital Research Institute, who oversees the conduct of the research at this location
- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your sex, age, neuromuscular condition (if applicable), and the first three characters in your postal code. This research study is collecting information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond. Providing information on your race or ethnic origin is voluntary.

Communication via e-mail is not secure. We do not recommend that you communicate sensitive personal information via e-mail.

If the results of this study are published shared, or presented at scientific meetings, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and will be published/ presented to the scientific community at meetings and in journals. To help ensure confidentiality, all materials intended for presentation or publication will be first reviewed by The Ottawa Hospital Research Institute Methods Centre. Even though the likelihood that someone may identify you from the study data is very small, it can never be eliminated.

Compensation and Costs

You will not receive any monetary compensation for your participation in this study.

There is no cost to you, your private medical insurance (if any), or the public health insurance plan, for study participation.

Right of participants

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

If you would like to be informed of the results of this study, please let the research team know.

Questions:

If you have any questions about taking part in this study, you may contact:

Ian Smith, Clinical Research Associate, at iasmith@ohri.ca

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact the Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

CONSENT

By completing this survey your consent to participate is implied.