



From Researchers:

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You are invited to participate in a research study being conducted by a medical student at the University of Toronto with the Multiple Sclerosis Society of Canada. I have listed some important information about the study to help you decide if you wish to participate. Feel free to email me any questions at kristen.krysko@utoronto.ca.

The name of the project is: **The use of online networking by youth with multiple sclerosis**

A. STUDY INFORMATION

The purpose of this research study is to further understand how multiple sclerosis impacts aspects of everyday life and to understand how the MS Society of Canada can better meet the needs of youth with multiple sclerosis (age 15-25). We are specifically interested in how youth use online social networking (facebook, twitter, MySpace) to learn about MS and to connect with others who share your diagnosis. Understanding this will help the MS Society of Canada develop an online networking website to meet your needs.

B. STUDY PROCEDURES

This study involves completion of this online survey. This survey has several sections so that we can understand different aspects of your life. These sections include:

Part A: Online networking: This involves a number of questions to assess your Internet use and use of online social networking websites. We also would like to know which features of these sites you find useful and which features would be important to you in a new site to be created by the MS Society of Canada in the future.

Part B: Modified Social Support Scale: This involves five questions to assess your current level of social support.

Part C: Demographic Information: This includes questions about you so that we can understand more about you.

Part D: Short Form 36 Health Survey: This includes questions about your health and well being.

You are not required to answer any questions if you feel uncomfortable. There are some questions that you may find sensitive. You will be provided with links to resources to address these sensitive questions.

This questionnaire will take about 20 minutes of your time to complete. Your participation is appreciated.

C. POTENTIAL RISKS (Harm, Injury, Discomforts or Inconveniences)

This study is not expected to involve any risk; however, if you feel uncomfortable during the study, please contact the researcher. You are not required to answer any question you are uncomfortable with. The study will take about 20 minutes of your time.

D. POTENTIAL BENEFITS

There are no direct benefits to you from taking part in this study. Your participation in this study will broaden the understanding of multiple sclerosis in youth and how it impacts many aspects of everyday life. Your answers will help the MS Society develop new programs and resources that are important to youth with MS. You may directly benefit from these services in the future if you wish to use them, and these services may improve well being in many youth with multiple sclerosis.

E. COSTS TO PARTICIPATION and REIMBURSEMENT

There is no cost to participate in this research study. You will not be compensated financially for participating.

F. CONFIDENTIALITY

All persons associated with the study are committed to respecting your privacy. Your responses to these questions will be kept anonymous. You will not be asked to provide personal identifying information, although relative identifiers such as age and gender will be requested.

Files including the information you provide will be stored securely in the survey monkey account of the MS Society. Files will be encrypted and password protected. Despite these precautions in place, there is a risk of unintentional release of information. The researcher will protect your responses and keep all information confidential to the greatest extent possible. The chance that information may be released accidentally is small.

Your study data may also be used in reports and scientific publications. If the results of the study are published, your identity will remain confidential since personal identifying information will not be collected.

G. PARTICIPATION AND WITHDRAWAL

Participation in this research study is voluntary. If you decide to participate in this study you can change your mind without giving a reason, and you may withdraw from the study at any time.

H. RESEARCH BOARD ETHICS CONTACT

If you have any questions regarding your rights as a study participant, you should contact: Dr. Ian Johnson, organizer of the Delegate Research Ethics Review Board for medical student projects at 416-978-8649 during business hours.

I. STUDY CONTACT:

If you have any questions regarding the study, please contact: Kristen Krysko at kristen.krysko@utoronto.ca or Nicole Mellin 416-967-3004 or 1-800-268-7582 ext. 3004 or nicole.mellin@mssociety.ca

J. DECLARATION OF CONSENT

By filling out this survey, you have declared consent to participate in this study.

Sincerely,

Kristen Krysko

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MS Society of Canada

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