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Participant Information Letter

Exploring the extent, determinants, and consequences of cost-related non-adherence to medications among people with spinal cord injuries

You are invited to participate in a research study conducted by:

Principal Investigators: **Professor Mary Ann McColl**
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Shikha Gupta, PhD Candidate
School of Rehabilitation Therapy
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What is the purpose of this study?

The purpose of this study is to identify if people with SCI face any financial barriers in accessing necessary medications, and if so, what are the consequences for them? Approximately 140 participants will be recruited for this study over the course of 1 year.

Please Note: We define spinal cord injury as “*an injury that occurs when trauma (such as a fall, vehicle accident, act of violence) or disease (such as a motor neuron disease, tumor, infection, myelopathy, vascular, toxic, metabolic condition or a developmental disorder) damage the spinal cord, resulting in partial or complete paralysis.*”

What will my responsibilities be if I participate in this study?

After obtaining your consent, an email will be sent to you with a link for an online survey. You can also opt to answer the survey questions through phone. The survey contains 35 questions and will approximately require 15 minutes of your time for completion. Most of these questions will have multiple choice answers and you will need to select the best answer(s) that describe your situation. The questions will be about your demographic characteristics, spinal cord injury related characteristics, health service utilization, the number and type of medications

you use, the source of funding for your prescription medications and any type of financial burden that you may face because of medications related costs.

What is the basis for selection and participation in this study?

The individuals who will be selected to participate in the study are of 18 years of age and above; living in the community and sustaining spinal cord injury for more than 12 months, and having one or more prescription medications at the time of the survey.

What are the possible benefits for me or society?

Prescription medications play an important role in the treatment and prevention of disease, especially for people with chronic conditions such as a spinal cord injury. However, in Canada, the coverage for prescription medications is not universal and varies across the provinces, depending on the individual health and socio-economic status. Evidence is emerging that people with poor health status face financial barriers to access necessary medications that may lead to poor health outcomes. Therefore, this study will try to find out whether people with spinal cord injury in Ontario have access to necessary medications to ensure optimum health outcomes. The study will be beneficial to the people who face financial barriers to access their necessary prescription medications by bringing this issue to the knowledge of wider community including general public, researchers, policy makers, medical professionals and other stakeholders and contribute to driving change at the policy level.

What are the possible risks or discomforts?

There are no risks associated with your participation. Your participation in this study will not expose you to any risk or discomforts. Your information will be kept completely confidential and pseudonymous. No third party will be provided your data. You may decline answering any questions you do not wish to answer at any time without prejudice or penalty.

Will there be any payment or reimbursement if I participate in this study?

Your participation in this study will not provide you with any financial benefits but you will receive a \$5 gift card after completing your survey as a token of appreciation for your time.

What information will be kept private?

Your data will not be shared with anyone, except with your consent. The information obtained by me will be kept in a locked cabinet. Your personal information will be kept separate from the survey data at a secure place. If the results are published, no names or identifying information will be released or published without your specific consent to the disclosure.

What if I change my mind about participating in the study?

Your participation in this study is absolutely voluntary. If you volunteer to be in this study, you may withdraw at any time, even after signing the consent form. In cases of

withdrawal, your data will be destroyed if it is not aggregated and analysed. However, after data has been analysed and submitted for publication, it can't be withdrawn.

Will I find out about the study results?

All participants will be given the opportunity to contact the student investigator (Shikha Gupta) at the end of the study to receive a summary of the study results.

Can I get more information about participating as a study subject?

This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. If you have any concerns about your rights as a research participant please contact - Dr. Albert Clark, Chair - (toll-free number) - 1-844-535-2988 or clarkaf@queensu.ca. If you have questions or require more information about the study itself, please contact Shikha Gupta (shikha.gupta@queensu.ca; phone number: 6138761780). The information mentioned above will be discussed and all questions will be clarified prior to any involvement in the study.