PATIENT SELF-MANAGEMENT

Six months ago you participated in a self-management program. At that time, you completed a questionnaire as part of your participation in the study entitled Patient Self-Management that is being conducted by Patrick McGowan, PhD.

Patrick McGowan is a Professor of the School of Public Health and Social Policy and a member of the Institute on Aging & Lifelong Health at the University of Victoria. You may contact him if you have further questions by phoning 604-940-3574 or toll-free 1-866-902-3767 or emailing pmcgowan@uvic.ca.

This research is being funded by BC Ministry of Health.

Purpose and Objectives

The purpose of this research project is to determine the effectiveness of self-management programs in helping persons better manage their chronic health condition(s).

Importance of this Research

Research of this type is important because it helps to gain further understanding of self-care strategies used in the management of chronic health conditions, and can aid in refining programs that enhance the quality of life for persons living with chronic health conditions.

What is involved

You are being asked to complete the same questionnaire that you filled out six months ago. The questionnaire will take approximately 2 minutes to complete and asks your opinions about managing your health. Please answer the questions to the best of your ability, even if you do not have a chronic health condition. There are no right or wrong answers.

Inconvenience

The only inconvenience to you in participating in this study is the time it takes to complete the questionnaire now and again at six months.

Risks

There are no known or anticipated risks to you by participating in this research.

Benefits

The potential benefits of your participation in this research include ensuring that persons with chronic health conditions receive effective self-management programs and that the results will contribute to the body of knowledge on self-management of chronic illness.

Voluntary Participation

Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your questionnaire will not be used in the analysis and will be destroyed in a confidential manner (i.e., paper copies will be shredded and electronic data will be erased). To withdraw from the study please contact the Research Office by calling toll free 1-866-902-3767 or contacting the researcher, Dr. Patrick McGowan on 604-940-3574 or by email pmcgowan@uvic.ca or send a letter to Suite 210, 4907 Chisholm Street, Delta, BC V4K 2K6. You have the right to refuse to answer any question in the questionnaire. Your decision whether or not to participate in the research activities will in no way affect your continued participation in the six-session self-management program.

Anonymity

In terms of protecting your anonymity, your identifying information (i.e., your name, address, phone number and email) will be known only to the research team for the purpose of contacting you to complete the second questionnaire. Personal identifiers will be removed from the questionnaire data and stored in a separate password protected computer file. In the self-management program, the volunteer program leaders and other participants may know if you choose to participate in the research when the questionnaires are collected.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by the following actions: 1) printing out this questionnaire once received online and deleting your name from the questionnaire and replacing it with a secret code number; and 2) describing the results in aggregate form, which means the results are put together and individuals are not identified.

During the study, your confidentiality and the confidentiality of the data will be protected by storing paper copies of data in a locked filing cabinet and protecting access to electronic data with computer passwords. Data will be stored only for the duration of the study. When reporting your results, your identity will remain confidential because only aggregate data, and not individual data, will be reported. Your individual privacy will be maintained in all published and written data resulting from the study.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: public presentations, presentations at scholarly meetings, published articles in journals, and a report to the BC Ministry of Health. The results of this study will be posted on our website www.selfmanagementbc.ca.

Disposal of Data

Data from this study will be disposed of in April 2018. The data will be destroyed in a confidential manner i.e., electronic data will be erased and paper copies will be shredded.

Contacts

Individuals that may be contacted regarding this study include:

- Patrick McGowan (Researcher), at 604-940-3574 or by emailing pmcgowan@uvic.ca
- Dr. Scott M. Hofer, Director of the Institute of Aging and Lifelong Health at the University of Victoria, at 250-853-3862 or by emailing smhofer@uvic.ca
- Human Research Ethics Office at the University of Victoria at 250-472-4545 or by emailing ethics@uvic.ca

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at 250-721-4545 or ethics@uvic.ca.

Consent

By answering the questions in the online question, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers listed in the Contacts above.