



PATIENT SELF-MANAGEMENT

You are invited to participate in a 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.

Participants Selection

You are being asked to participate in this study because you are a participant in a self-management program.

What is involved

If you agree to voluntarily participate in this research, your participation will be to complete a questionnaire now and again in six-months. 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).

If you decide not to participate in the research please do not complete the questionnaire that is distributed by the volunteer program leaders in Session 1. As well, 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.

Researcher's Relationship with Participants

The researcher may have a relationship to participants as the volunteer program leaders are giving out the research questionnaire. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken:

- the volunteer program leaders will place the questionnaires at the back of the room for participants to choose to take voluntarily
- the program leaders will explain to you that the decision to participate should not be influenced by anyone present i.e., the leaders or fellow participants in the program
- the program leaders will explain to you that your decision whether or not to participate in the research in no way affects your participation in a self-management program.

The volunteer program leaders are acting as a third-party on behalf of the Researcher, Dr. Patrick McGowan, by collecting the completed research forms to pass along to him.

On-going Consent

To make sure that you continue to consent to participate in this research, in six months from now you will be sent this Consent Form again by email.

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) placing your returned questionnaire in a sealed envelope; 2) deleting your name from the questionnaire and replacing it with a secret code number; and 3) 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.

Your signature below 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.

Name of Participant

Signature

Date

Keep this copy for your own record

Please sign the pink copy and return it along with the questionnaire