Fostering Healthy Aging in Naturally Occurring Retirement Communities

Letter of Information and Consent for Health and Social Wellness Assessment, and Social Network Analysis

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Co-Researchers: Community residents, Queen's University researchers and community partners

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What is the purpose of the study?
The aim of this study is to understand how living in naturally occurring retirement communities promotes healthy aging in older adults who live in them. Naturally occurring retirement communities are communities with high numbers of older adults living in them. We will be using Participatory Research methods, which means the researcher and residents will work together on all parts of the project.

Who is being asked to participate?
We are inviting older adults who live in naturally occurring retirement communities. We invite you to participate as you are a resident of a naturally occurring retirement community and are 50 years of age or older.

What does the research involve and how much time will it take?
As part of this project, we would like to find out more about the residents of your community. You are invited to complete a brief assessment of your functional status. This will include measuring your ability to perform basic mobility-type activities such as rising from a chair, maintaining your balance in standing and walking. We will also check the strength of your handgrip.

These activities will be performed in your apartment or in a common area of your building or community. It will take about 45 minutes to complete all of this testing.

We will also ask you to wear a small device called an ActivPAL that measures your activity level over a period of one week. The ActivPAL device has been used to measure physical activity in thousands of individuals, including people with stroke, diabetes and older adults. We will show you how to put the monitor on and check in with you every day or so to make sure everything is all right. At the end of the week, we will meet you to pick up the monitor and use a computer to analyse your activity patterns over the week (for example how much time you spent standing and walking).

We also invite you to complete eleven (11) questionnaires that will ask you about how you are able to take care of yourself, move around your home and community, how you connect with your friend and family and your nutrition. We will also ask you some questions about your health and health care. The questionnaires will take up to 1 hour to complete. The questionnaires can be picked up in a convenient location to you, or we can arrange pick-up from you directly. You are also able to complete the questionnaires by telephone or through an online link.

The final part of this process is to describe the social networks of the residents. Social networks are made up of people that you interact with on a regular basis – for example, friends, family, neighbours, professionals or others in your life. You are invited to participate in an activity to share information about your social networks. This activity will take up to 1 hour and will be completed in a private and quiet space that is convenient to you (e.g., community room, your apartment, or at Queen's University). We will ask you questions about your social networks and to follow instructions that include listing names and initials on some activity sheets we will give you. No identifying information will be collected.

We will invite you to participate in both parts of this health and social wellness assessment each year for four years.

How long will you be in this study?
You may choose to complete the assessments now and end your involvement there. The follow-up assessments will be available each year for the next four years.

What are the risks and harms of participating in this study?
Because some of the assessments involve checking your balance in standing and having you walk, there is a small risk of losing your balance and falling during the assessment. We will ensure that the research assistant stands close to you during the assessments, minimizing the risk of harm.

Although the assessment is short and tailored to your abilities, you may find some of the assessments challenging and perhaps feel a little tired afterward. We will ensure you are given the opportunity to rest during the testing, and if necessary, we can do the testing over 2 sessions to suit your needs.

Most people who have worn the ActivPAL device find it comfortable and often forget they are wearing it once it is on. However, there is a small number of people (less than 1 in 10) who experience mild skin irritation from the material used to cover and place the device on your thigh. In order to minimize this risk, the ActivPAL is attached using hypoallergenic materials. However, if you notice any discomfort or irritation at any time, please remove the device and contact a member of the research team.

We do not believe there are any risks or possible discomfort associated with completing the questionnaires or social network analysis.

What are the benefits of participating in this study?
While there are no direct benefits to participation in this study, your participation contributes to our understanding the impact of living in naturally occurring retirement communities on the participating residents.

Will you be paid for participating in this study?
As a small token of appreciation, we would like to offer you a $10 honorarium delivered to you in person each time you participate in the health and social wellness assessment.

Can participants choose to leave the study?
Participation in this study is completely voluntary. You are not obliged to answer any questions that you find objectionable, or which make you feel uncomfortable. If you decide to participate you can leave the study at any time. You can do so by contacting the principal investigators, Drs. DePaul and Donnelly, or the research project manager. You will find contact information for them at the top of this document. If you decide to withdraw from the study, the information that was collected prior to you leaving the study will still be used as data analysis in the project will be ongoing. No new information will be collected without your permission.

How will participants' information be kept confidential?
Information shared while participating in this study will be kept private and will be protected to the extent permitted by the applicable laws. All information obtained during the course of this study is strictly confidential and your confidentiality will be protected at all times. The principal investigators (Drs DePaul and Donnelly) and their delegates will have access to your study data. There are organizations and their representatives that may look at or receive copies of some of the information in your study records and in some cases, your study data, for data analysis and quality assurance for monitoring, control, safety, and security. These may include:

- Members of the study team, as delegated by the study principal investigators, Drs DePaul and Donnelly.
- Canadian Institute of Health Research (CIHR), the funder of the study.
- Authorized Representatives of Queen's University, its affiliated hospitals and/or Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB).

We will be collecting personal information such as your age and gender.

All personal information such as your name will be removed from the notes and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data, with identifying information removed, will be securely stored in a locked cabinet in a locked office or on a password-protected computer server at Queen's University. We will keep the data for a minimum of 5 years, after which paper documents will be securely shredded and electronic files will be erased.

If the results of the study are published or presented anywhere, your name will not be used.

Who can you contact if you have questions about the study?
If at any time you have further questions, problems or adverse events, you can contact Dr. Catherine Donnelly at (613) 533-6385 or Dr. Vincent DePaul at (613) 533-6239 or Riley Malvern at (343) 363-5714 or Christina Luzius-Vanin at (613) 453-5410.

Who can you contact if you have complaints or concerns about the study?
If you have questions regarding your rights as a research participant you can contact the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 1-844-535-2988 or hsreb@queensu.ca.

Consent Statement
I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I am not waiving any legal rights by consenting to participate in this study. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

This study has received ethical approval by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

This letter is yours to keep for future reference.

Please Keep this Copy for your Records

Fostering Health Aging in Naturally Occurring Retirement Communities

Health and Social Wellness Assessment, and Social Network Analysis Consent Statement

Participant Signature:
By signing this consent form, I am indicating that I agree to participate in this study.
I have read the Letter of Information, have had the study explained to me and I agree to participate. All of my questions have been answered.

_____ _____
Name of Study Participant (print) Signature

_____
Date (DD-MMM-YYYY)

Witness Signature:
My signature means that I have explained the study to the participant named above. I have answered all questions.

_____ _____
Name of Person Obtaining Consent Signature

Date (DD-MMM-YYYY)

STATEMENT OF INVESTIGATOR: I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

Please Return to a member of the Research Team

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