

APPENDIX C (REVISED) – PARTICIPANT INFORMATION AND CONSENT FORM

Title: Community Hypertension Prevention Initiative (CHPI); Heart & Stroke ACTIVATE program

Activate is funded through a pay-for-performance agreement between the Heart and Stroke Foundation of Canada (Heart & Stroke) and the Public Health Agency of Canada (PHAC). Upfront cost has been provided by private investors who will receive a return from PHAC if the initiative achieves its intended results. To deliver the program, Heart & Stroke is working with the YMCA, Loblaw and has contracted NexJ Health (who was retained the expertise of the University of Ottawa Heart Institute) to provide you with access to their online Connected Wellness platform (the Platform) and health coaching services. If you have additional questions about the program or your privacy, please contact Heart & Stroke toll-free at 1-888-473-4636 or by email at activate@heartandstroke.ca.

Activate has been reviewed and has received ethics approval by the Community Research Ethics Office (CREO). If you have concerns or questions about your rights as a participant or about the way the initiative is being conducted, please contact CREO at 1-888-411-2736 or by email at creo@communitybasedresearch.ca.

ABOUT HEART & STROKE ACTIVATE

What is the goal of this program?

Activate is a free program that is aimed at helping you eat better, move more and stop smoking. The program is designed for pre-hypertensive adults aged 40 years and over and is intended to involve 7,000 individuals across Toronto and Vancouver between February 2018 and April 2021.

What does participating in this program involve?

If you fulfill the eligibility criteria, participating in Activate involves:

1. A 30-minute enrollment session during which you will:
 - Create a personal account on the NexJ Platform;
 - Complete a health questionnaire on the Platform (you will be asked your age, sex, ethnicity, health history, and lifestyle behaviours such as your level of physical activity and diet);
 - Receive a demonstration of the Platform.
2. A 6-month period during which you will be encouraged to:
 - Use the Platform to track your level of physical activity and diet, read content, and receive health coaching and incentives in the form of *PC Optimum* points;
 - Attend local community resources, including the YMCA, Loblaw's dietician services and other programs (for example, community centers, walking clubs, etc.).
3. After the 6-month period, you will be invited to attend a 20-minute return session to re-take your blood pressure and complete a follow-up health questionnaire.
4. Finally, in 12 months, you will be invited to complete a final health questionnaire on your cardiovascular risk factors and maintenance of lifestyle behaviours.

In addition, at some point during your participation in Activate, you may be invited to take part in one or more surveys or focus groups to share your feedback on the program. Quotes or verbal feedback that you may provide will only be used by Heart & Stroke with your express consent; for these, you will be asked to sign a separate form during the program evaluation.

What does health coaching involve?

Through Activate, you will be connected with health coaching services offered by either NexJ or the University of Ottawa Heart Institute. You can interact with a health coach by phone or online. Your health coach will provide you with information and support related to nutrition, physical activity and smoking cessation. Your health coach may be a nurse, social worker, occupational therapist, physiotherapist, nutritionist, or other trained or accredited healthcare professional. Any information provided by your health coach is not medical advice and is not intended as a substitute for medical professional help, advice, diagnosis or treatment.

Are there any risks in participating in this program?

There are no known risks involved in participating in Activate.

- You should check with your doctor before you start any exercise program or before engaging in more vigorous physical activity.
- It is possible that you experience no direct health changes from participating in this program.
- All the information you share during the program to NexJ is required to be kept secure and confidential by them. See the "Privacy and Confidentiality" section below for more details.

Are there any benefits in participating in this program?

You will have access to Activate, a free program that is aimed at helping you eat better, move more and stop smoking. You will receive a free 2-month membership to the YMCA. You will also earn up to 40,000 *PC Optimum* points for engaging on the Platform.

What if I change my mind about participating in this program?

Your participation in Activate is strictly voluntary. You can decide to stop taking part in the program at any time by emailing activate@heartandstroke.ca. In the event you decide to stop taking part in the program, all information you provided will be retained per the conditions set out in the "Privacy and Confidentiality" section below and NexJ's Connected Wellness End User Terms of Use and associated privacy policy. Your decision whether or not to be part of this program will not affect any other services you receive from Heart & Stroke, NexJ, the University of Ottawa Heart Institute, the YMCA, Loblaw, or other pharmacy and community locations.

PRIVACY AND CONFIDENTIALITY

What will happen to the personal information I provide and who will have access to it?

If you agree to join Heart & Stroke's Activate, the information you provide during the program is required to be kept secured and strictly confidential. Heart & Stroke has contracted with NexJ who is operating the Platform and will be responsible for the control and security of any personal health information you enter in the Platform. Information on the Platform is encrypted in-transit and at rest, and stored on a password-protected computer in a secure location.

Data will be collected and stored for as long as necessary by NexJ and disclosed for as long as necessary only for the following purposes: (1) monitoring and quality assurance, (2) audit of the program results, and (3) evaluation and research on the program.

- For program delivery, access to your name will be limited to you and your health coach from the University of Ottawa Heart Institute or NexJ.
- To anonymize your identity, personal information disclosed to Heart & Stroke will be always be presented by a unique ID number. No personally identifying information will be used in any reports or publications arising from this program. Heart & Stroke may:
 - share data with researchers for research and evaluation purposes, but this information will be presented by a number different than the unique ID given during the program, to further ensure your anonymity;
 - commission a health economic analysis to determine the overall benefit and cost-savings to the health system. This may require analyzing your sex, age, and first three digits of your postal code along with relevant portions of your blood pressure and lifestyle behaviours against information stored in provincial or federal administrative health databases. Once linked and analyzed, data will be reported in aggregate.
- To award you your *PC Optimum* points, Heart & Stroke will provide the administrator of the *PC Optimum* points program, owned by Loblaw, a record of your PC Optimum number along with the number of points you will have earned during Activate. No other personal information you provide during the program will be shared with Loblaw.
- The Social Research and Demonstration Corporation (SRDC), an independent auditing organization, will validate whether the program's intended results were achieved. SRDC will have access to a limited set of data (age, sex, health status, and blood pressure information) that will be presented by the unique ID given to each participant.

In the event NexJ's participation in the program is terminated prematurely, Heart & Stroke has the right to require NexJ to turn over personal information it has collected to a replacement service provider (but not to Heart & Stroke itself) provided such service provider will agree to comparable privacy protections in respect of such information.

Where can I access the results of this program?

A summary of the program's results will be shared on Heart & Stroke's Activate website once the program is completed and has been evaluated. At no time will your personally identifying information be used in any reports or publications arising from this program.

PARTICIPANT'S CONSENT

□	<ul style="list-style-type: none">• I have read the above information and have had the opportunity to have any questions answered.• I understand that the Platform is operated by NexJ and that any issue I have with the operation of the Platform, provision of health coaching services and/or use of my personal information that I enter into the Platform shall be between me and NexJ.• I agree to participate in Heart & Stroke Activate. I understand that this includes receiving health coaching offered by either NexJ or the University of Ottawa Heart Institute. I consent to the collection, use and disclosure of my personal information as set out herein, including having my identifying information (sex, age, and first three digits of my postal code) compared against administrative health databases for evaluation of the program.• I understand that my participation in Activate is voluntary and that I may stop at any time.• I understand that my participation in Activate signifies my agreement not to hold Heart & Stroke, its employees, directors, and/or agents liable for any damages I may suffer as a result of my use of the Platform, participation in Activate, any health coaching provided to me, or any unauthorized collection, disclosure or use of my personal health information other than by Heart & Stroke.• I understand that I have access at any time to this <i>Letter of Information and Consent Form</i> in my account in the Platform.
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