International Council of Cardiovascular Prevention and Rehabilitation (ICCPR)

take heart & breathe well

Informed Consent Form

Date: September 12, 2024

Study Name: International Cardiac Rehabilitation Registry: Patient-Reported Surveys

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Purpose of the Research: We aim to learn about the quality of cardiac rehabilitation programs, and to use this information to hopefully improve health outcomes for heart patients like you.

What You Will Be Asked to Do: You will be asked to provide your email address and/or mobile number. A brief survey consisting of approximately 16 questions would be sent to you at the beginning of your cardiac rehab program, at the end, and again each year from the beginning of your rehab program. The questions concern your sociodemographic characteristics, other health conditions, heart-health behaviour and psychosocial well-being. It would take about 5 minutes to complete.

Risks and Discomforts: We do not foresee any risks or discomfort from your participation in the registry surveys.

Benefits of the Registry and Benefits to You: By providing information directly to the registry, your cardiac rehab program will learn about how well it is performing, and this will inform ways to improve care. Also if you participate and complete the questions at the end of your rehab program, we can provide you specific information on the improvements you made through your rehabilitation program, and any ways you might need to further improve to optimize your heart health. We may also share newsletters with you on the findings of the registry from time to time.

Voluntary Participation and Withdrawal: Your decision to provide information directly to the registry is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the rehab treatment you receive or the nature of the ongoing relationship you may have with the staff or institution either now, or in the future.

If you chose not to complete any of the surveys, we will still use the data you did provide, and the data contributed by the program. If you want to withdraw from the registry at any time, all data collected for you will be immediately destroyed wherever possible.

Confidentiality: The information will be collected through any digital device you choose. Your information will only be identifiable by a registry number and will be anonymous. All information you supply during the research will be held in confidence and your name will not appear in any report or publication of the registry or future research stemming from the registry.

Your data will be safely stored on a secure server in a locked facility and only program staff and registry team members will have access to this information. The data will be stored indefinitely. Confidentiality will be provided to the fullest extent possible by law.

The researchers acknowledge that the software host of the Registry online surveys (Dendrite) may automatically collect participant data (i.e., IP addresses); This information will not be accessible to the researchers. Further, because this project employs e-based collection techniques, data may be subject to access by third parties as a result of security legislation now in place in many countries. Finally, the confidentiality and privacy of data cannot be guaranteed during web-based transmission.

Potential Future Use of the Information In the future, the anonymized data may be shared with a public repository so that other researchers could learn from the information. The data collected in this research project may be used –again anonymously - by members of the research team in subsequent research investigations exploring similar lines of inquiry. Such projects will still undergo research ethics review by all applicable institutional boards. This may involve linking to other information sources. Any secondary use of anonymized data by the research team will be treated with the same degree of confidentiality and anonymity as in the original registry project.

Questions About the Registry? If you have questions about the research in general or about your role in the study, please feel free to contact Lisa Banks either by telephone at (250) 475-7619 or by e-mail at lisa.banks@saanich.ca

This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I_________________, consent to contribute data directly to *the International Cardiac Rehab Registry* conducted by Sherry Grace on behalf of the ICCPR. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

You can send the registry surveys to my mobile and/or email, at: _______________________________ and / or ___________________________
(it may help to provide both in case your email or mobile number changes. Note we prefer to use email because there is a fee for using text; if you prefer text, please denote here: □ prefer text □ email is ok)

Signature_______________________ **Date**__________________
Participant

Signature_______________________ **Date**__________________
Registry Data Steward for CR Site