**Interview Consent Form**

**Title:** From the Heart: Canadian women’s lived experiences of heart failure

**Study title:** From the Heart: Canadian women’s lived experiences of heart failure

**Principal Investigator:** Dr. Susan Law - Project email: FromTheHeart@thp.ca

**Funding:** This project is funded by the Canadian Institute of Health Research (ID #175210) and has been approved by the Trillium Health Partners Research Ethics Board (ID #1063)

**Introduction**

Hello, my name is Susan Law. I am a researcher working at Trillium Health Partners’ Institute for Better Health. I am also the Director of the Canadian Health Experiences Research Program, a program that works in collaboration with our international partner and network of qualitative researchers known as DIPEx International (DI) – see [www.dipexinternational.org](http://www.dipexinternational.org). This document explains the research I am leading, why it is being done, and what you can expect if you agree to participate. Please read the information below carefully before you decide whether you would like to take part in our study. You can contact me if you have any other questions. Please take as much time as you like to decide. Thanks for your consideration.

**What is the purpose of this study?**

The purpose of this study is to contribute to improved experiences and decision-making for women living with heart failure through gathering and sharing stories of what matters to women, in their own voices. More specifically we aim to do the following:

* Interview 40 women (10 women each from British Columbia, Ontario, Quebec, and Nova Scotia) to learn about their experiences of living with heart failure
* Create an evidence-based online resource featuring experiences of women living with heart failure
* Evaluate the use and potential impact of this resource

**What will happen if I take part in this study?**

If you decide to take part in this study, you would participate in an interview with a researcher. The interview will be a conversation in which you will have the opportunity to tell your story of living with heart failure. We will then ask some questions to follow-up certain aspects of your experience. We would like to learn about the experiences of women living with heart failure, including but not limited to, knowledge about the condition, interactions with healthcare providers, diagnosis, treatment and self-care, etc. We also ask for some basic background information such as your age, relationship status, cultural background etc. You do not have to talk about anything you don’t want to talk about and you can decline to answer any question you don’t want to answer.

Typically, interviews last anywhere from 30 to 120 minutes. However, since there is also some additional paperwork, (including the basic questionnaire and making sure you have all the information you need before giving your consent) we ask that you allow 2 hours for the whole interview process. Once the interview transcript has been prepared, we will send it to you for review. This will take approximately another hour of your time. We will provide you with a $50 coffee or grocery gift card as a thank you for your participation.

We will ask if you would allow us to video-record the interview on Zoom. We ask to video interviews so that we can include short excerpts from the interviews on the Health Experiences website (You can see the website here: [www.healthexperiences.ca](http://www.healthexperiences.ca)). We will also be making a short film based on the experiences of the people we interview so that we can share parts of their stories in their own words. If you agree to participate, short excerpts from your interview will be included on the website and may be included in the film.

**What if I would like to participate but don’t want to be video recorded?**

If you would like to participate in the study but don’t want to be video recorded we can do an interview where we only record the audio. This means that only your voice would be included in extracts on the website. If you would like to participate but do not want even your voice to be included, we can just present your words as text.

**How do you protect my safety and privacy during the interview?**

No communication over the internet is 100% secure. However, our team will take all necessary precautions to ensure the safety and privacy of study participants. The Zoom platform has measures in place for the host, in this case the researcher, to control who can participate in the interview. We will send you a password that you will need to access the scheduled Zoom meeting and we will use the waiting room function to control who can enter the meeting. If you do not wish to be video-taped, the interview can be done by audio only (by Zoom or telephone).

**What would happen after the interview?**

The audio recording of the interview will be transcribed by a professional transcriber. The transcriber will type out everything that was said in the interview and will keep everything confidential. We will send you a copy of the interview transcript, by email, for you to review. We will ask that you read the transcript and let us know if there is any part of the interview you don’t want us to use on the website or in the film. We will not use any material you do not want us to use. You will also have the opportunity to decide whether to be identified by your first name on the website and/or the film (e.g. Mary, John) or by an alias of your choice. If you do not have access to email and/or would prefer to review the video/audio of your interview, this can be arranged. Please just let us know if you would like an alternative arrangement.

We will also prepare a brief participant biography that will be featured on the website. The participant biography is based on the information you provide us on the participant details form and on highlights from your interview. It provides some context for users of the website so they can better appreciate your story. We will send you a copy of your biography to review, along with your interview transcript. You may edit the biography and remove any information that you do not want included. We will only use the version that you approve for use online. You will also have an opportunity to review any audiovisual material (video/audio clips) that we develop, and we will remove any material you wish, prior to public release or dissemination.

**How would the researcher use the recorded interview and transcript?**

If you participate in an interview, your transcript will be analyzed to help us identify common themes in the stories people shared with us. The analysis will inform academic publications, reports to policy makers, educational or public presentations, our website and other online resources.

In the analysis, all interviews are considered together, as part of the whole set. The findings are grouped together and are presented anonymously. We might report, for example, that “Many of the people we spoke to, said it was challenging to get the help they needed” or that, “Several participants had negotiated new working arrangements with their employer because of the fatigue they were experiencing.” Any specific examples we include would just be identified by a first name, alias or participant study number. For example, “Mary felt that, at first, her doctor did not take her symptoms seriously.” (Participant 15)

**What am I consenting to?**By consenting to take part in an interview you are also consenting to have your interview included in the general analysis. Please note that, while you have the right to withdraw from the study at any time, we are unable to remove your data from the general analysis.

We will ask for additional consent to use video/audio extracts from your interview in the film, on our website or other approved websites, in teaching materials and presentations.

If you consent to video/audio use of your interview, short clips or extracts will be used to illustrate the experiences of people living with heart failure, for example, how people managed with heart failure, and what sorts of information and support were most helpful. You will be given an electronic copy of this consent form to keep.

All interview material, including video, audio, and text files will be housed on the Health Experiences Canada website indefinitely or until the research team decides to remove it. At any time, you may request that your information be removed and we will immediately release updated versions of the website that will not include any of your footage. Data will be used strictly in compliance with the laws of Canada. The Trillium Health Partners research ethics board may look at study data for the purpose of audit and monitoring

**How will my information be protected?**

We respect your privacy. Based on the current pandemic, the PI and research team are not working onsite and all data related to this study will be electronic. All electronic data and media files collected from the study will be stored on a closed and firewall protected THP secured server and will not be shared with anyone outside the study team unless required by law. We will not be storing or saving any audio and video file recordings to Zoom’s iCloud storage. Only the audio file recording will be sent for professional transcription. The transcriber has signed an agreement to keep everything you say in the interview confidential.

**What if I decide to withdraw after the interview has taken place?**

You are free to withdraw from the study at any time. If you decide to withdraw from the interview, all video recordings, transcripts, and documents related to the interview will be destroyed. We will be unable to remove participant data once analysis has been completed but no direct quotes will be included in reports and publications. If you decide to withdraw after the audiovisual resources have been finished, we would remove your contribution from all existing versions, although given that we will be posting this material online, there is always a chance that other people may have already seen or copied the material. A modified version of the website and any additional audiovisual material will be immediately released upon removal of your footage.

**What are the benefits of participating in this study?**

The benefits of this study include participant contributions to better understand the impact of living with heart failure, including how they managed living with heart failure, and what sort of information and supports were helpful for them and their families. This project provides a unique opportunity for individuals, groups and organizations to learn from a collection, featuring a range of experiences, from women living with heart failure. The findings of this study will also help inform future work to design, implement and evaluate improvements in local services for women with heart failure.

**Are there any risks involved in participating in this research?**

During the interview, the questions will be about your experiences living with heart failure. It is possible that some people may feel sad or emotional when sharing their experiences and stories to the researcher, and we have prepared a list of contacts which can be used to seek help or support as needed following the interview.

When you choose to give permission to have excerpts from your video published on the Internet, the statements you make about your personal health experiences will be viewable by members of the public, including third parties like colleagues or employers. It is possible, but unlikely, that third parties could use this information in a discriminatory way.You may be recognized by people – a little like appearing on TV or social media. You may wish to discuss this with members of your family, since they might be connected to your appearance online. For these reasons, if you have questions or doubts as how you want the interview to be included (as video, audio, text and/or with an alias) for analysis and web posting, or are concerned about any potential consequences for you or your family regarding, your work or other personal or social considerations, please speak with Michelle Marcinow (Research Associate) or Susan Law (Principal Investigator). We will only use material that you have given us permission to use in the analysis and online information.

**Do I have to take part?**

No. It is entirely up to you to decide whether or not you want to take part in this study. No questions will be asked if you withdraw from the study. Your decision not to participate will not influence: 1) the nature of your relationship with Trillium Health Partners either now, or in the future, or 2) with any of the researchers, study staff or anyone at Trillium Health Partners. By providing consent for this study, you do not give up any of your legal rights.

**Who has reviewed the study?**

This study has been reviewed and approved by the Research Ethics Board at Trillium Health Partners (Study #1063). Any future research will also be approved by the REB.

**Contact for further information**

If you have any questions at all about the study or wish to discuss anything, please contact the study team at FromTheHeart@thp.ca. If you wish to speak to Dr. Law directly you can reach her at susan.law@utoronto.ca or (416) 270-6643. If you want to talk to someone not connected with the study about your rights as a study participant, or if you have any concerns about your rights as a research participant, you can contact the Trillium Health Partners’ Research Ethics Board:

Phone: (905) 848 7580 x1682.

Email: THPREB@thp.ca

Address: Trillium Health Partner, 100 Queensway West, Clinical Administrative Building, 6th floor, Mississauga, ON, L5B 1B8

**Many thanks for reading this consent form.**

Dr. Susan Law

Senior Scientist, Institute for Better Health - Trillium Health Partners
Associate Professor, Institute for Health Policy, Management, & Evaluation, University of Toronto

Director, Canadian Health Experiences Research Program (CHERP)

Email: susan.law@utoronto.ca

Tel: (416) 270-6643

Dr. Michelle Marcinow

Research Associate

Institute for Better Health

Email: FromTheHeart@thp.ca

Tel: 416-565-6732

Mailing Address: Trillium Health Partners - Institute for Better Health

100 Queensway West, Clinical Administrative Building, 6th Floor, Mississauga, ON L5B 1B8

| **DOCUMENTATION OF INFORMED VERBAL CONSENT****Study Title**: From the Heart: Canadian women’s lived experiences of heart failureA researcher will review this consent form (Part A, B & C) with you and answer all of your questions before beginning the interview. The researcher will then verbally ask you to confirm the following statements below. Your verbal consent will be documented on this form and a recruitment log that will be saved separately from your video or audio interview file. The researcher will document, on this form, the date when verbal consent was obtained. You will receive an electronic copy for your records.**Part A: Consent to be part of an interview****Participant:** By consenting to this study, I **[insert name of participant]** confirm the following [researcher will check off each statement]:☐I understand the research being done, what is required to participate in this study, and what is expected of me. ☐I have had a chance to read each page of this form and have all of my questions answered to my satisfaction. ☐I understand that withdrawal from this study will not affect my current or future care. ☐I understand that my consent does not waive any of my legal rights, nor relieve the research team from any legal responsibility.☐I will receive a copy of the consent form by the research team member. ☐I agree to participate in this study. Preferred name (first name or alias): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Preferred phone number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Preferred email:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Mailing address (to send thank you note & gift card): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_☐I wish to receive general information in the future about the health experiences research (e.g. newsletter, announcements regarding new modules, etc.)**Statement of Research Team Member:** I will respect the rights and wishes of the participant as described in this informed consent document, and conduct this study according to all applicable laws, regulations, and guidelines relating to the ethical and legal conduct of research. I have verbally explained the purpose of the study to the participant and have answered all of his or her questions. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Name of researcher obtaining verbal consent Date verbal consent was obtained |
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***Part B:* Consent to use media clips**

I understand that excerpts of my interview will be posted to the collection of ‘health and illness experiences’ on the website [www.healthexperiences.ca](http://www.healthexperiences.ca) and its related social media accounts (Instagram -@healthexperiencescanada & Twitter - @HealthexpCAN). The extracts from my interview on the websites will be freely available to the public and extracts from my interview may appear on other sites approved by the organization.

I also understand that for these purposes, the interview and extractions from it, will be used for scientific and academic presentations, the making of audiovisual resources and other publications (including translation of the interview and extractions from it into other languages). My interview and extractions from it may be accessed with and used by academics, healthcare educators and other evidence-based healthcare information websites. It will not be used for advertising or commercial purposes.

I understand that by agreeing that my interview and extractions from it will be available on the internet, it will be accessible to internet users throughout the world including in countries that may have less extensive privacy protection laws than Canada. I also understand that the research group may sometimes wish to collaborate with our international DI partners and consent to my interview and extractions from it being accessed and used by such partners.

I **[insert name of participant]** consent to my interview being available in the following format(s) and used in the manner set out in this consent form [researcher will tick all that apply]:

☐ Video recording of interview

☐ Audio recording of interview

☐ Written transcript of interview

If I decide that I no longer want my interview to be used on the website (or for any other purpose) it will be removed immediately upon my request, although I accept that it may not be possible to remove all existing copies from circulation.

**Series title:** From the Heart: Canadian women’s lived experiences of heart failure

Participant ID#:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Recording available as:

☐Video

☐Audio

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Name of researcher obtaining verbal consent Date verbal consent was obtained



***Part C:* Consent to use my interview for future secondary research**

I **[insert name of participant**] agree that my interview will be available to the research team at the Institute for Better Health (IBH), and other members of the research team as a source of future data analysis and associated research activities, such as teaching, scientific and public presentations, the making of audiovisual resources and other publications. Any secondary research completed by the research team will be reviewed by the Research Ethics Board at Trillium Health Partners.

☐ I understand that I may request, at any time, that my interview not be made available for future secondary research.

☐ I agree to my data being used for future secondary research

I consent to my interview being available for future secondary research in the following format(s), tick all that apply:

☐ Video recording of interview

☐ Audio recording of interview

☐ Written transcript of interview

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Name of researcher obtaining verbal consent Date verbal consent was obtained

**Resources**

HEART HEALTH RELATED SUPPORT IN CANADA:

**Women@heart program:** https://cwhhc.ottawaheart.ca/programs-and-services/womenheart-program

**Heart & Stroke – Community of Survivors:** https://www.heartandstroke.ca/heart-disease/recovery-and-support/the-power-of-community

**GENERAL MENTAL HEALTH & WELL-BEING**

**Canadian Mental Health Association:**

Website:

General - <https://cmha.ca/>

Help & Info - <https://cmha.ca/document-category/mental-health>

**ONTARIO**

**Telehealth Ontario:** Free, confidential service you can call to get health advice or information. A Registered Nurse will take your call 24 hours a day, seven days a week.

Toll-free: 1-866-797-0000

Toll-free TTY: 1-866-797-0007

**ConnexOntario:** Access to addiction, mental health, and problem gambling services.

Toll-free: 1-866-531-2600

Website: <http://www.connexontario.ca/>

**BRITISH COLUMBIA**

HealthLinkBC: Provides reliable non-emergency health information and advice in British Columbia. Information and advice is available by telephone, our website, a mobile app and a collection of print resources.

Website: <https://www.healthlinkbc.ca/mental-health>

**NOVA SCOTIA**

Mental health and well-being resources

Toll-free: 1-888-429-8167

Website: <https://novascotia.ca/mental-health-and-wellbeing/>

**QUEBEC:**

**Info-Santé 811:** Free and confidential telephone consultation service. 811 is the only telephone number for this service. Dialing 811 promptly puts you in contact with a nurse in case of a **non-urgent** health issue. The service is available 24 hours a day, 365 days a year. Anyone living in Québec can call Info-Santé 811 for themselves or a family member.

Info-Santé 811 est un service de consultation téléphonique gratuit et confidentiel. Le 811 est le numéro de téléphone unique de ce service. Composer le 811 permet de joindre rapidement une infirmière en cas de problème de santé **non urgent**. Toutefois, en cas de problème grave ou de besoin urgent, il est important de composer le 9-1-1 ou de se rendre à l'urgence.

**Écoute entraide:** From 8 am until midnight 7 days a week. Do you need to talk, to trust, to share what you are going through? Our volunteers are there to listen to you and offer you resources when needed.

De 8 h am jusqu’à minuit 7 jours sur 7. Vous avez besoin de parler, de vous confier, de partager ce que vous vivez? Nos bénévoles sont là pour vous écouter et pour vous proposer des ressources en cas de besoin.

Montréal: 514 278-2130
Sans frais: 1 844 294-2130