a place of mind
THE UNIVERSITY OF BRITISH COLUMBIA

CANARY
CANNABIS ACCESS REGULATIONS STUDY

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Consent Form – Renewal for Follow-up

Title of Project: The CANARY Study: Impact of Regulatory Change on Patient Access to Medical Cannabis in Canada

Who is conducting the study?

Principal Investigator:

Dr. Lynda Balneaves, School of Nursing, UBC (on leave) Associate Professor, Faculty of Medicine, University of Toronto	647-628-7265

Knowledge Users:

Dr. Brian Emerson, BC Ministry of Health	250-952-1701
Dr. Kenneth Tupper, BC Ministry of Health	604-806-9116
Ms. Lynne Belle-Isle, Canadian AIDS Society	250-853-3235
Dr. Mark Ware, Canadian Consortium for the Investigation of Cannabinoids (CCIC)	514-934-8222

Co-Investigators:

Dr. Jane Buxton, University of British Columbia	604-707-2573
Ms. Rielle Capler, University of British Columbia	604-827-2160
Dr. Thomas Kerr, University of British Columbia	604-806-9116
Dr. Zachary Walsh, University of British Columbia, Okanagan	250-807-9373

Also collaborating on the study are the Canadian Medical Association, the Canadian Cancer Society, the British Columbia Cancer Agency, the Canadian Association of Medical Cannabis Dispensaries, Action Atlantic, the Chronic Pain Association of Canada, and the Canadian Pain Coalition.

You are being asked to continue to take part in a research study investigating the impact of changes to federal health regulations on how patients access cannabis for medical purposes (i.e., medical cannabis) in Canada and their use of health services and health outcomes.

Please read this explanation about the study before you decide if you would like to take part. Take as much time as you need to make your decision. You can ask the Principal Investigator, Dr. Lynda Balneaves, to explain anything that you do not understand and make sure that all your questions have been answered before agreeing to participate in this study. Feel free to talk about this study with anyone you wish. Ongoing participation in this study is completely voluntary and you can withdraw at any time.

Who is funding this study?
The Canadian AIDS Society and the British Columbia Ministry of Health are providing in-kind support (i.e., part of some co-investigators' salaries). Funding is being sought from the Canadian Association of Medical Cannabis Dispensaries and the Canadian Medical Cannabis Industry Association.

Why are we doing this study?
You are being asked to participate in this study because you are either someone who uses cannabis for medical purposes or someone who has a health condition that some people use medical cannabis to treat or to manage symptoms or the side effects of a related medical therapy. The purposes of this study are to learn more about how the new federal regulations on medical cannabis in Canada are impacting 1) patients' access to medical cannabis; 2) patients' satisfaction with the medical cannabis products and related health services available; and 3) patients' use of health services and their overall health. The purpose of this study is NOT to examine if medical cannabis is an effective treatment for different diseases.

How will the study be done?
If you agree to continue to take part in the study, you will be asked to complete an online follow-up survey The survey will take approximately 30 minutes to complete and must be completed in one sitting. You will have up to 3 hours to complete the survey.

If you previously indicated your willingness to take part in **a separate telephone interview** we may contact you for a follow-up interview. The interviews will take place at a date and time convenient to you, and will take **approximately 30 minutes**. Interviews can be conducted in French, upon request. The interviews will be recorded and typed out by a research assistant.

Study results
The results of this study will be reported in a graduate thesis and may also be published in reports, journal articles and books, and presented at conferences. Information from this study may be used again for teaching purposes by the Principal Investigator, Dr. Lynda Balneaves. The data collected will also become part of a database that may be used to study changes in access to medical cannabis in Canada in the future.

What are the risks of participating?
We do not think there is anything in this study that could harm you or be bad for you. There is a chance you may feel distressed by some of the questions in the surveys or interviews. You have the right not to answer any questions you feel uncomfortable answering and you may withdraw from the study at any time. If you feel distressed as a result of taking part in this study, you may contact Dr. Lynda Balneaves or Ms. Rielle Capler (telephone numbers above) to receive a list of resources that can help you cope with your distress.

What are the benefits of participating?
You may find the experience of sharing and describing your experiences of accessing

cannabis for medical purposes to be emotionally beneficial. Information from this study will also help to increase the current understanding of the use of medical cannabis in Canada. In addition, this study may help improve the federal Marihuana Medical Access Program, and the health services and health outcomes for those individuals using medical cannabis.

Will your information be kept confidential?

All information obtained during the study will be held in strict confidence. You will be identified on all study documents with a study identification number only. Because we will be discussing cannabis, which is a controlled substance (except for those individuals participating in Health Canada's medical cannabis program), all participants are encouraged to avoid writing about or discussing any identifying information (i.e., names, addresses, workplaces) when completing the surveys or the telephone interviews.

Please note that FluidSurveys is being used to collect survey data, and is a service provided by SurveyMonkey, a US based company. The servers on which FluidSurveys operate are located in Canada, so your information will be hosted in Canada. Additionally, your information may be processed in and transferred or disclosed to countries in which their affiliates are located and in which their service providers are located or have servers. In particular, the US Patriot Act allows authorities access to the records of Internet service providers. The survey or questionnaire does not ask for personal identifiers or any information that may be used to identify you. The web survey company servers record incoming IP addresses of the computer that you use to access the survey but no connection is made between your data and your computer's IP address. If you choose to participate in the survey, you understand that your responses to the survey questions may be accessed in the USA. The security and privacy policy for the websurvey company can be found at the following link: http://fluidsurveys.com/about/privacy.

The information you provide will be stored in a locked file cabinet and computer files will be password protected. All contact information (i.e., email addresses, telephone numbers) will be kept separately from the data in an unmarked file folder (stored in a locked filing cabinet) or on a password protected computer and destroyed at the completion of the study. Only the researchers associated with this project and their research staff who have signed confidentiality agreements will have authorized access to the data, and your contact information will not be released to anyone beyond the Principal Investigator or research staff contacting patients for follow-up surveys and/or interviews. No identifying information will be used in any publications or presentations that come from this study.

Will you be paid for taking part in this research study?

You will be entered into four draws for $50 each if you complete the follow-up survey. If you take part in the telephone interviews, you will be entered into a separate draw for $50.

Who can you contact if you have questions about the study?

If you have any questions or desire further information, you can contact the Principal Investigator, Dr. Lynda Balneaves, at lynda.balneaves@nursing.ubc.ca or 647-628-7265. Co-investigator, Ms. Rielle Capler, can be reached at rielle.capler@ubc.ca or 604-827-2160.

Who can you contact if you have complaints or concerns about the study?
If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent
Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your status with the Health Canada Marihuana Medical Access Program or the health care you receive. You can also ask Dr. Lynda Balneaves to remove your data from the CANARY study database at any time.

By reviewing this consent form and completing the survey, you are consenting to participate in this study and acknowledge that you have access to an electronic copy of this consent form for your own records.

☐ **I have read the above information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in this study. I freely choose to take part in this study and understand I can download a copy of the consent form, if I choose. By checking this box, you will be taken to the online survey.**