



Consent Form

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, University of British Columbia 604-822-7679

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 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. Participation in this study is completely voluntary and you can withdraw at any time.

Who is funding this study?

The study is being funded through a research fund of the Canadian Consortium for the Investigation of Cannabinoids and a grant application has been submitted to the Canadian

Institute for Health Research. The Canadian AIDS Society and the British Columbia Ministry of Health are also providing in-kind support (i.e., part of some co-investigators' salaries).

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 take part in the study, you will be asked to complete a maximum of **four (4) online surveys**, 3-6 months apart over a 15-month time period. Each survey will take approximately 30 minutes to complete and must be completed in one sitting. You will have up to 3 hours to complete each survey. You will receive invitations by email for the follow-up surveys which will contain a link to the survey.

If you indicate your willingness, we **may** also ask you to take part in **three (3) separate telephone interviews** spaced 3-9 months apart over a 15-month time period. The interviews will take place at a date and time convenient to you, and will take **approximately 30 minutes** each. Interviews can be conducted in French, upon request. The interviews will be tape 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 Marijuana 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.

The on-line survey company, *FluidSurveys*, is hosting this survey on their computer servers, which are located in the Canada and are subject to Canadian laws. The security and privacy policy for the web survey company can be found at the following link: (<http://fluidsurveys.com/about/privacy/>) Please note that you will not be asked to submit your name during the survey. *FluidSurveys* does not collect or store IP addresses. Email addresses and phone numbers will be collected so that we may contact you for follow-up surveys; however this identifying information will be kept separate from your survey responses and phone interviews.

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 all of the surveys. If you take part in the telephone interviews, you will be entered into a separate draw for \$50 if you complete all of the interviews.

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 604-822-7679. 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 surveys, 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.

Please provide your contact information (email, cell and telephone number) in order for us to contact you about the follow-up surveys in 3-6 months. We may also contact you about taking part in the telephone interviews, with your permission. Please indicate below if you would be willing to be contacted for the telephone interviews.

Because we will not have your name, please answer the security question below so that we can make sure we have the correct person on the telephone. We will not indicate in any email, voice or text message the focus of this study (i.e., cannabis) and will only identify ourselves as being part of the CANARY Study.

Your personal contact information will not be attached to the survey or interview data we collect and will be stored in secured location (i.e., password-protected computer file on a firewalled computer server at UBC; locked filing cabinet in the Principal Investigator's research office).

Email address: _____

Telephone number (for calling): _____

Cell number (for texting): _____

Security Question - What street did you grow up on?: _____

Would you be willing to be contacted for the telephone interviews?

- Yes
- No

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.