

Participant Information Sheet



Study title: *New Zealand Medicinal Cannabis Use Research Survey 2019*

Locality: **Online**

Ethics committee ref.: 19/CEN/54

Lead investigator: **Geoff Noller**

Contact phone number: +6421471042

You are invited to take part in a research study on the use of medicinal cannabis. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to read the Consent Form on the last page of this document. You will then be asked in the first page of the online research survey if you agree to the terms of the consent form. A copy of both the Participant Information Sheet and the Consent Form can be downloaded to keep.

This document is 5 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to survey trends in the medicinal cannabis patient community, including patient attitudes, experiences, ways of consuming medicinal cannabis, and what conditions it is used for.

Surveying patients will help us better support those who use cannabis medicinally, including providing information about different types of cannabis-based medicines and supporting access to treatment.

This is an online study and the research survey questionnaire can only be completed online, by using the research survey link. If you have questions about any part of the study you may contact the MCANZ Coordinator, Shane Le Brun, on 027 581 8305 or the study's coordinating investigator, Geoff Noller, on 021 471 042.

The study is funded by Medical Cannabis Awareness New Zealand (MCANZ), a medicinal cannabis patient advocacy organisation. MCANZ is a registered charity. The study has received ethical approval from the Health and Disabilities Ethics Committee (ref# 19/CEN/54).

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You are being invited to take part in the study because you are using or have used cannabis for medicinal reasons. Also, you are over the age of 18 years. You do not have to take part in this study, and if you choose not to take part this will not affect any future care or treatment.

To take part in the study you must be able to communicate in English, as there are no interpreters available.

If you decide to take part you will be asked to complete an online questionnaire. This asks about various aspects of your use of cannabis for medicinal reasons. This will take you between 15-20 minutes.

Some of the questions ask about your use of prescription medicines and aspects of your relationships with health professionals. However, no personal identifying information is collected and you are not able to be identified by anyone from providing answers to any questions or taking part in the study.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Risks of the study:

The main risk in this study is that people taking part by answering research survey questions will be admitting to using cannabis which is illegal. For this reason the study organisers (MCANZ) will not be collecting any personal information. Also the online research survey does not collect any digital information that can be traced back to your computer, to show how you answered any questions.

Therefore, because the study is anonymous none of the information you are asked for will be able to identify you. However, because you are answering questions about your use of an illegal drug you may feel anxious about taking part in the study.

Some of the questions you might be asked may be sensitive or embarrassing, as these may relate to specific medical conditions that you have. For this reason, you do not have to answer any questions you do not want to.

What are the benefits of the study?

There are no direct benefits from taking part in the study. However, by answering the questionnaire you may gain a clearer idea about your use of cannabis as a medicine. You

may also feel that by taking part in this study that you are helping yourself and others be better supported as people who use cannabis for medicinal reasons.

WHO PAYS FOR THE STUDY?

The study has been paid for by Medical Cannabis Awareness New Zealand (MCANZ), which is a medicinal cannabis patient advocacy not-for-profit registered charity. For this reason, taking part in this study does not cost you anything, other than 15-20 minutes of your time. You do not receive any compensation for taking part in the study.

WHAT IF SOMETHING GOES WRONG?

Because you are only answering questions anonymously, it is unlikely that you would be injured in this study. However, if something did go wrong you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

WHAT ARE MY RIGHTS?

Getting involved in this study is entirely voluntary (your choice). You do not have to answer all the questions if you don't want to. If you do, or do not, take part, it will in no way affect the service provided to you by MCANZ now or in the future, or any treatment you may be having with health professionals. If you wish to withdraw at any time you may do this without any disadvantage or negative consequences.

Any individual's information that is obtained through this study will remain confidential. Because the study is anonymous and the researchers are not able to track your personal information it is not possible to provide copies of individual participants' information to them. If you give us your permission by signing this document, we may plan to publish the results as journal articles. No material that could personally identify you will be used.

Participants will be told of any new information about negative or beneficial effects related to the study that becomes available during the study, which may have an impact on their health.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

All information is anonymous and it will not be possible to track individual participants digitally. Only the researchers will have access to the raw digital data. This will be password protected on MCANZ's online storage server, with two-factor authentication required. The raw data (i.e. your answers) will be deleted after seven years.

Any paper documents will be placed in a locked cabinet in the coordinating investigator's office.

Key study results will be provided through the MCANZ website. Results will be published in a peer-reviewed journal and presented at conferences. Other relevant organisations such as the Ministry of Health, medical professional bodies, media, potential medicine manufacturers, and other charities representing consumers may receive portions of the study results as combined data.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Shane Le Brun, MCANZ Coordinator

Mob. 027 581 8305

Email Shane@MCANZ.org.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

For Māori health support please contact :

Dr Huhana Hickey, MCANZ Chairperson

0220597752

huhana@mcanz.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Participant Consent Form



By Accepting to continue with the research survey, you consent to the following:

I have read and I understand the Participant Information Sheet.

I have been given sufficient time to consider whether or not to participate in this study.

I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.

I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.

I consent to the research staff collecting and processing my information, including information about my health.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I know who to contact if I have any questions about the study in general.

I understand my responsibilities as a study participant.