



Participant information sheet

Study title: Preferences for Asthma Treatment Regimens – A Qualitative Study.

Locality:

Ethics committee ref: 19/CEN/52

Lead investigator: James Fingleton

Contact phone number: 04 805 0234

Thank you for your interest in this study. You are invited to take part in a group discussion about inhaled asthma treatments. Some asthma inhalers have different purposes. Some are meant to relieve asthma symptoms, so they are meant to be taken when you feel short of breath or wheezy. Others are to prevent asthma symptoms or flare-ups from occurring so they are meant to be taken every day. Research shows that lots of people who are prescribed asthma inhalers every day don't take them every day. We want to know what is most important to people about their asthma treatments, and what they think a "perfect" asthma inhaler routine might be. We will use this information to let doctors and nurses know what is most important to patients and to help design future studies. We hope that this will help us develop better asthma treatment plans in the future which are easier to take and what people want.

You can be involved in the group discussion if:

- You're aged 18-75
- Your doctor has diagnosed you with asthma
- You're currently prescribed asthma medications by your doctor
- You've used the asthma medications at least once in the last month.

The study is being run by Dr Christina Baggott and Dr James Fingleton from the Medical Research Institute of New Zealand. Contact details are at the end of this information sheet.

The group discussions will include 4-8 people with asthma and 2 members of study staff. The study staff will start the group by asking some questions. You will be asked to talk about your thoughts and opinions of asthma treatments with everyone. The group will take about 45–60 minutes. The discussion will be audio-recorded. This is so we don't miss any important details. Then the researchers will copy the discussion into text.

We will ask some basic details about you and your asthma. Any details about you will be anonymised so you can't be identified. The study staff team will analyse what people have said in the group discussions. Then aim to publish it in a medical journal. Any publications may contain quotes of something you have said, but they won't contain any details which could identify you. The recordings and text will be held in a secure place accessible only to study staff for 15 years. After that they will be destroyed.

The results of this study may benefit people with asthma in the future. There is no guarantee that you will directly benefit from taking part. But there are no known risks from taking part. Your usual medical care will not be affected in any way whether you decide to take part or not. Anything you say is confidential and will not be passed on to your doctors. Your involvement is entirely voluntary. You are welcome to leave the group at any time, or to decline to answer any questions. If you do decide to withdraw from the group discussion early, any details that you've already provided will not

be used by the research team. It isn't possible to remove your voice from the audio recording but your information will be removed from the text and not analysed.

The study has ethical approval from the Central Health and Disability Ethics Committee. To protect the privacy and confidentiality of the other people in the group discussion, we ask that you don't talk about the group discussion with other people. You are welcome to bring a family/whānau member with you, but they will be asked not to take part in the discussion. They will need to keep everything discussed confidential. So we will ask them to sign a confidentiality form. We will reimburse people who takes part in the group discussion \$50, but not accompanying family/whānau. This is to cover people's travel and expenses.

Consent form



Please tick to indicate your consent to the following:	
I have read and understood the participant information sheet.	
I have been given enough time to consider whether or not to participate in the group discussion. I've had the chance to access family/whānau support if needed.	
I understand that taking part in the group discussion is confidential and no information which could identify me personally will be used. But direct quotes and de-identified data may be shared with other researchers and published in a medical journal.	
I consent to being audio-recorded.	
I consent to the research staff collecting and processing my information, including information about my health.	
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	
I understand that taking part in the group discussion is voluntary (my choice) and I can leave the group at any time, and it won't affect my ongoing medical care.	
If I withdraw early from the study I understand that my voice can't be removed from the audio recording but all other data will be withdrawn and none of my data will be analysed.	
I understand the information I provide will be stored securely and only study staff will be able to access the information.	
I know who to contact if I have any questions about the study in general.	
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 my responsibilities as a study participant.	

I would like to receive an anonymised summary of the main findings of my group discussion with the opportunity to comment on it

Yes / No

I would like to receive a copy of the results of the study once published

Yes/ No

My email address to receive these is: _____

Declaration by participant:

I hereby consent to take part in this group discussion:

Signature
Name (print)
Date

Declaration by member of research team:

I have given a verbal explanation about the group discussion to the participant and have answered all their questions about it. I believe that the participant understands the group discussion and has given informed consent to participate.

Signature
Name (print)
Date

Study Doctor Christina Baggott:
Phone: 04 805 0262
Email: christina.baggott@mrinz.ac.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@hdc.org.nz

For Māori health support please contact:

Matire Harwood
Papakura Marae Health clinic
Phone: 09 297 2160

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

Phone: 0800 4 ETHICS
Email: hdec@moh.govt.nz