Te Whatu Ora
Health New Zealand

UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

Participant Information Sheet

Study title:	**Oral corticosteroid use in asthma**		
Locality:	University of Auckland	Ethics committee ref.:	**AHREC AH28664**
Lead investigator:	Amy Chan	Contact phone number:	09 3737599 ext 85224

You are invited to take part in a study to help us understand what your opinions, perceptions and beliefs are about use of oral steroids in asthma. We are interested in hearing about your views so that we can understand what people think about oral steroid treatment in asthma, your experiences, and how we can improve asthma treatment. This is being undertaken as a summer student project.

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 will 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 sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

Why are we doing this study?

At present there has been very little research undertaken to understand people's specific views about steroid use in asthma. The purpose of the study is to explore what people living with asthma think about the use of oral steroids for the management of asthma and what their experiences have been in the past. This will include exploring what information they have received or know about oral steroids, their views on when oral steroids are needed for asthma treatment, their experiences of taking steroids and what concerns if any they have about steroid treatment. Your views will help us understand what people living with asthma think about steroids and what their experiences have been. Understanding this better will enable GPs, respiratory specialists and other health providers to deliver better information in a way that best suits the needs of people with asthma and inform the use of steroids in asthma treatment.

What will my participation in the study involve?

You have been invited to participate as you have indicated that you are interested in taking part in this study via responding to an email about the study, or via social media advertisement, are aged 18 years or older, have asthma and have taken oral steroids before.

If you choose to participate, you will be asked to share your views about oral steroids in asthma. This will take place as a one-on-one interview, over telephone or Zoom video conferencing, lasting about 45-60

minutes, at a date and time that suits you. You are welcome to have a support person attend this interview if you wish.

To make sure we can accurately remember your views we will need to either audio or video record the conversation or take notes, whichever you are most comfortable with. We will ask you prior to starting the interview which method you prefer, and this will be documented before the interview proceeds. The interview recordings will be transcribed by the interviewer and /or by a professional transcribing company or University-approved transcribing software to help us identify the common views and opinions between different people. To ensure we keep your views as confidential as possible, we will assign a participant number to the recordings and the transcripts so we cannot identify you (i.e. the data is de-identified). The recordings and the transcriptions will be stored in a secure, University-managed password protected server. Only the researchers on the team will have access to the information from the interview; the data will be deleted after six years. Any third-party transcribers used to transcribe the interviews will be asked to sign a confidentiality agreement to protect the privacy of the participants.

During the interview we will ask you to describe what your experiences have been about oral steroids, what you think are the benefits and harms of steroid use, and when you think steroids may be needed. We will also explore what information about oral steroids should be given by your GP and health provider. We will ask you some background information about yourself such as age, sex, and when the last time was that you had steroids for asthma and your experiences including any positive or negative experiences. If you have any questions about your health, we encourage you to discuss these with your GP or other healthcare team involved in your asthma care to address these.

If you volunteer to be interviewed, please indicate on the consent form if you would like to receive a copy of the transcript of your interview for you to check and edit. If you request this, we will send you your transcript and ask that you respond with/highlight the changes you would like to make and return it to us within two weeks of the date of receipt. If you do not return the transcript or contact us within two weeks, we will assume that you do not have any changes to make to its content.

Your views will be combined with other participants in this study. The information will be summarized in a written report or presentation. All contributions will remain deidentified and none of the material in the results will personally identify you. We may use direct quotes from the interviews in the report or presentation as an example of experiences of oral corticosteroid use – however these quotes will be de-identified (i.e. personally identifiable information about you will not be shared). However, there is a small chance that if people are aware that you took part in this study, they may be able to infer that you were the person who said those things. The researchers will minimise this risk as much as possible by removing all identifiable information from the quotes and referring only to your participant number, sex and age when referring to quotations.

What are the rights of participants in the study?

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 – before, during or following the interview. You do not need to give a reason for withdrawing.

- If you have been interviewed then you have two weeks to withdraw your responses, after which your data will have been added to others and cannot be separated out.

It is possible that during the interview, you may recall a distressing or difficult experience with your asthma or treatment. If this occurs, feel free to let the interviewer know if you'd like to stop the interview, or if you wish to withdraw from the study. The interviewer may encourage you to contact your usual health provider or Healthline if you are concerned about any aspects of your asthma management, or with your permission, they can contact them for you.

All participants who take part have the option of being emailed a short summary of the results when they are completed – if you wish to receive this, please provide your email address at the end of the consent form.

All participants will be offered a $50 grocery (supermarket) or online retail voucher to thank them for their time.

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 Associate Professor Amy Chan (Principal Investigator) Email: a.chan@auckland.ac.nz or any of the investigator team below. This research project is being conducted by Ollie Simcock (as part of a Summer Research Studentship) and is under the supervision of Associate Professor Amy Chan.

Name of Principal Investigator/Supervisor (PI):

Associate Professor Amy Chan, School of Pharmacy, University of Auckland

Name of Co-investigator(s):

Dr Jay Gong, School of Pharmacy, University of Auckland

Mr Adam Wright-St Clair, School of Nursing, University of Auckland

Dr Christina Baggott, Te Whatu Ora Waikato

Dr Cat Chang, Te Whatu Ora Waikato

Name of Student Researcher(s):

Ollie Simcock, School of Pharmacy, University of Auckland

Name of Research assistant:

Liam Petrie, Te Whatu Ora Waikato

Principal investigator:	**Head of School:**
A/Prof Amy Chan School of Pharmacy The University of Auckland Private Bag 92019 Auckland, New Zealand 85 Park Road, Grafton Telephone: (09) 923 5224 Fax: (09) 367 7192 Email: a.chan@auckland.ac.nz	A/Prof Shane Scahill School of Pharmacy The University of Auckland Private Bag 92019 Auckland, New Zealand 85 Park Road, Grafton Telephone: (09) 923 5226 Fax: (09) 367 7192 Email: s.scahill@auckland.ac.nz

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext. 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Thank you for reading this and considering participating.

Approved by the Auckland Health Research Ethics Committee on 16 Dec 2024 for three years. Reference number AH28664

Consent Form

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Oral corticosteroid use in asthma

• 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, I/ family support or a friend to help me ask questions and understand the study.		
• I understand that taking part in this study is voluntary (my choice) and that I may withdraw (not continue to participate in the study) at any time (before, during or after the interview) without this affecting my medical care.		
• If I have been interviewed and I decide to withdraw from the study, I understand I have two weeks to ensure my information is not included in the study, and that after that time, the information collected about me will be collated with other participants' information and therefore cannot be separated and excluded.		
• I consent to the research staff collecting my views through an interview, including information about my health, such as about my medicines.		
• I agree to the interview being recorded either in audio, video or written form		
• I agree to the interviewer or a professional transcription company or third party software transcribing my interview recording		
• I understand that all interview data will be stored in a de-identified form		
• 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 agree that anonymised quotes from my interview can be used in publications or reports resulting from the research.		
• I know who to contact if I have any questions about the study.		
• I understand my responsibilities as a study participant.		
• I wish to receive an electronic copy of my transcript to check and edit, and understand I will need to return any changes or edits to the transcript within 14 calendar days of receipt	Yes ☐	No ☐
• I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Email address I would like my interview transcript to be sent to (please write):

_____

Email address I would like the summary sent to (please write)

_____

Declaration by participant:

I consent to take part in this study.

Participant's name: _____

Signature: Date:

Declaration by a member of the research team:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

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