Kia ora. My name is Dr. Julie Spray and I am a researcher at the University of Auckland and I am working in partnership with the National Hauora Coalition to learn more about children's health care.

You are invited to take part in my study on children’s involvement in asthma management. New Zealand has one of the highest rates of childhood asthma in the world, but not much is known about how children, families, and health professionals negotiate how children are involved in their asthma management. I am hoping that this study will give health professionals an opportunity to share their experiences of, approaches to and challenges with children’s involvement in their asthma management to inform guidelines and policies for managing children’s chronic illnesses such as asthma.

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. You are welcome to talk about the study with other people, such as family, whānau, friends, or healthcare providers before you decide.

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.

This document is 7 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS 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.

**WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study is to understand how children, families, and health professionals think about children’s roles and responsibilities for their asthma management. This is important because children often have to take on many asthma management tasks, but it's
not always clear what children’s roles are or should be. The findings from this study will be used to inform asthma guidelines and models of care for families with a child with asthma.

**HOW IS THE STUDY DESIGNED?**

There are three parts to this study. You are invited to participate in Part A. If you are interested, and have interested patients, you might also decide to take part in Part C, but you can make a decision about this after Part A. You may also choose to help with recruiting families for Part B but this is not required for participation in Part A.

Part A involves the researcher interviewing health professionals. About 20 health professionals may participate in this part of the study.

Part B involves 2 researchers visiting children and their families in their homes to talk about how children and families manage asthma. About 20 families with a child with asthma may participate in this part of the study.

Part C involves the researcher joining families as they visit with a health care professional to observe how health care professionals, children and families work together to manage asthma. About 10 families and their health professionals may participate in this part of the study. The researcher will join with 1-2 clinic visits per family.

**WHO CAN TAKE PART IN THE STUDY?**

You are invited to participate if you:

- Are a health professional of any kind
- Work in the wider Auckland region
- Work with children with asthma
- Are happy to be interviewed in English
- Agree to participate in the study

**WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?**

If you choose to participate, the lead researcher Julie Spray will contact you to schedule an interview at a time convenient for you. The interview will take about 15-30 minutes, depending on how much time you would like to contribute to the study. You can choose to have the interview in person at your clinic or home, or over the phone, Zoom, or Microsoft Teams.

The interview will include questions about your position and role, any practice models you use and how you like to approach working with children and their families, the way you think about children’s roles in their care, challenges you experience, and ways you would like to be better supported with managing asthma with children and families.
**WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?**

One risk of participating in this study is that confidential information about you may be accidentally disclosed. I will use my best effort to keep the information about you secure. I will use pseudonyms in any publications.

**WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?**

By participating in this study, your contributions may help to improve how New Zealand supports health professionals working with children with chronic illnesses and their families.

**WILL ANY COSTS BE REIMBURSED?**

It will not cost you any money to participate in the study.

**WHAT WILL HAPPEN TO MY INFORMATION?**

The interview with you will be audio recorded. Access to these recordings is limited to research team members only.

Any information I gather about you will be kept confidential and will not be made public or shared with your organisation or employer.

You may choose to receive a copy of your interview transcript for your review. Any edits you make to your transcript must be returned to the researcher within two weeks of the date it was sent.

**Identifiable Information**

Identifiable information is any data that could identify you (e.g. your name, date of birth, or address). Only researchers will have access to your identifiable information.

**De-identified (Coded) Information**

To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the researchers. Instead, you will be identified by a code and pseudonym. The researcher will keep a list linking your code with your name, so that you can be identified by your coded data if needed. The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

**Security and Storage of Your Information.**

Your identifiable information is held at the University of Auckland during the study. After the study it is transferred to a secure archiving site and stored for at least six years then destroyed. Coded study information will be kept by the researcher in secure, cloud-based storage indefinitely. All storage will comply with local and/or international data security guidelines.

**Risks.**

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified.
Rights to Access Your Information.
You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected.
If you have any questions about the collection and use of information about you, you can ask Dr. Julie Spray.

Rights to Withdraw Your Information.
You may withdraw your consent for the collection and use of your information at any time, by informing the lead researcher, Dr. Julie Spray.
If you withdraw your consent, your study participation will end, and the study team will stop collecting information from you.
If you agree, information collected up until your withdrawal from the study will continue to be used and included in the study. You may ask for it to be deleted when you withdraw, unless you withdraw after the study analyses have been undertaken.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?
If you wish to withdraw from the study, you can do so by informing the lead researcher, Dr. Julie Spray.
If you decide to withdraw your information collected from the study, the information will be permanently deleted from the servers.

CAN I FIND OUT THE RESULTS OF THE STUDY?
A summary of study findings will be made available to all participants within one year after the data collection has finished.

WHO IS FUNDING THE STUDY?
This study is funded by The Royal Society Te Apārangi and the Auckland Medical Research Foundation.
The lead researcher, Dr. Julie Spray, is with the section of Social and Community Health at the University of Auckland.
Julie is supported by Dr. Anneka Anderson, who is with Te Kupenga Hauora Māori at the University of Auckland and the National Hauora Coalition, and Dr. Janine Wiles who is with the section of Social and Community Health at the University of Auckland.

WHO HAS APPROVED THE STUDY?
This study has been approved by an independent group of people called the Auckland Health Research Ethics Committee (AHREC), who check that studies meet established ethical standards.
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:

Dr. Julie Spray, Research Fellow
02102752009
j.spray@auckland.ac.nz

Head of Department contact details: Associate Professor David Newcombe, Head, Section of Social and Community Health, School of Population Health, Faculty of Medical & Health Sciences, The University of Auckland, Private Bag 92019, Auckland. Telephone +64 9 923 6361, Email: d.newcombe@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 x 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

For Māori cultural support please contact: Dr. Anneka Anderson (Kāi Tahu, Kāti Māmoe), Te Kupenga Hauora Māori, The University of Auckland. Telephone: (09) 923 3373, Email: a.anderson@auckland.ac.nz

APPROVED BY THE AUCKLAND HEALTH RESEARCH ETHICS COMMITTEE ON 16/11/2021 FOR 3 YEARS, REFERENCE NUMBER AH23301
Consent Form
PART A: For Health Professionals

Breathing Together: Children’s involvement in asthma management

National Hauora Coalition
Lead Researcher: Julie Spray
Study Site: Auckland
Contact phone number: 02102752009

Please sign to indicate you consent to the following

- I have read, or have had read to me, 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, whanau/ 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 employment.
- I agree to participate in this study.
- I understand that my participation in this study is confidential and that my name or any identifying details will not be used in any reports on this study.
- I know who to contact if I have any questions about the study in general.

I wish to receive a copy of my interview transcript for editing. I understand that after the transcript is sent I will have two weeks to return edits to the researcher. Yes □ No □

I wish to receive a summary of the findings from the study. Yes □ No □

Send my requested transcript/summary by post / email to (address):

____________________________________________________________

Declaration by participant:

I hereby consent to take part in this study.

Participant name: ____________________
Participant signature: ___________________________ Date: ____________

Member of research team check here if consent was recorded verbally □ Yes □

Declaration by member of 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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