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, along with your whānau/family members, 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 are involved in their asthma management. This is important because how children manage their asthma could affect their health. I am hoping that this study will give children and their families an opportunity to be heard by the people who make 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. 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. The participating children and the parent/guardian who is giving consent for their participation will sign a separate Consent Form.

This document is 8 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 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 improve asthma guidelines and how health professionals support children and families with asthma management.

**HOW IS THE STUDY DESIGNED?**

There are three parts to this study. Your child and family are invited to participate in Part B. If you are interested, you might also decide to take part in Part C, but you can make a decision about this after the researchers visit you.

- **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. The visits will be 1-2 hours long. The researchers will bring activities like drawing, photography, poster-making, storytelling or show & tell activities to work with the child who has asthma and any siblings who wish to take part. The researchers will also ask children and families to fill out a survey about asthma management and symptoms. 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.

The study will take place over 24 months, finishing in August 2023.

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

You are invited to participate if you are a family member of a participating child and parent/guardian, and you’re happy to participate in English.

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

If you agree to participate in the study, this is what will happen. Two researchers will visit your family in your home twice over approximately three months. We will come for about 2 hours at a time and that is convenient for your family. We will talk to you and your family to learn about how you manage asthma at home. At the beginning of each visit we will talk to everyone together. Then we will work with the children separately on some activities, and, if you are happy to, we will also talk to you about your experiences supporting a child with asthma. You are free to skip any questions that you would prefer to not answer.
In between our two visits, your family may choose to participate in a PhotoDiary project by taking photos of your life with asthma. On our second visit, you can share the photos with us and talk about what they mean to you. We will provide more detailed instructions during our first visit. Anyone in the family can take photos of anything that feels important to the story of your lives with asthma. Your family can choose which photos you share with the researchers and whether or not you agree that they can be published.

**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 cares for and supports families with a child with asthma.

**WILL ANY COSTS BE REIMBURSED?**

It will not cost you any money to participate in the study. In recognition of your time, your family will receive a $30 supermarket voucher per visit as koha. I will also bring snacks and art supplies that will be the children’s to keep after the study.

**WHAT WILL HAPPEN TO MY INFORMATION?**

During this study the research team will record information about you and your study participation.

During our visits, we will make audio recordings of our conversations. Access to these recordings is limited to research team members only. We might also invite children and family members to take photographs or make drawings. If you take photographs or do drawings you will be able to choose whether or not to share any photos or drawings with us. Any photos or drawings you share with us will only be used in a way that you and your family members cannot be identified. The researchers might also make drawings with the children or after the visit as well. If our drawings are of your home or family we will ask your permission to use the drawings in our study. You may choose to keep any of the drawings you or the researchers make.

Any information the research team gathers about you will be kept confidential, and will not be made public. Anything you say to us in confidence will not be shared with your other family members.

**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.

This research includes basic information such as your ethnic group, geographic region, age range, and sex. It is possible that this research could one day help people in the same groups as you. However, it is also possible that research findings could be used inappropriately to support negative stereotypes, stigmatize, or discriminate against members of the same groups as you. To minimise this risk, I am working in partnership with the National Hauora Coalition and with Dr. Anneka Anderson (Kāi Tahu, Kāti Māmoe), an experienced Māori health researcher.

**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. You will only be able to withdraw information you give to the researchers individually (i.e. in a 1-on-1 interview). If the consenting parent/guardian of participating children chooses to withdraw their information from a family group interview then all information from the group interview, including yours, will be deleted.
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?

If you wish, we will create a summary of our research with your family for you to keep, including any drawings made. Anything told to us in confidence will not be included in the family summary. You will have an opportunity to check and correct anything we got wrong.

A summary of study findings will be made available to all participants within one year after the research with families 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
0211351300
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 B: For Adult Whānau Members

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 medical care.
- 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.

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 wish to receive a summary of the research with my family

I wish to receive a summary of the findings from the study.

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

_______________________________________________________________

Declaration by participant:

I hereby consent to take part in this study.

Participant name: ____________________________________________
Participant signature: _______________________________ Date: _____________

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: ________________

APPROVED BY THE AUCKLAND HEALTH RESEARCH ETHICS COMMITTEE ON 16/11/2021 FOR 3 YEARS, REFERENCE NUMBER AH23301