Kia ora!

My name is **Julie Spray** and I am a researcher. My team and I are doing a study to find out about young people with asthma living in New Zealand. Lots of young people in New Zealand have asthma, but no-one has ever asked how you deal with it in your life. I think this is important though, because at the moment all the decisions about asthma are being made by adults without hearing any young person’s opinion on what you do to care for asthma.

You get to decide if you would like to take part in this study. I will go through these pages with you, and answer any questions you may have. You do not have to decide today whether or not you want to be in this study. You can talk to other people like family or whānau to help you decide. You can change your mind about being in the study at any time.

You can be in this study if you are a child aged 6-14 with asthma, or if you are the sibling of a child this age with asthma who is also participating.

If you agree to be in this study, there is a special form at the end of these pages for you to sign, called an assent form. Your parent or guardian will also need to say it is okay for you to be in the study.
### Who else is in this study?

There are three parts to this study. For Part A, we are talking to about 20 health professionals like doctors or nurses about what they think children do to care for asthma. For Part B we will talk to about 20 families like yours. For Part C, we will visit join about 10 families when they visit a doctor.

### What will happen if I say yes?

If you agree to be in this study, this is what will happen.

Two researchers will make two visits to you and your family in your home. We will visit for about two hours each time.

We will talk to your family about how you all care for asthma. And, we will do activities with you and any other children from your family who want to be in the study. You will get to choose from different activities we bring, like drawing, show and tell, or making posters. If you are the child with asthma, we will also ask you to fill out some surveys about your asthma.

I will also bring snacks and art supplies that will be yours to keep after the visit.
In between the visits, we will invite you and your family to take photos of your life with asthma. If you do, on the second visit, we will look at your photo diary and you can tell us about your pictures. Your family can choose which photos you show us and decide if we are allowed to publish them in our reports.

We want you to feel happy and comfortable, so you don’t have to do anything you don’t want to do. If you don’t want to answer any question we ask, you can say ‘pass’ or ‘skip’ or just not answer!

If a Covid-19 lockdown happens when we are supposed to visit, we might make a new visit time or see if you want to talk to us online instead.

**Will you keep what I say private?**

You can choose a secret name that I will use for all your information. I might write about you and the things you tell me, but I will always use the secret name you chose and never your real name. I won’t tell anyone else anything you’ve said to me, unless I am concerned for your safety, and then I would always discuss my concerns with you first.

**What if I change my mind?**

If you decide you don’t want to be in the study anymore, that’s okay! You can tell your parent/guardian or Julie and we will stop the visit.

**What should I do now?**

Please talk to your parent/guardian about whether you would like to take part in the study. You don’t have to decide right away, but if it sounds interesting to you then I can come and meet you at your house to tell you a little more about what we might do and answer any questions you have.

If you have any questions or wish to know more, you can contact me:

Dr. Julie Spray, Research Fellow
02102752009
j.spray@auckand.ac.nz
Assent Form
PART B: For Children 8-14

Breathing Together: Children’s involvement in asthma management

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

If you agree to all these things, please sign below:

I have read this form or someone has read it to me.
A researcher has explained this study to me.
I understand what this study is about.
I have asked all the questions I want.
I am happy to take part in this research study.

Participant Name: Date:

Participant Signature:

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 assent 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