

Participant Information Sheet

Participant Information for a family member of child/young person with LUPUS

Date Information Sheet Produced:

2/9/2021

Project Title

Experience and perspectives living with systemic lupus erythematosus

Kia ora, Talofa lava, Malo e lelei, Kia orana, Fakaalofal lahi atu, Nǐ hǎo, hello,

You are invited to participate in a study that explores the experience and perspectives of living with systemic lupus erythematosus (lupus). We are interested in how you and your family describe this experience and what supports, strengthens, and challenges you in daily life.

What is the purpose of this research?

Lupus is a chronic disease that affects many body systems and requires complex and ongoing management for you and your family on a daily basis. We want to know about your experiences of living with lupus. We want to understand your perceptions, experiences and coping strategies in hopes of giving you and your family as well as health care providers better tools to improve care.

The findings of this research may be used for academic publications and presentations.

How was I identified and why am I being invited to participate in this research?

You were invited to be part of this study because you expressed an interest and have a child with a diagnosis of lupus. In addition, you will be encouraged to invite members of your family to participate with you. You and your child will decide who you would like to attend.

How do I agree to participate in this research?

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. The nurse, physiotherapist, doctor and/or researcher will talk to you about the study and answer any questions you have. You can take a copy of this information sheet to think about it or talk about with your family, whānau, aiga, friends, or other healthcare providers before you decide.

Once you understand what the research is about and if you agree you would like to take part in it, you will be asked to sign a Consent form on the last page of this document. You will be given a copy of this information sheet and the consent form to keep.

Your participation in this research is voluntary (it is your choice) and whether you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

In addition, to consenting for yourself to participate, if you have a child who is under the age of 16 years then you will also need to sign an additional consent form on their behalf. They will sign an assent form.

What will happen in this research?

If you choose to participate, you will take part in an interview with a researcher where you will be asked to describe your experiences of living with lupus. You will invite anyone you consider to be part of your

whanau to attend the interview with you. There will be only one family interview, which will take **60-90 minutes**. The interview will be tape recorded. The stories and comments from the interviews will be used to find themes and patterns.

What are the discomforts and risks?

Living with chronic disease such as lupus can be challenging. There is a possibility that you may feel uncomfortable talking about some of your experiences. It is entirely up to you what experiences and stories you wish to discuss.

How will these discomforts and risks be alleviated?

If you decide to join the study and then change your mind, the interview will be stopped, and you do not have to give a reason. Any information provided by you will be confidential and anonymized, and available only to the research team. If during the course of the interview you or any other member of your family become upset by the topics discussed during the interview and would like to talk to someone for support and counselling then you can contact AUT Counselling and Mental Health services.

AUT Student Counselling and Mental Health can offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly because of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9998.
- let the receptionist know that you are a research participant and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

What are the benefits?

There may not be any direct benefit to you, but the interview will provide an opportunity for you to tell your story and share your thoughts and perceptions about how the management of lupus might be improved. The benefits to the wider lupus community are that health providers will have greater insight and better understand the patient experience, and this will feed back directly into care.

How will my privacy be protected?

Should you decide to participate in this research study, your participation would be confidential i.e., any information such as your name, and other personal information that could identify you will be removed from the transcripts by the interviewer who is not associated with the lupus clinic.

Interview recordings and transcripts will be de-identified. They will only be available to members of the research team. All identifiable details will be held securely and accessible only to the interviewer; these will keep separate from the interview data and no information identifying you as a participant will be included in any of the project reports or publications. You will be able to indicate on the consent form if you would like to review and correct the transcript and/or receive a summary of the results from this study. Information gathered from the interviews may be used for future research only upon your consent.

Although every effort will be made to protect your privacy, only limited confidentiality can be guaranteed. The risk of people accessing and misusing your information is currently very small. If you have any concerns regarding your rights, please contact any of the research team below.

What are the costs of participating in this research?

The only cost to you taking part in this research is your time. If you choose to take part, you will take part in a 60–90-minute family group interview with a researcher (s). The researcher(s) will meet you at a place convenient for you. This could be your home or a mutually agreed community venue close to your home. A koha/gift for the time and knowledge you have contributed; an additional petrol voucher will be provided to participants required to travel to the interview venue

What opportunity do I have to consider this invitation?

Someone from the research team will touch base within two weeks of you receiving this information to check if you have decided about participating in this study and to set up an interview time for you and your family.

Will I receive feedback on the results of this research?

A summary of the study findings will be sent to you if you have requested this on the consent form. Study findings will be presented at different health forums and published in appropriate journals.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project co-ordinator *Dr. Julie Blamires*; email: julie.blamires@aut.ac.nz Mob 0212387275

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz , (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Ko Julie ahau, noo Kaanata ahau. He neehi ahau.

Julie Blamires is a Canadian-born lecturer at AUT University. Prior to joining the university, she was a rheumatology nurse specialist at Starship Children’s Hospital. She currently works full time at AUT University running courses for new graduate nurses, and post-graduate nurses wanting to work with children and youth.



Anthony Concannon works as a paediatrician at Kidz First and as a paediatric rheumatologist for the Paediatric Rheumatology National Service based at Starship Hospital.



Annette Dickinson is a senior lecturer at AUT and experienced child health researcher. She comes from a strong clinical background of paediatric nursing. Annette is program leader for the Post Graduate Child Health Programs at AUT.



Tia Pousini is a research officer within the NZ institute for Pacific research and has a strong background population health, framework development, and design with experience in working with Pacific communities to addressing health inequities in the research and health sector.



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