

The research is being carried out in partial fulfilment of a PhD under the supervision of Sophie Hill. The following researchers will be conducting the study:		
Role	Name	Organisation
PhD Candidate	Jack Nunn	La Trobe University
Chief Investigator	Dr Sophie Hill	La Trobe University
External Investigator	Dr Paul Lacaze	Monash University
External Investigator	Dr Kylie Gwynne	The University of Sydney
Research funder	This research is supported by in kind support by La Trobe University.	

1. What is the study about?

You are invited to participate in a study of which ways the public can shape the future of human genomics research that are preferred by the public. We hope to learn about people's perspectives about who should be involved in genomic research, how this should be done so that we can help improve future research.

Your contact details were via your response to an advertisement shared by AusEE staff.

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully and ask us any questions.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

You have been asked to participate because:

- You are part of an online community of people affected by Eosinophilic Gastrointestinal Disorder (EGID) managed by AusEE.

Please note, **only people who are 18 and over are able to participate.**

If you do not have EGID and are representing someone who is under 18 you are welcome to join. If you are representing someone who is 18 or over (for example, as a partner or carer) unfortunately we are not able to include you as a participant in this study.

4. What will I be asked to do?

If you want to take part in this study, we will ask you to share your views and perspectives about who should be involved in genomic research, how this should be done.

You will be invited to join an online discussion. When you register, you are requested to choose a name – this can be your real name or a made-up name (pseudonym) if you wish to remain anonymous to other participants.

The online discussion will take place over two weeks and we expect as a minimum it will take an hour of your time to be part of this study (including reading and responding to discussion), although naturally you may wish to spend more time than this. Jack Nunn (La Trobe University) will be facilitating and moderating online discussions, with support from Dr Kylie Gwynne (a researcher at the University of Sydney School of Medicine and member of AusEE).

The online platform we will use is called 'Loomio'. Loomio is discussion software. It is a free, secure, open source software web application. It facilitates discussion between people with an internet connection, anywhere in the world.

Loomio can be used with most web-browsers and it supports mobile phone usage for internet connected smart phones.

Loomio's software and service has been assessed and approved by the New Zealand Government Ministry of Social Development Cloud Computing User Assessment (https://loomio.gitbooks.io/manual/content/en/security_privacy.html). In addition it has been assessed and approved for use by research by La Trobe University, and is hosted by the University on La Trobe University servers.

We will give you detailed instructions about how to access it from different platforms and how to control any emails you will receive from the service.

5. What are the benefits?

The benefit of you taking part in this study is that you will have an opportunity to share your thoughts and perspectives in a safe and secure online environment, which will be facilitated and moderated by professionals. This will give you a chance to share your views and explore those of others in a respectful way. The expected benefits to society in general are that the learning from this research will provide useful data on effective methods of involving people in designing involvement, which could improve the design of future genomic research studies.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Dr Sophie Hill – La Trobe University	Chief Investigator	+61 3 9479 1941	sophie.hill@latrobe.edu.au

We have described the risks we know about below. This will help you decide if you want to be part of the study. While every effort will be made by the facilitators to keep discussions within the agreed boundaries, some subjects may trigger emotions that may be experienced as stressful or unpleasant. This might include discussions about genomic variations of known or unknown significance (including those affecting a risk of certain diseases). Participants will be offered appropriate support. For example, if appropriate, they will be given information about free local counselling services,

7. What will happen to information about me?

If you use the same name or email address at different stages of the research, researchers will know that it is the same person throughout. You may choose to use the same name (or pseudonym) at each stage, or to change it and your email address at each stage. If you keep the same name or email at each stage this will be used by the researchers to help analyse the data.

However, once the data has been analysed, it will be anonymised (name and email address removed) and you will **not** be personally identified in any type of publication from this study. In addition, we will invite representatives from those participating to be part of a working group that will review the information we will share before publication to ensure it is acceptable.

The La Trobe University's Research Data Management Policy requires that we keep the data from this study securely (including information you have shared) for 7 years after the project is completed. After this time we will destroy all of your data. The intellectual property of the data will be owned by La Trobe University. We will collect, store and destroy your data in accordance with La Trobe University's Research Data Management Policy which can be viewed online using the following link: <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The information you provide is personal information for the purposes of the Information Privacy Act 2000 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

8. Will I hear about the results of the study?

We will let you know about the results of the study by informing you directly at each stage of the research, letting you know if and how you can be involved. For example, we will inform you when we have finished collecting data, are analysing it and are preparing to disseminate (publish) results and findings.

Results from individuals will be anonymised (email addresses removed). We intend to share the learning from this project in the public domain, which may include being published in:

- Journal article(s)
- Books
- Research report to collaborating organisations
- Conference presentation(s)
- Social media
- Podcasts
- Online videos
- Appropriate news organisations
- Other online media

9. What if I change my mind?

At any time you can choose to no longer be part of the study. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us;
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed. When you withdraw we will stop asking you for information. You will have 2 weeks after the survey data has been collected to request to withdraw from the research study. After this time has elapsed we will begin to analyse the data.

The researchers cannot withdraw participants' information once it has been collected as part of an online discussion and/or analysed.

Whether or not you withdraw from the study, once the data has been analysed, any identifying information about all participants (for example, your email) will be removed from the data and it will be anonymised.

You will not be personally identified in any type of publication from this study and you will have a chance to review any information before it is shared in the public domain.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Sophie Hill, La Trobe University	Head, Centre for Health Communication and Participation	+61 (0)3 9479 1941	sophie.hill@latrobe.edu.au

What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC18242	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au



Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

Only used for this specific study;

I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

Participant Signature

I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;

I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group

***if you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data

- Destroyed and not used for any analysis
 Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	Sophie Hill
Email	Sophie.Hill@latrobe.edu.au
Phone	+613 9479 1941
Postal Address	Head, Centre for Health Communication and Participation, Coordinating Editor, Cochrane Consumers and Communication Review Group, College of Science, Health and Engineering School of Psychology and Public Health Department of Public Health Health Sciences 2, room 527, Melbourne (Bundoora) Australia