

EXPLANATORY STATEMENT

Project ID: ERM 121492

Project title: Consumers' preferences for food allergy treatments

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We invite you to take part in this study. Please read this Explanatory Statement in full before deciding whether to take part. If you want learn more about this project, please contact us at the email addresses listed above.

What does the research involve?

We are asking caregivers of children with food allergy to complete a survey to determine what they think is important when they are deciding whether their child should undergo food allergy treatment.

The survey consists of several parts and will include questions on:

- Your child's food allergies and treatments they have received for this previously.
- Yours and your child's age and gender.
- Your income (broad range only).
- Your stresses and anxieties relating to your child's food allergy.

Part of the survey will include a choice experiment, where you will be given information about different treatments. You will be asked to consider hypothetically whether or not you would like your child to receive these treatments based on different factors like risk of side effects, costs and the outcome that is expected at the end of treatment.

Why were you invited to participate in this research?

We invite you take part in this research because you are either:

- a caregiver of a child who has undergone food allergy treatment through one of our clinical trials, and you have expressed interest in being contacted about our other research studies, or
- a caregiver of a child with food allergy and you have registered your interest to participate in food allergy research with the National Allergy Centre for Excellence or Allergy and Anaphylaxis Australia (A&AA), or

- You are an interested survey participant, registered as a caregiver of a child with food allergy with a panel research company that has been contracted to run the survey.

We have obtained your contact details from the clinical trial, NACE or A&AA participant database, or the panel research company as relevant.

Consenting to participate in the project and withdrawing from the research

By completing and submitting your answers to the survey you are confirming your consent to participate in this research. If you agree to participate in the survey you can withdraw at any time while completing the survey questions. Once you have completed the survey you will not be able to withdraw your consent because the survey is anonymous and we cannot link you to your responses to withdraw them. There will be no consequences to you for withdrawing your consent.

What are the benefits of taking part?

We do not anticipate that there will be any direct benefits to you for participating in this study. However, findings of this study will advance our understanding of the preferences of families considering treatment for food allergy. Consequently, this research may influence the development and delivery of therapies in the future.

What are the possible risks of taking part?

While all research projects can carry an element of risk, we do not foresee any significant harms to you from participating in this study. The content of the survey may make you feel uncomfortable as you share details of you and your child's experiences of managing their food allergy. Whilst we do not foresee others being able to identify your participation in the research, if this were to occur it could result in stress or worry.

Reimbursement for participant time

If you were recruited to complete the survey by Pureprofile, you will be reimbursed directly by Pureprofile. If you followed the public survey link, you will be asked at the conclusion of the survey if you wish to be included in a prize draw for a one in 25 chance to win a \$100 gift card, and given a link to enter your email address. Your email contact details will not be linked to your survey responses which will remain anonymous. You will also be asked if you consent for the research team to contact you via email about opportunities to participate in other future research studies.

Confidentiality

Survey data will be anonymous and stored within the password protected survey database, with access to survey data only available to study investigators at Murdoch Children's Research Institute.

Publishing project information

The findings of this study will be circulated to the scientific community via presentation at conference/s and/or through publication in a peer reviewed journal.

Who is running and paying for this project?

This project is funded by a National Health and Medical Research Council Australia Investigator Grant held by the Chief Investigator Professor Mimi Tang. The project is being run by the Murdoch Children's Research Institute.

Who has reviewed and approved this project?

The Royal Children's Hospital HREC has approved this project. This is an independent committee that makes sure that this project meets Australian ethical standards for research that involves people.

Comments or complaints about how this project is being run

If you have any comments or complaints about this project, please contact the Director of Research Operations at The Royal Children's Hospital and quote this reference number 121492.

You can phone the Director on (03) 9345 5044 or email them at rch.ethics@rch.org.au.