

**Exploring healthcare use, burden of disease and satisfaction with care in
paediatric eosinophilic oesophagitis
GU Ref No:2018/120**

INFORMATION SHEET

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Why is the research being conducted?

Currently, there is no cure for Eosinophilic Oesophagitis (EoE) and treatment involves strict food elimination diets, steroid medication and special nutritional formulas. EoE patients often feel socially isolated due to their food restrictions and may seek complementary medicines and therapies, such as acupuncture, herbal medicine and nutritional supplements, to help manage their symptoms. There have been limited studies to assess use with, and satisfaction of these medicines by EoE patients, particularly children.

We are seeking your consent to take part in this study as you are a parent or carer of a child with EoE in Australia, and we would like to find out about the impact of paediatric EoE on your family and your treatment experiences, including the use of complementary medicines and therapies.

What you will be asked to do

As a parent or carer of an EoE child you will be asked to complete an online survey (approximately 25 mins duration). Questions will explore quality of life and experiences of using complementary medicines and therapies and conventional treatment for EoE. Survey participants will be given an option to go into the draw to win one of ten \$50 gift vouchers.

Survey participants will be invited to participate in a telephone interview to further explore the healthcare journey and treatment experiences for their child with EoE. Interviews will take approximately 45 minutes, at a time convenient to you; participants will be given a \$30 gift card.

The expected benefits of the research

Currently there is no known research into the use of complementary medicines and therapies in paediatric EoE. This research aims to identify what types of complementary medicines and

therapies are being used for the treatment of paediatric EoE, to gain further understanding as to why they are being used and who is recommending them; and to obtain insight into parents' perspectives of the physical and emotional impact of paediatric EoE. The results will highlight areas in which additional support may be needed to improve the management of paediatric EoE.

Risks to you

We do not anticipate any risks to you as a result of participating in this research. You are able to answer any questions that you choose to, however, four specific questions will need to be answered as they are linked to the core research question. If you do not wish to answer the compulsory questions none of your survey responses will be included in the final data. Because this study is asking questions about a personal matter (the health of your child with EoE and impact on your family), this could result in an emotional response. If you require further assistance or someone to talk to, there are a variety of support organisations available, e.g. AusEE Inc. (www.ausee.org), Lifeline (13 11 14) or speak to a health professional.

Survey responses will remain anonymous. If you agree to an interview being audio-recorded, information will be de-identified upon transcription to protect the privacy of you, your child, and practitioners. While AusEE Inc. has agreed to support the promotion of this project, information about study participants will not be disclosed to this organisation. Any personal details obtained in order to conduct the interviews or to post gift vouchers to survey prize draw winners (such as name and phone number) will only be accessible to the research team. All data will be stored securely on a protected file on Griffith University's G drive. Information you provide for this study will be retained for a period of five years post-publication and then destroyed.

Your participation is voluntary

Your participation is voluntary and you are free to withdraw from this study at any time. As survey responses will be anonymous, this information will be unable to be withdrawn after survey submission. If you decide to participate in an interview and later change your mind, you will be able to withdraw from the study at this stage and your information will not be included.

Expressing consent

Completion of the survey will be taken as consent. If you choose to participate in an interview, you will be asked to read a consent form and provide verbal consent prior the start of the interview.

The ethical conduct of this research

This project has been ethically approved by Griffith University Human Research Ethics (GU Ref No: 2018/120). Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research* (2007). If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Research Ethics on 3735 4375 or research-ethics@griffith.edu.au.

Feedback to you

Please contact Nicole Hannan on nicole.hannan2@griffithuni.edu.au if you would like to be directly notified of the results of this research. Interview participants will be offered a copy of their individual transcript and a summary of the findings.

Questions or further information

If you have questions or require further information please contact Nicole (nicole.hannan2@griffithuni.edu.au) or Sara (s.mcmillan@griffith.edu.au; 07 555 27266).

Thank you for your assistance

Nicole Hannan, Evelin Tiralongo, Sara McMillan, Amie Steel

Privacy Statement

The conduct of this research may involve the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.

Prize Draw Information and Entry Form: Exploring healthcare use, burden of disease and satisfaction with care in paediatric eosinophilic oesophagitis (GU Ref No: 2018/120)

1. The prize draw is being run by the research team of Griffith University School of Pharmacy to encourage participation in the online research survey for the project on “Exploring healthcare use, burden of disease and satisfaction with care in paediatric eosinophilic oesophagitis.”
2. By electing to participate, you accept these terms and conditions as governing the prize draw. Instructions on how to enter the prize draw and details advertising the survey form part of the conditions. Any personal information you provide to us in the course of entering the prize draw will be dealt with by us in accordance with our privacy policy (published at: <https://www.griffith.edu.au/about-griffith/governance/plans-publications/griffith-university-privacy-plan>)
3. Five prizes will be awarded in prize draw, each prize being a supermarket Gift Card and being worth \$50. Should the advertised prize become unavailable as a result of circumstances beyond our control, we are free (at our sole discretion) to substitute a cash prize equivalent to the value of the prize advertised.
4. Entry is free (other than the cost of accessing the website, which is your responsibility). Entry is open between 5th September 2018 and 28th February 2019. Entries received after the closing date will not be accepted.
5. To enter the prize draw, you must: (a) be a parent or carer of an EoE child in Australia; (b) have completed the online research survey; and (c) provide a valid postal address.
6. You may not enter the prize draw if you are: i) a member of the research team, ii) employed by the research team; iii) an immediate family member (i.e. a spouse, partner, child or sibling) of someone identified at 1 or 2 above.
7. You may only submit one entry in the prize draw.
8. All survey and other materials provided by you become our property. No responsibility is taken for late, lost or misdirected surveys or entries.
9. Following the closing date, the prize winners will be selected randomly from valid entries received. Each entry can only be drawn once.
10. Subject to system malfunction, prize draws will occur on 7th December 2018 (to win one of five \$50 gift vouchers), and 7th March 2019 (to win one of five \$50 gift vouchers). Winners of the first prize draw will not be entered into the second prize draw. If the systems supporting the draw are not functioning as they should when the draw is due, the draw will be held as soon as possible once the systems become functional again. Prize winners do not need to be present at the time of the draw.
11. Prize winner names will not be published.
12. The relevant prize will be sent to each prize winner at the postal address they provided with the prize draw entry. If an address has not been supplied, the entry will be treated in accordance with clause 14. The majority of prizes will be mailed within two weeks of each draw.
13. The right to a prize is not transferable or assignable to another person.
14. If any prize winner cannot be contacted within three (3) months of the draw, then that person’s right to the prize is forfeited and the prize will be treated as an unclaimed prize.
15. Only one redraw of unclaimed prizes will take place, and other existing prizes are not affected. The redraw prize winner(s) will be randomly selected from remaining valid entries and notified within two (2) weeks of the redraw. If the redraw prize winner(s) cannot be contacted within three (3) months of the redraw, then we may determine that the relevant prize(s) will not be awarded.
16. Prizes cannot be substituted for another prize at the election of the prize-winner.
17. We are not liable for any loss, expense, damage or injury sustained by any entrant in connection with this prize draw, the prize or redemption of the prize, except for any liability which cannot be excluded by law (in which case, that liability is limited to the minimum allowable by law).
18. We may suspend the promotion if we determine that the integrity or administration of the promotion has been adversely affected due to circumstances beyond its control. We may disqualify any individual who tampers with the entry process.

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Verbal consent for interviews

By agreeing to participate, you confirm that:

- You understand that your involvement in this research will include participation in a telephone interview with an approximate duration of 45 minutes;
- You have had any questions answered to your satisfaction and that if you have any additional questions you can contact the research team;
- You understand the risks involved;
- You understand that upon completion of the interview you will be given a \$30 gift voucher for your time;
- You understand that your participation in this research is voluntary and that you are free to withdraw at any time, without explanation or penalty;
- You understand that your name and other personal information that could identify you will be removed or de-identified in publications or presentations resulting from this research;
- You understand that confidentiality of the data collected will be maintained throughout the project and data will be de-identified upon transcription. Written data collected will be stored in a lockable filing cabinet at Griffith University's Gold Coast campus. Electronic data will be stored securely on the Griffith University hard drive and only accessible to the research team. Your results will only be identified by a number and will not be stored with this consent form;
- You understand that you can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 4375 (or research-ethics@griffith.edu.au) if you have any concerns about the ethical conduct of the project; and

You agree to participate in this research.

You agree to the telephone interview being audio-recorded

You consent to the inclusion of your de-identified information in publications or presentations resulting from this research.

Name:

Date:

Privacy Statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University's Privacy Plan at <http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan> or telephone (07) 3735 4375.