



Summary of results of the ausEE research priorities survey

Thank you for participating in our research survey. There were 72 respondents who provided great advice about prioritising the research ideas we had, as well as adding some new research ideas. We will use the findings of this survey to inform our decisions about research funding and to encourage our fundraising efforts.

Question 1

I think research will help find better care and treatment options for me/my family member with an eosinophilic disorder. The more stars you mark, the more important research is to you/your family.

Results

4.92 out of 5 stars

66 respondents gave five stars, four respondents gave four stars, one respondent gave three stars, one did not respond.

Overall there was very strong support for research finding better outcomes for people with eosinophilic disorders.

Question 2

We are developing a priority list of projects for our research fund and would really value input from members. Please respond to each of the suggested projects below with a rating of between 1 (not important) and 5 (critically important).

Results

The research priorities of respondents were in the following order of importance:

- 1. Care and treatment guidelines for eosinophilic disorders**
66 of the 72 respondents thought research in this area was critically important or very important. This research had the strongest support of respondents.
- 2. Quality of life impacts for people living with eosinophilic disorders and their families/carers**
56 of the 72 respondents thought research in this area was critically important or very important.
- 3. The cost of living with eosinophilic disorders for individuals and families**
44 of the 72 respondents thought research in this area was critically important or very important.
- 4. The prevalence of eosinophilic disorders in Australia**
32 of the 72 respondents thought research in this area was critically important or very important.

The cost and prevalence items had three and four respondents respectively who indicated the research in those areas was not important to them.



Question 3

Do you have any other comments, questions, or ideas about our research priorities?

Results

The suggestions made by respondents are summarised below:

- Developing other ways to diagnose EoE.
- Including Australia and NZ in the costing and quality of life.
- Medication exit strategies once EoE is under control.
- Comorbidity with other illnesses and the appropriate treatment to deal with these.
- Appropriate pain relief strategies.
- What impact the state of the persons microbiome has on EoE & associated illnesses. Are the medications used as treatment affecting this - either positively or negatively, and what are the long-term impacts of this.
- What to do when current treatments don't bring symptomatic relief.
- Genetic markers and potential for gene therapy.
- Increasing awareness of EoE and training for all health professionals.
- Psychological impacts of EoE and ways to promote inclusion.
- Effect of probiotic strains on EoE allergies.
- Effects of low THC cannabis products, like CBD oil, that have been shown to impact on white blood cell activity.
- Education for parents on the long-term effects of PPIs and steroid therapy.