



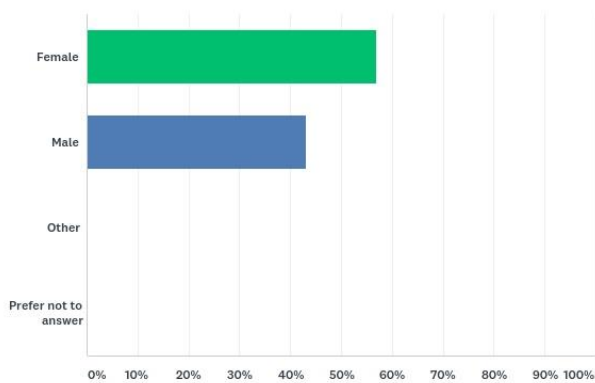
a charity dedicated to improving lives affected by eosinophilic disorders

ausEE EGIDs Survey Results

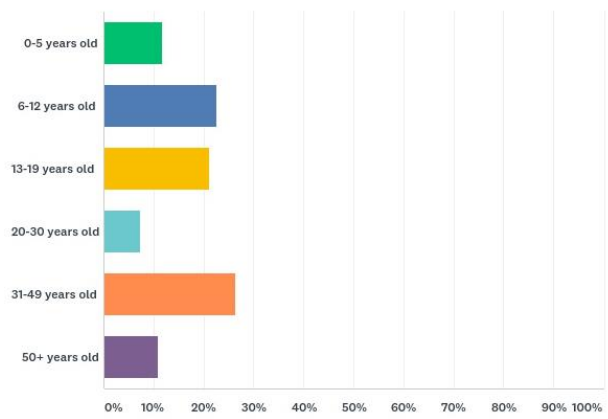
Summary

There were 157 respondents to the survey from people with eosinophilic gastrointestinal disorders (EGIDs) and from people caring for someone with an EGID. Of these, 57% were female and 43% male. The age at diagnosis ranged from 6 months to 66 years which raises some important questions about onset, timely diagnosis and severity of illness which would be worth exploring in a future survey.

Is the person with EGID:



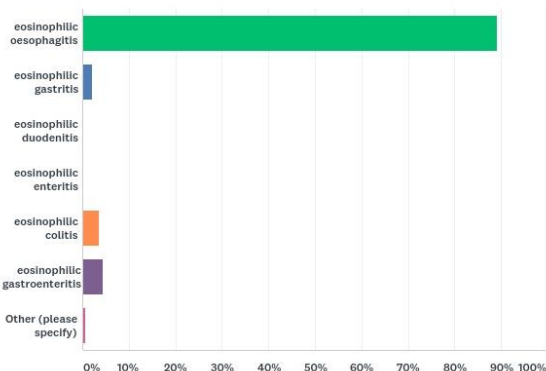
How old is the person with EGID?



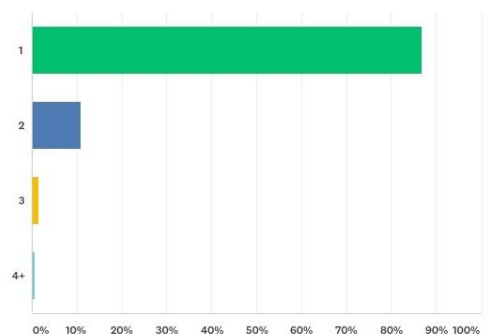
In 89% of cases the diagnosis was Eosinophilic Oesophagitis. The next most likely diagnosis was Eosinophilic Gastroenteritis at 4.4% and Eosinophilic Colitis at 3.6%. This broadly reflects the rates of EGIDs with EoE being the most common form.

Genetic/precision medicine is the subject of significant research globally and offers the promise of treatment and prevention for some people with rare diseases. ausEE recently participated in a research study about consumers and co-design in the genetic/precision medicine research arena (results will be available soon) and familial/genetic patterns of EGIDs requires further exploration as it may offer the potential for better treatments for people with EGIDs and their families in the future. Interestingly however, 87% of respondents to this survey said there was only one person with an EGID in their family and 11% said there were two people in their family.

What type of EGID was diagnosed?



How many people in your family have an EGID?

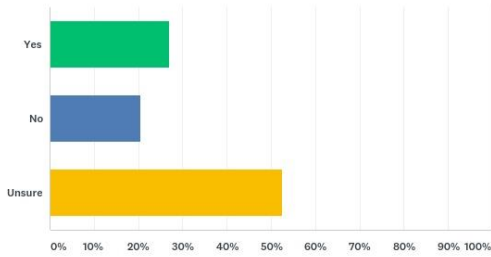




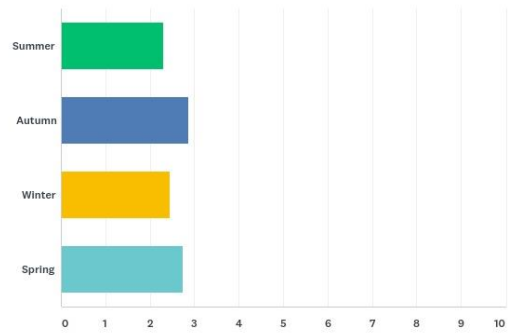
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Most respondents, around 63%, were unsure of any seasonal impacts of EGIDS and the worst and best seasons for EGID were spread pretty evenly across each season. The postcode data collected provide little insight into patterns of EGIDs geographically and only 5% of respondents reported moving address to be closer to services and hospitals.

Does the person with EGID have flares that are seasonal?



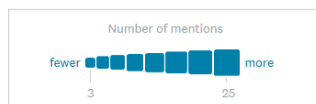
Which seasons are worst to best for the person with EGID?



The symptoms of an EGID flare and strategies to manage flare were remarkably similar between respondents to the survey and are presented in the word clouds below.

What are the main symptoms experienced by the person with an EGID during a flare?

food Chocking throat loss appetite vomiting
 swallowing pain feeling nausea sore Chest pain
 Difficulty Reflux abdominal pain fatigue stuck
 stomach pain discomfort Food impaction trouble swallowing
 chest stomach cramps food stuck throat irritation headaches



How do you treat/manage a flare?

avoid Hospital eat meds steroids strict Medication
 food elimination Flixotide go food Nothing diet Increase
 antihistamines pain rest water flare pain relief Panadol

