

UNDERSTANDING THE BEHAVIOURS AND MEETING THE NEEDS OF YOUNG PEOPLE LIVING WITH SEVERE ALLERGY

Sandra Vale^{1,2,3}, Merryn Netting^{1,3,4,5}, Heather Roberts^{1,3}, Phoebe George², Kevin Murray², Sandra Salter⁴, Maria Said^{1,3,4,5}, Melanie Wong^{1,3,7}.

¹ National Allergy Council, Sydney, NSW, Australia

² School of Population & Global Health, The University of Western Australia, Crawley, WA, Australia

³ Australasian Society of Clinical Immunology and Allergy, Sydney, NSW, Australia

⁴ Faculty of Health and Medical Sciences, Adelaide University, Adelaide, SA, Australia

⁵ School of Health and Clinical Sciences, The University of Western Australia, Crawley, WA, Australia

⁶ Allergy & Anaphylaxis Australia, Sydney, NSW, Australia

⁷ The Children's Hospital at Westmead, Sydney, NSW, Australia



Abstract

Introduction: In Australia more than 250,000 12-24 year-olds have severe allergies, with anaphylaxis rates rising fastest in the 15–24 age group. In 2017, the Knowledge and Barriers to Anaphylaxis Management (KABAM) survey informed the development of the National Allergy Council's Allergy 250K youth program. In 2024, the survey was updated (KABAM-2) in order to identify more contemporary behaviours and needs of young people living with severe allergies.

Method: KABAM-2 modified questions from the original KABAM and was presented in a shorter format to Australians aged 10-30 years living with severe allergies. Promotion was via email and social media (5 June – 2 August 2024) with surveys completed via a Qualtrics link.

Results: KABAM-2 was completed by 65 participants, of whom 62% (n=40) were female. Most (89%; n=58) were aged 12-25 years. Eighty eight percent (n=57) reported knowing how and when to use their adrenaline device, 63% (n=41) carried it at all times and 69% (n=45) felt confident to use it. Only 29% (n=19) of participants with food allergy reported they often (but not always) read food labels. Additionally, 29% (n=19) reported they often worried about experiencing a severe allergic reaction and 58% (n=37) had sought help managing their allergy. Websites were the preferred source of allergy information (83%; n=54), while 32% (n=21) supported allergy camps. Overall, the findings from KABAM-2 were similar to the survey conducted in 2017. Reported anxiety regarding anaphylaxis risk was lower in KABAM-2, except for anxiety regarding anaphylaxis risk when eating out, which was higher in KABAM-2 (17% compared to 7%).

Conclusion: KABAM-2 identified ongoing gaps in device carriage, label reading, confidence, and emotional support among young Australians with severe allergies. As the preferred information source, the National Allergy Council's Allergy 250K website should be further promoted and expanded to address these needs.

Aim: This study aimed to identify the current management behaviours of young people at risk of anaphylaxis.

“Sometimes I feel left out when I can't eat what everyone else can.” 2024.

Table 1: Demographic information

	2017 % (n=173)	2024 % (n=65)
Gender		
- Male	35	37
- Female	65	62
Age		
- 10-11 yrs	-	5
- 12-15 yrs	45	22
- 16-18 yrs	27	35
- 19-25 yrs	24	32
- 26-30 yrs	2	6
- 31-40 yrs	2	-
Country of birth		
- Australia	91	94
- Other	9	6
English is parent's first language	95	92

Table 2: Adrenaline carriage and use

	2017 % (n=155)	2024 % (n=65)
I know how and when to use my adrenaline device		
- Yes	97	88
- No	1	8
- Unsure	2	4
Confident to use my adrenaline device		
- Yes	65	69
- No	10	12
- Unsure	25	19
How often do you carry your adrenaline device?		
- All the time	75	63
- Most of the time	12	25
- Only when eating out	7	4
- Sometimes	4	8

Results:

- Fewer young people reported knowing how and when to use their adrenaline device in 2024 compared to 2017.
- 69% reported that they were confident to use their adrenaline device in 2024, compared to 65% in 2017.
- 63% reported carrying their adrenaline device all the time in 2024, compared to 75% in 2017.
- There was little behaviour change relating to reading food labels when comparing survey responses in 2017 and 2024, with 65% and 62% respectively 'always' reading food labels.
- A greater proportion of responders told 'all their friends' about their food allergy in 2017 (63%) compared to 2024 (55%).

“The majority of the time I feel like a burden because of my allergies – it does affect how I eat at times.” 2024.

Conclusion

- Young people living with severe allergies need ongoing support to help them manage their severe allergies.
- Greater promotion of the Allergy 250K program is needed to engage more young people.

How does Allergy 250K support young people?

- The school aged kids camps help connect young people living with each other and with Allergy 250K peer mentors. The camps also help increase their confidence in managing their allergies, particularly food allergies.
- The young adult camps connect young adults with each other as well as helping to train more Allergy 250K peer mentors. Like the school aged kids camps, the young adult camps increase their confidence in managing their allergies.
- Regular young adult video chats keep young adults living with severe allergies connected and also provides an opportunity for them to share experiences. They also provide us with an opportunity to gain insights about how we can expand and improve the program.
- The Allergy 250K websites provide tailored evidence-based information on a site specifically designed for young people.
- The Allergy 250K social media campaigns aim to share information with young people in a range of creative ways based on their feedback.

“I often feel criminalised by hospitality staff when I eat out, as they have to go to extra effort to read labels and check ingredients. I wish they knew that I'm not trying to be difficult, I am just trying to protect myself.” 2017.

www.allergy250k.org.au

“Be supportive, be inclusive and see me as a person, not just a person with allergies.” 2017.

Acknowledgements

The National Allergy Council would like to thank the Allergy 250K peer mentors, project co-leads and working group. This project has received funding from the Australian Government Department of Health, Disability and Ageing.