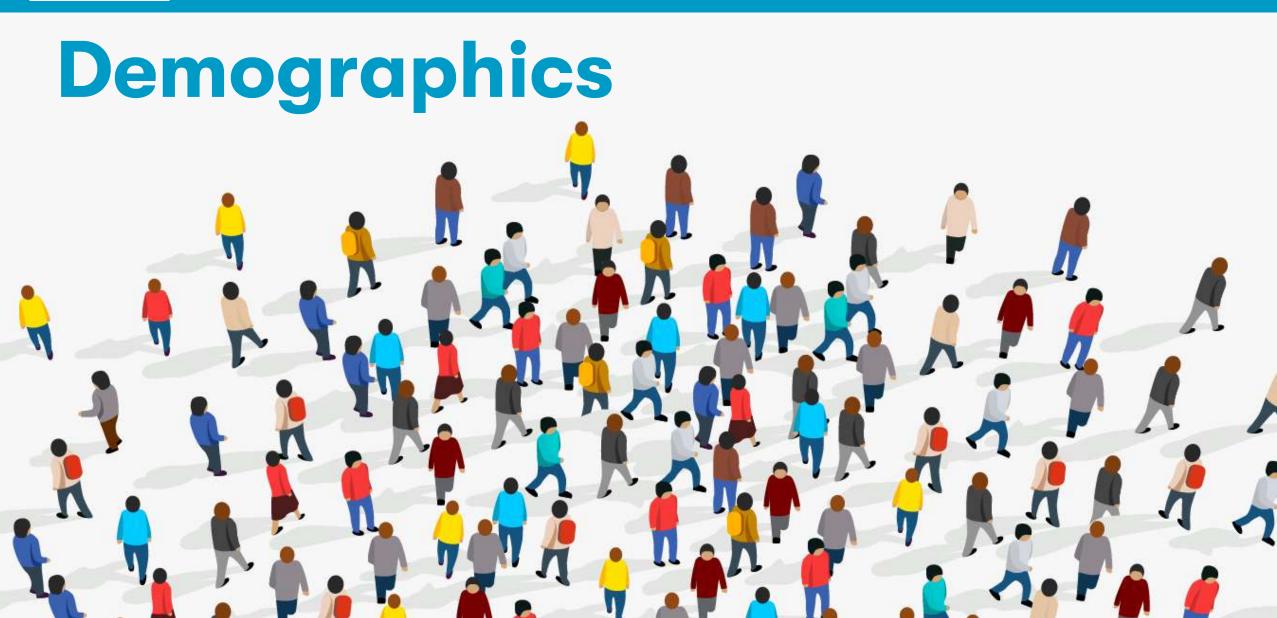






Let's Talk About Epilepsy survey







Demographics

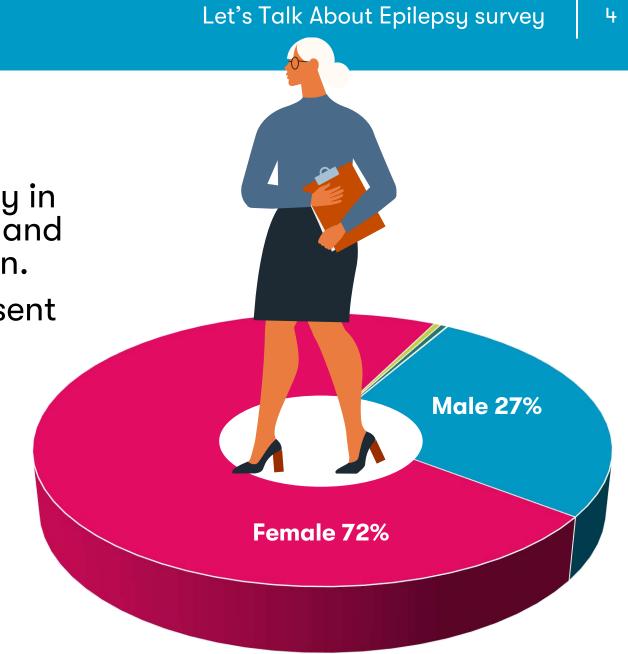
This section outlines the people who responded to the Let's Talk About Epilepsy survey. This information is important to understand whose experiences, ideas and opinions are being reflected in the results.

Gender

Roughly 48% of people with epilepsy in the general population are women, and 72% of our respondents were women.

Our results significantly over-represent women.





Let's Talk About Epilepsy survey

Ethnicity

These results overrepresent white people and underrepresent all other groups.



Asian - Asian British, Chinese, Indian, Pakistani or any other Asian background



Mixed or multiple ethnic groups



Black - Black British, Caribbean, African or any other black background



White – White British, Irish or any other white background 92%



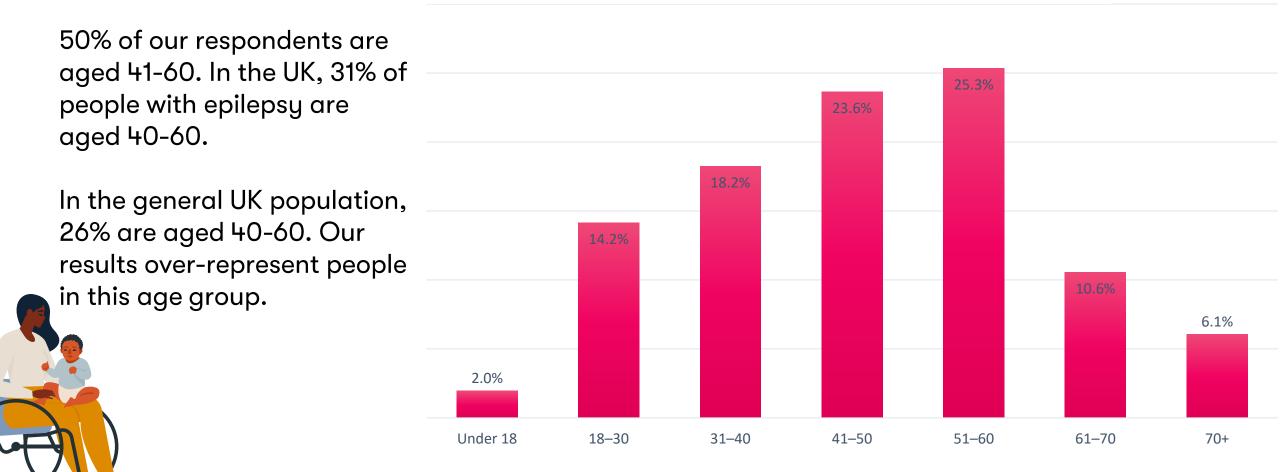
White - White British, Irish or any other white background





Age

Our results **overrepresent** people aged 18-60 and **underrepresent** people who are younger and older.



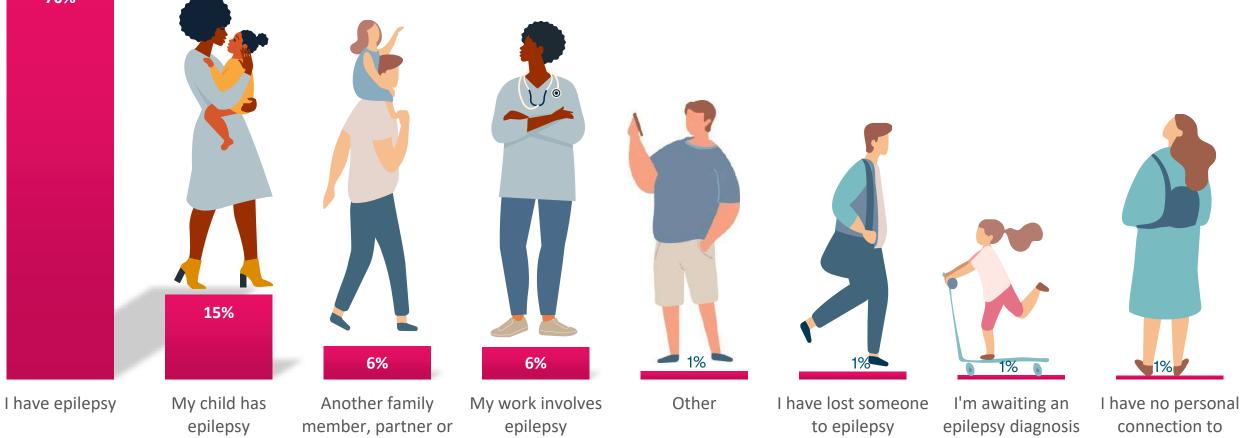


Let's Talk About Epilepsy survey

Relationship to epilepsy

friend has epilepsy

70%

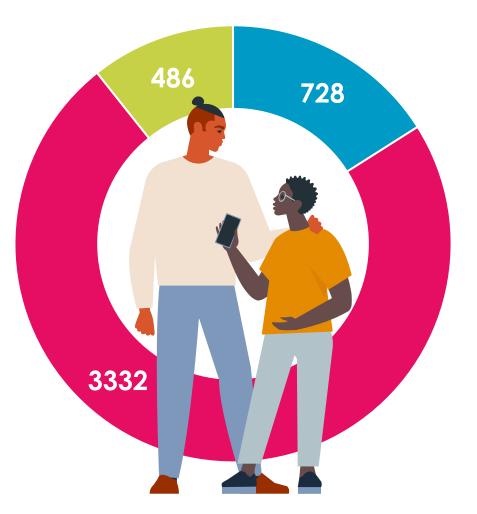


epilepsy



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Experience



Epilepsy is pretty new to me	16%	
Epilepsy has been part of my life for a while now	73%	
Epilepsy rarely affects my life now	11%	



9





Horrendous

Controlling

What one word would you use to describe epilepsy?



Inconvenience

This graph shows the percentage of responses using each type of language. For example, 'Difficult' is general negative language, 'disruptive' is about practical impact, 'scary' is about fear, etc.

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What do you think the most challenging thing about living with epilepsy is? (Choose up to three options)

'Other' responses:

- Worry (76 respondents)
- Memory (24)
- Impact on health (21)
- Quality of healthcare (17)
- Impact on rest of family, fear of death/SUDEP, having children, confidence, money

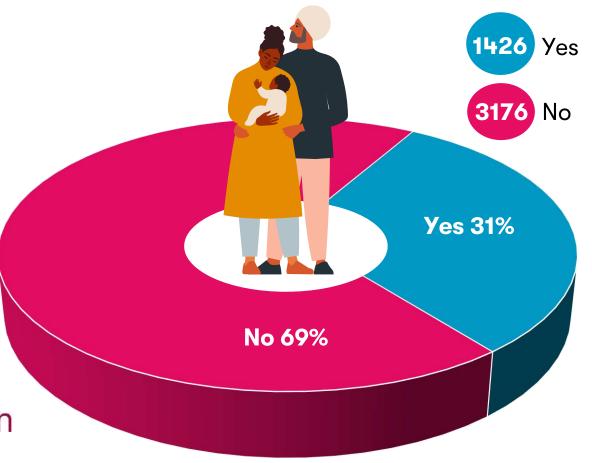
50%		The impact on independence
47%		Medication and side-effects
41%		of public understanding about epilepsy
6%	36%	Managing seizures
6%	36%	The impact on work or education
%	35%	The impact on social life/relationships
	9%	Accessing healthcare
	7%	Other



Do you think there are any positive aspects to life with epilepsy?

illness met worse controlled stronger prescriptions Meeting appreciation conditions bus managed under normal good medical seizures know accept nurse health care condition keep appreciate work helped sleep helps resilient right lifestyle manage bad years learned perspective sure part Well healthy experience benefits daughter helping empathetic son determined challenges friends public transport alcohol world Knowing ability awareness educate strong seizure help brain **CONTRO** learn realise prescription determination body enjoy love aware strength Learning disabilities use positive disabled without drive important better travel give resilience diagnosis support knowledge driving community disability understand taught medication experiences empathy

It's important to remember that the positive words in the word cloud were entered only by the 31% who said there are positives, and not the 69% who said there weren't any positives.



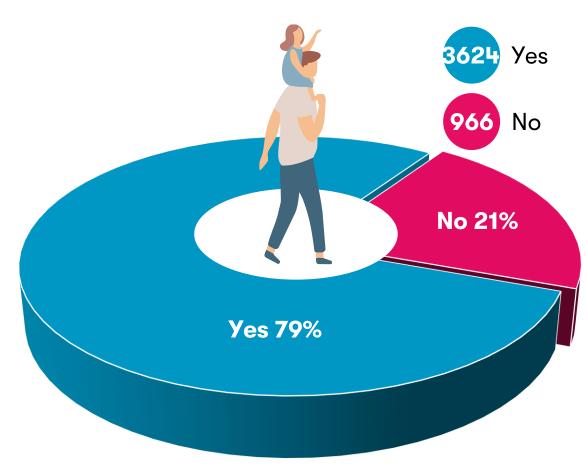
12



Do you feel that people with epilepsy are treated differently to others?



It's important to remember that the word cloud reflects the responses of the 79% of respondents who said there was a difference. 21% of respondents don't think people with epilepsy are treated differently.

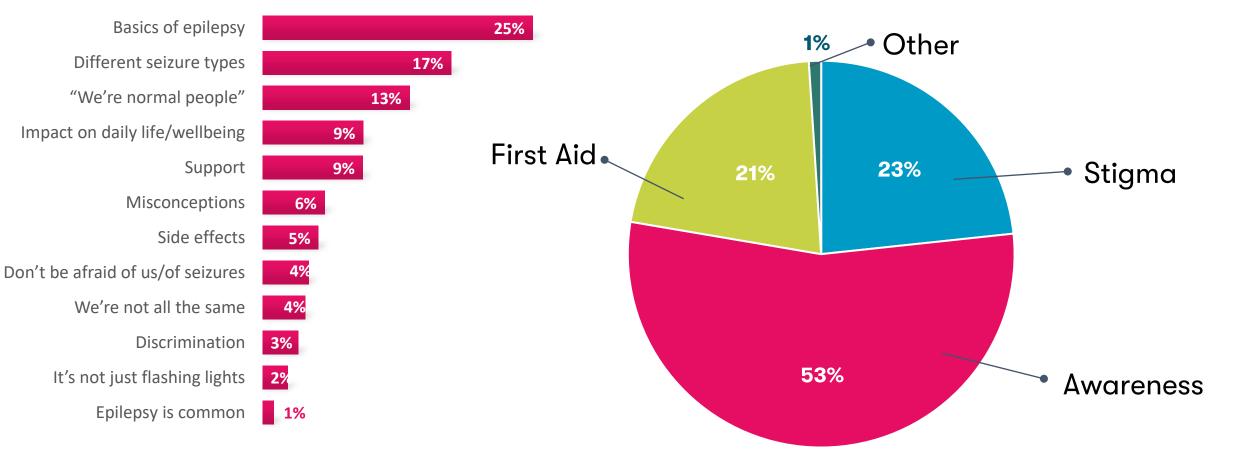




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If you could educate the public about one thing to do with epilepsy, what would it be?

The responses to have been broken down into four broad categories, shown on the pie chart, and more specific aspects of stigma and awareness are shown in the bar chart.



Let's Talk About Epilepsy survey 15

If you were in charge of a charity like Epilepsy Action for a week, what would your priorities be? (choose up to three options)

'l've got a better idea' responses:

- Support for PWE (56)
- Healthcare (36)
- Training (schools, employers and others)
- Campaigns
- Women's health
- Social support
- The positives of epilepsy

41%	Improving public attitudes to epilepsy
38%	Helping people with epilepsy feel less isolated
36%	Research to improve the lives of people with epilepsy
32%	Providing more advice and information about life with epilepsy
28%	Supporting families affected by epilepsy
24%	Supporting people with epilepsy in getting work
22%	Supporting young people with epilepsy
21%	Providing more information about medicines and side- effects
15%	Supporting nurses and medical professionals who deal with epilepsy
8%	Supporting older people with epilepsy
6%	I've got a better idea