

Background

Meningitis Now collaborated with the Picker Institute Europe to understand the support needs and care experiences of UK adults leaving hospital after a recent experience of meningitis.

Aim

The study's aim was to develop a questionnaire to explore the experiences and support needs of the UK adult population with a recent meningitis experience.

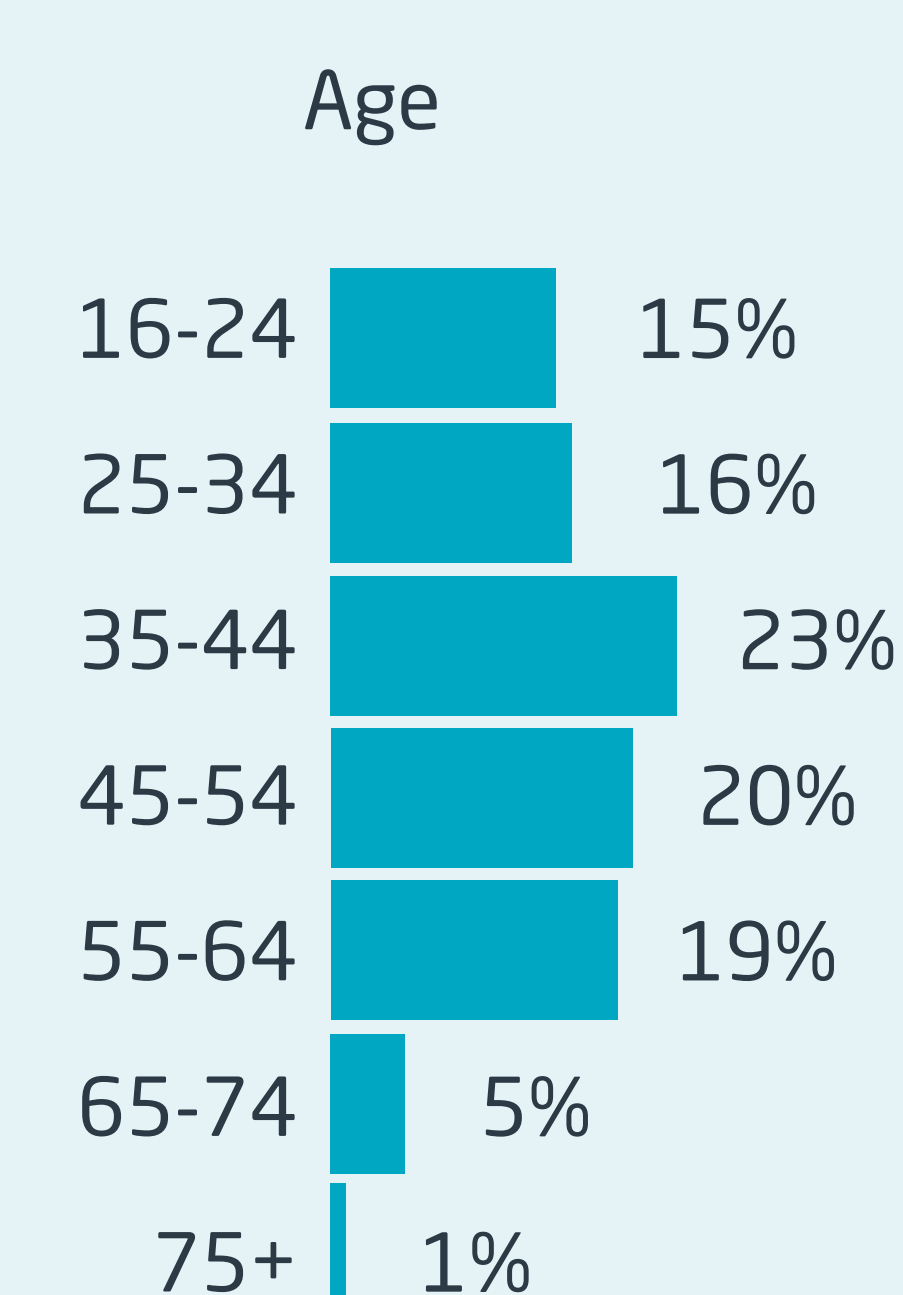
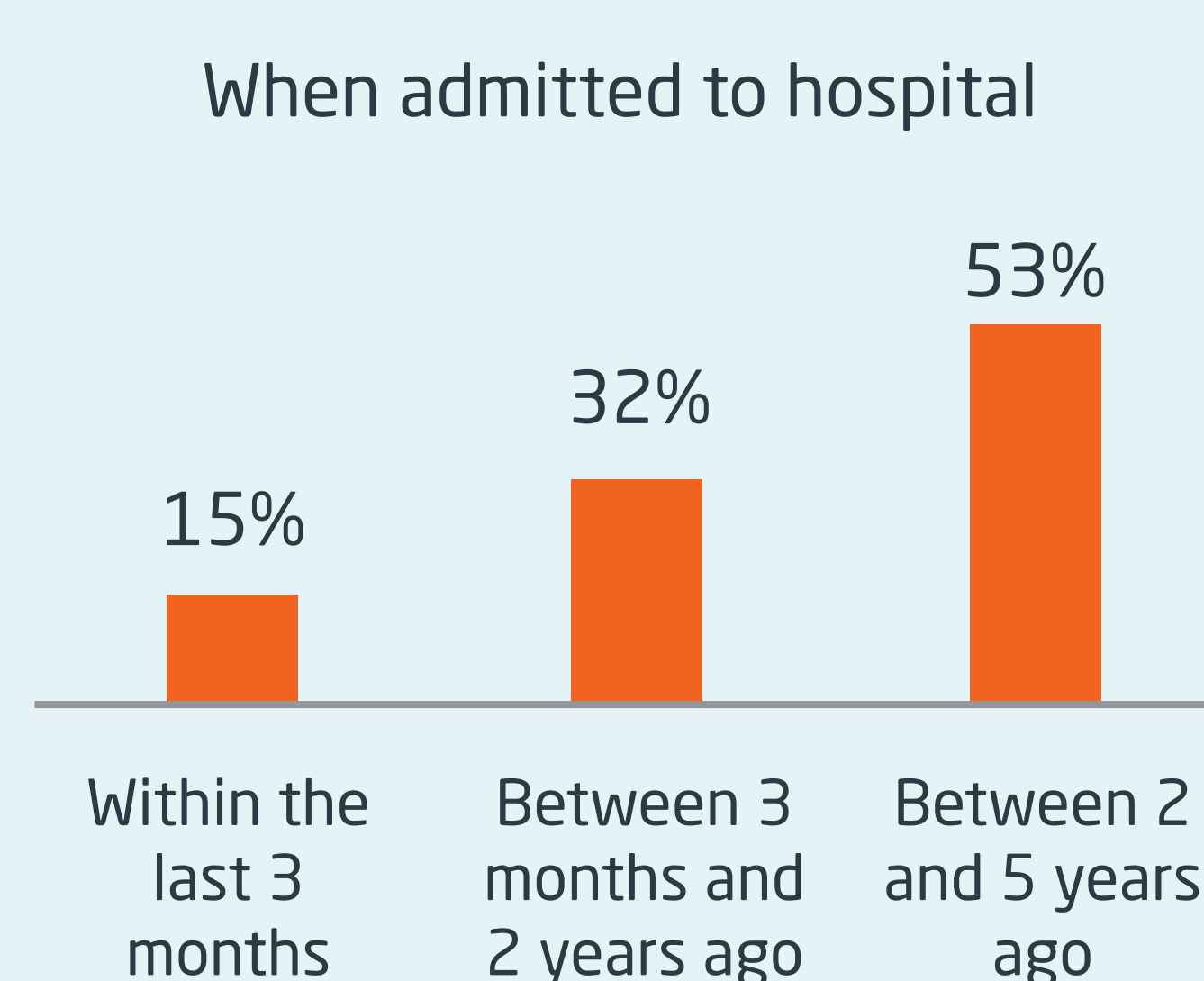
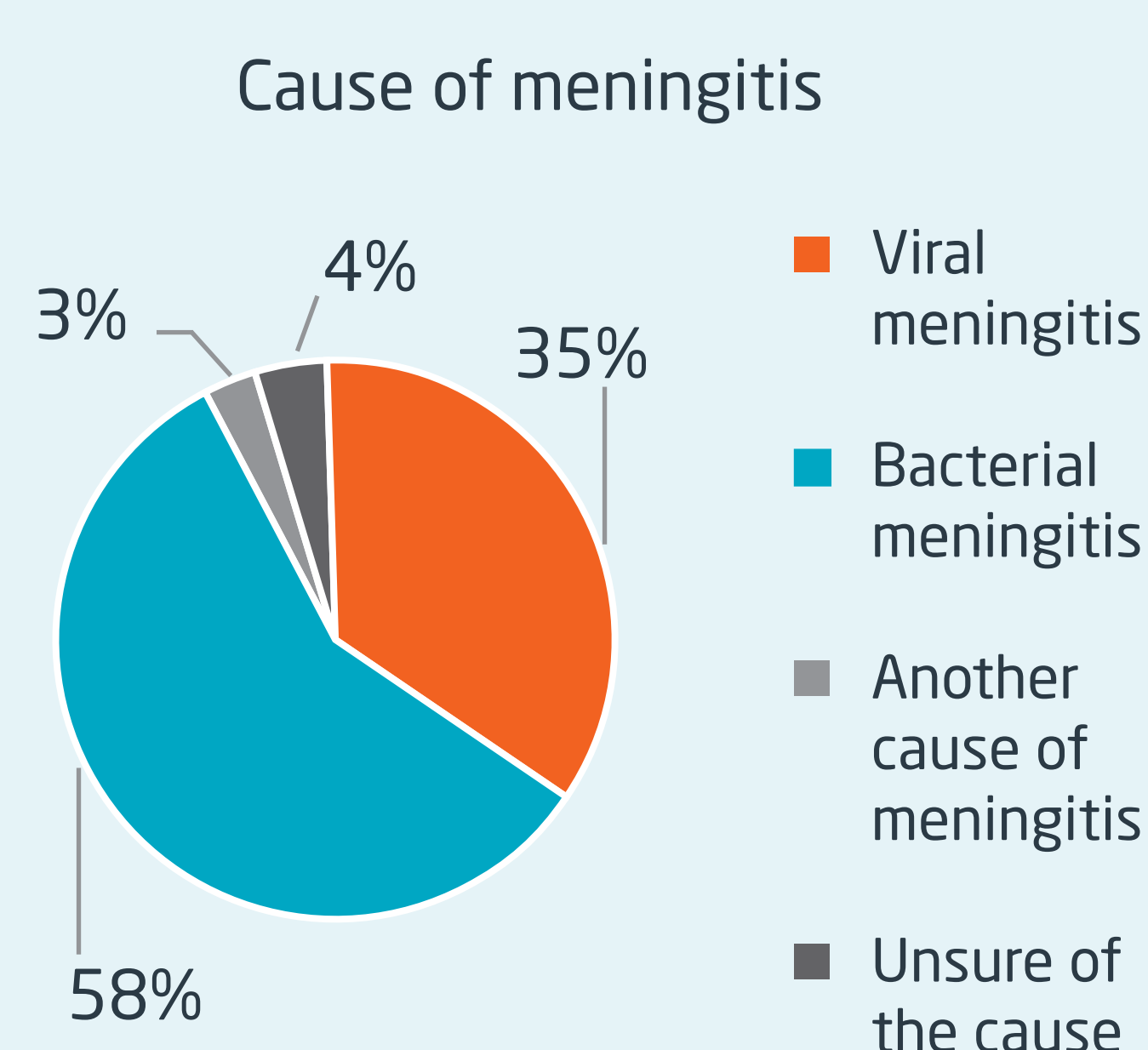
Method

The survey content was informed by qualitative research involving twenty participants:

- Five individual depth interviews, conducted remotely via Microsoft Teams
- An online asynchronous focus group with fifteen participants, held on Facebook

Participants were eligible if they were 16 years or older, had a UK hospital stay for bacterial or viral meningitis within the last five years, and lived in the UK. The findings from the qualitative stage were used in conjunction with Picker's survey development experience and Meningitis Now's understanding of the needs of those who had experienced meningitis, to form a 32-question survey. The survey was hosted online and publicised through a variety of channels by Picker and Meningitis Now. The survey ran from 15th September 2022 to 28th February 2023.

Results = 228 responses were received



Key findings

- 98% of respondents felt that improvements could have been made to their meningitis aftercare and support
- 80% of respondents were not provided with enough information about what to expect or how to manage their recovery before discharge
- 71% of respondents were not directed to any support services (statutory or voluntary) before leaving hospital
- 95% of respondents sought further information relating to meningitis since leaving hospital
- 54% of respondents were not offered any follow-up after discharge
- 94% reported that meningitis has negatively affected their home, work and social lives

At the end of the survey, respondents were asked the following open-ended question "What is the one thing you would change about meningitis aftercare and support in the UK?" Below are some of the responses received.

"Coping with the fear of a life-threatening condition and having aftercare. I had good care in hospital, but no one told me I would experience longer term issues."

"I was made to feel like I should recover in a week or two. It took me over a year to be anywhere near like myself."

"More follow-up after discharge. I was sent home and forgotten about."

"Misinformation from doctors was a huge factor in trying to rush back to normal life. At the very least I wish they had pointed me in the direction of charities like Meningitis Now from the start."

Conclusions

This survey focused on hospital discharge, recovery and information provision and support during aftercare. Regardless of the cause of meningitis, our findings highlighted gaps in follow-up care for adults with a recent experience of meningitis.

Meningitis often results in people suffering from ongoing and multifaceted after-effects, which impacted many aspects of their lives. Many respondents did not feel they received enough information, nor were they directed to appropriate support services, despite reporting that they would have liked both. A lack of care continuity began at discharge from hospital but extended beyond primary to secondary and tertiary care.

Meningitis Now presented the findings of this survey at the House of Commons to MPs and NHS leaders, calling for accessible information on hospital discharge, better training for NHS staff about the impact of meningitis, and signposting to services that help people living with the impact of meningitis. Meningitis Now has also shared the findings of this survey with NICE (National Institute for Health Care and Excellence) as evidence towards the guideline: Meningitis (bacterial) and meningococcal disease : recognition, diagnosis and management, currently in development.

Acknowledgements: We would like to acknowledge the Picker Institute Europe, who have been involved in the development and implementation of this study and subsequent report.

Funded by: Meningitis Now.
The full report is available at:
<https://www.meningitisnow.org/aftercarereport>