



Engagement, follow up and aftercare Lessons from the 'Meningitis Now' report

Bev Corbett and Claire Donovan
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Introduction

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Meningitis Now

- A UK wide charity founded in 1986
- Research, Awareness and Support
- Our Vision: A future where no-one in the UK loses their life to meningitis, and everyone affected gets the support they need to rebuild their lives



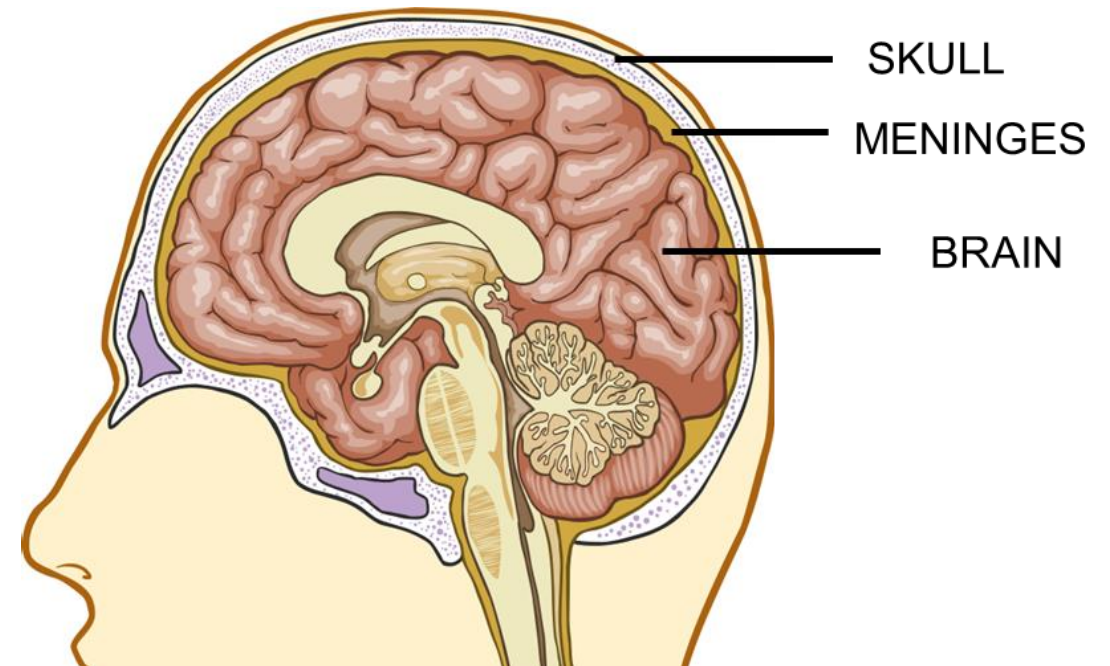
Meningitis and Meningococcal Disease

Inflammation of the meninges that surround the brain and part of the spinal cord

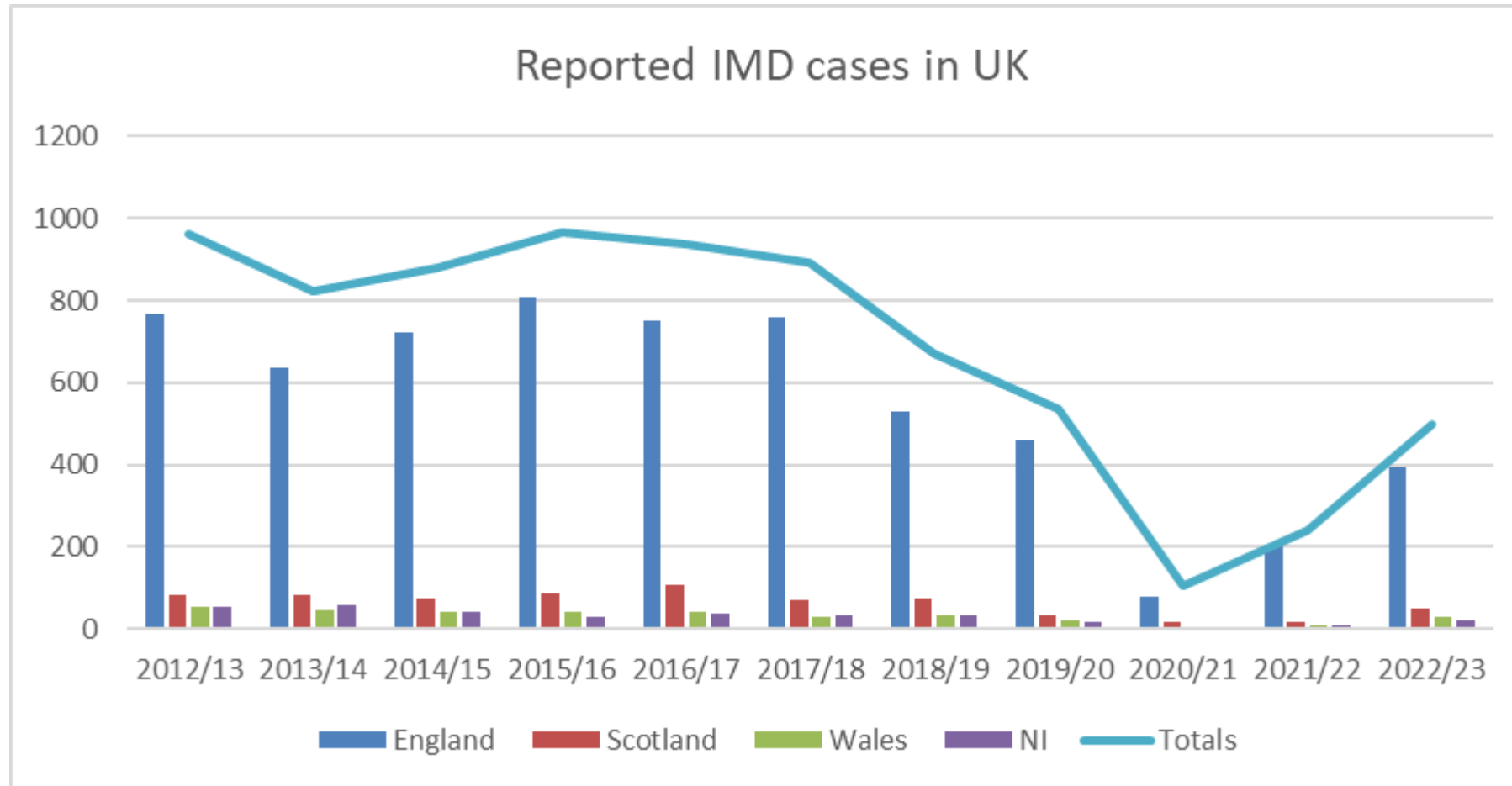
Meningitis is usually caused by a viral or bacterial infection

Meningococcal bacteria can cause meningitis and/or septicemia. This is known as meningococcal disease

Meningitis and septicemia can trigger sepsis



Meningococcal Disease



The Impact of Meningitis

Many people will make a good recovery with prompt treatment:

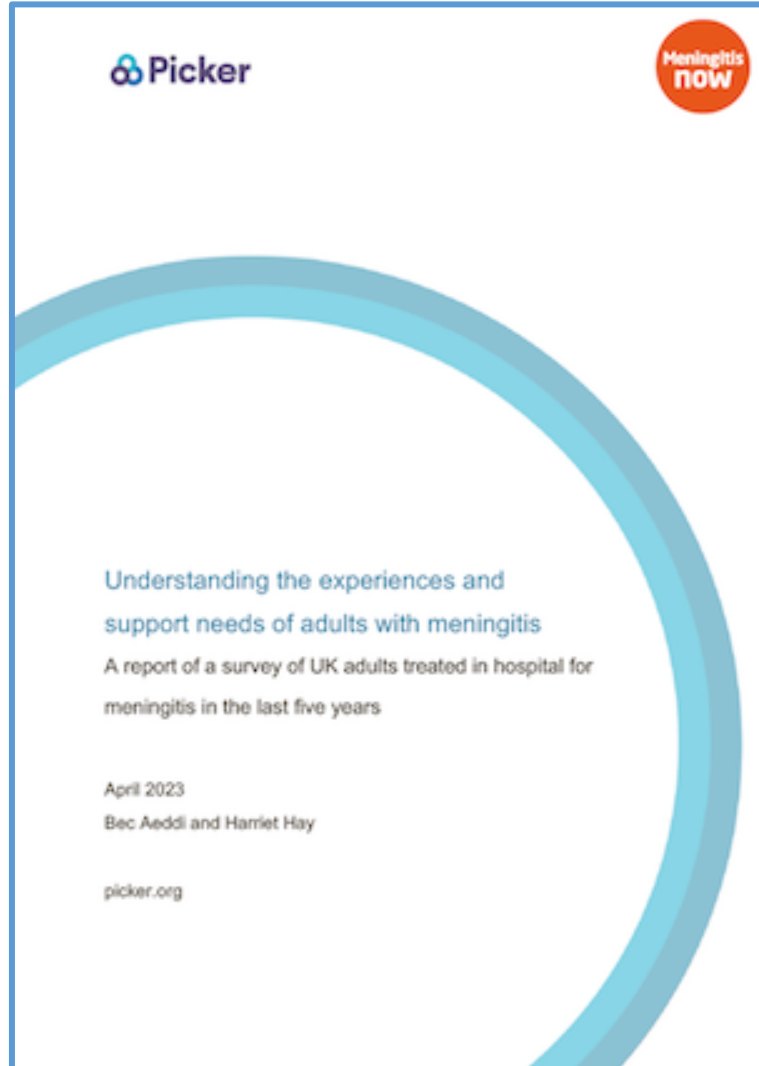
- Around 10% of those who contract bacterial meningitis will die
- Others are left with life changing after-effects which can include hearing loss, limb loss, sight problems, acquired brain injury, and learning difficulties and behavioural changes
- The impact of meningitis, whatever the outcome, can cause a range of emotional difficulties and common mental health problems e.g. anxiety and low mood



The Impact of Meningitis

- The long-term impact of Meningitis and Meningococcal Disease often represent a significant burden for families and health and social care services
- Even though the disease is now uncommon in the UK the burden is significant. With many people faced with lifelong after-effects and complications
- Families caring for someone with serious health needs following meningitis are often under immense physical, practical and emotional strain
- As a rare disease people can become isolated along the way, because inadequate and inconsistent follow up and ongoing care and support, has a significant impact on their quality of life.
- Healthcare services are designed to support the immediate needs of people with common diseases, and not the long-term impact of rare diseases like meningitis. This means people facing life after meningitis can sometimes have complex needs that are not met
- There is variation across the UK in follow up and aftercare of meningitis particularly in adults (NICE, 2019) and that there is a need to further develop expertise and best practice.

Research Overview



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:

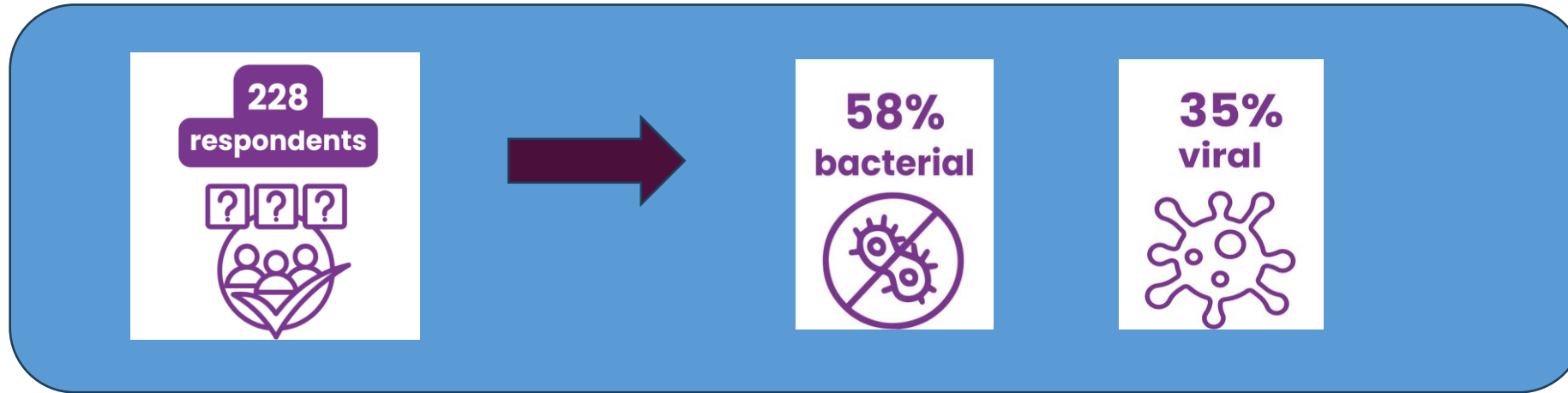
The survey content was informed by qualitative research involving twenty participants:

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

Eligibility


- 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.


About the Respondents





- 15% of respondents had been admitted to hospital for meningitis within three months of completing the survey,
- 32% between three months and two years ago and
- 53% between two and five years ago


Key Findings

 98% experienced after-effects of meningitis. 74% of those still suffered with them at the time of completing the survey

 46% were offered a follow-up appointment with a GP or hospital doctor after their hospital stay

 12% were provided with helpful information about recovery expectations and management before they left hospital. 80% reported that they did not receive this information but would have liked this

 94% experienced impacts of meningitis which negatively affected their home, work and social lives

 98% felt that improvements could have been made to their overall experience of meningitis aftercare and support

Key Findings

“What is the one thing you would change about meningitis aftercare and support in the UK?”

“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.”

“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.”

“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.”

A Patients Experience: Jennifer's Story



Jennifer, 64yr, contracted bacterial meningitis in Nov 2023. She was seriously ill requiring intensive care. Jennifer was left with lasting after-effects including seizures, mobility issues, anxiety and panic attacks. Her daughter takes up the story:

“Upon mum’s discharge, there was no information given to her about meningitis and its effects, and she was given no referrals, she was just sent on her way which left her and the family feeling very upset and confused”

Jennifer's Story contd...

“We often felt overwhelmed and wish there had been more direct support from the hospital. Our experience highlights the critical need for comprehensive care and support for families dealing with meningitis.”

“Throughout the ordeal, we found invaluable support and information from Meningitis Now. It provided information on the disease and hearing other people's stories allowed us to provide information to my mum. Their resources helped me understand the disease and advocate effectively for my mother's care”

<https://www.meningitisnow.org/meningitis-now-stories/news-centre/news/jennifer-hs-story/>

A Patients Experience : Liam's Story



Improving Follow Up and Aftercare

Meningitis Now's report, identified 3 specific recommendations for the health and care system:

1. Greater information provision at discharge for people who have suffered from meningitis and their family, friends and employers, would help to reduce the negative impact of meningitis on people's social and financial wellbeing
2. Care should be accessible both at the time of being diagnosed with meningitis and beyond
3. Standardised aftercare support packages should include both psychological and recovery support services and should direct people who have suffered from meningitis to charities, from the point of discharge

We believe that implementation of these findings would help promote timely and better continuity of care and enable and improve people's ability to self-care and to access charitable support

We also believe that this analysis and recommendations has relevance to many other diseases/health conditions.

<https://www.meningitisnow.org/meningitis-now-stories/campaigns/meningitis-follow-up-and-aftercare-report/>

Conclusions and Next Steps

- Meningitis and meningococcal disease are uncommon, but its impact on the lives of those that have it can be significant
- In many case, adults are given little information about recovery or aftercare and support – during or following a hospital stay
- People need relevant information when discharged to help support their recovery
- This should include information on recovery expectations as well as follow up checks and medication advice where relevant
- Health charities can play an important role in providing information and ongoing support

Conclusions and Next Steps

- Shared with NICE to inform the following guideline covering babies, children, young people and adults:

[‘Meningitis \(bacterial\) and Meningococcal Disease: Recognition, Diagnosis and Management’](#)

- The above guideline was revised and updated in March 2024 to include a greater emphasis on follow up and aftercare
- Currently developing a fact sheet on recovery and a discharge checklist – due for completion in January 25 and available as a download from our website



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Self Reflection:

- What information is due you provide for your patients before discharge?
- How do you know this meets their needs?
- Do you signpost or provide information from relevant charities?