



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

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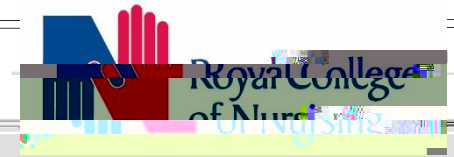
# Introduction

- #Meningitis Now
- #Meningitis and Meningococcal Disease
- #The Impact of Meningitis and the Ongoing Challenge
- #Report Summary and Findings
- #Case Studies
- #Conclusions and Next Steps



# Meningitis Now

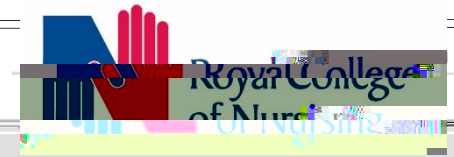
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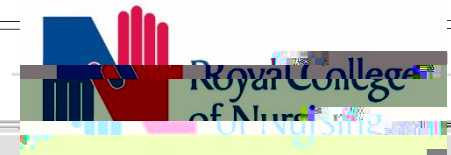
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# Meningitis and Meningococcal Disease



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# Meningococcal Disease



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# The Impact of Meningitis

Many people will make a good recovery with prompt treatment:

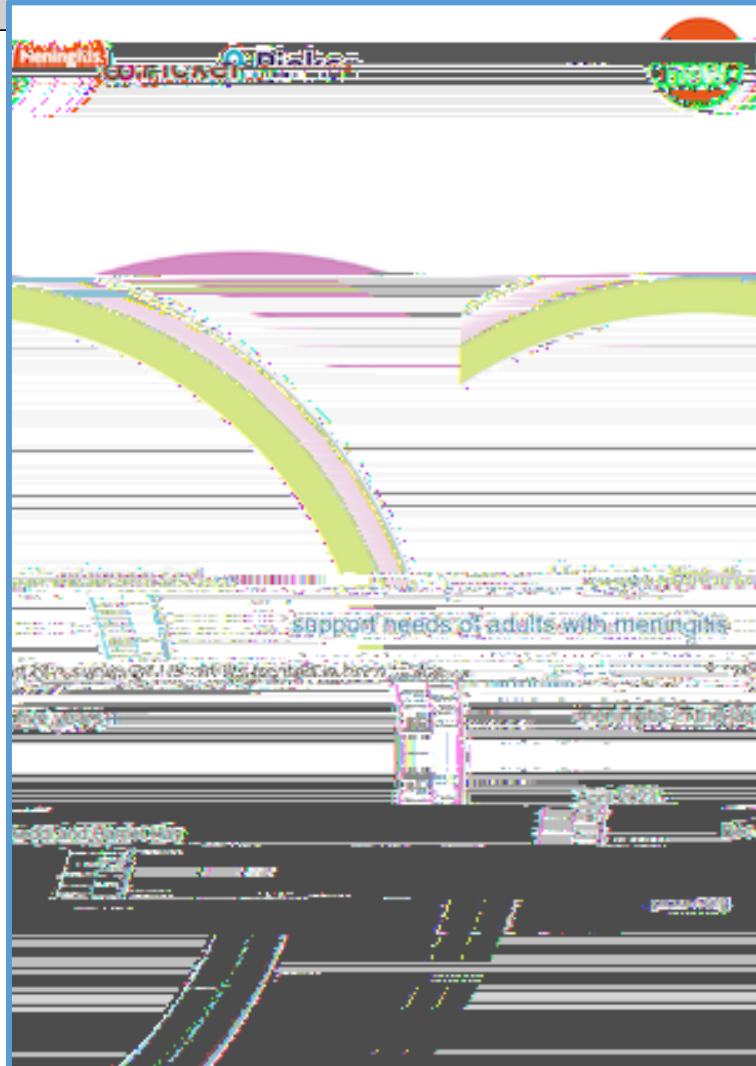
- ‡ Around 10% of those who contract bacterial meningitis will die
- ‡ Others are left with life changing after-effects which can include hearing loss, limb loss, sight problems, acquired brain injury, and learning difficulties and behavioural changes
- ‡ The impact of meningitis, whatever the outcome,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

# 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:

remotely via Microsoft Teams

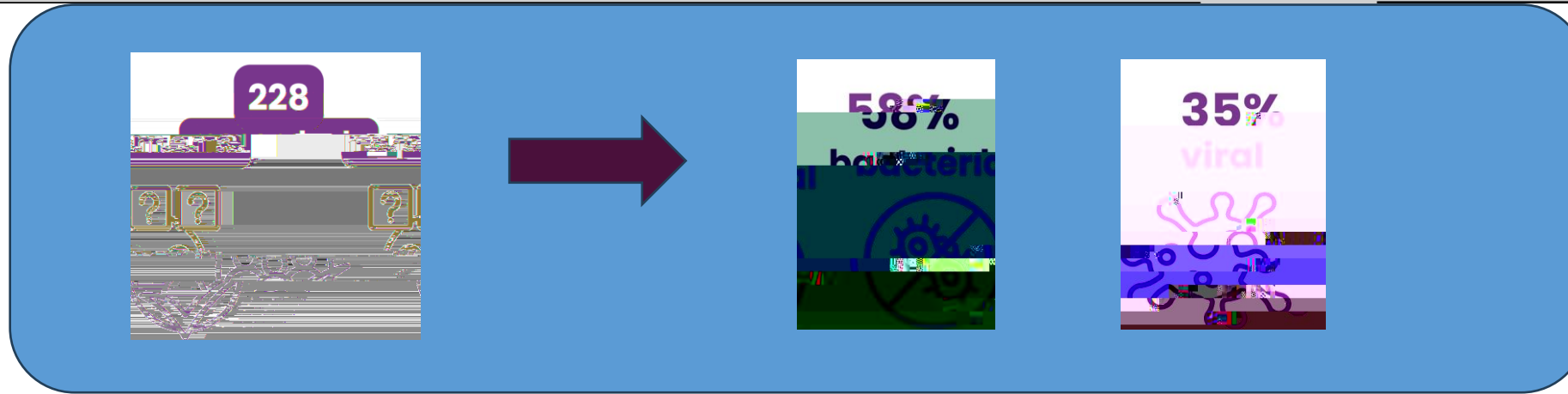
fifteen participants, held on Facebook







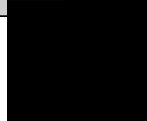
# About the Respondents



- ‡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



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



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



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



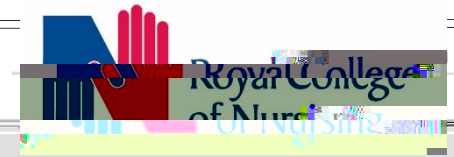
experienced impacts of meningitis which negatively affected their home, work and social lives



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



# Key Findings



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3 & RSLQJ ZLWK WKH IHDU R  
threatening condition and  
having aftercare. I had good  
care in hospital, but no one told  
me I would experience longer  
WHUP LVVXH V

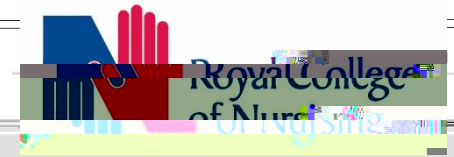
Misinformation from doctors  
was a huge factor in trying to  
rush back to normal life. At the  
very least I wish they had  
pointed me in the direction of  
charities like Meningitis Now  
from the start

3 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



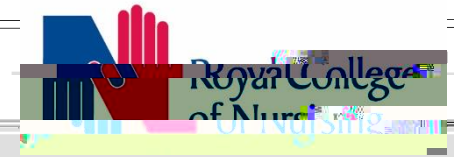
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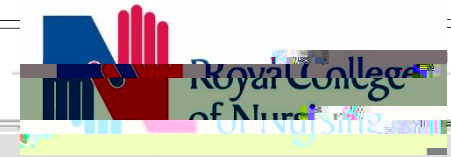


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# Improving Follow Up and Aftercare



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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

S H R S O H p V V R F L D O D Q G I L Q D Q F L D O Z H O O E H L Q J

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

R I F D U H D Q G H Q D E O H D Q G L P S U R - Y a h e a n d t o s o c i e t y a n d a b l e O s u p p o r t W R

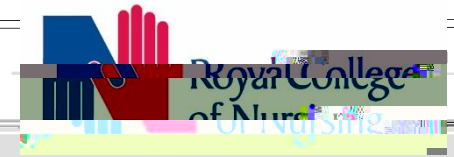
We also believe that this analysis and recommendations has relevance to many other diseases/health conditions.

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# Conclusions and Next Steps



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# Conclusions and Next Steps

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

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‡ 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





## 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?