

Public knowledge of meningitis and septicaemia impairments and after-effects

Survey responses from polling: UK and Ireland

Meningitis and septicaemia can be caused by the same infections. Meningitis is inflammation of the membranes that surround and protect the brain and spinal cord. Meningitis can be caused by various bugs such as bacteria, viruses and fungi. Most severe cases are caused by bacteria. Septicaemia is blood poisoning caused by large numbers of bacteria in the blood stream (sometimes referred to as sepsis).

Some examples of meningitis and septicaemia after-effects are outlined below. Information on after-effects and data table 1 have been taken from '[DEFEATING MENINGITIS BY 2030: baseline situation analysis](#).'

Introduction

Meningitis and septicaemia can be deadly and survivors can be left with life-long impairments, such as brain injury and amputations.

Meningitis Research Foundation commissioned OnePoll (European Society for Opinion and Marketing Research and Market Research Society member employees) to ask the UK and Irish public what they knew about the potential outcomes of meningitis and septicaemia.

We also asked families and individuals affected by meningitis how they rated the specialist support and aftercare they had received. This survey was conducted by Meningitis Research Foundation using our Facebook audience.

Potential impacts of meningitis and septicaemia

Meningitis and septicaemia can be deadly and those who survive can be left with impairments or challenging, life-changing after-effects which can be short- or long-term.

A review of data from 1980 to 2010 estimated the average case fatality rate for bacterial meningitis globally as 14.4% (meaning 14.4 out of every 100 people with bacterial meningitis will die).ⁱ It also showed variation by region – the rate was 31.3% in the African Region. However, the severity of meningitis and the number of people who die as a result can vary according to which bacteria caused it; for example with invasive meningococcal disease, case fatality rate can be between 5 and 20%.ⁱⁱ

Life-changing impairments and after-effects occur at a high degree in survivors of meningitis (see Table 1 below). These can include: strokes, seizures, hearing loss, limb weakness, and difficulties with sight, speech, language and communication. New-borns are a particularly high-risk population, with acute complications such as fluid accumulation around the brain and brain abscess. Studies in children have shown that measures of intelligence and learning can be lower on average in meningitis survivors. Septicaemia can also cause severe complications leading to amputations (fingers, toes, limbs), skin scarring and bone growth problems.

Table 1. Risk of after-effects and impairments by bacterial pathogen and data source

Source		Risk for all cause meningitis	Risk for meningococcal	Risk for Pneumococcal	Risk for Hib	Risk for GBS
Risk of disability	Edmond et al ⁱⁱⁱ (>=1 major after-effect) Median risk.	12.8%	7.2%	24.7%	9.5%	-
	Kohli-Lynch ^{iv} Moderate to severe neurodevelopmental impairment 18 months after GBS meningitis. Mean risk.	-	-	-	-	32%

A systematic review of the global and regional risk of disabling after-effects from bacterial meningitis performed in 2010 found that approximately 13% of survivors experienced severe impairments.ⁱⁱⁱ The proportion of survivors with severe after-effects varied by pathogen, with the highest for pneumococcal meningitis, and survivors in low-income countries (LIC) were worst affected.

The 2016 Global Burden of Disease study found that pneumococcal meningitis resulted in more years of life lived with disability than for other bacterial causes.^v

Meningitis after-effects can have an enormous impact on families and communities, both financially and emotionally. In the United Kingdom, significant reductions in quality of life were found in those who care for meningitis survivors with disability.^{vi}

In low-income settings, the devastating costs of meningitis on households and communities has been described,^{vii} illustrating how meningitis prevention could contribute to reducing poverty.

Public Knowledge

OnePoll asked 2,000 UK adults and 500 adults in Ireland about their knowledge of the impacts of meningitis.

UK

Most of the 2000 people surveyed (90%) did not know deafness was a common after effect of meningitis, despite it being a leading cause of acquired hearing loss.

Most people (87%) also under-estimated or didn't know how many people were left with impairments as a result of bacterial meningitis.

Around nine in ten people surveyed (92%) did not know or underestimated the full cost of severe meningitis; MRF estimated the costs to the state for a severe case of meningitis to be in the region of £3 to 4.5m over the person's lifetime.

1. Which of the following do you think a possible consequence of bacterial meningitis and septicaemia? (tick all that apply)

Choice	%
Early death	62.90% 1258
Tooth damage	20.15% 403
Amputations	60.55% 1211
Scars or skin problems	37.50% 750
Tinnitus	22.00% 440
Brain damage	60.20% 1204
Memory loss	33.85% 677
Mental health issues such as depression and anxiety	34.65% 693
Deafness	39.50% 790
Blindness	45.45% 909
Seizures	42.10%

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Behavioural disorders	25.95% 519
Speech or communication problems	35.40% 708
Damage to internal organs	54.00% 1080
Learning difficulties	28.60% 572
Problems with muscles or bones	37.65% 753
None of the above	1.30% 26
I don't know	12.85% 257

2. All of the below can be a possible consequence of bacterial meningitis and septicaemia. Which of the following do you think are the most common? Select up to 3

Choice	%
Early death	32.95% 659
Tooth damage	5.20% 104
Amputations	38.10% 762
Scars or skin problems	13.85% 277
Tinnitus	4.55% 91
Brain damage	31.75% 635
Memory loss	7.70% 154
Mental health issues such as depression and anxiety	10.10% 202
Deafness	10.00% 200
Blindness	10.85% 217
Seizures	14.10%

	282
Behavioural disorders	3.40% 68
Speech or communication problems	7.75% 155
Damage to internal organs	25.25% 505
Learning difficulties	4.70% 94
Problems with muscles or bones	10.85% 217
None of the above	0.90% 18
I don't know	16.00% 320

3. Given that one of the below is accurate, what do you think the estimated lifelong financial cost is on the government and NHS for one person with severe meningitis? Please select best match

Choice	%
Up to £50,000	8.60% 172
£50,001 to £100,000	19.05% 381
Between £100,001 and £1m	24.95% 499
Between £1m and £2m	10.60% 212
Between £2-4m	4.50% 90
Over £4m	2.95% 59
Not sure	29.35% 587

**4. How many people do you believe will be left with an impairment caused by bacterial meningitis?
Please select best match**

Choice	%
1 in 5	12.50% 250
1 in 10	19.70% 394
1 in 20	16.50% 330
1 in 30	8.90% 178
1 in 50	11.45% 229
Other amount	2.35% 47
Not sure	28.60% 572

Ireland

1. Which of the following do you think a possible consequence of bacterial meningitis and septicaemia? (tick all that apply)

Choice	%
Early death	54.20% 271
Tooth damage	15.00% 75
Amputations	41.60% 208
Scars or skin problems	30.20% 151
Tinnitus	15.20% 76
Brain damage	56.60% 283

Memory loss	28.40%	142
Mental health issues such as depression and anxiety	25.00%	125
Deafness	28.60%	143
Blindness	32.20%	161
Seizures	36.20%	181
Behavioural disorders	20.00%	100
Speech or communication problems	29.60%	148
Damage to internal organs	48.40%	242
Learning difficulties	23.80%	119
Problems with muscles or bones	34.20%	171
None of the above	2.60%	13
I don't know	8.00%	40

2. All of the below can be a possible consequence of bacterial meningitis and septicaemia. Which of the following do you think are the most common? Select up to 3

Choice	%	
Early death	38.60%	193
Tooth damage	3.80%	19
Amputations	26.60%	133
Scars or skin problems	15.20%	76
Tinnitus	4.40%	22
Brain damage	41.00%	205

Memory loss	11.00%
	55
Mental health issues such as depression and anxiety	9.40%
	47
Deafness	12.40%
	62
Blindness	10.20%
	51
Seizures	17.60%
	88
Behavioural disorders	7.00%
	35
Speech or communication problems	10.20%
	51
Damage to internal organs	31.60%
	158
Learning difficulties	7.00%
	35
Problems with muscles or bones	16.80%
	84
None of the above	1.80%
	9
I don't know	6.20%
	31

3. Given that one of the below is accurate, what do you think the estimated lifelong financial cost is on the government and NHS for one person with severe meningitis? Please select best match

Choice	%
Up to £50,000	14.80%
	74
£50,001 to £100,000	23.40%
	117
Between £100,001 and £1m	22.20%
	111
Between £1m and £2m	12.40%
	62
Between £2-4m	7.80%
	39
Over £4m	3.60%
	18

Not sure	15.80% 79
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4. How many people do you believe will be left with a severe impairment caused by bacterial meningitis? Please select best match

Choice	%
1 in 5	14.80% 74
1 in 10	20.80% 104
1 in 20	15.00% 75
1 in 30	11.40% 57
1 in 50	16.40% 82
Other amount	5.20% 26
Not sure	16.40% 82

Support and aftercare

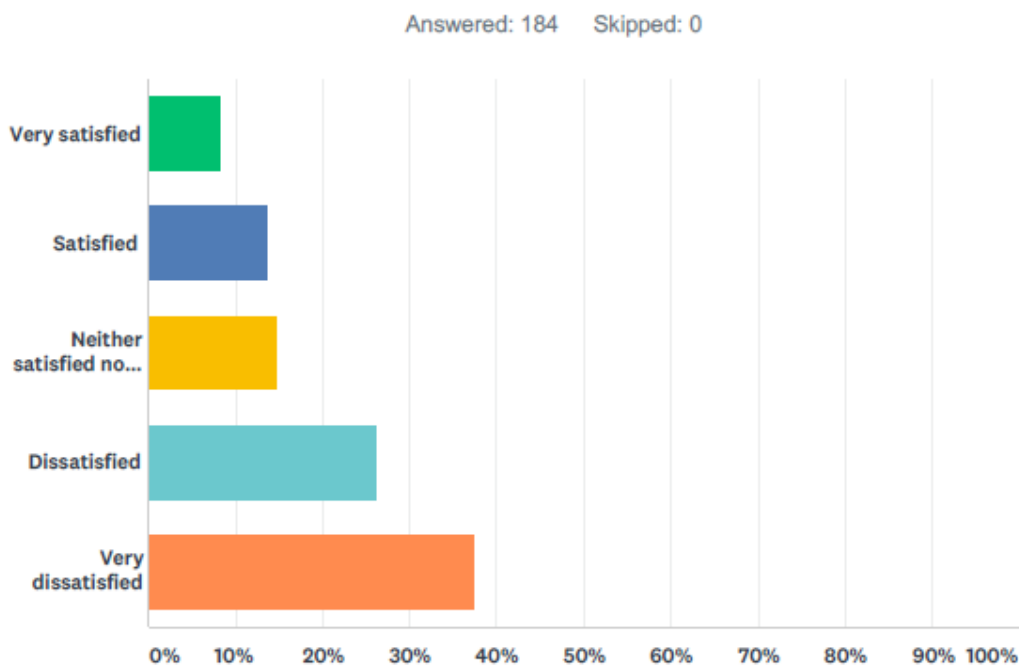
A study of survivors of bacterial meningitis and septicaemia, conducted by MRF and academics, in 2013^{viii} found:

- 57% needed aftercare or support
- Most parents reported that their child received a hearing test (98%) and follow-up appointment with a paediatrician (66%)
- Psychosocial after-effects were most common and the greatest need was for educational support
- About half of participants felt their children's needs for aftercare were met
- Access could be limited by: parents' inability to navigate systems in place, child's age, and delayed identification of impairments
- Good communication between professionals enabled a service tailored to the child's needs

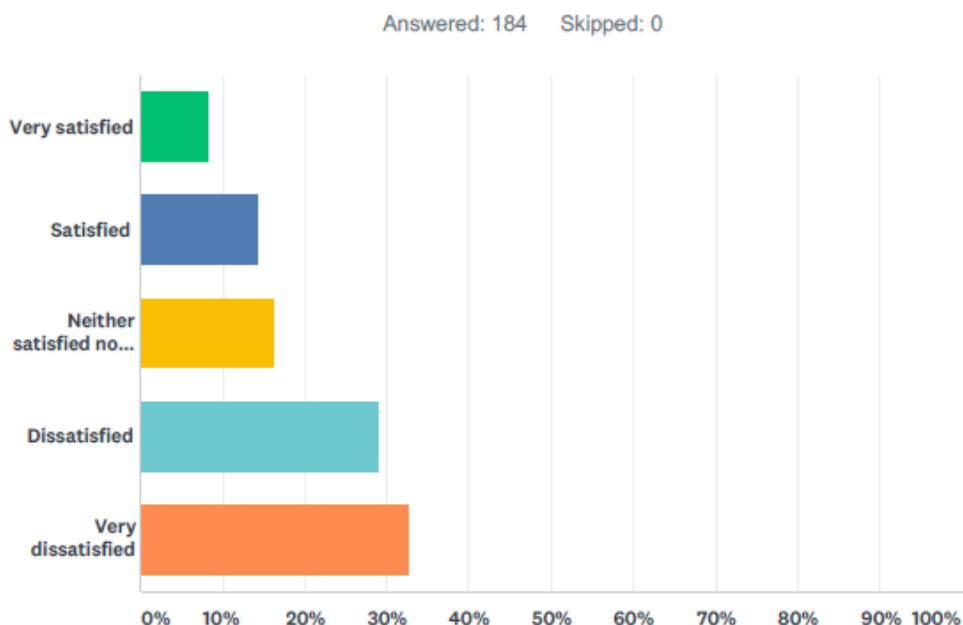
In 2019, we asked families and individuals affected by meningitis how they rated the specialist support and aftercare they had received for these impairments. This market research survey was conducted by Meningitis Research Foundation using our Facebook audience.

We asked them how satisfied they were with the follow-up care they had received:

1. Assessment for possible long-term effects of meningitis (physical and psychological)

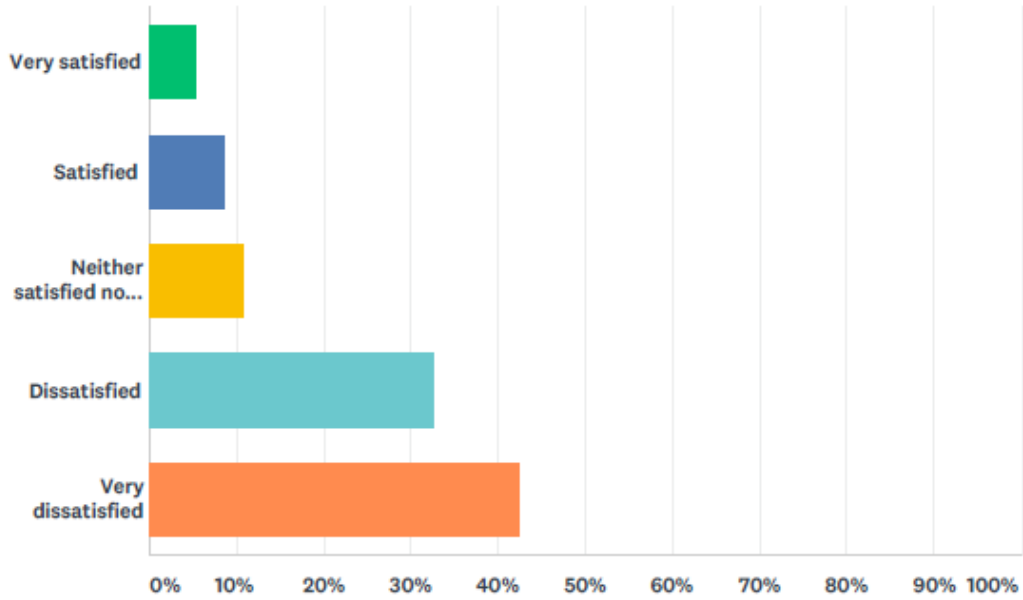


2. Given information about possible long-term effects of meningitis (such as hearing loss, scarring, and amputation recovery)



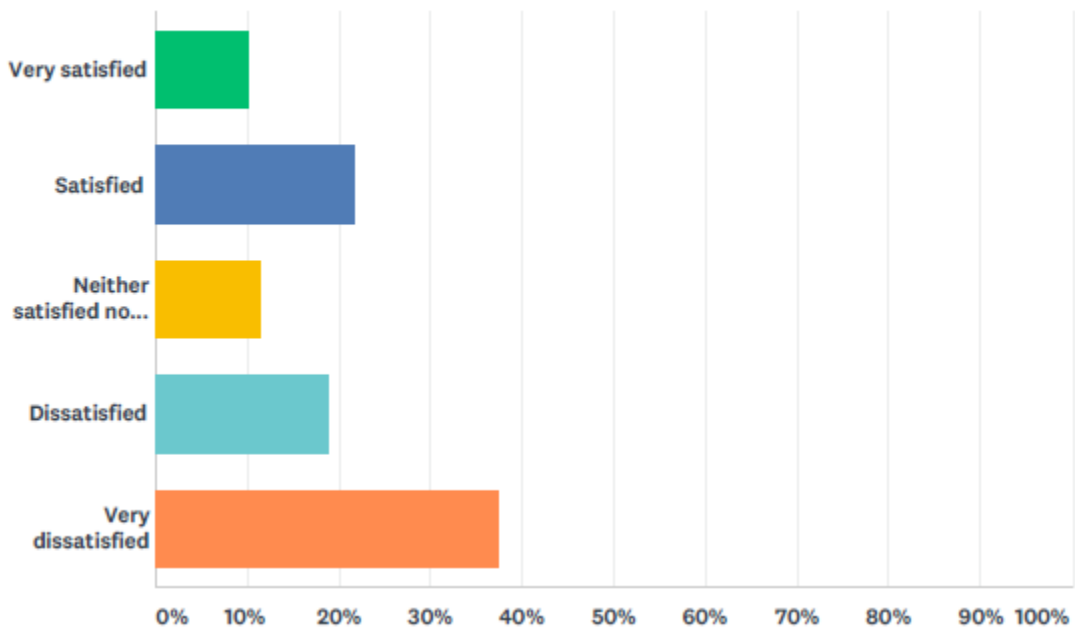
Q3 Given information about support organisations

Answered: 184 Skipped: 0

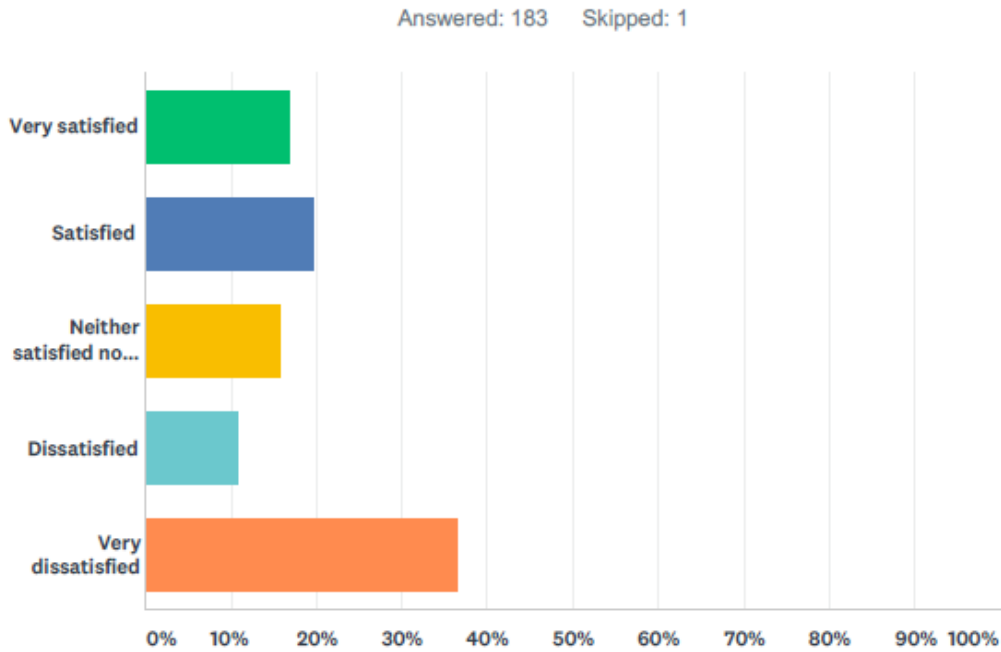


Q4 Appropriate hospital follow up was arranged

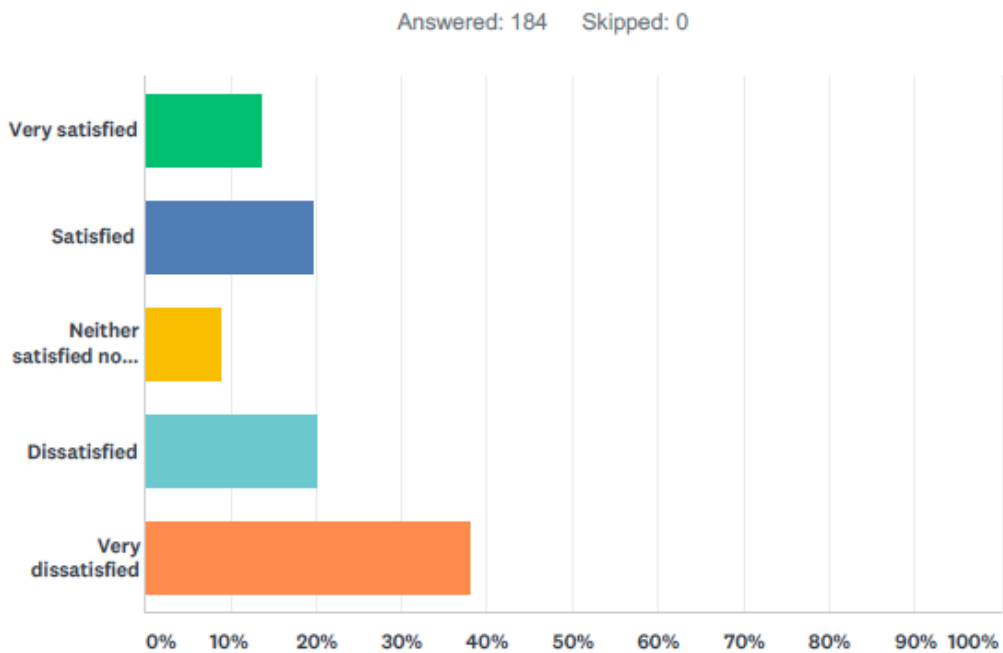
Answered: 184 Skipped: 0



Q5 A hearing test before discharge or within 4 weeks of being well enough to test (only in children and young adults or those unable to notice hearing loss and in)



Q6 A review 4-6 weeks after hospital discharge to assess recovery



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- ⁱ Luksic I, Mulic R, Falconer R, Orban M, Sidhu S, Rudan I. Estimating global and regional morbidity from acute bacterial meningitis in children: assessment of the evidence. *Croat Med J.* 2013;54(6):510–8.
- ⁱⁱ WHO. Defeating Meningitis by 2030. Baseline Situation analysis. Accessed 10/09/2019. https://www.who.int/immunization/sage/meetings/2019/april/2_DEFEATING_MENINGITIS_BY_2030_baseline_situation_analysis.pdf?ua=1
- ⁱⁱⁱ Edmond K, Clark A, Korczak VS, Sanderson C, Griffiths UK, Rudan I. Global and regional risk of disabling sequelae from bacterial meningitis: a systematic review and meta-analysis. *Lancet Infect Dis.* 2010;10(5):317–28.
- ^{iv} Kohli-Lynch M, Russell NJ, Seale AC, Dangor Z, Tann CJ, Baker CJ et al. Neurodevelopmental impairment in children after group B streptococcal disease worldwide: systematic review and meta-analyses. *Clin Infect Dis.* 2017;65(suppl_2):S190–s9.
- ^v Zunt JR, Kassebaum NJ, Blake N, Glennie L, Wright C, Nichols E et al. Global, regional, and national burden of meningitis, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2018;17(12):1061–82
- ^{vi} Al-Janabi H, Van Exel J, Brouwer W, Trotter C, Glennie L, Hannigan L et al. Measuring health spillovers for economic evaluation: a case study in meningitis. *Health Econ.* 2016;25(12):1529–44.
- ^{vii} Griffiths UK, Dieye Y, Fleming J, Hajjeh R, Edmond K. Costs of meningitis sequelae in children in Dakar, Senegal. *Pediatr Infect Dis J.* 2012;31(11):e189–95
- ^{viii} Clark, Laura J., et al. "The health, social and educational needs of children who have survived meningitis and septicaemia: the parents' perspective." *BMC public health* 13.1 (2013): 954.