

Responses from the Meningitis Research Foundation consultation on the Global Roadmap to Defeat Meningitis

Meningitis all causes

Responses in English

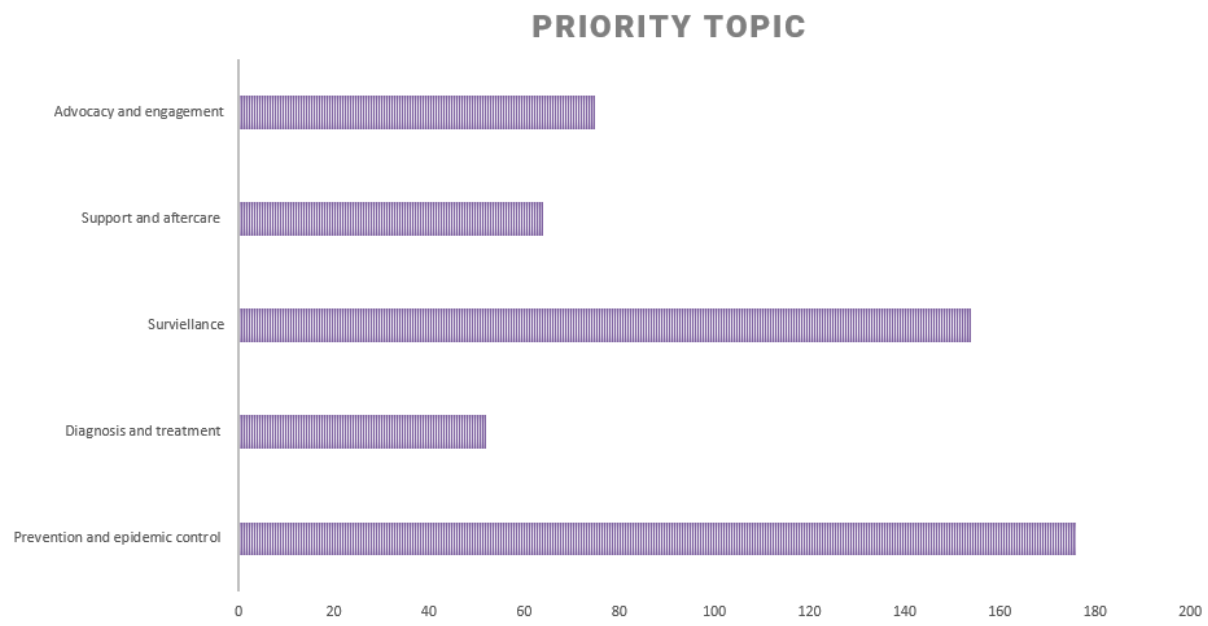
Number

- 640 responses
- 82 countries

Priority topic

Prevention was the highest priority topic. This was followed by improving surveillance (knowing how much meningitis there is and where it is).

However, many people commented that all were important.



What is missing from these priorities?

When asked about areas that people felt were missing from the current pillars, most people listed actions that could sit under the existing pillars or specific activities that they felt should be prioritised.

Prevention and epidemic control

- Many respondents focused on affordability and access to vaccines: widening existing programmes, more local health clinics, working with manufacturers to reduce prices, supporting countries with funding.
- Vaccine education was also important: dispelling myths, banning fake information and pseudoscience.
- Four respondents commented on preventing infections in healthcare settings that could lead to meningitis, noting: avoiding iatrogenic causes, prevention at ICU and hospital acquired infection.
- One respondent asked what was been doing about prevention in the absence of vaccines.

Diagnosis and treatment

- The most popular theme here was adequately educating health professionals. This ranged from health worker training to a call for a meningitis specialist in every hospital.
- Several respondents wanted rapid diagnosis tests and techniques improved.
- Rapid referral was also highlighted.
- Mandatory training outside of health workers was also highlighted, such as university staff and nursery staff.
- One participant highlighted antimicrobial stewardship.

Surveillance

- Several respondents wanted better access to accurate data and the publication of key statistics (ages affected, places etc.)
- One respondent called for better equipment for surveillance.

Advocacy and engagement

- Public awareness was mentioned more than any other subject (28 times). Several people mentioned sensitisation campaigns. School-based education was also seen as important.
- Several people mentioned the need for educating new mothers and parents.

Support and Aftercare

- Ensuring there is appropriate support resonated with many people.
- Some focussed on the location of support being important with the need for community based approaches.
- A few people mentioned specific targets for support or support types: support for carers and families, bereavement support, support for people impairments from meningitis.
- Two people highlighted that a better understanding of the long term impact of meningitis was needed.

General comments

- Research funding was a very popular focus, most did not specify the type but some suggested a cure or better treatment.
- Some were concerned how countries would pay for it all.
- Partnerships were mentioned several times and the need to coordinate with other actors and health initiatives.
- One participant suggested the need for a better understanding of genetic factors linked to the disease.

What one thing would people change?

We asked people what one thing they would like to see in the roadmap.

Topic	Number
Making vaccines more widely available/for everyone. <ul style="list-style-type: none"> • Some comments on affordability or wanting them to be free 	293 8 of which said they should be compulsory
Improved awareness <ul style="list-style-type: none"> • There were only a few specific answers: TV campaigns, community awareness and three mentioning schools 	90
Improved diagnosis <ul style="list-style-type: none"> • Most saying immediate, rapid, fast, or faster 	43
Educating people/sensitisation	33
Information or publicity (non-specific)	26
More research <ul style="list-style-type: none"> • Very few specified what research, one mentioned eradication and one said 'research on survivors' 	15
Clean water, cleanliness and hygiene improvement	12
Training for doctors and medical staff	11
More funding to implement to global plan	5
GBS test/screening	5
A cure	2

Other, individual priority actions that were called for are included below (exactly as they were filled in):

Check all pregnant women on strep B infection. In Netherlands this is not standard. My 1 day old daughter nearly died of meningitis/sepsis

A clear benchmark set by WHO for immunisation levels against all forms of meningitis and septicaemia

A form on immunisation

A global action plan with clear steps to defeating meningitis

A good and quality health care system

A strong campaign.

A vibrant health care force through Scholarships and training

Abstaining from teenage sex

Access of health services in remote area

Acknowledge lyme disease can cause meningitis

Affordable health care for all

Affordable treatment

All medical personnel and the leaders of my beloved country to have that burning desire and the drive to defeat meningitis

Annual health check-up for the risk aging group

Antibiotics available and testing pre and post birth.

Better doer for pregnant women

Better healthcare

Better infection control strategy at hospitals

Better understand the difference between bacterial and viral, and long term medical complications.

Better understanding of how easy it is to catch and also to misread the symptoms especially in very young children

Bro Nate life meningococcal septicaemia meningitis

Capacity reinforcing for community agent and peer educators

Doctors acting quicker. 3 times I was sent home with my son! Rule it out first.

Earlier testing when someone develops symptoms that could possibly be meningitis. Even if they could also be something else. Speed matters a lot

Effective healthcare in rural areas

Enlightment/Immunization

Ensure that HIV positive patient at risk of meningitis are screened and receive prophylaxis treatment

Environmental sanitation

Every person, given every vac for every strain, and have a program to ensure everyone is upto date

Exchange of technical knowledge, skills and resources.

Focus to under five children

Free counselling and free screening of all

Free tests.

Fully functional health institutions

Global plan for early recognition and treatment of meningitis

Government seriousness to cope up health issues

Have the government to be concern of their constituent health

Health programme

Health policy.

Immediate air services to lift the patient to right place rather than travelling in ambulance for hours.

Improve and structure tertiary hospitals

Increased work on antibiotic development &

Immediate plan of action for effective management of suspected cases of meningitis

Infection control

Let people learn more of how too recognize the symptoms

Making its treatment affordable in all the 47 counties

Mapping

Meningitis treated as a global health priority

More access to medicine and health care

More availability

More budget allocation to Health Departments to be able to handle the disease in terms of providing proper medical care and further assist those who have been affected by the disease and also sensitize the disease to the public

More checks

More leaflets put in primary's

More Preventive measures

More support to victims

Much sensitization

Need to render enough advocacy to the people on regards to particular disease.

People being made aware and more informed about meningitis, the symptoms and actions one needs to take to curb it.

Proper effective screening

Proper medical facilities

Proper treatment and screening equipments in health facilities.

Put greater importance on viral meningitis. It is dangerous.

Question all flu cases.

Quicker returns on lumbar puncture results

Road Side Garbage..

Screenings and intervention

Should let people know about the realities of the illness often and through all means

Specific target for the reduction and eradication of the disease strain by strain

Stop taking so many lives

Take the safe before unsafe. When it goes too far, there is nothing you can do. Giving high antibiotics in time is crucial.

That all babies & children that show any signs or symptoms are given a lumbar puncture. A small test with minimal risks can save a child's life

That the second series for B was mandatory by the schools so it would be automatically covered by insurance and not a choice

The government should insist more on sensitization of individuals and family as a whole concerning this deadly disease

To take into account some of the signs shown by any person of any age

Tought people about it

Training for health care professionals on early warning signs

Understanding of its cause and effect and learn how to defeat it

Using mask to prevent invasion of pathogenic organism with air droplets.

Meningitis all causes – suggestions received in other languages

French (France and Meningitis Belt)

Vaccination

- Systematic vaccination of populations in risk areas and free vaccination for children aged 0-5.
- Free screening for children and shot (even the most deprived)
- Vaccination campaign.
- Definitive vaccine.
- I would like the state officials to take charge of it. To be vaccinated you have to have money, in short. Public health problem.
- Organize national campaigns and introduce routine vaccinations in all hospitals, clinics and public and community health centers for anyone visiting these centers.
- Have access to vaccine stock for response based on the most common pathogens

Awareness

- In the field of football each player could advertise on meningitis as they are most followed
- Use social media to reach the world
- To sensitize the populations of the danger of the disease and when to be vaccinated
- Large awareness campaign in all regions.

Diagnosis and treatment

- Health system change
- Training of medical and paramedical staff
- Immediate care of patients with meningitis.

Epidemics

- Free treatment and availability of products during periods of epidemics
- Involvement of communities and civil society organizations in the creation of demand and also the monitoring of cases of occurrence of the epidemic.
- Response and preparedness for epidemics, especially in the countries of the meningitis belt.
- Anticipate before the period of the epidemic to make prevention

Surveillance

- Specific evaluation of the prevalence rate of meningitis.
- Facilitating access to vaccines (reduce the risk of vaccines if not free).
- Inform people more about this disease 'a lot do not know her

Arabic (Djibouti)

- The most important thing is Awareness of the disease

Bengali (Bangladesh)

- Emergency treatment and quick identification
- Use of Alternative medicine
- Awareness

Hindi (India)

- Reaching rural areas
- It needs to be prioritized, at a war level, so that it can be overcome

Italian (Italy)

- Timely and safe identification of the agent that is causing the disease.

Polish (Poland and UK)

- Financing of vaccinations by the state
- I believe that family doctors could recommend adults to be vaccinated against meningococci as recommended to young children
- Making society aware of lies, manipulation of vaccination groups and the importance of a high rate of vaccination for society
- General improvement of health care.
- Mandatory vaccinations
- High-profile campaigns to promote vaccination
- Lower price for vaccines. Greater accessibility to them.
- The affordable price of vaccines, so that everyone can afford them
- Education of a young parent.

Portuguese (Portugal and Cabo Verde)

- Children get the right messages at school
- More attention on meningitis
- Free vaccinations

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Spanish (Mexico, Nicaragua, Spain, Venezuela)

Vaccination

- Application of vaccines for all children and the elderly
- More awareness campaigns to vaccinate
- Investment of resources for research and vaccination.
- Incorporation of available vaccines against meningitis in a free vaccination schedule.
- Free access in all communities of my country to all vaccines that protect against meningitis
- And the importance of inventing in these vaccines that can save many lives.
- Investment and vaccination
- Vaccination Campaigns

Diagnosis

- Accurate diagnoses and recognition of the results are required.
- Increased education and health improvements.
- That better health care will be implemented for early detection,
- Teach people when they should look for a doctor and not wait
- That the test is given priority to detect meningitis and that as soon as the probability of it is suspected, the antibiotics or medications necessary to combat it are immediately applied.

Awareness and education

- That any exam do not leave it for three months
- Education
- Provide more information on ways to get the disease and how to prevent or reduce the chances of acquiring it.
- The spread of this disease more, since it is not well known in my country. As well as the main symptoms to go immediately to the doctor.

Advocacy

- More government support
- Better attention.
- Hospital provision with the medication and professional care trained
- More government support, capitulation and international help in medical advances for the treatment and cure of meningitis

Support

- Support for those affected, especially for amputees with access to better bionic prostheses.

Data

- Carry out Disease Burden Studies to show the real and total costs of meningitis and the need for its prevention

Responses from people affected by GBS

Distributed through GBS support

- 2671 responses, 95% from the UK

Priorities to help defeat group B Strep meningitis

- 57% said testing pregnant women
- 17% saying vaccination
- 13% awareness/information
- 5% education/training
- 4% funding/Government commitment.

Which strategic pillar was most important

- "Prevention and control" was most frequently identified as being the most important (40% of participants)
- "Diagnosis and treatment" was second in the order of preference for the five strategic goals
- "Disease surveillance" and "Support and care" were joint third in the order of preference for the five strategic goals
- "Campaigns and information" was fifth in the order of preference for the five strategic goals

Which actions would people like to see?

When asked what priority action people wanted taken forward, screening for GBS was chosen well above other activities.

Topic	Number
Testing or screening <ul style="list-style-type: none"> Routine (278), mandatory (47) 	1433
Vaccines or immunisation <ul style="list-style-type: none"> Mostly nonspecific with some comments on availability (e.g. Vaccines for all), and some mentioning pregnant women and new-borns. 	429
Awareness <ul style="list-style-type: none"> Mostly generic (e.g More awareness) with some focus on testing, vaccines and symptoms. 	326
Education/training <ul style="list-style-type: none"> 'Training' on training medical staff at all levels (GPs, in hospital, midwives etc.) on recognition/detection/symptoms. 'Education' was mainly non-specific but with some mention of health professionals and the general public 	132
Policy and funding <ul style="list-style-type: none"> No one focus but several similar comments on funding ' 	104
Media, publicity and campaigns	46

What is missing

When people were asked to highlight what was missing from the roadmap pillars, the following table highlights common themes:

Topic	Number
Testing <ul style="list-style-type: none"> Often qualifies with: routine, compulsory, regular, all pregnant women 	81
Awareness <ul style="list-style-type: none"> While many people mentioned general public awareness, there was a big focus 	73

on targeted awareness for pregnant women	
Screening <ul style="list-style-type: none"> • Similar to testing qualifications above 	71
Funding/finance <ul style="list-style-type: none"> • Generally a call for more funding with government funding, vaccine funding and research funding being mentioned. 	49
Education <ul style="list-style-type: none"> • Non-specific education or 'in schools' was most popular followed by health professional education 	43
Information <ul style="list-style-type: none"> • Mostly general public and during pregnancy 	38
Research <ul style="list-style-type: none"> • Often non-specific with mentions on treatment, causes and vaccines 	36
Vaccines <ul style="list-style-type: none"> • Effective vaccination, developing a vaccine and vaccinating wider groups 	32
Support <ul style="list-style-type: none"> • Cases, children affected, families, bereavement support, support and information during pregnancy 	20
Training <ul style="list-style-type: none"> • Health professionals at all levels 	20
Campaigns/campaigning	17
Diagnosis <ul style="list-style-type: none"> • The need for speed often mentioned 	9

In addition to these major topics, some people focussed on improvements at a hospital level (9) including hygiene, coordination and display notices.

Improvements for various types of health professional were also mentioned but the recommendations were very varied: forming an alliance; not making inaccurate assumptions; taking GBS seriously; speaking out more.

Comments not categorised:

A focus on pregnant mothers.

a holistic combined approach rather than the 1-5 approach prioritising and focusing resources on one area

A scan of the birth canal maybe don't know if the professions in midwifery would be able to do this. Or if a baby is stuck in the birth canal, don't leave it just go straight to a c section as I'm sure the strep b could be avoided

Access to appropriate help for those in remote areas

Access to counselling for parents and families affected by GBS.

After care when the baby is. born

Aftercare for those affected by group B strep

Automatic immunisation for all children as soon as possible would be my ideal.

Available for all children

Better back up in emergency services when parents phone explaining symptoms of a child with sepsis! Speed is of the essence!

Better living conditions for ordinary people the world over

Buy in from government

Care for the families whose babies are affected by group B Strep, including bereavement care

Carriers

Certain antibiotics need to be kept as reserve for critical infections. Rampant use of antibiotics is leading to resistance.

Cheap point of care detection followed by antibiotic treatment prior to birth

Checking should be standard practise where illnesses are not conforming.

Child birth

Clean water

co-morbid conditions and cross over treatment for people infected with other diseases such as HIV.

Consider most things have been covered.

Containment of infection

courtchange.wordpress.com/the-court-change-or-the-non-finality-situation/ It affects medical organisation + accountability.

Demographic monitoring

Don't know

Each was as important as each other

"Early prevention

"

Early signs in pregnant women

Effective cleaning at medical centres

Emphasis on good antenatal care

Emphasis on the speed needed for medical attention

Ensuring all midwives and gp practices know the importance of treating strep B in pregnant women

Ensuring policies are changed quickly.

Ensuring that treatments and prevention is within every economy's means

Ensuring the financial backing is in place

Enthusiasm!?

Every nurse and doctor she know what GBS is . Many don't and that is worrying

Every thing

Fast track anyone presenting with any symptoms

Financial Aid to enable these changes

Finding why people become Strep B positive

Follow up appts and long term assessment of children and young adults who have had group b as infants to see how it affects their development in later life

Gbs in pregnancy

Get more info out there. Seems to be not much about lately.

GPs and their reception staff, paramedics and urgent care/emergency services and NHS online and phone services

Highlighting to the public (and politicians) similar diseases to Group B Strep meningitis/sepsis so as to prevent confusion.

Hsv 1 and 2 is related to this and they need to take it more seriously

Huge publicity

Hygiene

Hygiene

I believe that all areas above are key areas and desperately need to be addressed.

I believe this statement covered most of the areas but the question missing is does every country covers all this key areas of this issue I will of course say no as it's happening here in my country ALGERIA, sad yes sadly I declare this as I'm the witness that the pregnant women here are treated like cows, sadly in country where there are a money to spend in this issues but they just neglect it and people are suffering so I would urge to take action all over the world so this will be a prior issue in every corner in every country in the world.

I don't think so

I think all aspects are covered

I think everything that I thought about has been covered

I think it's all been covered

I think that all previous boxes should have a score of 5. I found it really hard to decide those score as all are equally important measures to be taken.

I think that last question was stupid!!!! As they should ALL BE ANSWERED AS AN EQUAL 5

I wanted to click 5 for #2 &5

Identification of vulnerable groups.

Identifying vulnerable patients

If each heading is covered fully I think you have it all prioritised

Important to ensure all are given free inoculations to prevent free of charge heart

Increased media I go

Is it hereditary?

is it recognised using the glass technique rolling the "tumbler" on spots?

It seems these points have covered the most immediate and important issues.

Just more knowledge. Teaching everyone sigs and what it is

Lack of swabbing

Leaflets delivered into every home nationwide highlighting the early signs of meningitis and sepsis that can be kept for future reference

Make it well known as I had never heard of it

Make sure all measures are extended globally

Make sure GP's & A&E personnel can recognised he symptoms of sepsis quickly and deliver the relevant medication asap.

Making sure the patient understands what's happening and the low resistance to illness afterwards

Mandatory daily inspection and changing of the dressings of surgical patients.

Media campaigns to get knowledge about the symptoms out there.

Midwives actually knowing about strep b money

Monitoring of newborns after birth and antibiotics provided for mothers during labour

More action needs to be taken immediately not in years to come. Act now

More advertising in schools /doctors/pregnancy books

More financial involvement from governments and more governments taking it seriously.

More knowledge of the disease

Most here in UK

Most of them.

Most people have never heard of it.

Motivate politicians

multi professional approach like agriculture, nutrition etc

Parents should be able to say to people please can you not touch my child.

People should be advised to look after all cuts and grazes (regardless of how small they appear) and give them regular attention with antiseptic and visit their nurse in case antibiotics are required.

Perhaps anti natal classes

Personal hygiene.

Poor working women don't always have pre-natal care.

Pregnancy

Pregnant women and new borns

Pregnant women don't always know about strep b and how their unborn child can be affected

Pregnant women unborn babies

Pregnant women who can pass to babies during labour causing newborn deaths.

Preparing parents in case their baby is put in special care. Maybe a visit to the u it before the baby is born. So that it's not such a shock and stress in the event that the baby is taken away.

Prevention is better than cure

Prevention is far better, no baby should have to risk getting this, my baby nearly died

Prevention is the absolute key

Prices controls on medicines to make them affordable to developing nations.

Prompt action by doctors if disease is suspected

Prompt action, fast track suspected patients through a and e

Prompt treatment for pregnant women

Public knowledge

Putting pressure on governments to action these points.

Putting the above into law

Record keeping of all incidents

Regularly remind the public

Related to pregnancy

sadly in an ideal world all of the above would have equal importance.

School children

School learning and medical practitioners

Schools and Universities

Should be in all pregnancy packs.

Specialized NICU for babies with GBS

"Specific Technologies such as

Chimaeric Antigen Receptor T lymphocyte treatments (CAR-T lymphocytes treatments)

Other RNAi based therapies "

Specifically classes for those most at risk and for those caring for them

Staffing - more doctors and nurses

Swab everyone

Swab in pregnancy

Swabbing pregnant women before delivery

Tackling the environmental and social conditions that makes this condition more prevalent in certain regions.

Talk to the women that have had this while carrying their unborn child

teaching about it as part of the PSHE curriculum in secondary schools

Teaching in antenatal classes including options

That every pregnant mother is taught properly what to look out for so they can be treated asap

That strict guidelines are followed once someone is found to be strep b positive

The causes of it

There is still a need to persuade many people that diseases can and should be prevented.

To get midwives to tell pregnant women about it

To painful to write

Treatment pathway that can be easily followed by all

Treatment should be given if in doubt don't rule it out. Act and be safe than sorry

TV campaigns

Understanding the causes and prevention of meningitis/sepsis

When antibiotics are needed make sure lady is in ward at first labour twinges

Common words used to describe meningitis

Common words (most common are largest)

