



Meningitis Research Foundation

Written Evidence for the Petitions Committee  
MenB Petition

February 2018

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## Executive Summary

In early 2016 a petition calling for wider access to the MenB vaccine was signed by 823,345 people - the largest petition of its time. As a result, on 25<sup>th</sup> April 2016 the issue was debated in parliament and as part of that process Meningitis Research Foundation (MRF) submitted evidence about the fairness of the rules the JCVI (the government's vaccine advisory committee) are obliged to use to make recommendations for the introduction of vaccines to the National Immunisation Programme. At the end of the debate, the government committed to publishing a report, due for completion in summer 2016, which made recommendations about the methodology that should be used for assessing the cost effectiveness of vaccines.

Two years on we are being told that yet more time is needed before the report can be published.

While we continue to wait, MRF have very serious concerns about the transparency of process and the contents of the report. There are indications that some of the recommendations contained within it could be very unfavourable for vaccines.

We want to ensure that the petitioners' voices are heard and that a fair, open and transparent process is in place when making decision about vaccines. It is crucial that this report is published and opened up for wider consultation so that its contents can be scrutinised by experts and the public and any concerns addressed. We would also like to see how any recommended changes would have impacted past vaccine decisions.

Meanwhile a number of deaths from MenB disease in age groups too old to be vaccinated has prompted the formation of a government a working group on meningococcal disease to be set up, which does not include any issues relating to vaccination within its scope. During the debate in April 2016 Dr Sarah Wollaston identified a series of vaccine related issues which she argued government should be held accountable for. We would like to see the working group include these issues within its scope to ensure they are addressed.

## Introduction

1. Meningococcal infection has for decades been the single largest cause of meningitis in the UK. It strikes without warning, affecting mainly healthy children and is one of the few illnesses in modern Britain that can kill a healthy child within hours of the first symptoms. Babies, toddlers and adolescents are most at risk of this disease which leads to death in 10% of all cases and to long-term after effects in a further 36%[1].
2. Introducing MenB vaccine for babies in 2015 was a major step forward, but restricting the vaccine to only this narrow highest risk age group can never prevent the majority of cases[2].
3. The tragic death of Faye Burdett and others too old to have routine vaccination provoked an unprecedented demand for the vaccine privately. A petition to widen access to the MenB vaccine was signed by 823,345 people - the largest health petition on record.
4. MRF gave oral and written evidence at the request of the Petitions and Health Committees in 2016 stating our concerns around the fairness of the rules which are used to decide whether or not vaccines should be introduced routinely on the NHS. At the same time a specialist group called the Cost Effectiveness Methodology for Immunisation Programmes and Procurement (CEMIPP) working group had been assessing these rules and were producing a report with recommendations regarding how the rules should be changed.
5. During the debate on 25<sup>th</sup> April 2016, the government promised to publish CEMIPP's report at the end of that year. Following a series of delays we have been told that yet more time is needed to get the recommendations from this report right and it has been referred to another group, the Appraisal Alignment Working Group (AAWG).
6. While we continue to wait for the report, Meningitis Research Foundation has very serious concerns about the process. We want to see a fair, open and transparent process is in place when making decisions about vaccines.

## What we do

7. Meningitis Research Foundation:
  - [Supports research into the prevention, detection and treatment of meningitis and septicaemia and shares the knowledge gained by research so everyone can benefit](#)
  - [Raises awareness of meningitis and septicaemia and promotes best practice in diagnosis and treatment](#)
  - [Supports those affected by meningitis and septicaemia](#)
8. We firmly believe that prevention is the key to defeating meningitis and septicaemia, yet whilst there continue to be cases that vaccines cannot prevent, early recognition, diagnosis and treatment, and public awareness continue to be important.

## What are we asking for?

9. Following the death of two-year-old Faye Burdett from MenB on February 14th 2016, and the biggest ever petition in public health, the government promised to review unfair vaccine rules that deny access to the MenB vaccine for children over two years of age.
10. A report on the rules that govern decision-making on the introduction of vaccines was produced by the Cost Effectiveness Methodology for Immunisation Programmes and Procurement (CEMIPP) and the government promised to publish this at the end of 2016.
11. Following a series of delays we have been told that yet more time is needed to get the recommendations from this report right and it has been referred to another group, the Appraisal Alignment Working Group (AAWG). While we continue to wait for the report, Meningitis Research Foundation has very serious concerns about the process. We would like the government to commit to the following actions to ensure over 800,000 petitioners voices are heard and that a fair, open and transparent process is in place when making decision about vaccines:
12. **Face public scrutiny**  
The consequences of the CEMIPP report will have huge ramifications for public health and will directly affect which vaccines each and every one of us is entitled to. A formal written consultation that is open and transparent needs to take place these recommendations on vaccines, as is the case with NICE consultations that affect decisions about treatments.
13. **Consult experts**  
Consult experts properly. As the AAWG expertise is vastly weighted towards health economics and a few choice academic institutions (four experts from York University), how is diverse experience on public health and immunisation being considered? Where are the health professionals, public health experts and patient/public representatives? It is crucial that representatives from these groups be involved in discussions in a meaningful and transparent way.
14. **Check your workings**  
We were promised an analysis which demonstrates how the CEMIPP recommendations would impact on vaccines already in use today. Would current vaccines have been introduced if the new CEMIPP recommendations were in place? This analysis will help public health experts to determine if the recommendations are appropriate and we are yet to see this
15. **Communicate with the petitioners**  
Communicate with more than 800,000 petitioners who called for action. Your website still tells petitioners that the report is promised in 2016. They have not been told that the CEMIPP process has finished. Please update the petitioners with recent actions and ensure they are informed about the new process in an open and transparent way.
16. **Answer the JCVI's concerns**  
Address the concerns put to you by the Joint Committee on Vaccination and Immunisation about the CEMIPP report (which they published in their June 2016 minutes). This includes concerns that incremental analysis methods may not adequately value the control of disease; risks around disinvestment in vaccine programmes; the need for a flexible time horizon to allow for individual vaccine circumstances, and how new methodology may affect previous decisions made by the JCVI. The JCVI have also stressed the importance of ensuring that those involved in the work of CEMIPP, including charities, are kept aware of developments (Feb 2017 minutes).

17. Following more deaths from MenB disease within those too old to have received MenB vaccination on the NHS, a meningococcal disease working group has been set up in recent months. However, this group does not have vaccine related issues within its scope. We would like the scope of the working group to include follow up of the CEMIPP report and other vaccine related issues such as vaccine uptake rates.

## Unfairness in cost-effectiveness evaluations for vaccines

18. MRF has the following concerns about the cost effectiveness rules the JCVI currently apply for vaccines:

### *The 3.5% discount rate used to assess the cost effectiveness of vaccines is too high*

19. A discount rate of 3.5% can undervalue the benefits of preventative and public health interventions such as vaccination since large costs are borne upfront, but the benefits accrue over decades[3-5]. The true lifetime costs of treating a child who suffers brain damage due to bacterial meningitis at 3 years of age are £3.3 million, but when a discount rate of 3.5% is applied, these projected costs drop to just £1.1 million[6]. In addition, the life years saved from preventing the death of a baby with a life expectancy of 81 years, drops from 80 to only 27.7 when a discount rate of 3.5% is applied. Current NICE guidance[7] acknowledges this bias and advises that where large health benefits are attained over long periods i.e. beyond 30 years, a discount rate of 1.5% can be used. In addition, when NICE considers public health interventions (which tend to have high upfront costs and long term benefits), a 1.5% discount rate is routinely used for costs and benefits[8]. Despite this, a discount rate of 3.5% is currently used for vaccines.

### *Rare, severe illness in children is undervalued*

20. Extensive, peer-reviewed research shows that society prioritises health interventions for the most severely ill and for children and also values preventative over curative interventions. These preferences are not well reflected in the cost effectiveness rules. In addition, the tool currently recommended to calculate health loss, the EQ-5D, is insensitive to health impacts in children. NICE recognises that societal preferences and methodological constraints should be taken into account in the decision-making process and in the past has given a special weighting to severe illness and children[9]. The JCVI took a similar approach in their final assessment of the cost effectiveness of Bexsero by applying a quality adjustment factor to the QALYs gained from vaccination[2]. However, it is unclear how this issue will be resolved in future cost effectiveness analyses.

### *The JCVI rules on uncertainty are too risk averse*

21. The JCVI must follow strict rules on the uncertainty of the calculated cost effectiveness of vaccines. The rules about uncertainty were first specified in the JCVI's code of practice in July 2013 in a report from the working group on uncertainty (annex5) [10]. The rules are rigid and take an extremely risk averse approach to uncertainty. There is real concern that the rigid uncertainty rules that the JCVI must follow will put vaccines at a considerable disadvantage compared to treatments.

*Peace of mind benefits gained from vaccination are not included*

22. The petition asking for wider protection from MenB was signed by more than 820,000 people. This, and the unprecedented demand for the vaccine privately, shows how anxious parents are about meningitis. Parents gain peace of mind by getting their children vaccinated but this benefit is not quantified in the cost effectiveness analysis.

## Cost-effectiveness Methodology for Immunisation Programmes and Procurements working group (CEMIPP)

### What CEMIPP was set up to address

23. Following deliberations on the cost effectiveness of MenB vaccine in 2013, the JCVI expressed concerns about the difficulty in capturing the impact of a severe, fatal and rare disease, particularly in children, and called for the establishment of a working group to specifically address this issue[11]. The resulting working group on Cost Effectiveness Methodology for Immunisation Policy and Procurement (CEMIPP), first met in September 2014. The report has since been considered by the Appraisal Alignment Working Group (AAWG) and we are still waiting to hear the recommendations[12].

### What has been taken forward by CEMIPP

24. CEMIPP presented their near final report to the JCVI in June 2016, where it was revealed that the group had been considering the following areas of cost effectiveness[13]:

- perspectives on costs and outcomes (incl. how broadly costs and benefits should be considered);
- incremental analysis;
- discounting rate and time horizon;
- measuring and valuing health effects (incl. the relative value of QALYs);
- the relationship between cost and outcome (incl. non-linearity); and
- appraisal of evidence (incl. QALY price thresholds, uncertainty analysis and disinvestment)

25. We are pleased that discounting has been considered more extensively by the working group, as the existing discounting regime puts vaccines at a great disadvantage compared to therapeutics.

### MRF's concerns about the contents of the CEMIPP report

26. We are concerned that peace of mind benefits, public preferences and the difficulty in measuring health loss in children will not have been addressed by the report because the JCVI said that more primary evidence was needed to quantify some of these wider issues[13]. Lack of guidance on such aspects brings into question how CEMIPP have dealt with how to assess vaccines which prevent severe, fatal and rare disease in children (the JCVI's original reason for requesting the group to be set up).

27. Like the JCVI[13], MRF are concerned that incremental analysis methods may not adequately value the control of disease; that there are risks around disinvestment methods which could potentially lead to patchy and incomplete control of serious diseases; and there is lack of clarity about how this new methodology may affect previous decisions made by the JCVI. Such undesirable outcomes are not only uncomfortable from an equity standpoint, but have the potential to completely undermine public confidence in vaccines which could be disastrous for public health and community 'herd' protection.



28. MRF note that whilst considering the CEMIPP report, the Appraisal Alignment Working Group (AAWG) have been considering the latest evidence on the marginal cost of a QALY on the NHS[14] in close consultation with a group of health economists from the University of York[15]. This same group of health economists have previously suggested that the cost-effectiveness threshold should be reduced from £20,000/QALY to £13,000/QALY[16], although their findings have been widely contested by other academics in the field of health economics[17]. We are concerned that a drop in the threshold is being considered for vaccines. This could put vaccines at a severe disadvantage compared to treatments. The statement in the JCVI minutes that “should the JCVI adopt the recommendations it may be operating differently to other bodies such as NICE” means that there is a real possibility that a different threshold for vaccines compared to treatments is being considered.

## Appraisal Alignment Working Group (AAWG)

29. MRF responded to the draft CEMIPP report in May 2016. We have not seen the final report. After the final report was delivered to the health minister in 20<sup>th</sup> July it was referred to the AAWG for consideration. The government has refused to publish the CEMIPP report as originally promised, and has said that they would first need to consider the AAWG report which was delivered to the Department of Health in autumn 2017.

### Membership

30. Membership of the AAWG was published in Annex A of a letter to Helen Jones from Nicola Blackwood (available from <https://www.parliament.uk/documents/commons-committees/petitions/Correspondence-relating-to-petition-on-meningitis-b-vaccine.pdf>)



**Appraisal Alignment Working Group (AAWG): Membership**

**Department of Health**

- Keith Derbyshire (Chair), Chief Analyst and Chief Economist
- Danny Palnoch, Senior Economic Adviser
- Dr Mark Bale, Deputy Chief Medical Officer
- Dr Gavin Roberts, Economic Adviser
- John Henderson, Economic Adviser
- Dr Peter Grove, Senior Principal Analyst
- Dr Ian McKay, Senior Scientific Officer

**Office for Life Sciences**

- David Glover, Head of Analysis

**National Institute for Health and Care Excellence**

- Leeza Osipenko, Associate Director

**Public Health England**

- Prof Brian Ferguson, Director for Knowledge & Intelligence
- Dr Anne Mackie, Director of Screening

**NHS Improvement**

- John Curnow, Economics Project Director
- Rebecca Hand, Senior Economist

**NHS England**

- Dr Donald Franklin, Senior Economic Adviser NHS England
- Lindsay Gardiner, Senior Economist

**Brunel University**

- Prof Martin Buxton, Emeritus Professor of Health Economics

**London School of Hygiene & Tropical Medicine Representing Joint Committee for Vaccines and Immunisations and Safety of Blood Tissues and Organs**

- Prof John Cairns, Professor of Health Economics

**Other attendees:**

- Prof John Brazier, Sheffield University
- Prof Karl Claxton, York University
- Prof Mark Sculpher, York University
- Dr James Lomas, York University
- Dr Steve Martin, York University
- Tongtong Qian, Department of Health
- Caroline Lee, Department of Health
- Timothy Davies, Department of Health

31. Expertise on the AAWG is heavily weighted towards health economics with no input from health professionals. There is very little diversity in experience on public health and no immunisation representative on the AAWG.
32. In addition, in terms of academic institutions, expertise health economists from the University of York[15] are very well represented. This same group of health economists have previously suggested that the cost-effectiveness threshold should be reduced from £20,000/QALY to £13,000/QALY[16], although their findings have been widely contested by other academics in the field of health economics[17]. We are concerned that a drop in the threshold is being considered for vaccines, which could put vaccines at a severe disadvantage compared to treatments.

## AAWG Terms of Reference & Objectives

33. The terms of reference and objectives outlined below were published on 9<sup>th</sup> November 2015 in response to a parliamentary question from Lord Hunt of Kings Heath.
34. The Appraisal Alignment Working Group (AAWG) is comprised of policy and analytic staff who work in, or give advice to, DH and its ALBs on the cost-benefit and cost-effectiveness of programmes, technologies and policies.
35. The purpose of the group is to share knowledge on the various techniques employed across the Health and Care sector, to discuss and debate the pros and cons of different approaches employed, to consider ways of rendering results comparable, and to understand the reasons for differences in approaches.
36. The working group is not a decision making body. Rather it is advisory. Individual members representing different organisations will take back recommendations and questions to their parent bodies for consideration.
37. It is proposed to have meetings every six to eight weeks to achieve the 'Must Do' (e.g. primary) objective described below.
38. The 'Must Do'  
Before the next Spending Review, (pencilled in for June to October 2015), it is essential the Department of Health (DH) and its Arm's Length Bodies (ALBs) can present a consistent approach to HM Treasury (HMT) on the cost benefit of different programmes (e.g. vaccinations, screening new technologies). The cost benefit case for spending presented to HMT should follow public sector best practice as set out by HMT, in its Green Book. Therefore results of appraisals need to be capable of being expressed in HMT Green Book methodology terms (ie using the Green Book methodology as a "reference case").
39. Having successfully achieved that, the Working Group will take stock and decide if the group (or some other forum) should continue and progress on three desiderata:
  - economic justification for methods employed in each area and clear rationale for when methods differ and/or diverge from HMT's Green Book.
  - achieve greater alignment of techniques between the different sectors and organisations
  - serve as an expert panel to advise on the development and application of new techniques on an on-going basis.
40. This work would be less time critical and could be pursued by meetings every eight to twelve weeks.
41. Available from: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2015-10-29/HL3140>

## Timeline

DATE	KEY POINTS
2 Oct 2013 JCVI	Joint Committee on Vaccination and Immunisation (JCVI) calls for joint Public Health England (PHE)-JCVI-Department of Health (DH)-NICE working group to be established due to difficulties fairly assessing vaccines for severe, rare diseases in children.
11-12 Feb 2014 JCVI	Cost Effectiveness Methodology for Immunisation Programmes and Procurement (CEMIPP) terms of reference are set. They are very general, and do not refer to the purpose above. They refer to the uncertainty guidelines which are unfair. There is real concern that the rigid uncertainty rules will put vaccines at a considerable disadvantage compared to treatments.
Feb/March 2014	Appraisal Alignment Working Group (AAWG) established. Their purpose according to JCVI is to reconsider methodology for health economic assessments, including changes to the quality-adjusted life-year (QALY) – a generic measure of disease burden used to assess the value for money of medical interventions, and discounting rates across health systems - which seeks to take into account the impact of time on how costs and outcomes of health interventions are valued. Their official terms of reference do not mention this specifically.
4 June 2014 JCVI	CEMIPP established.
Sept 2014	First CEMIPP meeting held.
21 Jan 2015	Meningitis Research Foundation officially asked to be represented on CEMIPP.
April 2015	Charities included as stakeholder on CEMIPP. Several points are raised on the scope, in particular the unfairness of the uncertainty.
2015-2016	Ongoing CEMIPP subgroup meetings throughout the year and each subgroup produced a report for submission to the main CEMIPP working group.
14th February 2016	The death of Faye Burdett from MenB results in the largest ever petition on health calling for wider access to the vaccine.
22 March 2016	John Cairns tells petitions/health committee that CEMIPP has decided that most methods appropriate for other health technologies are also appropriate for vaccines.
22 April 2016	At parliamentary debate on MenB, Jane Ellison commits to publishing CEMIPP report, and promises to provide a summary briefing for committee. None of this happened.
26 April 2016	MRF, RCPCH, RCGP and 265 doctors call for public scrutiny of CEMIPP.
Apr-May 2016	Circulation of Draft CEMIPP report to internal consultees, MRF wrote formal response highlighting concerns.
10 May 2016	Sec State responds to April 26 <sup>th</sup> call for public scrutiny saying CEMIPP will be published and that consultation will be considered.
1 June 2016 JCVI	JCVI discuss draft CEMIPP report highlighting many key concerns and risks, including incremental analysis; disinvestment and time horizon.
20 June 2016	CEMIPP meeting to consider comments from consultees
20 July 2016	CEMIPP report delivered to Health Minister.
1 - 3 Oct 2016	Nicola Blackwood confirms she has received CEMIPP report and it will be published 'in due course'.
19 Dec 2016	John Watson's letter to charities says CEMIPP referred to AAWG, publication not until after autumn 2017. Charities told that AAWG is 'ideally placed to take account of views of key stakeholders'. Nicola Blackwood asks that both charities can input into discussion. No mention of public consultation.
10 Jan 2017	A letter from Nicola Blackwood's is published. It highlights that the CEMIPP report is referred to AAWG and that there is no public consultation on CEMIPP.
14 Feb 2017	MRF 'Broken Hearts Broken Promise' campaign covered in national media to highlight that the government broke a promise to publish the CEMIPP report in 2016.
22 Feb 2017	A letter from Nicola Blackwood is published saying that the CEMIPP purpose was "to consider whether there are ways in which the economic evaluation of immunisation programmes should differ from that of other health-related activities

	using public resources.” It also confirms that the CEMIPP report has been referred to AAWG.
1 Feb 2017	A meeting of JCVI noted that CEMIPP had passed to AAWG and that it was important to ensure that groups involved in the work of CEMIPP, including charities, were kept aware of developments.
27 March 2017	One meeting with DH, members of AAWG, and meningitis charities. Not a formal consultation
27 March 2017	MRF met with the Deputy Chief Medical Officer, the Department of Health Chief Economist, and representatives from the AAWG at the Department for Health to highlight our concerns
April – June	MRF sent evidence to the Deputy Chief Medical Officer
18 July 2017	MRF wrote to Steve Brine MP, the then new Parliamentary Under Secretary of State for Public Health and Primary Care
September 2017	During Meningitis Awareness Week MRF’s members and supporters wrote to their local MPs asking why the CEMIPP report was delayed and telling their personal stories
7 October 2017	MRF met with Bristol MP Darren Jones alongside Nicole Zographou, whose brother George tragically died from MenB during the summer
11 October	MPs Jim McMahon and Kerry McCarthy - both of whom have families in their constituencies who lost children or teenagers to MenB - called for more to be done to protect people from meningitis. The Prime Minister responded with the promise of a meeting between the Health Secretary, Jeremy Hunt, families, charities and campaigners
19 October 2017	MRF received a reply to the letter sent to Steve Brine MP in July
29 November	<p>MRF supported the Health and Petitions Committee when it criticised the government for breaking their promise to publish the CEMIPP report</p> <p>Families affected by MenB and meningitis charities met with Jeremy Hunt. In this meeting Jeremy Hunt committed to setting up a working group to make recommendations to improve awareness of meningitis and septicaemia. Jeremy Hunt asked for evidence showing that vaccine rules are unfair to be sent to him directly, and MRF is providing this. We look forward to his response.</p>

# Meningococcal Disease Working Group

## Draft Terms of Reference

### *Scope and Responsibilities*

42. This group has been set up at the request of the Secretary of State for Health to, build on existing work and guidance and advise him on:
- a. what action needs to take place to further raise awareness among the public or professionals of the signs and symptoms of meningococcal disease and clarify vaccination-related messages;
  - b. good practice in the early diagnosis and treatment of meningococcal disease and how this can best be spread to health care professionals and other staff to whom potential cases might present;
  - c. the challenges in diagnosing meningococcal disease and how these might best be overcome.
43. In scope:
- All meningococcal disease (not just meningococcal group B).
44. Out of scope
- detailed review of specific cases (although lessons learned can be fed in);
  - vaccination policy for meningococcal disease.

### Meeting Frequency

45. It is intended that the working group will meet on three occasions (January, February and March) with telecons arranged in between if needed.

### Deliverable

46. A short report (5-10 pages) to the Secretary of State with recommended actions and reasoning to be delivered by 31 March 2018.

### Constraints

47. The main constraint to delivering the report on time will be availability of members to attend the meetings.

## Membership

Jonathan Van Tam	Deputy Chief Medical Officer – <b>Chair</b>
Clinical Experts	
Andrew Riordan	Consultant in Paediatric Infectious Diseases and Immunology at Alder Hey Children's NHS Foundation Trust
Jackie Cornish	National Clinical Director Children, Young People and Transition to Adulthood, NHS England
Jeff Keep	Royal College of Emergency Medicine
Simon Stockley	General Practitioner, Lead for Sepsis, Royal College of General Practitioners
Rob Read	Royal College of Physicians
Stephen Flanagan	Royal College of Nursing
Calum Semple	Senior Lecturer in Child Health & Consultant Respiratory Paediatrician.
DH & ALB representatives	
Andrew Frankel	Post Graduate Dean, Health Education England
Linda Dempster	Head of Infection Control, NHS Improvement
Luke O'Shea	Director of Clinical Policy and Operations, NHS England
Meera Sookee	Strategy Lead, Quality Strategy Team, NHS England
Mary Ramsay	Consultant Epidemiologist and Head of immunisation, Public Health England
Charity & Patient Reps	
Rob Dawson	Meningitis Research Foundation
Tom Nutt	Meningitis Now
Kirsty Ermenekli Paul Gentry Nicole Zogaphou	Parent representatives

## Why we believe the meningococcal disease working group should consider vaccines

48. Many parents who attended the meeting with Jeremy Hunt prior to the working group first and foremost wanted to see wider access to meningococcal vaccines. Meningococcal disease strikes without warning, affecting mainly healthy children. It is one of the few illnesses in modern Britain that can kill a healthy child within hours of the first symptoms, so whilst improvements in recognition and treatment are always welcome, prevention is key to defeating this disease. However, the response from the Secretary of State for Health and Social Care has so far been that vaccine issues are up to the JCVI.
49. MRF agree that it is up to the JCVI to consider and recommend vaccine policy, and that it is important to allow the JCVI to carry out its work without undue political interference. However, three areas were mentioned by Sarah Wollaston as part of the parliamentary debate on 25<sup>th</sup> April which are beyond the remit of the JCVI and warrant further consideration by government:
- Reviewing the framework under which the JCVI operates
  - Making sure that decisions of the JCVI are implemented in a timely manner (it took considerable time to carry out negotiations on the cost of MenB vaccine).
  - Looking into the levels of variation and gaps in coverage of existing meningococcal vaccinations\*. Sarah Wollaston called on the minister during the debate to “update the House on where we are in that regard, because it clearly cannot make sense that artificial barriers have sprung up between those who are responsible for implementing the programme and those who are delivering it on the ground. It would be helpful to have an update on that issue.”

### **\*Coverage of routine meningococcal vaccines**

50. MenB coverage data shows that in December 2017 some CCGs had very poor uptake of the MenB booster dose by the time children had read 78 weeks (around 18 months of age). Some of the lowest performing areas were:
- City and Hackney – 64.9%
  - North and West Reading – 69.5%
  - Hammersmith and Fulham – 69.7%
51. Only 33 out of 149 local authorities achieved 95% coverage of the Hib/MenC booster in 24 month olds in 2016/17.
52. Areas with the lowest uptake of Hib/MenC were:
- Westminster – 65.6%
  - Kensington and Chelsea – 68.5%
  - Lewisham – 69.7%



## References

1. Viner, R.M., et al., *Outcomes of invasive meningococcal serogroup B disease in children and adolescents (MOSAIC): a case-control study*. *Lancet Neurol*, 2012. **11**(9): p. 774-83.
2. Christensen, H., et al., *Re-evaluating cost effectiveness of universal meningitis vaccination (Bexsero) in England: modelling study*. *BMJ*, 2014. **349**: p. g5725.
3. NICE Citizens Council. *How should NICE assess future costs and health benefits?* 2011 [cited 2012 August]; Available from: [http://www.nice.org.uk/media/06B/B8/Citizens\\_Council\\_report\\_on\\_Discounting.pdf](http://www.nice.org.uk/media/06B/B8/Citizens_Council_report_on_Discounting.pdf).
4. Starkie Camejo, H., X. Li, and G. Van Krieking, *Does it matter? Discounting and its role in the cost-effectiveness of preventative interventions. The case of HPV vaccination*. Public Health, 2015.
5. Beutels, P., P.A. Scuffham, and C.R. MacIntyre, *Funding of drugs: do vaccines warrant a different approach?* *Lancet Infect Dis*, 2008. **8**(11): p. 727-33.
6. Wright, C., R. Wordsworth, and L. Glennie, *Counting the cost of meningococcal disease : scenarios of severe meningitis and septicemia*. *Paediatr Drugs*, 2013. **15**(1): p. 49-58.
7. NICE. *Guide to the methods of technology appraisal 2013*. Process and methods guides; Available from: <https://www.nice.org.uk/process/pmg9/chapter/foreword>.
8. NICE. *Methods for the development of NICE public health guidance*. 2012 [cited 2013 August]; Available from: <http://publications.nice.org.uk/methods-for-the-development-of-nice-public-health-guidance-third-edition-pmg4/incorporating-health-economics>.
9. Rawlins, M., D. Barnett, and A. Stevens, *Pharmacoeconomics: NICE's approach to decision-making*. *Br J Clin Pharmacol*, 2010. **70**(3): p. 346-9.
10. JCVI. *Joint Committee on Vaccination and Immunisation Code of Practice June 2013*. 2013 [cited 2013 August]; Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/224864/JCVI\\_Code\\_of\\_Practice\\_revision\\_2013\\_-\\_final.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224864/JCVI_Code_of_Practice_revision_2013_-_final.pdf).
11. JCVI. *Minute of the meeting on Wednesday 2 October 2013*. 2013; Available from: <https://app.box.com/s/iddfb4ppwkmjtusir2tc/1/2199012147/18992166933/1>.
12. Petitions and Health Committees *Oral evidence from John Cairns: Petition on the meningitis B vaccine, HC900 Tuesday 22 March 2016*. 2016.
13. JCVI. *Joint Committee on Vaccination and Immunisation. Draft minute of the meeting on 1 June 2016*. 2016; Available from: <https://app.box.com/s/iddfb4ppwkmjtusir2tc/1/2199012147/74115536926/1>.
14. JCVI. *Joint Committee on Vaccination and Immunisation. Draft minute of the meeting on 4 October 2017*. 2017 [cited 2018 January]; Available from: <https://www.gov.uk/government/groups/joint-committee-on-vaccination-and-immunisation>.
15. Nicola Blackwood. *Correspondance relating to petition on meningitis b vaccine. Letter from Nicola Blackwood to Helen Jones. December 2016*. 2016 [cited 2018 January]; Available from: <https://www.parliament.uk/documents/commons-committees/petitions/Correspondence-relating-to-petition-on-meningitis-b-vaccine.pdf>.
16. Claxton, K., et al., *Methods for the estimation of the National Institute for Health and Care Excellence cost-effectiveness threshold*. *Health Technol Assess*, 2015. **19**(14): p. 1-503, v-vi.
17. Barnsley P, T.A., Karlberg S, Sussex J, , *Critique of CHE Research Paper 81: methods for the estimation of the NICE cost effectiveness threshold*. *OHE. Occasional Paper 13/01*. 2013.