

COUNTING THE COST OF MENINGITIS:

A severe case of bacterial meningitis

Meningitis Research Foundation

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Introduction

Cost benefit analysis is used to aid decisions on vaccination policy, and has become an increasingly important factor in reaching such decisions[1], however accurate cost of illness data is essential for this to be reliable.

At present there is little information in the UK about the direct and indirect lifetime costs associated with treating long-term sequelae of bacterial meningitis and meningococcal disease and in particular, the costs of specialist rehabilitation for people disabled by their illness[2].

This work identifies costs associated with a severe case of bacterial meningitis. Our contact with families affected and professionals involved in rehabilitation enable us to contribute new information in this area.

Scenario development and costing

The following scenario is based on an amalgamation of several actual cases. The result of this amalgamation is a fictional child 'Emma', who at the age of 3 survives bacterial meningitis resulting in severe neurological damage. The medical aspects of the scenario are briefly outlined in Box 1. Preliminary discussions with paediatricians, paediatric neurologists, hearing specialists, and paediatric infectious disease specialists took place to ensure that our scenario was a reasonable representation of the severe end of meningitis.

BOX 1: Scenario

Emma is hospitalised with raised intracranial pressure, reduced conscious level and seizures. The child had acute hydrocephalus and has a shunt inserted. The total acute hospital spell (including PICU) lasts 6 months.

The child recovers from the acute meningitis with acquired brain damage resulting in severe hemiplegia, homonymous hemianopsia, profound deafness, severe learning difficulties and double incontinence.

She requires cochlear implantation and becomes a life-long patient of a cochlear implant centre.

She requires hospital admissions for shunt revision several times later on in her life.

There is further provision of medical follow-up, therapy, and specialist equipment in the community.

In order to get an idea of the sort of support that a survivor with such sequelae would need, we interviewed several of our members with a child with similar sequelae following meningitis. In each case we worked through their treatment and rehabilitation to date. We also reviewed some of the available literature about such sequelae and rehabilitation following acquired brain damage [3-9]

Once we had a comprehensive list of the kind of treatment and after care that survivors with these types of sequelae should receive, we set up meetings with relevant health professionals, social care professionals, educational professionals and academics.

Consultation with these professionals allowed us to refine the specifics of our scenario to ensure that we accurately represented the treatment that an individual with such sequelae might realistically receive.

Costing

Costs were split into three categories; medical, educational and social. Where possible, costs are based on 2008/2009 prices.

1 Medical Costs

Medical costs are detailed in section 1.1 to 1.9 and include costs associated with the following:

- Emma's initial period in hospital fighting the illness and having rehabilitation
- the public health response to the case
- hospital outpatient appointments
- appointments with community therapists
- cochlear implantation
- general health issues such as pain management, constipation and incontinence
- epilepsy management
- special equipment
- shunt revision surgery

1.1 Acute Care

Acute care costs were based on the scenario outlined in below:

Emma was 3 years old when her mother took her to the GP with a fever, seizures and reduced consciousness. She was rushed to hospital via 999 ambulance. From the Emergency department she was transferred to the paediatric intensive care unit (PICU) of the regional tertiary centre by a retrieval team. She had raised intracranial pressure and intractable seizures and required ventilation and intubation. Acute hydrocephalus was immediately treated by insertion of an external ventricular drain and later by insertion of a shunt. She required prolonged airways management for neurological complications, including repeated seizures. Emma spent 26 days in PICU. Once stable she was transferred to a paediatric ward where she spent five months recovering and undergoing specialist neurological rehabilitation under the care of the brain injury rehabilitation team.

Hospital Spell Cost

Medical components of the patient journey have been costed using the National Schedule of Reference Costs 2008-09 (NHS Trusts and PCTs combined)[10]. Reference costs work

by categorising patients who require similar levels of treatment into certain codes, known as Healthcare Resource Group (HRG) currency codes.

Costing a spell in hospital using a HRG currency code does not include costs associated with critical care (PICU), diagnostic imaging (such as CT and MRI scans) and rehabilitation costs[11]. These costs have therefore been added separately.

The hospital spell was costed using the appropriate HRG code. The HRG code relevant to our scenario was obtained using the HRG4 Code to Group Reference Cost Grouper 2008/09 software version 4.2.2[12]. When the appropriate ICD10 diagnosis codes and operating procedure codes (OPCS) are input into the grouper, the software generates a HRG currency code descriptive of the hospital spell which in this case was AA10Z - Intracranial Procedures Except Trauma with Non-Transient Stroke or Cerebrovascular Accident, Nervous system infections or Encephalopathy - category 3. Codes that were input into the grouper are provided in table 1. The software also generates a trimpoint which is specific to the HRG code. The trimpoints are set so that extreme values (long hospital stays) do not skew the average cost calculations for that particular group.

An HRG currency code has a range of costs associated with it. The National Schedule of Reference Costs 2008-09 quotes the upper quartile, mean and lower quartile unit costs associated with the HRG. The cost of the hospital stay within the trim point has been calculated by using the mean cost of the relevant HRG code. The length of stay in hospital is within the trim point of 72 days for HRG AA10Z, so there is no need to add a cost for excess bed days. This means that the hospital spell cost is the same as the cost of the HRG code AA10Z (see Item 6 of table 1 of Appendix A) at £12,828.

Table 1: ICD10 and OPCS input codes used to generate the hospital spell HRG*

ICD 10 Code	Description
G001	Pneumococcal meningitis
G911	Obstructive hydrocephalus
G403	Generalized idiopathic epilepsy and epileptic syndromes
OPCS Code	Description
A201	Drainage of ventricle of brain NEC
A124	Creation of ventriculoperitoneal shunt

*The ICD10 and OPCS codes used to put into the grouper were obtained by submitting descriptions of the procedures undertaken to data standards at NHS Connecting for Health, who then provided the required codes. Descriptions of the procedures were obtained by talking through the scenario with health professionals such as paediatricians, a paediatric neurologist, and paediatric intensivists (see Acknowledgements)

Critical Care (PICU) Cost

At present, hospitals are reimbursed at £2,000 to £2,500 per PICU patient per bed day depending on their particular contract[13]. The amount currently reimbursed is not related to the level of dependency of the patient.

Department of Health Reference costs 2008-09 record costs of PICU according to five different currency codes which have been produced to reflect the level of resource required by a particular patient. The costs associated with these currency codes range from £1651 to £2327 per bed day (see Appendix, Item 4)[10]. Costing data are available within five PICU HRG currency codes so that Payment by Results (PbR) can be used in the future to reimburse hospitals according to the treatment they have provided[14]. It has been suggested however, that the data associated with these particular HRG codes is poor in quality because these HRG codes are relatively new[15]. It is certainly evident that the costs that are associated with these codes are substantially less than those reimbursed under the current system.

In this scenario Paediatric Critical Care Intensive Care Basic with currency code XB05Z was used as the cost of PICU at £2,327 per bed day. This cost code was considered to be the most accurate because it had the highest amount of activity associated with it and was one of two that fell within the range of costs currently reimbursed to hospitals.

Rehabilitation cost

When the need for acute surgery comes to an end, more emphasis is placed on the rehabilitation aspects of Emma's care. A significant number of bed days are used in this type of care and this is why rehabilitation is separately identified from the acute HRG[11].

Emma spends 150 days in hospital receiving inpatient rehabilitation from the brain injury rehabilitation team including physiotherapy, occupational therapy, speech and language therapy, play therapy, clinical psychology and music therapy.

The rehabilitation is classified as code VC06Z – Rehabilitation of brain injuries and is a Specialist Rehabilitation Service (SRS) (level 2) as defined in the 2008/9 reference cost collection guidance[16]. Rehabilitation costs an average of £368 per bed day (see item 7 of Table 1 in the appendix).

Total Cost of Acute Episode

The acute hospital phase has been calculated as follows:

$$\text{£Acute phase} = \text{£}(GP + AT + A\&E + RT + (PICU_{dr} * PICU_{los}) + HS + CT + MRI + (RHB_{dr} * RHB_{los}))$$

Where:

GP	=	£40	Cost of GP appointment[17]
AT	=	£240	Cost of Ambulance transfer[10]
A&E	=	£136	Cost of A&E investigation[10]
RT	=	£2417	Cost of Paediatric critical care transportation[10]
PICU _{dr}	=	£2327	Cost of PICU per bed day[10]
PICU _{los}	=	26 days	Length of stay in PICU
HS	=	£12,828	Cost of hospital spell
CT	=	£101	Cost of a CT Scan[10]
MRI	=	£206	Cost of an MRI Scan[10]
RHB _{dr}	=	£368	Costs of Rehab for brain injuries per bed day[10]
RHB _{los}	=	150 days	Length of stay in Rehab

1.2 Public Health

The hospital reported the diagnosis of bacterial meningitis to the Consultant in Communicable Disease Control (CCDC) at the local Health Protection Unit (HPU). Chemoprophylaxis to stop carriage of the bacteria was offered to Emma's immediate family at the hospital. Health protection nurses at the HPU undertook contact tracing which established that wider prophylaxis was not needed. Microbiological samples were sent to the Meningococcal Reference Unit (MRU) for PCR and culture to identify the bacteria responsible for Emma's illness.

Table 2: Costs associated with public health action

Public Health Action	Assumption	Cost	Source
Chemoprophylaxis is supplied to the immediate family	The child has one brother aged 4 and lives with both parents. The parents each take 600mg Rifampicin twice daily for two days and the child takes 150mg Rifampicin twice daily for two days[18]	£8	BNF[19-20]
Contact Tracing and Information sharing	HPU undertakes contact tracing. The CCDC ensures that information is made available to the nursery and to the parents of children who attend that nursery. The CCDC must also ensure that information about the case is shared with other NHS colleagues and external agencies as necessary[18]	£100	Estimate (four hours of staff time)
Cerebrospinal fluid (CSF) sample is processed at MRU	The sample is processed and PCR undertaken to identify the type of bacteria present in the blood	£46	Personal communication with Professor Ray Borrow, HPA Manchester.
	The sample is cultured and the bacterial isolate is processed to identify the bacterial serotype.	£111	

1.3 Hospital Outpatient Appointments

Once discharged from hospital, Emma had regular follow up appointments with the hospital doctors who treated her in the acute stage. Emma had been left with severe neurological damage, including severe cognitive deficits, epilepsy, severe hemiplegia, homonymous hemianopsia, communication problems and profound deafness (see 1.5). Although Emma eventually learned to walk, this was only for very short distances. This meant that she was predominantly a wheelchair user and had problems with her posture.

Table 3: Hospital Outpatient appointments

Type	Description	Assumption*	Unit costs	Source**
Paediatrician	PICU/Infectious disease follow up to check immune function and discuss PICU medical issues	There are four follow up appointments in the 18 months following discharge	Follow up attendance: £305	Department of Health reference costs 2008/9[10]
Neurologist	Appointments with the neurologist who was involved in the acute care episode	There are six follow up appointments for the first year. After that the appointments drop to one every four months and become six monthly appointments one year after the acute illness. These six monthly appointments continued until the age of 16 and then dropped to yearly. At age 4, Emma undergoes neuropsychological assessment. From age 4 to 16 the annual reviews with the neurologist include neuropsychologist input and so have been costed as multiprofessional.	Paediatric Follow up attendance: £243 Neuropsychological assessment: £346 Multiprofessional paediatric follow up attendance: £295 Adult follow up attendance: £131	Department of Health reference costs 2008/9[10]
Neurosurgeon	Appointments with the neurosurgeon who was responsible for the shunt operation	Emma returned to the hospital for yearly appointments with the neurosurgeon that fitted the shunt.	Follow up attendance: £265 Adult follow up attendance: £120	Department of Health reference costs 2008/9[10]
Orthopaedic surgeon	Appointments with an orthopaedic surgeon to check spinal development	As Emma is a wheelchair user, from age 6 until 20, she has yearly appointments with an orthopaedic surgeon who is looking for signs of scoliosis and keeps an eye on hip alignment. Corrective surgery may be required to prevent future pain.	First attendance: £143 Follow up attendance: £116	Department of Health reference costs 2008/9[10]
Orthotist	A raised shoe is required to help Emma's posture when walking short distances	Emma is prescribed a special raised shoe and splinting to maintain the ankle at 90 degrees. She is reviewed every six weeks, then three monthly and then every 6 months. It has been assumed that an hour long orthotist appointment costs £60 and that the appointment time is 20 minutes[21]	£20 per appointment	York Health Economics Consortium[21]
Ophthalmologist	The ophthalmologist diagnoses homonymous hemianopsia	Emma goes to see the ophthalmologist aged when it becomes apparent that she only seems to be aware of movement to one side of her field of vision.	First attendance: £110 Follow up attendance: £73	Department of Health reference costs 2008/9[10]

*Assumptions based on the clinical opinions of a paediatric immunologist, neurologist, paediatricians, and orthopaedic surgeons (see Acknowledgements).

**Department of Health outpatient service codes and costs are listed in Table 2 of Appendix A.

1.4 Community Medicine

Emma was 3 years old on discharge from hospital and needed regular and frequent care. She received regular home visits from community health professionals until she started school full time.

Table 4: Appointments with community medics and associated costs

Type	Description	Assumption*	Unit costs	Source
Community paediatrician	Emma is referred to the nearest child development centre (CDC)	Emma see the community paediatrician on a six monthly basis for the first three years post discharge which then decreases to yearly until age 16	£293 per visit	Dept. of Health ref costs 2008/9[10]
Community physiotherapist	The physiotherapist assesses Emma and provides the parents with a written care episode and ideas to help Emma's lower body posture	The physiotherapist sees Emma on a fortnightly basis for the first four months. Then on average every 6 weeks until age 5 (this estimate includes assessments for equipment and instruction on use, which on average takes four sessions of therapist's time. It also includes equipment review which is every three months before the age of 5). A physiotherapy technical instructor carries out 3 blocks (six hour long sessions) of treatment with Emma per year at home or at school from ages 3 to 6. Beyond 6 years of age the physiotherapy management focuses around both general and equipment reviews and visits are twice per quarter until she is 19. Physio is temporarily increased again for 6 months after the hemispherectomy operation with the physiotherapist visiting every fortnight and then six weekly.	£48 per home visit	Unit costs[17]
Hydrotherapy	Course of hydrotherapy to help Emma learn to walk	Emma has 12 sessions of hydrotherapy aged 4 and another 12 sessions aged 11 after having her hemispherectomy.	£89.26 per hour long session	Personal communication with physio (KD)
Community Occupational Therapist (OT)	The OT helps Emma with her upper body posture	The OT sees Emma on a fortnightly basis for the first four months. Then on average every month until age 6. Beyond age 6 there are three monthly reviews which include school visits where they provide advice to teachers and support assistants until age 19. The OT also makes recommendations for home adaptations. It has been assumed that each time the home needs adaptations there are an additional 5 home visits from the OT and another 10 hours of OT time associated with completing the necessary paperwork.	£48 per home visit £26 per hour	Unit costs[17]
Health Visitor	The health visitor checks Emma's general health	The health visitor comes once every two weeks for the first six months after Emma is discharged from hospital.	£41 per home visit	Unit costs[17]
Speech and Language therapists (SALTs)	SALTs work with Emma to help her with speech	Community speech and language therapists review Emma quarterly, whilst the actual therapy is delivered by a teaching assistant. At 8 years of age Emma is provided with a communication aid with input from a specialist SLT.	£48 per home visit	Unit costs[17]

*Assumptions based on the clinical opinions of paediatricians, occupational therapists, physiotherapists, and on the care received by children with similar disabilities (see Acknowledgements).

1.5 Cochlear Implantation

Emma was profoundly deaf and was referred to the cochlear implant team as soon as possible for bilateral cochlear implants. To be successful, cochlear implantation following meningitis needs to be carried out within months of the acute illness. Once she had had the initial implantation operation, she became a lifelong outpatient of the cochlear implant centre as ongoing care and technical support is required.

Table 5: Costs of bilateral cochlear implantation*

Service	Description	Cost
Full assessment	Detailed hearing assessment before undergoing implantation	£4,900
Bilateral Implantation	Includes all costs associated with the operation and the device implanted plus a second device	£28,872
Additional costs in Year 1**	Second set of external parts including processor, rehabilitation and tuning, spares and batteries	£15,475
Additional costs in Year 2***	Ongoing care and technical support for bilateral implants including medical; check, tuning, batteries, spares and upgrade of processors	£7,550
Additional costs in Year 3***	Ongoing care and technical support for bilateral implants including medical; check, tuning, batteries, spares and upgrade of processors	£5,150
Additional costs each year until age 18	Ongoing care and technical support for bilateral implants including medical; check, tuning, batteries, spares and upgrade of processors	£4,900
Additional costs each subsequent year from 18 onwards	Ongoing care and technical support for bilateral implants including medical; check, tuning, batteries, spares and upgrade of processors	£4,550

* Based on 2010 prices from South of England Cochlear Implant Centre[22]

**Additional costs include 10 appointments with the key contact (speech and language therapist or teacher of the deaf) either at home, at school/nursery or in the clinic and eight tuning appointments with the audiologist in the clinic

***Additional costs include 6 appointments with the key contact (speech and language therapist or teacher of the deaf) either at home, at school/nursery or in the clinic and two tuning appointments with the audiologist in the clinic.

1.6 General Health Problems

When Emma initially returned home from hospital she was in a lot of pain and was given medication daily to help relieve this. She also required medication to assist bowel movement because she was very constipated. Emma's brain damage meant that she was doubly incontinent.

Table 6: Costs associated with general health problems

Health Issue	Assumption	Cost	Source
Pain	Emma is given approximately 480 mg of paracetamol throughout the day in the form of Kalpol for the first two months out of hospital	£0.06 per day	BNF[20]
	After two months, Emma is given paracetamol suppositories to help the pain. She is given 750 mg of paracetamol throughout the day in the form of suppositories until she reaches 6 years old	£6.90 per day	BNF[20]
Constipation	Emma is given lactulose daily to relieve her constipation. She takes 10ml per day until age 5 and 20ml per day until age 10	£0.03 per 5ml	BNF[20]
Double Incontinence	Emma is provided with 4 nappies per day by the NHS.	£0.55 per day	Bladder and Bowel Foundation[23]
	When she reached 7 she was provided with 4 incontinence pants per day on the NHS	£1.73 per day	

1.7 Epilepsy Management

Emma was diagnosed with epilepsy during her initial stay in hospital. This was managed with epilepsy medication which was reviewed on a regular basis by a neurologist. Emma's epilepsy got progressively worse and at the age of 6, Emma's medication was changed because the sodium valproate was not controlling her seizures sufficiently.

Appointments with the neurologist who deals with Emma's epilepsy are covered in Section 1.3 hospital outpatient appointments.

Table 7: Costs of epilepsy medication

Age of Emma	Medication type and dosage	Cost per day	Cost per year	Source
3 to 5	600mg sodium valproate per day	£0.39	£142	
6 to 10	375 mg levetiracetam 3 times per day	£2.73	£996	
	45mg topiramate 3 times per day	£2.26	£825	
	5mg clobazam 2 times per day	£0.16	£58	
11 onwards	600mg sodium valproate per day	£0.39	£142	

Hemispherectomy

At the age of 10, Emma was admitted to hospital for electroencephalograph telemetry (EEG) tests over a number of days to see how many seizures she had when not taking her medication. Results from the EEG led to Emma having a hemispherectomy operation (where one side of the brain was disconnected from the other) in order to reduce the frequency of her seizures. The operation was a success and afterwards, Emma was able to return to her original anti-epilepsy medication.

The cost of each hospital stay was calculated using department of health reference costs[10].

The HRG code relevant to our scenario was obtained using the HRG4 Code to Group Reference Cost Grouper 2008/09 software version 4.2.2[12]. The appropriate ICD10 diagnosis codes and operating procedure codes (OPCS) were input into the grouper, generating an HRG currency code descriptive of the hospital spell (see table 8). The resultant HRG currency codes were used to cost the hospital spell. Hospital spell costs do not include costs associated with PICU and diagnostic imaging, so these were added separately (see table 9). For a detailed methodology for costing a stay in hospital, please refer to section 1.1 of this document.

Table 8: ICD10 and OPCS input codes and resultant hospital spell HRG currency codes

Electroencephalograph telemetry		Hemispherectomy	
ICD 10 Code	Description	ICD 10 Code	Description
G403	Generalised idiopathic epilepsy and epileptic syndromes	G403	Generalised idiopathic epilepsy and epileptic syndromes
OPCS Code	Description	OPCS Code	Description
U221	Electroencephalograph telemetry	A011	Hemispherectomy
Hospital spell HRG	AA20Z - Intracranial Procedures Except Trauma with Muscular, Balance, Cranial or Peripheral Nerve disorders; Epilepsy; Head Injury - category 1 or 2	Hospital spell HRG	AA08Z - Intracranial Procedures Except Trauma with Muscular, Balance, Cranial or Peripheral Nerve disorders, Epilepsy or Head Injury - category 4

Table 9: Details of epilepsy associated hospital stays with associated costs

Reason for Hospital admission	EEG tests	Hemispherectomy
Type of admission	elective	elective
Intensive care	n/a	5 days PICU
Total time in hospital (not including PICU)	Under 12 days	Under 12 days
PICU cost*	n/a	£11,635
MRI scan cost**	£206	£206
Hospital spell HRG cost***	£2,704	£5,487
Total cost	£2,910	£17,328

*Item 4 of Table 1, Appendix A, **Item 5 of Table 1, Appendix A, ***Items 8 and 9 of Table 1, Appendix A

1.8 Special Equipment

Once Emma was discharged from hospital, certain special equipment was provided for the home to help with mobility, day to day activities and Emma's posture.

Table 10: Special equipment provided for the home

Item	Description/Assumption	Cost	Source
Small therapy bench	Emma has a small therapy bench at home to help position her for her physiotherapy exercises.	£227	Quest88
Standing frame	Emma needs to use a standing frame once a day to help her posture for the first couple of years after discharge from hospital. She has a Leckey size 2 prone stander, which is changed to a size 3 Leckey prone stander as she grows.	£1,820	Personal communication with community physiotherapist
Specialist seating	Emma was provided with a Leckey squiggles chair and Tumbleform feeder seat and wedge after being discharged from hospital.	£1,000	Personal communication with physiotherapist
Walkers	Emma is provided with a walker, which needed upgrading as she grew. She had four different walkers in her lifetime.	£500-£600 per walker	Personal communication with community physiotherapist
Specialist toys	The physiotherapist and occupational therapist (OT) brought specialist toys to help Emma's movement.	£100	Estimate
Lycra suit	Emma is fitted for a full body lycra suit aged 4, which she continues to wear until age 6. The suit is changed on average every six months as she grows. Costs do not include fitting fees	£456 per suit	Dynamic Orthotics Ltd[18]
Sleep system	A sleep system designed to support the body during sleep is provided. This needs changing as Emma grows. She has her first one aged 3 and this is upgraded at age 10 and 18.	£1,200 per bed	Personal communication with community physiotherapist.
Manual wheelchair	Emma gets her first wheelchair at age 4. It is a fairly basic manual chair.	£417	Stockport Wheelchair Services
Wheelchair maintenance and renewal	Although Emma can walk short distances she is predominantly a wheelchair user and upgrades her chair as she grows. It is estimated that £300 is spent each year on wheelchair maintenance and upgrades	£300 per year	Stockport Wheelchair Services
Orthotic Shoes	Assumes that Emma gets two shoes amended every year until age 17. After age 17 she gets two shoes amended every 5 years.	£36 per pair of shoes	Quote from C and S footwear[19]
Splinting to maintain ankle at 90 degrees	Assumes that Emma requires splint replacement annually.	£350 per splint	Personal communication with community physiotherapist.
Communication Aid	Emma is provided with a Vanguard Plus communication aid aged 12	£5,995	Liberator

*Equipment has been based on the equipment received by a real child with similar disabilities. The list of equipment is not exhaustive, but an example of some of the types of equipment that an individual with such disabilities might need

1.9 Shunt Revision Surgery

Emma needed multiple shunt revision operations throughout her lifetime. In total she had five operations which averaged out at approximately one operation every ten years. Four of her operations were planned, but one was carried out as an emergency operation due to blockage of the shunt.

The total costs of the hospital spell was calculated using department of health reference costs[10]. For a detailed methodology, please refer to section 1.1 of this document.

The HRG code relevant to our scenario was obtained using the HRG4 Code to Group Reference Cost Grouper 2008/09 software version 4.2.2[12]. The appropriate ICD10 diagnosis codes and operating procedure codes (OPCS) were input into the grouper, generating an HRG currency code descriptive of the hospital spell which in this case was AA19Z - Intracranial Procedures Except Trauma with Cerebral Degenerations or Miscellaneous Disorders of Nervous System - category 1 or 2 (see Appendix A, Item 7). Two scenarios of codes were input into the grouper and both resulted in the generation of the same HRG code. The input codes for both scenarios are outlined in table 9.

Table 11: ICD10 and OPCS input codes used to generate the hospital spell HRG

Scenario 1		Scenario 2	
ICD 10 Code	Description	ICD 10 Code	Description
G911	Obstructive hydrocephalus	G911	Obstructive hydrocephalus
OPCS Code	Description	OPCS Code	Description
A132	Maintenance of distal catheter of cerebroventricular shunt	A141	Renewal of cerebroventricular shunt

It has been assumed that when Emma was admitted to hospital due to blockage of the shunt she spent 2 days in PICU/ICU. None of the other shunt revision operations resulted in a stay in intensive care.

Table 12: Details of shunt revisions with associated costs

Age	5	11	28	33	48
Reason for admission	Shunt maintenance	Blocked shunt	Shunt maintenance	Blocked shunt	Shunt maintenance
Type of admission	elective	non-elective	elective	non-elective	elective
Intensive care	n/a	2 days PICU	n/a	2 days ICU	n/a
Total time in hospital	Under 15 days	Under 15 days	Under 15 days	Under 15 days	Under 15 days
ICU/HDU cost*	n/a	£4,654	n/a	£2,388	n/a
CT scan cost**	£202	£202	£202	£202	£202
Hospital spell HRG cost***	£4,415	£5,408	£4,415	£5,408	£4,415
Total cost	£4,617	£10,264	£4,617	£6,804	£4,617

*See items 4 and 11 of Appendix A

**See item 5 of Appendix A

***See item 10 of Appendix A

2 Educational Costs

Educational costs refer to any cost associated with Emma's education which is over and above the cost of educating a child who does not have any disability. These costs are detailed in sections 2.1 to 2.3 and include costs associated with the following:

- The cost of educating a child with special educational needs (SEN) in a maintained special school (day provision) over and above the costs associated with educating a child with no SEN in a maintained mainstream school.
- Specialised transport to take Emma to and from school
- SEN statementing process and annual reviews

2.1 School

Emma attended a special needs preschool, a special educational needs nursery and maintained special primary and secondary schools.

Table 13: Surplus cost per year of a child with SEN attending a special mainstream school compared to a non disabled child attending maintained mainstream school

Age and School	Assumptions	Additional cost per year	Source
Age 4, Special needs nursery	At 4 years of age Emma attends a special educational needs nursery for five days a week (£135/day x 5 days/week x 38 weeks = £25,650). At 3 and 4 years of age, non disabled children are entitled to 12.5 hours per week of free early education for 38 weeks each year at a cost of £3.50 per hour[24] (£3.50 x 12.5 x 38 = £1,662).	£23,988	Centre for Child and Family Research, Loughborough University [25] House of commons Children schools and families committee[24]
5 to 19 years old Special needs school	At 5 years of age, Emma attends a maintained special school full time (from 0845 to 1530 five days a week) at a cost of £73 per school day[26] (£73 x 190 school days = £13,870) Costs of a primary school are £16 per school day[26] (£16 x 190 school days = £3,040). Costs of a secondary school are £21 per school day[26] (£21 x 190 school days = £3,990).	£10,830 Until age 10 £9,880 Until age 19	Unpublished work undertaken by Coventry City Council and Loughborough University, part-funded by the Economic and Social Research Council http://www.ccfcs.org.uk/research-and-development/education/ [27]

2.2 Transport

Emma is entitled to free transport to and from school.

An investigation of SEN transport costs undertaken by the department for education and skills (DfES) found that the average cost of transport per year per pupil carried was £3,594[28]. Costs are based on the child being provided with this transport from age 5 to age 19.

2.3 Statement of Special Educational Needs (SEN)

Emma has a statement of special educational needs because she was assessed by the local authority as having severe learning difficulties and multiple needs. Her statement of SEN is reviewed by the school and the local authority on an annual basis.

Table 14: Costs associated with SEN statementing and review

Process	Description	Cost	Source
Issue of statement	Producing a SEN statement including an initial assessment, decision at a SEN panel and drafting the statement	£504	Unpublished work undertaken by Coventry City Council and Loughborough University, part-funded by the Economic and Social Research Council http://www.ccfcs.org.uk/research-and-development/education/ [27]
	Additional work associated with statementing a child with complex needs	+£499	
	Additional work associated with making changes to the statement before issue	+£138	
Review of statement	Annual review	£176	
	Additional work associated with amendments made to the statement following the annual review	+£97	
	Additional work associated with reviewing a statement for a child with complex needs	+£199	

It has been assumed that the child has complex needs regarding statementing. She is issued with the statement aged five and no amendments are required before issue. There is a review every year until she reaches 19. Two of these reviews lead to amendments in the statement once at secondary transfer and again at age 16.

3 Social Care Costs

Emma is one of two children in a two parent family. When she became ill, one parent gave up work to care for her. The other parent earns the 2009 national average wage of £25,800 a year[29]. Emma lives with her parents until she is 40 when she moves to full time residential care.

Social costs were divided into three separate categories: direct costs to the state, indirect costs, and transfer payments (which are defined as a redistribution of income in the market system, so are not conventionally included in cost benefit analysis because they do not directly absorb resources or create output). We decided to show transfer payments because although they are not considered a use of resource, they do represent a financial outlay to government and therefore may have some relevance in the consideration of vaccine strategy.

3.1 Direct Social Costs

Direct social costs were calculated under the categories outlined in table 15.

Table 15: Direct Social costs

Cost category	Assumption	Cost	Source
<p>Disabled Facilities Grant</p> <p>This grant can be used for adaptations to give an individual better freedom of movement into and around their home and/or to provide essential facilities within it.</p>	<p>The family home needs extensive work including simple concrete access ramps (£674 each), a new downstairs bathroom/shower and bedroom with hoist (£8122), widening doors (£529 each), stair lift (£2728), lowering light switches etc. Emma receives one of these grants during her lifetime.</p>	<p>£30,000 per grant received</p>	<p>Unit costs[17]</p>
<p>Government's Specialised Vehicle Fund (SVF)</p> <p>The SVF provides financial assistance allowing disabled customers to enter a car as a passenger while remaining seated in their wheelchair or enabling them to drive their car while seated in their wheelchair.</p>	<p>In 2008-9 the government's Specialised Vehicle Fund received £17,036,000 in funding and adapted a total of 1,812 cars, giving an average cost of £9,402 per car adapted[30]. It has been assumed that Emma's parents get their car adapted to accommodate a wheelchair passenger every five years.</p>	<p>£9,402 per adaptation</p>	<p>Department of Work and Pensions[30].</p>
<p>Social care assessment, home visits and reviews.</p> <p>An assessment is undertaken to see what support the family require in terms of services such as home help and short break provision</p>	<p>Emma is given a core assessment followed by a panel discussion. The family are then subject to regular visiting and review procedures. Emma received a home visit by a social worker every six weeks and a review every six months[25]. Once she reached 19 years of age it has been assumed that she had two visits from a social worker per year and an annual review.</p>	<p>£505 per core assessment £96 per panel discussion £76 per home visit £193 per annual review</p>	<p>Centre for child and family research, Loughborough University[25]</p>
<p>Direct Payments</p> <p>Families that require home help can receive direct payments. This enables them to employ a helper directly.</p>	<p>As Emma is one of two children and one parent leaves early for work, it has been decided that the family are entitled to a home helper for three hours a day, five days a week. The family receive this help whilst Emma is at school (for 38 weeks of the year) Once Emma is 16 the home help is reduced to 8 hours of home sitting per month. The cost of the home care worker is £19/hour which includes employer related funds required for employing a home helper.</p>	<p>£285 per week before age 16 £38 per week after age 16</p>	<p>Unit costs[17]</p>
<p>Residential overnight provision</p>	<p>From age 7 onwards, Emma spends one weekend every two months in a specialist residential unit to give the family a break from caring.</p>	<p>£565 per weekend</p>	<p>Centre for child and family research, Loughborough University[25]</p>
<p>Residential care home</p>	<p>At 40 years of age Emma moves full time to residential care for younger adults with physical and sensory impairments</p>	<p>£1,331 per week</p>	<p>Unit costs[17]</p>

3.2 Indirect Social Costs

Indirect social costs are outlined in table 17:

Table 16: Indirect Social Costs

Indirect Cost Category	Assumption	Cost	Source
Lost opportunity earnings from Emma's mother's job	Emma's mum was 25 when she gave up her job to care for Emma. 84% of mothers of disabled children do not work compared to 39% of other mothers[31] It has been assumed that she previously earned the average wage of £25,800[29]. She remains Emma's carer until Emma moves to a residential care home aged 40. It has been assumed that had Emma not become ill, that her mother would have continued to work full time until age 65.	£25,800 per year of unemployment	ONS[29]
Lost Tax Revenue from mother's unemployment	We have assumed that Emma's mother would have earned the 2009 national average wage of £25,800. 20% of these earnings have been assumed to count as lost tax revenue.	£5,160 per year of unemployment	Citizens advice bureau[32]
Lost earnings from Emma's job	Emma's disabilities mean that she is unable to work. It has been assumed that with no disabilities, Emma would work full time from age 20 onwards and receive the average wage of £25,800[29].	£25,800 per year of unemployment	ONS[29]
Lost Tax Revenue from Emma's unemployment	We have assumed that from age 20 onwards, Emma would have earned the 2009 national average wage of £25,800. 20% of these earnings have been assumed to count as lost tax revenue.	£5,160 per year of unemployment	Citizens advice bureau[32]

3.3 Transfer Payments

Transfer payments were subdivided into the categories outlined in table 15.

Table 17: Transfer Payments

Transfer Payment Category	Assumption	Cost	Source
Carers Allowance	One parent has given up work to be full time carer to their child	£2,803 per year	Directgov[33]
Child Tax Credits	Tax credits have been based on the difference between a family where both parents are working and both children are healthy and a family where one parent is working and one child of two is severely disabled. It has been assumed that each working adult earns the average wage of £25,800.	£3,254 per year	HM Revenue and Customs[34]
Disabled Living Allowance (Mobility)	Emma receives the highest rate mobility allowance from age 3 onwards. She is classed in the virtually unable to walk category.	£2,592 per year	Disability Alliance[35]
Disabled Living Allowance (Care)	Emma requires full time care for the rest of her life and as such, qualifies for the highest rate of disability allowance	£3,713 per year (high)	Disability Alliance[35]

Consultation

Throughout the project there was continuous consultation with health professionals, allied health and social care professionals, educational professionals, and with our case studies to further refine our scenario. Lifelong needs for continuing care and support were considered as the child grew, attended school, and made the transition to adulthood.

In order to ensure that the correct codes were used to identify the hospital spell there was ongoing communication with key individuals and expert groups involved in developing Healthcare Resource Groups used for cost coding within the Department of Health's Payment by Results team. Health economists and modellers were also consulted.

In the final consultation stage, a reference document was produced that detailed all the assumptions made. This was sent to all of our professional consultees: health and educational professionals, economists and academics for validation. The assumptions were then amended according to the responses received.

As the costs in this scenario are distributed across a lifetime, discounting has been used to give less weight to those that occur in the future compared with those that occur in the present. In keeping with recommendations from NICE[36], all costs have been presented at a discount rate of 3.5%.

Costs are based on a reduced life span of 50 years of age (32 years younger than the average life expectancy for a UK female[37]). This shorter lifespan was considered appropriate according to the paediatricians consulted, because of the individuals increased likelihood of contracting pneumonia and other conditions associated with severe disabilities.

Results

Category	Sub Category	Discounted cost (3.5%)	Non-Discounted cost	
MEDICAL COSTS	Acute care	131,668	131,670	
	Public health	265	265	
	Hospital outpatient appointments	16,281	25,890	
	Community medicine	22,050	27,702	
	Cochlear implantation	156,510	271,247	
	General health problems	21,511	37,874	
	Epilepsy management	25,281	35,739	
	Special equipment	30,420	51,046	
	Shunt revision surgery	16,874	30,919	
	MEDICAL TOTAL	420,860	612,352	
EDUCATIONAL COSTS	School	133,345	177,888	
	Transport to and from school	38,641	53,910	
	SEN Statementing and review	4,729	6,447	
	EDUCATIONAL TOTAL	176,715	238,245	
SOCIAL CARE COSTS	Direct social costs	Disabled facilities Grant	28,005	30,000
		Government's Specialised Vehicles Fund	41,512	75,216
		Social care assessment, home visits and reviews	16,242	25,726
		Direct Payments	126,874	186,238
		Residential overnight provision	57,282	111,870
		Residential care home	174,464	761,332
		Total direct social costs	444,380	1,190,382
	Indirect social costs	Mother's employment - missed opportunity costs	531,592	954,600
		Emma's employment - missed opportunity costs	255,460	774,000
		Total missed opportunity costs - employment	787,052	1,728,600
		Mother's lost income tax revenue	106,318	190,920
		Emma's lost income tax revenue	51,092	154,800
		Total lost income tax revenue	157,410	345,720
	Transfer Payments	Disabled Students' Allowances (University equipment)	174,464	761,332
		DLA (Care)	52,669	87,173
		DLA (Mobility)	58,649	123,130
		Carers Allowance	56,456	102,410
		Child tax credits	35,962	47,185
		Total Transfer Payments	378,201	1,121,230
	SOCIAL CARE TOTAL - lost resources to society (excludes transfer payments and lost income tax revenue)		1,231,432	2,918,982
TOTAL LIFE LONG COSTS (includes lost resources to society but excludes transfer payments and lost income tax revenue)		1,829,007	3,769,579	

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Six families with similar experience to the fictional Emma, most have given consent for their names to be published in connection with this document, and can be supplied on request.

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Appendix: HRG codes and costs

Table 1: Department of Health Reference Cost Currency codes and associated costs

Item Number	Description and duration of hospital spell	Currency Code	Currency Description	National Average Unit Cost	Trimpont
1	Ambulance to A&E	PSETU	Emergency Transfers / Urgents	£240	n/a
2	A&E investigation	VB01Z	Any investigation with category 5 treatment	£116	n/a
		VB02Z	Category 3 investigation with category 4 treatment	£298	
		VB03Z	Category 3 investigation with category 1-3 treatment	£184	
		VB04Z	Category 2 investigation with category 4 treatment	£184	
		VB05Z	Category 2 investigation with category 3 treatment	£160	
		VB06Z	Category 1 investigation with category 3-4 treatment	£114	
		VB07Z	Category 2 investigation with category 2 treatment	£149	
		VB08Z	Category 2 investigation with category 1 treatment	£142	
		VB09Z	Category 1 investigation with category 1-2 treatment	£94	
		A&E Investigation Weighted Average	£135.97		
3	Transferral to PICU by retrieval team	XB08Z	Paediatric Critical Care Transportation	£2,417	n/a
4	PICU	XB01Z	Paediatric Critical Care Intensive Care - ECMO/ECLS	£1,651	n/a
		XB02Z	Paediatric Critical Care Intensive Care Advanced Enhanced	£1,932	
		XB03Z	Paediatric Critical Care Intensive Care Advanced	£1,186	
		XB04Z	Paediatric Critical Care Intensive Care Basic Enhanced	£2,110	
		XB05Z	Paediatric Critical Care Intensive Care Basic	£2,327	
5	Diagnostic Imaging	RA01Z	Magnetic Resonance Imaging Scan, one area, no contrast	£206	n/a
		RA08Z	Computerised Tomography Scan, one area, no contrast	£101	n/a
6	Medical care during acute illness	AA10Z	Non-Elective Inpatient (Long Stay) HRG Data - Intracranial Procedures Except Trauma with Non-Transient Stroke or Cerebrovascular Accident, Nervous system infections or Encephalopathy - category 3	£12,828	72
7	Rehabilitation	VC06Z	Rehabilitation for Brain Injuries - 'Specialised' rehabilitation services (SRS) (Level 2) - Bed Days: Admitted Patient Care	£368/day	n/a
8	Neuro-psychological assessment	AA25Z	Outpatient procedures - Cerebral Degenerations or Miscellaneous Disorders of Nervous System	£346	n/a
9	Hospital stay for EEG	AA20Z	Elective inpatient HRG data - Intracranial Procedures Except Trauma with Muscular, Balance, Cranial or Peripheral Nerve disorders; Epilepsy; Head Injury - category 1 or 2	£2,704	12
10	Hemispherectomy	AA08Z	Elective inpatient HRG data - Intracranial Procedures Except Trauma with Muscular, Balance, Cranial or Peripheral Nerve disorders, Epilepsy or Head Injury - category 4	£5,487	12
11	Shunt maintenance and renewal operations	AA19Z	Elective inpatient HRG data - Intracranial Procedures Except Trauma with Cerebral Degenerations or Miscellaneous Disorders of Nervous System - category 1 or 2	£4,415	15
		AA19Z	Non elective inpatient HRG data - Intracranial Procedures Except Trauma with Cerebral Degenerations or Miscellaneous Disorders of Nervous System - category 1 or 2	£5,408	15
12	Adult Critical Care - 2 Organs Supported	XC05Z	NHS Trusts and PCTs combined Critical Care Services - Adult: Critical Care Unit	£1,194	n/a

Table 2: Department of Health service codes, descriptions and associated costs

Service Code	Service Description	Activity	National Average Unit Cost	Lower Quartile Unit Cost	Upper Quartile Unit Cost
256	Paediatric Infectious Diseases - Consultant led follow up attendance non-admitted face to face	2,855	£305	£257	£451
421	Paediatric Neurology - Consultant led follow up attendance non-admitted face to face	36,279	£243	£121	£388
421	Paediatric Neurology - Consultant Led: Follow up Attendance Multiprofessional Non-Admitted Face to Face	178	£295	£62	£387
400	Neurology - Consultant led follow up attendance non-admitted face to face	521,836	£131	£101	£149
218	Paediatric Neurosurgery - Consultant led follow up attendance non-admitted face to face	8,493	£265	£88	£258
150	Neurosurgery - Consultant led follow up attendance non-admitted face to face	122,637	£120	£79	£153
214	Paediatric Trauma And Orthopaedics - Consultant led first attendance non-admitted face to face	53,424	£143	£95	£198
214	Paediatric Trauma And Orthopaedics - Consultant led follow up attendance non-admitted face to face	94,325	£116	£72	£137
130	Ophthalmology - Consultant led first attendance non-admitted face to face	1,411,961	£110	£83	£134
130	Ophthalmology - Consultant led follow up attendance non-admitted face to face	3,224,273	£73	£59	£90
CP60FO	All Community Paediatrician Services [excluding TFC 291 and vaccination programmes] : Face to Face - Other - Community Medical Services: Other Services	282,081	£293	£197	£333