

COUNTING THE COST OF MENINGITIS:

A severe case of meningococcal septicaemia

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call for evidence for first meeting of meningococcal sub group.
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Document 1 of 2

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Summary

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 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 meningococcal disease. Our contact with families affected and professionals involved in rehabilitation enable us to contribute new information in this area.

Methods

Although the majority of cases of meningococcal disease make a full recovery, many are left with disabilities that can have a profound effect on the lives of the individuals and their families[3]. Such disabilities can often result in substantial financial costs to the state as well as to the families themselves.

The aim of this work is to estimate lifelong costs for two example scenarios of survivors of meningococcal disease with severe long-term sequelae. This document discusses a scenario that is based on severe long-term sequelae associated with septicaemia. Another scenario is currently under development which is based on severe long-term sequelae associated with meningitis.

Scenario Development

There are a wide range of potential long-term sequelae following meningococcal disease. The first stage of our scenario development was to produce a comprehensive and exhaustive list of the sequelae associated with two different clinical presentations of meningococcal disease i.e. meningitis and septicaemia.

It was decided that the case of meningococcal septicaemia would be based on an amalgamation of several actual cases. The result of this amalgamation is a fictional child 'Peter', who at the age of 12 months, survives meningococcal septicaemia resulting in multiple amputations and who later develops behavioural problems. The medical aspects of the scenario are briefly outlined in Box 1. Preliminary discussions with paediatricians and paediatric infectious disease specialists took place to ensure that our scenario was a reasonable representation of the severe end of meningococcal septicaemia.

BOX 1: Scenario

Child is hospitalised with severe septic shock and purpura fulminans, acute respiratory distress syndrome and renal failure. Both legs are amputated above the knee and one arm below the elbow. The total acute hospital spell (including PICU) lasts 6 months.

Child becomes a lifelong outpatient of a disablement services centre for upper and lower limb prostheses and rehabilitation.

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

ADHD is diagnosed through CAMHS age 4.

There are nine additional hospital in-patient spells for stump revision and plastic surgery.

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 who either had a child with similar sequelae following septicaemia or were themselves affected. In each case we worked through their treatment and rehabilitation journey to date. We also reviewed some of the available literature about such sequelae and rehabilitation following meningococcal septicaemia [4-12].

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 1.8 and include costs associated with the following:

- Acute costs of inpatient stay in intensive care and on the paediatric ward
- The public health response to the case and laboratory confirmation at MRU
- Rehabilitation outpatient appointments for prosthetic limb fittings
- Prosthetic limb replacements and adjustments
- Community therapy/medicine
- Specialist equipment provision to help Peter's mobility
- Hospitalisation associated with later stump revision and scar surgery
- Intervention for behavioural problems (ADHD)

1.1 Acute Care

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

Peter was 12 months old when he visited the GP with a fever and a rash and was subsequently rushed to hospital with suspected meningococcal disease. He was taken to the Emergency department by ambulance and from there transferred to PICU by a retrieval team. Peter spent 31 days in PICU with severe septic shock, acute respiratory distress syndrome and renal failure. He also developed gangrene of the limbs due to purpura fulminans. His respiratory and renal problems were resolved in PICU, and he was transferred to a paediatric ward where he needed both legs amputated above the knee and one arm below the elbow. After the initial amputations, Peter had to return to theatre several times for tissue debridement and dressing changes under anaesthetic. Once his wounds had begun to heal a little, Peter also underwent various skin grafting operations to repair damaged skin on his remaining limbs. In total he was in hospital for 6 months.

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)[13]. 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) or diagnostic imaging such as CT and MRI scans[14]. 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[15]. 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 HR06B – Reconstruction Procedures Category 1 18 years and under. 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.

A 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 amount of time that the patient stayed in hospital beyond the trim point was costed at the mean excess bed day rate for that HRG code (see equation 1). The costs and trimpoint associated with code HR06B are provided in table 1 item 6 of the Appendix.

$$\text{Equation 1: } \text{£Hospital Spell} = \text{£}(HR06Buc + ((HPlos - PICUlos - HR06Btp) * HR06Bebdr))$$

Where:

PICUlos	=	31 days	Length of stay in PICU
HR06Buc	=	£3,364	National average unit cost for hospital stays under currency code HR06B[13]
HPlos	=	186 days	Hospital length of stay
HR06Btp	=	6 days	Trimpoint associated with HRG currency code HR06B[15]
HR06Bebd	=	£490	Excess bed day rate associated with HRG currency code HR06B[13]

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

ICD 10 Code	Description
A392	Acute meningococemia
D65X	Disseminated intravascular coagulation [defibrination syndrome] (includes purpura fulminans)
L905	Scar conditions and fibrosis of skin
B948	Sequelae of other specified infectious and parasitic diseases
T875	Necrosis of amputation stump
OPCS Code	Description
X075	Amputation of arm through forearm
X093	Amputation of leg above knee
X093	Amputation of leg above knee
X121	Reamputation at higher level
X124	Revision of coverage of amputation stump
S358	Other specified split autograft of skin
X125	Drainage of amputation stump
S369	Unspecified other autograft of skin
S571	Debridement of skin NEC
S576	Cleansing and sterilisation of skin NEC
S574	Dressing of skin NEC

*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 numerous health professionals such as orthopaedic surgeons, plastic surgeons, paediatricians and consulting with families of survivors of the disease (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[16]. 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)[13]. 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[17]. 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[18]. 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. In addition, Peter would have had a high level of dependency (resulting in higher costs) because he required advanced respiratory support, inotropes, dialysis and (initially) isolation. Further details of the interventions that relate to the different PICU HRGs are available in Appendix M of the PICANet annual report[17].

Total Cost of Acute Episode

The acute hospital phase has been calculated as follows:

$$\text{£Acute phase} = \text{£}(GP + AT + A\&E + RT + (PICUdr * PICUlos) + HS + CT + MRI)$$

Where:

GP	=	£40	Cost of GP appointment[19]
AT	=	£240	Cost of Ambulance transfer[13]
A&E	=	£136	Cost of A&E investigation[13]
RT	=	£2417	Cost of Paediatric critical care transportation[13]
PICUdr	=	£2327	Cost of PICU per bed day[13]
PICUlos	=	31 days	Length of stay in PICU
HS	=	£76,374	Cost of hospital spell
CT	=	£206	Cost of a CT Scan[13]
MRI	=	£101	Cost of an MRI Scan[13]

1.2 Public Health

When Peter was diagnosed with meningococcal disease, the hospital reported this 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 Peter's immediate family at the hospital. Health protection nurses at the HPU undertook contact tracing which established that wider prophylaxis was not needed. Peter had been attending nursery before he became ill, so the nursery were contacted by public health and advice given to staff along with information provided for the parents of all the children who attend nursery with Peter. A blood sample was sent from the hospital to the Meningococcal Reference Unit (MRU) for laboratory confirmation by PCR.

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[20]	£8	BNF[21-22]
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[20]	£100	Estimate
Blood 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, Ray Borrow, HPA Manchester

1.3 Outpatient Appointments

Once discharged from hospital, Peter became a lifelong outpatient of a disablement services centre which provided prosthetic limbs. He was seen by a multidisciplinary team consisting of a consultant in rehabilitation medicine, a prosthetist, a physiotherapist and an occupational therapist on a regular basis. He also had regular appointments with the hospital paediatrician until follow-up is transferred to Community Paediatrics after age 3.

Table 3: Outpatient appointments attended with associated costs per appointment

Type	Description	Assumption*	Unit costs	Source
Prosthetic Appointments	Patient has access to: Lead prosthetic therapist Prosthetist Counsellor.	The child is followed up every three months for the first year, then every four months until age 16, then 6-monthly until age 30 and yearly thereafter.	First attendance: £742 Follow up attendance: £325	Department of Health reference costs 2008/9[13]
Prosthetic Physiotherapy Appointments	Specialist physiotherapy to help gait etc when using prosthetic legs	The physiotherapist will see the child at every prosthetic outpatient's clinic. However when there is a change in circumstances such as change in prosthetics the child receives a block of physiotherapy. The average number of sessions in a block of physiotherapy with the prosthetics physiotherapist is about 16. It has been assumed that the child will receive 4 blocks of physiotherapy throughout his development.	£44 per hour of client contact	Unit costs[19]
Prosthetic Occupational Therapy appointments	Specialist OT to help use the prosthetic arm for specific tasks	The OT sees the child at the quarterly rehabilitation appointments, but has more of an input when there is a change in circumstance such as when the child starts to use a myoelectric arm or wants a specific prosthetic tool for a given activity. It has been assumed that the child sees the OT outside of the routine appointments for 4 extra sessions per year until age 18. This is ongoing input because the child may require new equipment as the activities he participates in change. After age 18 it is assumed that as an adult he may need to see the OT for one extra session (outside of the routine prosthetic rehab appointments) per year.	£44 per hour of client contact	Unit costs[19]
Combined Clinic Appointments	Patient sees Plastic surgeon, lead prosthetic therapist and sometimes orthopaedic surgeon in a combined clinic.	These appointments take place on a six monthly basis until the child reaches 18 years of age. They then take place on an as needed basis. For this particular scenario the patient has four extra appointments beyond age 18. These appointments are for issues such as the breakdown of existing skin grafts.	First attendance: £188 Follow up attendance: £130	Department of Health reference costs 2008/9[13]
Hospital Paediatrician Appointments	Patient is followed up by the hospital paediatrician in charge of his acute care	These appointments are quarterly until the child reaches 3 years of age at which point care is handed over to a community paediatrician.	First attendance: £98 Follow up attendance: £34	Department of Health reference costs 2008/9[13]
Plastic surgery appointments	Plastic surgeon	The patient has five appointments on an as needed basis beyond age 18. These appointments are for issues such as the breakdown of existing skin grafts.	First attendance: £113 Follow up attendance: £54	Department of Health reference costs 2008/9[13]

*Assumptions based on the clinical opinions of occupational therapists, physiotherapists, consultants in rehabilitation medicine, prosthetists, plastic surgeons, orthopaedic surgeons and paediatricians (see Acknowledgements).

1.4 Prosthetic Provision

The prosthetic limbs needed changing and upgrading as Peter grew and his needs changed. Tables 4 and 5 show the types of prosthetic legs and arms that Peter needed as he grew and how often these needed replacing.

Table 4: Types of prosthetic legs used throughout Peter's lifetime with associated costs

Lower Limb Prosthetic Types and Assumptions*	Component	Cost**	Total cost per limb
CHILD'S NON ARTICULATING PROSTHESIS			
For the first 18 months the child goes through 3 non articulating prosthetics because the skin is settling down and the stumps are changing shape	socket	80	558
	socket lock	110	
	socket block	31	
	pyramid adapter	56	
	tube clamp	50	
	tube	56	
	foot	75	
	cosmesis	20	
CHILD'S MODULAR SAKL			
At 3 to 5 years old the child is provided with modular SAKL prosthetics. The sockets are replaced twice throughout this period and the length of the legs etc is adjusted a couple of times. It was therefore assumed that the child went through two sets of SAKLs in this period of time.	socket	80	828
	socket lock	110	
	socket block	31	
	pyramid adapter	56	
	tube clamp	50	
	Knee	320	
	tube	56	
	foot	75	
	cosmesis	50	
JUNIOR ARTICULATED PROSTHESIS (MODULAR)			
At 5 years old the child has modular articulated prosthetics. Two sets are provided so that the ones not in use can be amended when required. The sockets are changed every 9 months. The feet are changed every 2 years (on both sets). Initially the limbs are fitted with a basic foot, but at age 10 onwards the flexfoot junior is used. The entire limb is replaced once every two years on both sets, minus feet, sockets and cosmesis which are already accounted for.	socket	80	1938
	socket lock	110	
	socket block	31	
	pyramid adapter	56	
	tube clamp	50	
	Total knee junior	930	
	tube	56	
	foot	75	
	cosmesis	50	
	Flexfoot junior	500	
ADULT ARTICULATED PROSTHESIS (MODULAR)			
At 14 years of age, adult articulated prosthetics are provided. Two sets are provided so that the ones not in use can be amended when required. Sockets are replaced yearly on both sets until age 21. From then on sockets are replaced on average once every five years (on both sets). One set of limbs is used for every-day use and the other is a spare set. The everyday set of limbs are renewed completely, once every two years with feet. The spare set are renewed completely once every 5 years with feet. Cosmesis on the everyday set is replaced yearly and every five years on the spare set.	socket	80	3100
	socket lock	110	
	socket block	45	
	pyramid adapter	50	
	tube clamp	50	
	Adult knee	1350	
	tube	15	
	Flexfoot adult	1100	
	Cosmetic skin cover	250	
	Foam cosmesis under skin	50	
STUBBIES			
At 3 years of age the child has stubbies for getting around the house in (same as non-articulating prosthesis without the feet). These are replaced on a 9-monthly basis throughout his childhood and on average every four years as an adult.	socket	80	403
	socket lock	110	
	socket block	31	
	pyramid adapter	56	
	tube clamp	50	
	tube	56	
	cosmesis	20	
	SOCKET REPLACEMENTS		
The interface between the stump and prosthetic needs to be changed every time the stump changes shape	socket	80	221
	socket lock	110	
	socket block	31	
SILICON GEL LINER			
Liners for the lower limbs are changed on a 6 monthly basis	gel liner	350	350
SWIMMING PROSTHESIS			
At six years of age the child is provided with waterproof swimming legs so that he can get to and from the swimming pool unaided. Sockets are replaced yearly until he reaches 21 years of age and from then on sockets are replaced once every five years. The rest of the limb is replaced on average once every five years	socket	80	1185
	socket lock	110	
	socket block	45	
	pyramid adapter	50	
	tube clamp	50	
	Knee	300	
	tube	15	
	Foot	85	
	Flipper ankle	400	
	Waterproof cover	50	

*Assumptions based on the clinical opinions of occupational therapists, physiotherapists, consultants in rehabilitation medicine and prosthetists (see Acknowledgements).

**Source: NHS Catalogue of Prosthetic Components, NHS Supply Chain

Table 5: Types of prosthetic arms used throughout Peter's lifetime with associated costs

Upper Limb Prosthetic Types and Assumptions*	Component	Cost**	Total cost per limb
SILICON GEL LINER			
Liner for the upper limb is changed on a 6 monthly basis	gel liner	411	411
CHILD'S COSMETIC BELOW ELBOW PROSTHESIS			
The child has a cosmetic below elbow prosthesis from 22 months onwards. The limb is replaced on average twice a year while the child grows and the socket size needs changing. The child upgrades to an adult prosthetic arm aged 15.	Hand	113	213
	Cosmetic glove	68	
	Corset	21	
	Housing	11	
CHILD'S MECHANICAL FUNCTIONAL BELOW ELBOW PROSTHESIS			
The child has this prosthesis from 22 months onwards. The socket is replaced on average twice a year and the limb is used up until age 15. The cosmetic glove for the mechanical hand needs replacing once every six months. The hands are replaced once every two years to keep up with the child's growth.	Wrist rotary	157	1152
	Mechanical hand	224	
	Hand plate	98	
	TRS Sports hand	550	
	Wrist Adaptor for TRS Sports Hand	40	
	Cosmetic glove for mechanical hand	83	
CHILD'S MYOELECTRIC FUNCTIONAL BELOW ELBOW PROSTHESIS			
The child has this prosthesis from 22 months onwards. The socket is replaced on average twice a year and the limb is used up until age 15. The cosmetic glove needs replacing once every six months. The hand is upgraded in size three times as the child grows and serviced three times (i.e. upgraded or serviced once every two years).	Bock Electrohand	4028	7044
	Electrodes x2	1208	
	Cables x2	66	
	Laminating ring	83	
	4 in 1 controller	795	
	Coding plug	14	
	Battery cable	35	
	Battery holder	39	
	Battery x2	395	
	Battery charger	220	
	Cosmetic glove	161	
	Hand Service	900	
	Exchanged hand	1950	
ADULT COSMETIC BELOW ELBOW PROSTHESIS			
This prosthesis is worn from age 15 upwards. As most growth has already happened the socket and rest of the arm has been estimated to need replacing once every 5 years on average. The high definition glove needs replacing once every four years.	Foam Hand	113	3110
	Hand plate	31	
	Foam kit	29	
	High definition silicone glove	2938	
ADULT BELOW ELBOW PROSTHESIS WITH A SPLIT HOOK			
This prosthesis is used from age 15 upwards. The whole limb has been estimated to need replacing once every 10 years. The socket has been estimated to need changing every 5 years.	Wrist rotary	192	811
	Wrist housing	41	
	Split hook (Stainless Steel)	485	
	Adaptor	41	
	TD Con35nector	7	
	S Hook	6	
Hand plate	39		
ADULT BELOW ELBOW MYOELECTRIC PROSTHESIS			
This prosthesis is used from age 15 upwards. The socket and housing have been estimated to need replacing once every five years. It has been assumed that the hand will be serviced once every two years and returned for exchange once every eight years. The cosmetic glove is estimated to need replacing once per year and the batteries estimated to be lasting two years at a time before needing replacement.	Bock hand	3363	5662
	Lamination ring	80	
	Coupling	25	
	Coax plug	100	
	Electrodes (2)	1208	
	Cables	67	
	Batteries	356	
	Battery holder	27	
	Battery charger	226	
	Battery cable	32	
	Coding plug	14	
	Cosmetic glove	166	
	Hand Service	900	
Exchanged hand	1950		
SOCKET REPLACEMENTS			
	socket	80	80

*Assumptions based on the clinical opinions of occupational therapists, physiotherapists, consultants in rehabilitation medicine and prosthetists (see Acknowledgements).

**Source: NHS Catalogue of Prosthetic Components, NHS Supply Chain

1.5 Community Medicine

Community therapists played a role in Peter's rehabilitation regarding prevention of contractures and providing a programme of exercises to improve posture, strength and dexterity. The community therapists support parents and teachers who carry out the exercises with the child.

Table 6: Appointments with community medics and associated costs

Type	Description	Assumption*	Unit costs	Source
Community Paediatrician Appointments	Patient is followed up by a community paediatrician	When the child reaches three years of age a community paediatrician sees him six monthly and then yearly until age 16.	£293 per visit	Department of Health reference costs 2008/9[13]
Community physiotherapist and OT	Patient is followed up by community therapists	Initially the community therapists (physiotherapist and OT) saw the child on average once a fortnight until he reached 4 years of age. From 4 to 13 years of age the therapists saw the child on average once a month either at school or at home. From age 13 onwards the therapists visited the school once a term.	£44 per hour of client contact	Unit costs[19]

*Assumptions based on the clinical opinions of occupational therapists and physiotherapists (see acknowledgements).

1.6 Specialist Equipment Provision

Peter needed specialist equipment from the hospital and the community therapists to assist him with his exercises and ultimately help him to move around independently.

Table 7: Specialist equipment provided to Peter with associated costs*

Equipment*	Description	Unit Cost	Source
Splints	3 x Elbow splints to help prevent contractures	£6.11 per splint	Promedics - www.promedics.co.uk
Pressure suit	8 x Pressure suit to help reduce scarring provided by the children's hospital (the suits needed changing as he grew).	£225 per suit	Jobskin - www.jobskin.co.uk
Wheelchair	Manual wheelchair with paediatric cushion and adapted leg rests	£452	Stockport wheelchair services
	Power wheelchair with low profile cushion and adapted leg rests	£2,374	Stockport wheelchair services
	Wheelchair replacement/maintenance costs	£300 per year	Estimation based on wheelchair voucher scheme
Walker	2 x Crocodile walker with forearm supporters and flip down seat (he was provided with this aged 3, but he required a larger version aged 5)	£865 per walker	Personal communication with community physiotherapist
Crutches	Adapted crutches	£20	NHS Supply Chain
Therapy bench	Small therapy bench	£227	Quest88
Standing Frame	Lecki size 2 prone stander	£909	Personal communication with community physiotherapist

*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

1.7 Stump revisions and skin graft surgery

As Peter grew, the bones in his amputation stumps grew at a different rate to the surrounding tissue and he had to undergo numerous operations to trim his bones and alter the coverage of his amputation stumps. In addition to this, the skin on one of his legs was in such bad condition that it needed to be covered with healthy skin taken from his back. In order to harvest enough skin for the operation skin expanders were inserted to stretch the skin.

Table 8: ICD10 and OPCS input codes with the corresponding hospital spell HRGs and costs*

Procedure	Code type	Inputs	Hospital Spell HRG**	Cost
Bony overgrowth in arm stump	ICD10	T876 Other unspecified complications of Amputation stumps	QZ12Z	£3,284
	OPCS	X123 Shortening of length of amputation stump		
		X124 Revision of coverage of amputation stump		
		S576 Cleansing and sterilisation of skin NEC		
	S574 Dressing of skin NEC			
Bony overgrowth in leg stump	ICD10	T876 Other unspecified complications of Amputation stumps	QZ12Z	£3,284
	OPCS	X123 Shortening of length of amputation stump		
		X124 Revision of coverage of amputation stump		
		S576 Cleansing and sterilisation of skin NEC		
	S574 Dressing of skin NEC			
Insertion of skin expanders and contracture relaxation procedure	ICD10	L90.5 Scar conditions and fibrosis of skin	JC04C	£2,226
	OPCS	T876 Other unspecified complications of Amputation stumps		
		B948 Sequelae of other specified infectious and parasitic diseases		
		S488 Other specified insertion of skin expander into subcutaneous tissue		
	S238 Other specified flap operations to relax contracture of skin			
	S576 Cleansing and sterilisation of skin NEC			
	S574 Dressing of skin NEC			
Removal of skin expanders and flap operation***	ICD10	L90.5 Scar conditions and fibrosis of skin	JC03C	£2,156
	OPCS	T876 Other unspecified complications of Amputation stumps		
		B948 Sequelae of other specified infectious and parasitic diseases		
		S494 removal of skin expander from subcutaneous tissue NEC		
	Y573 Harvest of axial pattern flap of skin from scapular region			
	S312 Transfer of flap of skin NEC			
	S576 Cleansing and sterilisation of skin NEC			
	S574 Dressing of skin NEC			
Bony overgrowth in arm stump	ICD10	T876 Other unspecified complications of Amputation stumps	QZ12Z	£3,284
	OPCS	X123 Shortening of length of amputation stump		
		X124 Revision of coverage of amputation stump		
		S576 Cleansing and sterilisation of skin NEC		
	S574 Dressing of skin NEC			
Bony overgrowth in leg stump and contracture relaxation	ICD10	T876 Other unspecified complications of Amputation stumps	QZ12Z	£3,284
	OPCS	X123 Shortening of length of amputation stump		
		X124 Revision of coverage of amputation stump		
		S238 Other specified flap operations to relax contracture of skin		
	S576 Cleansing and sterilisation of skin NEC			
	S574 Dressing of skin NEC			
Bony overgrowth in leg stump	ICD10	T876 Other unspecified complications of Amputation stumps	QZ12Z	£3,284
	OPCS	X123 Shortening of length of amputation stump		
		X124 Revision of coverage of amputation stump		
		S576 Cleansing and sterilisation of skin NEC		
	S574 Dressing of skin NEC			
Skin grafting due to break down of previous skin grafts (two separate operations)	ICD10	L90.5 Scar conditions and fibrosis of skin	JC17Z x 2	£3,305
	OPCS	B948 Sequelae of other specified infectious and parasitic diseases		
		S369 Unspecified other autograft of skin		
	S574 Dressing of skin NEC			

*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, which provided the appropriate codes. Descriptions of the procedures were obtained by talking through the scenario with orthopaedic surgeons and plastic surgeons (see Acknowledgements).

**Full department of health reference cost data associated with each of the hospital spell HRG codes are available as item 7 of Table 1 in the Appendix.

***After the flap operation the child spends a day in PICU at £2,327.

1.8 Behavioural Problems

By the time Peter reached four years of age, he was starting to show signs of difficult behaviour. Peter was referred to the child and adolescent mental health services (CAMHS) by the community paediatrician where ADHD was diagnosed.

Table 9: Costs associated with ADHD management

Treatment	Assumption*	Cost	Source
First appointment with child psychiatrist	The cost of the appointment includes a clinical psychiatric assessment	£394	Department of Health reference costs 2008/9[13]
Ten sessions at a parenting group	Assumes that the group size is 13 parents per session[23]	£152 per child for ten sessions	NICE[24]
Outpatient appointments with a child psychiatrist	The child attends outpatient appointments six times in the first year, and then attends on a six monthly basis until age 18.	£208 per appointment	Department of Health reference costs 2008/9[13]
Medication	The child starts taking modified release methylphenidate medication at age 5 when he starts primary school in order to help his concentration and remains on this medication until age 12. The price is based on an average dosage of 40mg/day	£723per year	NICE[24]

*Assumptions have been based on the clinical opinions of a psychiatrist and community paediatrician

2 Educational Costs

Educational costs refer to any cost associated with Peter’s education which is over and above the cost of educating a child who does not have Peter’s disabilities. These costs are detailed in sections 2.1 to 2.4 and include costs associated with the following:

- Employment of a learning assistant to help Peter to carry his books and undertake day to day activities
- Specialised transport to take Peter to and from school
- SEN statementing and annual assessments
- Adaptations and equipment for school to accommodate Peter’s special needs

2.1 Learning Support Assistant

At three years of age, Peter attended nursery. Whilst at nursery, Peter had a learning support assistant to help him with his mobility and he continued to need this support throughout his schooling. Before attending nursery, the community therapists would visit his home regularly to provide his parents with an exercise programme to build up his strength and weight bearing through his legs. Once he attended school, however, the therapists performed school visits and part of the learning assistant’s role was to ensure that Peter completed certain strengthening exercises as part of his school day.

Table 10: Cost per year of a learning assistant in different educational settings

Age and School	Assumptions	Cost Per Year
3 and 4 Nursery	The child attends Nursery for 570 hours each year. This is based on the entitlement of all children to 15 hours free education per week for 38 weeks a year aged 3 and 4. Learning support assistant is on a salary of £12,000 per year and is with the child throughout the day. Total cost including pension at 5% and NI contributions is 13,380	£5,018
5 to 13 Primary school, secondary school and sixth form college	The learning assistant has a salary of £12,000 per year and is with the child throughout the entire school day. Total cost including pension at 5% and NI contributions is 13,380	£13,380

2.2 Transport

Peter's is unable to walk for long distances unaided so he 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[25]. Costs are based on the child being provided with this transport from age 5 to age 18.

2.3 Special Educational Needs (SEN) Statement

Peter has a special educational needs statement because of his physical disabilities and his ADHD. As part of the statementing procedure his statement of SEN is reviewed by the school and a SEN Officer from the Local Authority annually.

Table 11: 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 writing up the statement	£504	Unpublished work undertaken by Coventry City Council and Loughborough University, part-funded by the Economic and Social Research Council http://www.cfcfs.org.uk/research-and-development/education/ [26]
	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 changes made to the statement as a result of 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. He is issued with the statement aged five and no changes are required before issue. There is a review every year until he reaches 18. Three of these reviews lead to changes in the statement.

2.4 Special Adaptations and Equipment

Peter has his own specially adapted bathroom at primary school equipped with a ceiling hoist, grab rail, closimat toilet and adapted sink. He had a therapy bench as an exercise aid. He also had a specially adapted bathroom when he went to secondary school.

Table 12: Special equipment or adaptations provided by the school

Description	Cost	Source
New Bathroom x 2	£15,562	Unit Costs[19]
Grab rail x 2	£55	Unit Costs[19]
Hoist x 2	£2,724	Unit Costs[19]
Small Therapy Bench	£227	Quest88
Large Therapy Bench	£268	Quest88

*School equipment/adaptations have been based on a case of a real child with similar disabilities

3 Social Care Costs

Peter is one of two children in a two parent family. When he became ill, one parent gave up work to care for Peter. The other parent earns the 2009 national average wage of £25,800 a year[27]. Peter goes on to further education age 18 and completes a three year course. At age 21 he moves out of home into rented accommodation and gets a part-time job. He works 16 hours a week until he retires at age 65.

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 13.

Table 13: Direct Social costs

Direct 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 adding simple concrete ramps (£674 each), adapting existing rooms to make a new downstairs bathroom/shower (£8122) and bedroom, widening doors around the house suitable for wheelchair access (£529 each), stair lift (£2728), lowering light switches etc. It has been assumed that Peter will receive two of these grants during his lifetime. One to adapt the family home he lives in as a child and another to adapt a home he lives in as an adult. It has been assumed that he receives the maximum grant of £30,000.</p>	£30,000 per grant received	Unit costs[19]
<p>Government's Specialised Vehicle Fund</p> <p>The Specialised Vehicles Fund provides financial assistance to those severely disabled scheme customers who require complex vehicle adaptations that allow them to enter a car as a passenger while remaining seated in their wheelchair or enables them 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 spend of £9,402 per car adapted[28].</p> <p>It has been assumed that as a child Peter's parents get their car adapted to accommodate a wheelchair passenger three times and that from age 30 onwards Peter gets a newly adapted car every five years.</p>	£9,402 per adaptation	Department of Work and Pensions[28]
<p>Direct payments including assessments and reviews</p>	<p>It has been assumed that at 21 when Peter begins to live independently he will have a personal assistant home care worker who is paid via direct payments. The home care worker comes in for 7 hours a week at a cost of £19 an hour includes all the 'employer related' funds required for employing a personal assistant.</p> <p>Peter has his initial assessment at 21 and then has a review on an annual basis thereafter.</p>	<p>£6,916 per year in direct payments</p> <p>£335 for initial assessment</p> <p>£193 per annual review</p>	<p>Unit costs[19]</p> <p>Centre for child and family research, Loughborough University[29]</p>
<p>Disabled Students' Allowances (University non medical helper)</p>	<p>Peter requires a non medical helper to assist in lectures and library.</p>	£20,520 per year	Directgov[30]
<p>Disabled Students' Allowances (University equipment)</p>	<p>Peter gets a yearly grant for any special equipment he requires to help him access the curriculum</p>	£5,161 for entire course	Directgov[30]

3.2 Indirect Social Costs

Indirect social costs are outlined in table 14:

Table 14: Indirect Social Costs

Indirect Cost Category	Assumption	Cost	Source
Lost earnings from Peter's mother's job	Peter's mum gives up her job when Peter becomes ill so that she can look after him full time. 84% of mothers of disabled children do not work compared to 39% of other mothers[31] It has been assumed that she earned the average wage of £25,800. She remains without a job until Peter reaches 21 years of age.	£25,800 per year of unemployment	ONS[27]
Lost earnings from Peter's job	Peter's job opportunities are restricted by his disabilities. He gets a part-time job aged 21 which pays £6,000 per year. It has been assumed that with no disabilities, Peter would work full time and receive the average wage of £25,800.	£19,800 per year of employment	ONS[27]

3.3 Transfer Payments

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

Table 15: 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[32]
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[33]
Disabled Living Allowance (Mobility)	Peter receives the highest rate mobility allowance from age 3 onwards. He is classed in the virtually unable to walk category because he is limited by the distance and length of time he is able to walk using his prosthetics.	£2,592 per year	Disability Alliance[34]
Disabled Living Allowance (Care)	Peter receives different levels of the care component of DLA throughout his lifetime. From the age of 2 onwards he receives the high rate of DLA. From age 12 to 18 this is reduced to medium rate and from age 18 to 64 he gets low rate DLA. From 65 onwards he collects medium DLA as he needs extra assistance day to day.	£3,713 per year (high) £2,486 per year (medium) £985 per year (low)	Disability Alliance[34]
Disabled Students' Allowances (General)	Peter is entitled to claim for the general allowance whilst he is a student.	£1,724 per year	Directgov[30]
Working Tax Credits	Peter has a part time job and works 16 hours per week. His annual salary is £6,000 which entitles him to the maximum tax credit for his circumstance.	£4,490 per year	HM Revenue and Customs[33, 35]
Housing Benefit	Payment is based on Peter living in a two bedroom house in Bristol. They start from when Peter moves into his own place aged 21.	£7,480 per year	Directgov[36]
Council Tax Benefit	Payments are based on Peter living in a band B area for council tax purposes.	£914 per year	Directgov[36]
Pension Credit	By the time Peter reaches pensionable age (65) he has less than £3,000 of savings. He receives state pension and other benefits, but also receives pension credits to top up his income. It has been assumed that his rent is £375 per month for the calculation.	£6,895 per year	Directgov[36]

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.

A child who uses prosthetic limbs becomes a lifelong outpatient of a disablement services centre. To gain better understanding of the work carried out in these centres CW visited both Exeter Mobility Centre and Manchester Disablement Services centre. Both of these visits provided an opportunity to see first-hand how prosthetic limbs are fitted and discuss the proposed scenario fully with prosthetists, occupational therapists and physiotherapists at the centres.

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 a result the costs presented here have been adjusted and differ slightly from an earlier draft presentation which some JCVI members may have seen.

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[37], all costs have been presented at a discount rate of 3.5%.. Costs are based on a life-span of 70 years of age (seven years younger than the average life expectancy for a UK male[38]) after discussion with several paediatricians and paediatric intensivists who felt that the limitations to mobility in this scenario might give rise to cardiovascular problems that could shorten life-span, although they knew of no published evidence for this in meningococcal disease. Additionally, it has been reported that survivors of meningococcal septicaemia report poorer general health than the population as a whole[39].

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Many Individuals at NHS Information Centre and Connecting for Health

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

Results

Category	Sub Category	Discounted cost (3.5%)	Non-Discounted cost	
MEDICAL COSTS	Acute care	151,651	151,651	
	Public Health	154	154	
	Outpatient appointments	30,150	55,046	
	Prosthetic provision	245,481	655,024	
	Community Medicine	9,895	12,925	
	Specialist Equipment provision	13,814	27,630	
	Stump revisions and skin graft surgery	21,827	33,045	
	Behavioural problems	11,790	16,601	
	MEDICAL TOTAL	484,762	952,076	
EDUCATIONAL COSTS	Learning Assistant	89,048	117,076	
	Transport to and from school	32,268	46,722	
	SEN Statementing and review	4,094	5,794	
	Adaptations/special equipment for school	28,422	37,177	
	EDUCATIONAL TOTAL	153,832	206,769	
SOCIAL CARE COSTS	Direct social costs	Disabled facilities Grant	38,972	60,000
		Government's Specialised Vehicles Fund	44,740	122,226
		Direct payments Personal Assistant	74,225	276,640
		Direct Payment assessment and reviews	2,140	7,862
		Disabled Students' Allowances (University non medical helper)	32,033	61,560
		Disabled Students' Allowances (University equipment)	2,778	5,161
		Total direct social costs	194,890	533,449
	Indirect social costs	Mother's employment - missed opportunity costs	341,752	490,200
		Peter's employment - missed opportunity costs	221,732	871,200
		Total missed opportunity costs	563,484	1,361,400
		Mother's lost income tax revenue	41,965	77,400
		Peter's lost income tax revenue	2,636	17,424
		Total lost income tax revenue	44,601	94,824
	Transfer Payments	Disabled Students' Allowances (General Disabled Students' Allowances)	2,691	5,172
		Pension Credits	4,064	41,371
		DLA (Care)	57,453	125,497
		DLA (Mobility)	60,136	173,677
		Carers Allowance	31,544	43,551
		Child tax credits	39,027	53,159
		Council tax benefit	10,776	45,708
		Housing Benefit	86,867	360,715
		Working Tax Credits	50,282	197,560
		Total Transfer Payments	342,840	1,046,410
	SOCIAL CARE TOTAL - lost resources to society (excludes transfer payments and lost income tax revenue)		758,374	1,894,849
	TOTAL LIFE LONG COSTS (includes lost resources to society but excludes transfer payments and lost income tax revenue)		1,396,968	3,053,694

Discussion

The JCVI's terms of reference explicitly require consideration of cost-effectiveness when making recommendations regarding new provision of vaccines or changing the existing national vaccination programme[40]. Under recent legislation (Health Protection (Vaccination) Regulations 2009) a JCVI recommendation confers the right to the vaccine concerned to the population of England Wales provided that that the vaccination is shown to reach a cost-effectiveness threshold.

UK cost effectiveness studies aim to encompass all resource costs associated with the treatment and rehabilitation of survivors. However, the long-term costs of survivors with permanent disability are difficult to estimate[41]. This work aims to estimate the lifelong costs to society of living with multiple amputations and behavioural problems and in doing so, fill a gap in current UK knowledge as there is currently no published information detailing such costs.

Our results show that there are considerable medical, educational and social costs to the state associated with the treatment and rehabilitation of a survivor with severe orthopaedic sequelae such as amputations. Although the scenario we have costed represents severe sequelae following meningococcal septicaemia, it by no means represents the worst case. Patients requiring PICU in meningococcal disease often have multiple organ failure. This is usually resolved in PICU as in our scenario, but survivors may have permanent renal failure with ongoing dialysis and transplantation. Lung and gut damage and destruction of endocrine glands may also be permanent.

NICE estimated that 3% of survivors of meningococcal disease have amputation and that 3% have other orthopaedic complications[3] in particular, damage to growth plates, usually in the legs, which often only becomes apparent a few years after the acute illness. This requires repeated surgery, fitting with frames, and intensive rehabilitation to repair angular deformities to enable walking or to allow for correct fitting of prosthetics in those who also have amputations.

NICE also estimates that 13% of survivors of meningococcal disease have skin complications including scarring and this will require reconstructive surgery during the acute illness and often subsequently, as the skin may not stretch as the child grows.

The HPA have estimated that the total burden of disease can be estimated by multiplying laboratory confirmed cases by a factor of 1.79 to include clinically diagnosed cases[42]. There has been an average of 1299 lab confirmed cases of menB per epidemiological year from 1998/9 to 2008/9. Using the uplift factor of 1.79 we can estimate the total average number of cases per year to be around 2326. Assuming that 3% of survivors end up with amputations it's estimated that around 70 people per year are affected in this way. Another 70 per year are estimated to have other orthopaedic complications and 302 people per year are estimated to be left with scarring. We look forward to learning the results of the MOSAIC study, funded by the Meningitis Trust, which should provide more detailed information on the prevalence of sequelae amongst survivors of meningococcal disease in England.

The case we have looked at is an example of the life-long costs associated with multiple limb amputations. Although there are relatively few such cases each year we are aware of three cases of children undergoing multiple limb amputations in the month of November 2010 alone. In addition, it has been noted that survival rates of meningococcal disease have improved[43], which may increase those surviving with serious morbidity.

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