NHS
Commissioning Board

Manual for prescribed specialised services

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Manual for prescribed specialised services

First published: November 2012

Prepared by Specialised Services Commissioning Transition Team

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Background

Specialised services are those services provided in relatively few hospitals, to catchment populations of more than one million people. The number of patients accessing these services is small, and a critical mass of patients is needed in each treatment centre in order to achieve the best outcomes and maintain the clinical competence of NHS staff. These services tend to be located in specialist hospital Trusts in major towns and cities. Concentrating services in this way ensures that specialist staff can be more easily recruited and their training maintained. It is also more cost-effective and makes the best use of resources such as high tech equipment and staff expertise.

The Health and Social Care Act 2012 set out four factors that should be taken into consideration when determining which prescribed specialised services should be directly commissioned by the NHS Commissioning Board (NHS CB):

- The number of individuals who require the provision of the service or facility;
- The cost of providing the service or facility;
- The number of persons able to provide the service or facility; and
- The financial implications for Clinical Commissioning Groups (CCGs) if they were required to arrange for the provision of the service or facility

During 2011/12 and 2012/13, Ministers commissioned a piece of work to test whether those services that had previously been described as ‘specialised’ met the four factors. The work was undertaken by the Clinical Advisory Group (CAG), a multi-disciplinary committee that included GP and senior hospital doctor membership. The CAG concluded that virtually all those services previously described as ’specialised’ should be commissioned by the NHS CB along with some additional services. This included all those highly specialised services currently commissioned on a national basis by the National Specialised Commissioning Team (NSCT).

The CAG drew on advice from policy leads in the Department of Health and from 60 service-specific Clinical Reference Groups (CRGs)[1] when drawing up its recommendations. The 60 CRGs are organised into five Programmes of Care, which are reflected in the NHS CB operating model:

A. Digestion, renal and hepatobiliary and circulatory system
B. Infection, cancer, immunity and haematology
C. Secure and specialised mental health
D. Traumatic injury, orthopaedics, head and neck and rehabilitation
E. Women’s and children’s health, congenital and inherited diseases

Each CRG has a reference number (for example, Specialised Respiratory is A3D) which is included in the relevant service description. Services that are currently commissioned on a national basis do not have a reference number.

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[1] The Chairs of the CRGs were appointed through a nationally advertised approach. Other clinical members were nominated by Specialised Commissioning Groups on a regional basis. CRGs also include commissioners, public health input and patient group representatives.

The CAG also received assurance through financial, informatics, clinical and patient & public engagement procedures; there was a particular focus on the feasibility of splitting the specialised elements of services from the more outline elements to allow separate and direct commissioning of services by the NHS CB.

Ministers endorsed CAG's recommendations[2] and, as set out in the Health and Social Care Act 2012, consulted with the NHS CB on the list of services. The NHS CB agreed the list of 143 services, which are set out in Regulations [insert SI number].

The purpose of the manual

The Manual is one of a suite of 'products' that have been developed to facilitate the effective commissioning of specialised services and it should be considered alongside these products, for example, service specifications and policies. In particular, the Manual should be considered alongside the Identification Rules. These are the (technical) means by which specialised activity will be captured by providers so that it can be identified as being commissioned by the NHS CB.

The Manual is intended to describe which elements of specialised services are directly commissioned by the NHS CB and which by CCGs. It takes the 143 services and, for each, addresses the following sections:

- Service summary – this section gives a short summary of the service that the NHS CB commissions.

- Other relevant services – this section lists other services relevant to the service in question. This includes: specialist services elsewhere on the patient pathway (including the corresponding children's/adult service) or, in the case of some services that are currently nationally commissioned, the broader service within which the highly specialised service sits.

- About the condition/service – this section describes the service or condition and gives an estimate of the number of patients involved where it is possible to do so. It also explains why a specialist service is necessary.

- How the service is organised – this section describes how the service operates and gives an estimate of the number of providers where it is possible to do so.

- What the NHS CB commissions – this section sets out what the NHS CB commissions.

- What CCGs commission – this section sets out what CCGs commission. In some cases, CCGs do not directly commission any elements of the service in question. They do, however, commission local, non-specialist secondary

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[2] http://www.dh.gov.uk/health/2012/09/cagreport/

medical care for patients with the condition or who require access to the specialist service. In a small number of cases, local authorities commission some elements of services.

- Why the service is being commissioned by the NHS CB – this section sets out the rationale (referencing the four factors) for the NHS CB commissioning the service.

- How the activity for this service is identified – this section sets out – at a high level – how activity is identified. There are four categories:

    - *Activity is identified through local flows, which apply to established designated centres only* – this category is for those services that were previously commissioned on a national basis with centres designated by Ministers. Relevant providers are aware of the local data flows.
    - *This service includes ALL activity at specified centres* – this category applies where the NHS CB commissions the entire patient pathway from specified centres; CCGs do not commission any element of the service
    - *This service includes specified activity at specified centres* – this category applies where the NHS CB commissions specialist elements of the patient pathway from specified centres; CCGs commission routine elements of the service or pathway
    - *This service includes specified activity* – this category applies where the NHS CB commissions specialist procedures or facilities

- Whether there are plans to review the service commissioner – this section identifies those services that the CAG agreed should be subject to early review, i.e., whether there are elements of the service that might be better commissioned by CCGs rather than by the NHS CB. These services are:

    - Adult specialist cardiac services
    - Adult specialist eating disorder services
    - Adult specialist pulmonary hypertension services
    - Bone anchored hearing aid services (all ages)
    - Neuropsychiatry services (all ages)
    - Specialist morbid obesity services (all ages)
    - Specialist neonatal care services
    - Specialist rehabilitation services for patients with highly complex needs (all ages)
    - Specialist services for severe personality disorder in adults

The CAG also agreed that there were some services that had previously been described as ‘specialised’ (but which had not been commissioned as such) and which should not be prescribed:

(a) Specialised services for Asperger syndrome and autism spectrum disorder (all ages)

The CAG was unable to identify an adult service that met the four factors and recommended that CCG commissioning was a better option, especially in light of the national focus on localism set out in the national strategy[3]. Children's services were prescribed under Tier 4 child and adolescent mental health services. This recommendation would be subject to 'early review'.

(b) Complex and/or refractory mental health services
The CAG was unable to identify any services that met the four factors (aside from the severe obsessive compulsive disorder and body dysmorphic disorder service, which was described elsewhere).

(c) Maternal medicine
CCGs are responsible for commissioning maternal care, outside of that provided in primary care. The CAG recognised that some women need specialist maternal care but were unable to identify any elements of the service that were not described within other specialist services, for example, cystic fibrosis. In order to ensure that these specialist maternal elements are fully recognised, the specification for each relevant specialist service includes a paragraph setting out the requirements in relation to specialist maternal care.

CCGs will need to ensure that they commission a range of maternal care, including specialist care from providers that is delivered within a dedicated, multi-disciplinary service staffed by a maternal medicine specialist, a physician and supporting multi-disciplinary team.

(d) Immunoglobulins
The CAG agreed that all immunoglobulins, regardless of the service in which they used and whether or not it was commissioned by the NHS CB, should be commissioned by the NHS CB. Usage can be identified through the National Clinical Database.

(e) Orthotics
The CAG agreed that the most appropriate way to ensure that the most complex orthotic devices were directly commissioned was to include their provision in the associated specialist pathway, for example, spinal surgery, orthopaedics, paediatric neurology, etc.

For the purposes of describing services in the Manual, the adjective 'specialist' means those prescribed specialised services that – on balance – meet the four factors set out in the Health and Social Care Act 2012. 'Highly' specialist services are those services that on balance meet the four factors in the Act but which are delivered in very small numbers of centres.

Prescribing

Discussions are continuing on the most appropriate way of prescribing drugs that are initiated in specialist services. In some cases, it will be appropriate for the responsibility for prescribing the drug to transfer to GPs. It will be important to ensure that there is a consistent approach across services and across CCGs.

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[3] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Drugs marked with an *asterisk have not yet been approved for routine funding by the NHS CB. Clinicians may apply under exceptional circumstances through the Individual Funding Request process. CCGs should not consider requests for drugs for the indications listed.

1. Adult ataxia telangiectasia service

Service summary
Adult ataxia telangiectasia services include services provided by Highly Specialist Adult Ataxia Telangiectasia Centres.

Other relevant services:

- 3. Adult highly specialist respiratory services
- 21. Ataxia telangiectasia service for children

About the condition/service
Ataxia telangiectasia (AT) is a rare, neurodegenerative and progressive condition that starts in early childhood causing severe disability and premature death. It affects many parts of the body and a wheelchair is usually needed by the age of 10. The average life expectancy is 25 years. During the adult stage of the condition, there is increased susceptibility to leukaemias, lymphoma, pneumonia, chronic lung disease and neurological decline. About 200 people in the UK have AT.

How the service is organised
The service undertakes annual multi-disciplinary inpatient assessment for all diagnosed adult AT patients. This comprises a CT scan, video fluoroscopy, pulmonary function testing, sleep studies, brain imaging, neurophysiology and immunological blood testing. Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress.

The service is responsible for patients who already have a diagnosis of AT and who have been under the care of a Specialist Children's Ataxia Telangiectasia centre.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult ataxia telangiectasia services from Highly Specialist Adult Ataxia Telangiectasia Centres.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by Highly Specialist Adult Ataxia Telangiectasia Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Papworth Hospital NHS Foundation Trust (Cambridge)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

2. Adult congenital heart disease services

[E5 – Congenital Heart Services]

Service summary
Adult congenital heart disease services include activity provided by Highly Specialist Adult Congenital Heart Disease Centres including outreach when delivered as part of a provider network.

Other relevant services:

- 85. Paediatric cardiac services

About the condition/service
Adult congenital heart disease affects people aged 16 and over living with a heart defect that developed in the womb and was present at birth. The condition is relatively rare, affecting 1 in 133 people. Congenital heart disease is sometimes diagnosed in the womb, but often it is not identified until after birth or may even remain undetected until adulthood. Thanks to medical advancements over the last few decades most people born with congenital heart disease now survive into adulthood, so there is a growing population of adults in this country living with the condition. Major heart operations are most commonly carried out during childhood. People with congenital heart disease need ongoing care throughout their lives from services that specialise in the needs of adults.

How the service is organised
There are about 20 Highly Specialist Adult Congenital Heart Disease Centres in England. Services are delivered directly at the centres and through outreach arrangements.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all Adult Congenital Heart Disease Services from Highly Specialist Adult Congenital Heart Disease Centres. This includes services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is relatively small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

3. Adult highly specialist respiratory services

[A3D – Specialised Respiratory]

Service summary
Adult highly specialist respiratory services include services provided by Highly Specialist Respiratory Centres for patients with specified rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network.

Other relevant services:

- 1. Adult ataxia telangiectasia
- 34. Chronic pulmonary aspergillosis service (adults)
- 47. Diagnostic service for primary ciliary dyskinesia (adults and children)
- 70. Lymphangioleiomyomatosis
- 128. Specialist respiratory services for children and young people

A. COMPLEX HOME VENTILATION

About the condition/service
Assisted ventilation is used in the management of acute and chronic respiratory failure. In the acute setting it is typically delivered in high dependency or intensive care units. However, the development of effective portable ventilators has resulted in a rapid increase in the use of assisted ventilation in the domiciliary setting as a treatment for chronic respiratory failure. It allows patients with complex ventilatory needs and/or a high degree of ventilator dependence, many of whom would have previously died or remained in hospital, to be managed in community settings.

How the service is organised
Complex home ventilation is delivered by about 12 providers catering for patients who: are difficult to wean from invasive ventilation following an acute illness requiring intensive care; those admitted to hospital with an acute decomposition in their chronic respiratory failure; and outpatients with complex ventilatory needs and/or requirement for ventilatory support for more than 14 hours per day. Conditions resulting in the need for long term ventilation include end-stage lung disease, neuromuscular conditions and severe skeletal deformity.

What the NHS Commissioning Board commissions
The NHS CB commissions complex home ventilation services from Highly Specialist Respiratory Centres.

B. SEVERE AND DIFFICULT-TO-CONTROL ASTHMA

About the condition/service
Over five million people suffer from asthma in the UK and it remains responsible for more than 1,200 deaths each year. The vast majority of patients with asthma have mild to moderate disease and have the potential to be well-controlled with existing therapies, assuming that well-established national guidelines are followed. A small

proportion of patients, estimated at less than 5% of all asthmatics, have severe, difficult-to-control asthma. These patients have ongoing daily symptoms despite maximal medical therapy and are more likely to be admitted to hospital and to access out of hours emergency healthcare than asthmatics with mild to moderate disease. It is estimated that only 0.01% of patients with asthma (about 1,000 new referrals each year) have 'difficult-to-control' asthma.

How the service is organised

Currently five centres in England are members of the British Thoracic Society (BTS) severe asthma network and contribute to their patient registry.

What the NHS Commissioning Board commissions

The NHS CB commission severe and difficult-to-control asthma services from Highly Specialist Respiratory Centres.

The British Thoracic Society[4] defines 'difficult' asthma as patients who have symptoms despite step 4 of the therapeutically defined threshold being applied. For the purposes of this guidance, the definition is further refined by one of the following criteria also being present:

- An event of acute severe asthma which is life threatening, requiring invasive ventilation within the last 10 years
- Requirement for maintenance oral steroids for at least six months at a dose equal to or above 7.5 mg prednisolone per day or a daily dose equivalent of this calculated over 12 months
- Two hospitalisations within the last 12 months in patients taking and adherent to high dose inhaled steroids (greater than or equal to 1000mcg of beclomethasone or equivalent)
- Fixed airflow obstruction, with a post bronchodilator FEV1 less than 70% of predicted normal
- Referred as an adolescent transition patient from a paediatric severe asthma service.

The NHS CB commissions the following drugs: novel biological agents

C. INTERSTITIAL LUNG DISEASE

About the condition/service

Interstitial lung diseases comprise a broad spectrum of conditions, all of which are characterised by inflammation or fibrosis of the alveolar wall with impairment of gas exchange. The commonest of these conditions are idiopathic pulmonary fibrosis (IPF), sarcoidosis and extrinsic allergic alveolitis (EAA). Together these conditions affect between 1,500 – 3,000 individuals in England each year. In addition up to 30% of patients with connective tissue diseases (also known as collagen vascular diseases) such as rheumatoid arthritis and scleroderma develop ILD. There are also a myriad of less common ILDs (non-specific interstitial pneumonitis, desquamative interstitial pneumonitis, respiratory bronchiolitis interstitial lung disease, acute

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[4] http://www.brit-thoracic.org.uk/Portals/0/Guidelines/AsthmaGuidelines/sign101%20revised%20June%2009.pdf

interstitial pneumonia, lymphocytic interstitial pneumonitis, pulmonary alveolar proteinosis, histiocytosis X and lymphangioleiomyomatosis (LAM)[5] each with an estimated incidence of between 0.1 – 5 per 100 000 individuals per year

How the service is organised

Between 2,000 and 4,000 new patients are diagnosed with ILD in England each year with the majority having either sarcoidosis or IPF. There are about 11 current providers in England. Disease-specific management plans are drawn up following MDT assessment at regional specialist units. Networks of care need developing so that the majority of subsequent follow up is provided in local secondary care units.

What the NHS Commissioning Board commissions

The NHS CB commission interstitial lung disease services from Highly Specialist Respiratory Centres.

The NHS CB commissions the following drugs: for ILD: pirfenidone for IPF*, rapamycin for LAM*, rituximab for connective tissue disease ILD*, infliximab for sarcoidosis*, cladrabine for pulmonary Langerhans histiocytosis* and inhaled GM-CSF for antibody positive pulmonary alveolar proteinosis*; specialist interventions such as embolisation of pulmonary-AVMs or whole lung lavage for pulmonary alveolar proteinosis.

D. ALL ADULT HIGHLY SPECIALIST RESPIRATORY SERVICES

Clinical Commissioning Groups (CCGs) commission all other respiratory services, including:

- All asthma services that are not defined as ‘difficult’
- Sleep disorder breathing that fails to respond to simple therapy, except where patients fall under the scope of complex home ventilation
- Advanced pulmonary function testing, except where the patient falls under the scope of one of the four areas commissioned by the NHS Commissioning Board
- Occupational lung disease, except where the patient falls under the scope of interstitial lung disease
- Alpha 1-antitrypsin deficiency
- Existing secondary and primary care services supporting the local care of patients with PCD, ILD, complex home ventilation and severe and difficult-to-control asthma as determined by the specialised centres
- Patients requiring non-invasive ventilation, but falling outwith the criteria for complex home ventilation, managed in Home Ventilation Units
- Ventilatory equipment and individual home care packages for all ventilated patients supported in the community, in liaison with local social services, education and housing departments

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

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[5] See section 70

- the number of patients requiring the service is small (there is about one patient across six GP practices with difficult to control asthma and one patient across two GP practices with interstitial lung disease);
- the cost of providing the service is high because of the specialist equipment, drugs and interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

4. Adult highly specialist pain management services

[D8 – Specialised Pain]

Service summary
Adult highly specialist pain management services include services provided by Adult Highly Specialist Pain Management Centres. The service includes interdisciplinary and multispecialty assessment including outreach when delivered as part of a provider network. For specified interventions, the service includes procedure costs (including devices), specialist pain-specific psychological interventions, inpatient care, follow up and rehabilitation.

Other relevant services:
- 31. Breast radiotherapy injury rehabilitation (a discrete cohort of adult females)
- 63. Highly specialist pain management services for children and young people

About the condition/service
Chronic pain is recognised as a long term condition in its own right or as a component of other long term conditions. About eight million people in the UK suffer with chronic pain. The routine assessment and management of pain is a required competency of all healthcare professionals as well as being an important component of health care planning. Most patients with chronic pain can be well managed in the community or local hospitals by appropriately trained members of interdisciplinary Pain Management Services; however, some patients with more complex chronic pain problems require management in Highly Specialist Pain Management centres.

There are likely to be opportunities for better management of individuals who remain on wards for significant periods of time, some of whom are reliant on opioids but who could be discharged following proper assessment and ongoing support. Specialist Pain Management Services may also be a feature of other specialist services such as facial pain, urogenital pain and hypermobility.

How the service is organised
There are about six Adult Highly Specialist Pain Management Centres. These are providers that meet the following criteria:
- Deliver interdisciplinary and multidisciplinary pain assessment, management and rehabilitation by appropriately trained pain specialists;
- See patients with complex pain and pain associated-disability
- Provide complex pain interventions
- Provide training for pain management specialists working in secondary and community care settings
- Operate in an dedicated pain management environment
- Collect pain management specific outcome data to inform future developments

Referrals are usually from secondary or tertiary care sources.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions adult highly specialist pain management services from Adult Highly Specialist Pain Management Centres, including services delivered on an outreach basis as part of a provider network. The service includes interdisciplinary and multispecialty assessment and, for specified interventions, the service includes procedure costs (including devices), specialist pain-specific psychological interventions, inpatient care, follow up and rehabilitation.

The NHS CB commissions the following drugs/devices: pain-relieving blocks, neuromodulation, intrathecal pumps

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund zicotinide. Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission community and secondary care pain management services, including those secondary care services where the provider is also an Adult Highly Specialist Pain Management Centre.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of patients requiring the services is very small;
- the cost of providing the service is very high because of the specialist interventions involved and because of the significant lengths of stay some patients have in residential care packages;
- the number of expert doctors and other staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

5. Adult highly specialist rheumatology services

[A3C – Specialised Rheumatology]

Service summary
Adult highly specialist rheumatology services include services provided by Adult Highly Specialist Rheumatology Centres for patients with rare conditions or common conditions with complex needs. The service includes outreach when delivered as part of a provider network.

Other relevant services:

- 27. Behçet's syndrome service (adults and adolescents)
- 38. Complex Ehlers Danlos syndrome service (adults and children)

About the condition/service
Rheumatology is a multidisciplinary branch of medicine that deals with the investigation, diagnosis and management of patients with arthritis and other musculoskeletal conditions. This incorporates over 200 disorders affecting joints, bones, muscles and soft tissues, including inflammatory arthritis and other systemic autoimmune disorders, vasculitis, soft tissue conditions, spinal pain and metabolic bone disease.

How the service is organised
There are 20-25 Specialist Rheumatology Centres, each of which is a Highly Specialist Rheumatology Centre for the treatment of one or more rare conditions or specified common conditions with complex needs. Most of these work in informal networks, sharing care with the referring unit.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult highly specialist rheumatology services from Adult Highly Specialist Rheumatology Centres for patients with rare conditions or patients who have specified common conditions with complex needs. This includes services delivered on an outreach basis as part of a provider network.

The NHS CB commissions:

A. Paediatric and transitional care rheumatology[6]

B. Inherited disorders of connective tissue:
    - Ehlers Danlos[7]
    - Marfan's syndrome
    - Skeletal and other dysplasias
    - Osteogenesis imperfecta
    - Dysostoses
    - Fibrous dysplasia

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[6] See section 129
[7] See section 38

    - Osteopetroses
    - Osteosclerosis

C. Severe manifestations of autoimmune rheumatic disorders:
    - Systemic lupus erythematosus
    - Antiphospholipid syndrome
    - Systemic sclerosis
    - Sjogrens syndrome
    - Inflammatory muscle disease (myositis)
    - Overlap syndromes
    - Relapsing polychondritis
    - Myositis/inflammatory muscle disease

D. Severe manifestations of vasculitides, including:
    - Giant cell arteritis (and polymyalgia rheumatica)
    - Rheumatoid vasculitis
    - Wegener's granulomatosis
    - Polyarteritis nodosa and micropolyarteritis
    - Churg Strauss vasculitis
    - Behçet's disease[8]
    - Takayasu's arteritis
    - Henoch Schonlein purpura
    - Cryoglobulinaemia

E. Severe manifestations of other rare inflammatory disorders:
    - Eosinophilic fasciitis
    - Familial Mediterranean fever and other periodic syndromes
    - Relapsing polychondritis

The NHS CB commissions the following drugs: immunoglobulins

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund rituximab for severe manifestations of systemic lupus erythematosus. Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission all other rheumatological services, including:
- all new patients presenting with undiagnosed musculoskeletal symptoms for evaluation and initial management;
- patients transferring from paediatric to adult rheumatology services with well-controlled disease;
- rheumatoid arthritis, spondarthritis, reactive arthritis, septic arthritis, crystal arthritis, polymyalgia;
- the majority of bone conditions (for example, osteoporosis, Paget's disease, regional bone disorders, osteomalacia, other metabolic bone diseases); and

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[8] See section 27

- all patients with autoimmune rheumatic diseases or rare arthropathies, where the diagnosis is already established and the manifestations are well-controlled by conventional management and the patient and the rheumatologist are satisfied with treatment response and progress of the disease.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of delivering the service is high because of the specialist drugs involved, the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

6. Adult specialist vascular services

[A4 – Vascular Disease]

Service summary
Adult specialist vascular services include all vascular surgery and vascular interventional radiology services excluding the treatment of varicose veins. The service includes outreach when delivered as part of a provider network.

About the condition/service
Vascular services manage the treatment and care of patients with vascular disease relating to disorders of the arteries, veins and lymphatics. The diseases can be managed by medical therapy, minimally-invasive catheter procedures and surgical reconstruction.

Patients with vascular disorders are cared for by specialist vascular teams, which include vascular surgeons, vascular interventional radiologists, vascular anaesthetists, vascular scientists, nurses, radiographers, physiotherapists and rehabilitation specialists.

How the service is organised
All providers of specialist vascular services work together in agreed network configurations that support: centralisation of arterial surgery (to maintain expertise); and clear patient care pathways to enable some elements of the pathway to be provided in local settings.

There are currently over 70 centres that deliver specialist vascular services although this number will reduce over time as network and arterial centre configurations are established.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Adult Specialist Vascular Services, including all vascular surgery and vascular interventional radiology services, with the exception of the treatment of varicose veins. This includes services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission services for the treatment of varicose veins.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the services is relatively small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

7. Adult secure mental health services

[C2 – Forensic and Secure Mental Health]

Service summary
Adult secure mental health services include high, medium and low secure inpatient care and associated non-admitted care including outreach when delivered as part of a provider network.

Other relevant services

- 98. Secure forensic mental health service for young people

About the condition/service
Secure mental health services are specialist services for people who:

- Are a risk to others (where risk cannot be managed in a less restrictive environment); or
- Are subject to custody and who cannot be transferred to open conditions due to the nature of their offence or Ministry of Justice directions.

Services are provided in ‘secure’ units, which means that people who are referred there are not free to come and go. People are detained in secure units under mental health legislation.

The time spent in secure units depends on an individual’s recovery and progress towards rehabilitation. Professionals who work in these services take decisions about length of stay in collaboration with the professionals who are responsible for an individual's support and care following discharge. If someone has been found guilty of a violent offence, or has been considered to be dangerous, the Ministry of Justice and/or the Parole Board may be involved in decisions about discharge.

There are approximately 680 patients in High Security, 2,800 in Medium Security and 2,500 in Low Security at any one time.

How the service is organised
There are three High Secure providers, about 65 Medium Secure providers and about 150 Low Secure providers.

All secure services provide:

- Assessment, management and treatment of high risk mentally disordered offenders
- Services that provide varying levels of physical, procedural and relational security
- The provision of advice and collaborative working with multiple other agencies including the criminal justice system
- The provision of reports for legal purposes

The key components of non admitted care and outpatient services for those still deemed as ‘high risk’ include the following:

- Specialist care and treatment including expert risk assessment and management for:
    - the small high risk group of patients during transition from inpatient care to the community;
    - ongoing management of patients in the community for up to two to three years following an inpatient episode (such patients will have typically been discharged subject to Ministry of Justice conditions); and
    - services to those considered ‘high harm offenders’ as part of the Personality Disorder Offender Strategy
- Specialist prison in-reach services for individuals with very specialist needs (for example, Deaf, high harm personality disorder) in order to prevent their otherwise admission or re-admission into secure services
- Provision of specialist assessment or advice to local mental health services in order to ensure effective transition from secure services, or to prevent re-admission to secure services
- Provision of specialist assessments and advice to the Criminal Justice System in relation to high risk individuals, including liaison with MAPPA (Multi-Agency Public Protection Authorities) and statutory reporting to the Ministry of Justice of restricted patients

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult secure mental health services and associated non-admitted care including outreach for those detained under the Mental Health Act from:

- **High Secure providers**: patients in high secure services present a grave danger to the public and require a significant period of treatment, the average period being seven to eight years
- **Medium Secure providers**: patients in medium secure services typically have a history of serious offending and some will have been transferred from prison or from court to receive inpatient treatment. Typically, patients remain in treatment between two and five years. These services also provide non-admitted care, transition and outpatient services for those patients who are considered to remain ‘high risk’.
- **Low Secure providers**: patients in low secure services present a level of risk or challenge that cannot be treated in open mental health settings. Patients may have been transferred from prison or courts to receive inpatient treatment. Typically, patients remain in treatment between one and five years. These services also provide non-admitted care, transition and outpatient services for those patients who are considered to remain ‘high risk’.

Clinical Commissioning Groups (CCGs) commission services for patients on the secure pathway who no longer require High, Medium or Low secure care.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist ward environment required to provide adequate levels of both physical and

procedural security and the high levels of staff necessary to provide adequate relational security;

- the number of doctors and other expert staff trained to deliver the service is small (in particular, they require expert knowledge of risk assessment and management as well as knowledge of the criminal justice system); and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

8. Adult specialist cardiac services

[A9 – Complex Invasive Cardiology and A10 – Cardiac Surgery]

Service summary

Adult specialist cardiac services include services provided by Adult Specialist Cardiac Centres including outreach when delivered as part of a provider network. The service includes:

- All cardiac surgery activity
- Complex cardiac electrophysiology services
- Provision of complex device therapy
- Inherited heart disease services
- Complex invasive cardiology services
- Primary percutaneous coronary intervention (PPCI) services for ST-elevated myocardial infarction
- Provision of cardiac magnetic resonance imaging (cardiac MRI)

Other relevant services

- 57. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support) (adults and children)
- 93. Pulmonary thromboendarterectomy service (adults and adolescents)
- 85. Paediatric cardiac services

A. CARDIAC SURGERY

About the condition/service

Cardiac surgery is a surgical sub-specialty within the specialism of cardiothoracic surgery and includes provision of surgical interventions for coronary artery disease requiring surgical revascularisation and valve disease requiring surgical valve repair or replacement.

How the service is organised

There are about 30 cardiac surgery centres in England.

B. COMPLEX CARDIAC ELECTROPHYSIOLOGY SERVICES

About the condition/service

Cardiac electrophysiology studies and ablations are usually performed for symptomatic fast heart rhythms. The electrophysiology study allows the specialist to diagnose the precise problem and judge where to perform ablation. Ablation involves heating (or sometimes freezing) small areas of the heart muscle in order to prevent the heart racing. About two million people in the UK have atrial fibrillation, the most common form of heart racing. Most patients are treated by medication alone.

How the service is organised

There are about 80 centres in England that provide cardiac electrophysiology services.

C. COMPLEX DEVICE THERAPY

About the condition/service

Implantable cardioverter defibrillators (ICDs) are small, battery-powered electrical impulse generators that are implanted in patients at risk of sudden death. In 2010, about 3,780 patients had an ICD implanted (72 per million of the population). Cardiac resynchronisation therapy (CRT) resynchronises the contractions of the heart ventricles by sending tiny electrical impulses to the heart muscle. In 2010, about 6,000 patients had a CRT implanted (114 per million of the population). CRT defibrillators (CRT-D) also incorporate the additional function of an ICD to quickly terminate an abnormally fast, life-threatening heart rhythm. Depending on the device and the number of activations, ICDs/CRTs need replacing after a number of years as the battery life declines.

How the service is organised

There are about 50 centres that implant ICDs and about 50 centres that implant CRTs.

D. INHERITED HEART DISEASE SERVICES

About the condition/service

Inherited heart diseases are a group of about 50 cardiac conditions caused by a problem in one gene. The first indication is sometimes sudden cardiac death often in adolescence or early adulthood so, when an inherited heart disease is diagnosed, there are implications for relatives. It is estimated that about 220,000 individuals in the UK have an inherited heart disease, the most common being hypertrophic cardiomyopathy, long QT syndrome and arrhythmogenic right ventricular cardiomyopathy. The majority of these patients are undiagnosed but most would benefit from specialist care.

A further 120,000 individuals have familial hypercholesterolaemia: services for these patients are commissioned by Clinical Commissioning Groups.

How the service is organised

There are about 12 centres in England that specialise in the treatment of patients with inherited heart diseases, although many others provide elements of care through formal and informal links with these centres.

E. COMPLEX INVASIVE CARDIOLOGY SERVICES

About the condition/service

Invasive cardiology is a special aspect of cardiology that uses invasive procedures to treat heart disease. These procedures generally require insertion of instruments through the skin and into the body to treat a problem – hence the term ‘invasive’. Complex invasive cardiac procedures are simply those that utilise new and/or evolving techniques and/or devices needing a level of expertise that requires the centralisation of resources in a limited number of centres to ensure consistently good clinical outcomes.

How the service is organised
There are about 30 centres that undertake complex invasive cardiology in England.

F. PRIMARY PERCUTANEOUS CORONARY INTERVENTION (PPCI) SERVICES FOR ST-ELEVATED MYSCARDIAL INFARCTION

About the condition/service
Percutaneous coronary intervention (PCI), or coronary angioplasty, is a procedure carried out under local anaesthetic in which narrowing (stenosis) of the coronary arteries are dilated with a balloon catheter and are then treated with a stent (a tubular metal alloy device), which is implanted in the artery. The stent provides a permanent internal scaffold to maintain patency of the artery. In patients with a specific form of heart attack known as ST segment elevation myocardial infarction (or STEMI), the artery supplying the relevant area of heart muscle is usually completely blocked by a combination of atheroma and blood clot. Primary angioplasty (PPCI) is the use of the PCI technique to relieve the blockage as the main or first treatment for patients suffering a heart attack. The rate of primary PCI reached 287 per million of the population in 2010. In 2010, 18,042 patients were referred for PPCI.

How the service is organised
There are about 50 centres in England that provide PPCI on a 24/7 basis.

G. CARDIAC MAGNETIC RESONANCE IMAGING

About the condition/service
Cardiac MRI is a technique that allows assessment of the anatomy, function and viability of the heart but it can also: detect ischaemia (reduction in blood supply) and infarction (heart tissue death caused by reduced blood supply); and assess congenital heart disease, the cause of heart failure, heart valve dysfunction and the presence of inherited diseases.

How the service is organised
There are currently 30 cardiac MRI centres in the UK, 11 of which have scanners used predominantly for cardiac MRI.

H. ALL SPECIALIST ADULT CARDIAC SERVICES

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist cardiac services from Adult Specialist Cardiac Centres, including services delivered on an outreach basis as part of a provider network. Adult specialist cardiac services include:

- all cardiac surgery activity

- all complex cardiac electrophysiology services
- provision of complex device therapy
- inherited heart disease services, with the exception of services for patients with familial hypercholesterolaemia
- complex invasive cardiology services
- PPCI for ST-elevation myocardial infarction and provision of cardiac MRI.

Not all Adult Specialist Cardiac Centres provide all the sub-specialties.

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund:

- percutaneous closure of the foramen ovale
- Mitraclip
- Left atrial appendage occlusion devices for stroke prevention in people with atrial fibrillation

The NHS CB funds limited numbers of transcatheter aortic valve implantation procedures.

Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission all other cardiological services, including angioplasty and services for patients with familial hypercholesterolaemia.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is relatively small;
- the cost of providing the service is high because of the specialist interventions and devices involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

For cardiac surgery, complex device therapy, inherited heart disease services, PPCI services for STEMI and cardiac magnetic resonance imaging, this service includes ALL activity at specified centres.

For complex cardiac electrophysiology services and complex invasive cardiology services this includes specified activity at specified centres.

Review of the service commissioner

A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

9. Adult specialist eating disorder services

[C1 – Specialised Services for Eating Disorders]

Service summary
Adult specialist eating disorder services includes inpatient care and bespoke packages of care for intensive day care (as an alternative to admission) services provided by Adult Specialist Eating Disorder Centres. The service includes associated non-admitted care including outreach when delivered as part of a provider network.

Other relevant services

- 32. Tier 4 child and adolescent mental health services

About the condition/service
Eating disorders refer to a group of conditions defined by abnormal eating habits that may involve insufficient food intake, excessive exercise or purging behaviour that result in very low weight to the detriment of an individual's physical and mental health.

Patients with eating disorders who require care in a Specialist Adult Eating Disorder Centre generally fall into one of three categories:

- Have rapid and/or sustained weight loss with evidence of system or organ failure, which is potentially life threatening
- Have had outpatient psychological treatment that has not been sufficient to effect a change or improvement
- Are very low weight (usually chronically unwell), are not able to manage in daily life and who require help with weight stabilisation or modest weight restoration, often in the context of medical instability. In addition, these patients frequently have severe psychiatric co-morbidity and/or difficult social/ family circumstances.

About 900 individuals each year need access to this service.

How the service is organised
There are about 25-30 Specialist Eating Disorder Centres in England.

Inpatient services, including those provided to patients detained under the Mental Health Act, include:

- Assessment
- Inpatient stays
- Naso-gastro tube feeding
- Intensive medical monitoring once a patient’s medical condition has been stabilised
- Provision of evidenced-based psychological therapies
- Psychosocial interventions
- Bespoke packages of intensive day treatment for individuals who would otherwise be admitted as an inpatient or as part of a discharge pathway

- Liaison with referring community eating disorder/mental health services.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist eating disorder services, including inpatient care and bespoke packages of care for intensive day care (as an alternative to admission) from Specialist Adult Eating Disorder Centres. The service includes associated non-admitted care including outreach when delivered as part of a provider network.

Clinical Commissioning Groups (CCGs) commission multi-disciplinary adult community eating disorder services, which include a ‘gate-keeping’ function for admission (access assessment); this may also include less intensive day patient services.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across seven GP practices requires access to the service each year);
- the cost of providing the service is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

10. Adult specialist endocrinology services

[A3C – Specialised Endocrinology]

Service summary
Adult specialist endocrinology services include services provided by Adult Specialist Endocrinology Centres for specified conditions. The service includes outreach when delivered as part of a provider network.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people
- 131. Specialist services for complex liver, biliary and pancreatic disease (adults)

About the condition/service
Many endocrine conditions may be treated in local hospitals, but patients with complex or co-morbid conditions may require referral to specialist centres for consultant opinion or further management.

How the service is organised
About 30 Adult Specialist Endocrinology Centres provide services to patients; some deliver these services in more local hospitals through networking arrangements.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist endocrine services from Adult Specialist Endocrinology Centres for specified conditions. The service includes outreach when delivered as part of a provider network.

The NHS CB commissions:
A. Specialist thyroid conditions
    - All thyroid malignancies (differentiated thyroid cancer, medullary thyroid cancer and thyroid lymphoma, anaplastic carcinoma)
    - Thyroid ophthalmopathy
    - Complex parathyroid conditions in pregnancy
    - Hypoparathyroidism

B. Specialist calcium/bone conditions
    - Complex hyperparathyroidism (recurrent/with bone complications/localisation issues/familial)
    - Parathyroid surgery
    - Familial calcium/phosphate disorders
    - Complex problems of calcium/phosphate handling
    - Male or juvenile osteoporosis
    - Osteogenesis imperfecta
    - Metabolic renal stone disease
    - Paget’s disease of bone
    - Refractory hypocalcaemia

C. Specialist reproductive conditions
  - Turner’s syndrome
  - Male infertility
  - Virilising disorders
  - Disorders of gonadal and sexual development
  - Pituitary/adrenal/parathyroid endocrinology in pregnancy

D. Pituitary and hypothalamic diseases
  - Non-functioning adenoma
  - Acromegaly
  - Cushing’s disease
  - Macro-prolactinoma
  - TSHoma (thyroid stimulating hormone-producing pituitary adenoma)
  - Gonadotrophinoma
  - Para-sellar tumours
  - Infiltrative and granulomatosis, hypothalamo-pituitary disease
  - Craniopharyngioma
  - Hypothalamic tumours
  - Congenital and acquired anterior and posterior hypopituitarism including growth hormone deficiency
  - Complex pituitary conditions in pregnancy
  - Pituitary surgery

E. Adrenal disease
  - Primary adrenal failure (at diagnosis)
  - Congenital adrenal hyperplasia
  - Adrenal Cushing’s syndrome
  - Bilateral adrenalectomy for adrenocorticotropic hormone (ACTH)-dependent Cushing’s syndrome
  - Hyperaldosteronism
  - Phaeochromocytoma
  - Virilising adrenal lesions
  - Complex adrenal conditions in pregnancy
  - Adrenocortical carcinoma
  - Other adrenal tumours

F. Management of neuro-endocrine tumours of gut and elsewhere
  - Carcinoid syndrome
  - GI pancreatic neuroendocrine tumours
  - Insulinoma
  - Gastrinoma
  - Glucagonoma
  - Para ganglioma
  - Vipomas
  - Non-functioning pancreatic neuroendocrine tumours
  - Neuro-endocrine tumours outside the gut

G. Familial endocrine disorders
  - Multiple endocrine neoplasia Type 1
  - Multiple endocrine neoplasias Type 2a or b
  - Von Hippel Lindau disease
  - Neurofibromatosis
  - Familial paraganglioma syndromes
  - Familial medullary carcinoma

H. Reproductive conditions
  - Intersexual states and genetic malformation
  - Fertility treatments including recombinant gonadotrophins and clomiphene

The NHS CB commissions the following drugs:

- Pegvisomant
- Tolvaptan*
- Temozolomide*
- Cinacalcet
- Parathyroid hormone
- Somatostatin analogues
- Tyrosine kinase inhibitors*
- Mitotane

Clinical Commissioning Groups (CCGs) commission assessment and treatment services for all other endocrinology conditions, including:

A. Thyroid conditions:
  - Routine management of thyrotoxicosis.
  - Routine management of solitary thyroid adenomas and multinodular goitre
  - Routine management of thyroiditis
  - Routine management of hypothyroidism
  - Routine management of amiodarone and thyroid dysfunction

B. Pituitary conditions:
  - Microprolactinoma
  - Routine management of hypopituitarism in liaison with the specialist centre during establishment thereof
  - Initial assessment of pituitary incidental findings
  - Assessment on management of hyponatraemia and the syndrome of inappropriate antidiuretic hormone (ADH)

C. Adrenal conditions:
  - Diagnosis and initial assessment of adrenal insufficiency
  - Assessment of adrenal incidental findings

D. Reproductive conditions:
  - Assessment of hirsutism and polycystic ovary syndrome

E. Menopausal disorders:

  - Male hypogonadism and androgen replacement therapy
  - Gynaecomastia
  - Erectile dysfunction
  - Assessment of male infertility

F. Endocrine disorders of pregnancy:
  - Thyroid disorders

G. Calcium and bones conditions:
  - Assessment of hypercalcaemia
  - Management of uncomplicated primary hyperparathyroidism
  - Investigation and management of uncomplicated vitamin D deficiency
  - Osteoporosis

H. Miscellaneous:
  - Hypoglycaemia
  - Obesity
  - Endocrinology of critical illness

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

11. Adult specialist intestinal failure services (adults)

[A8 – Specialised Colorectal Services]

Service summary
Adult specialist intestinal failure services include management of patients with Intestinal Failure Type II and III (including the provision of home parenteral nutrition).

Other relevant services

- 101. Severe intestinal failure service
- 103. Small bowel transplantation service (adults and children)
- 110. Specialist gastroenterology, hepatology and nutritional support services for children and young people

About the condition/service
Patients with Type I intestinal failure have short-term, self limiting illness, often peri-operative in nature and relatively common. Patients are managed in a multitude of healthcare settings, especially surgical wards, units performing major abdominal surgery and high dependency/intensive care units.

Patients with Type II Intestinal Failure are metabolically unstable patients characterised as unable to meet their nutritional needs via absorption of nutrients and fluids through the intestines and requiring intravenous nutrition for prolonged periods. The incidence of cases is about 36 per million of the population each year.

Patients with Type III intestinal failure are metabolically stable patients requiring prolonged artificial nutritional support via intravenous feeding (parenteral nutrition) delivered to them in community settings by specialist suppliers of intravenous nutrition. This includes the supply of home parenteral nutrition (HPN) products and associated specialist nursing support for those unable to self-administer intravenous feeds. The prevalence of patients on HPN is about 18 per million.

How the service is organised
Adult specialist intestinal failure services are delivered at about 15 specialist centres in England.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist intestinal failure services for patients with Intestinal Failure Type II and Type III (including the provision of home parenteral nutrition).

Clinical Commissioning Groups (CCGs) commission services for patients who require parenteral feeding for short periods (usually peri-operatively) for less than 28 days and parenteral nutrition of extended duration due to circumstances where the **primary medical issue is not one of sub-optimal bowel function**, i.e. patients who do not have Intestinal Failure Type II and III. Examples include coma patients being managed in ITU, patients with significant burns affecting the upper GI tract, inpatient palliative care for end-stage oncology patients).

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across eight GP practices requires home parenteral nutrition);
- the cost of providing the service is high because of the specialist nutrition products involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs. A national review of providers of intestinal failure services is in progress.

12. Adult specialist neurosciences services

[D3 – Adult Neurosurgery and D4 – Neurosciences]

Service summary
Adult specialist neurosciences services include all services provided by Adult Neurosciences or Neurology Centres. These include:

- All neurosurgery activity
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care)
- Neurology outpatients

The service includes outreach when delivered as part of a provider network.

Other relevant services

- 78. Neuropsychiatry services (all ages)
- 48. Diagnostic service for rare neuromuscular disorders (adults and children)
- 73. McArdle's disease service (adults)
- 77. Neuromyelitis optica service (adults and adolescents)
- 119. Specialist neuroscience services for children and young people

About the condition/service
Clinical neurosciences include both medical and surgical neurology as well as diagnostic support and neurological rehabilitation services. The services are interdependent and the care pathway for many patients with neurological problems may span several neurosciences sub-specialties.

How the service is organised
Adult Specialist Neurosciences Services are provided by about 25 Adult Neurosciences Centres and 10-15 Adult Neurology Centres. Some services are delivered as outreach.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all adult specialist neurosciences services provided by Adult Neurosciences or Neurology Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions:

- All neurosurgery activity
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care)
- Neurology outpatients

The NHS CB commissions the following drugs/devices: immunoglobulins,

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund:

- Deep brain stimulation for conditions other than Parkinson's disease, tremor and dystonia
- Amifampridine (Firdapse) for Lambert-Eaton myasthenic syndrome
- Co-careldopa for Parkinson's disease
- Cerebellar stimulator implants for spasticity
- Famipridine for multiple sclerosis

Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission neurology inpatients and neurology outpatients where these are provided at local hospitals that are not Adult Neurosciences or Neurology Centres.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the services is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

13. Adult specialist ophthalmology services

[D12 – Specialised Ophthalmology Services]

Service summary
Adult specialist ophthalmology services include services provided by Adult Specialist Ophthalmology Centres including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex procedures only.

Other relevant services

- 79. Ocular oncology service (adults)
- 80. Ophthalmic pathology service (adults and children)
- 81. Osteo-odonto-keratoprosthesis service for corneal blindness (adults)
- 120. Specialist ophthalmology services for children and young people

About the condition/service
Ophthalmology services for adults encompass the investigation and management of visual, ocular and ocular adnexal disorders. Ophthalmology hospital services are provided by multidisciplinary teams of ophthalmologists, optometrists, orthoptists, specialist nurses, and technicians. Specialist services are provided by ophthalmologists trained in the appropriate sub-speciality. Ophthalmic specialist services, as in most other clinical disciplines, overlap with other specialist services.

How the service is organised
The service is provided within operational delivery networks. The networks comprise a group of providers working together within the patient pathway.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist ophthalmology services from Adult Specialist Ophthalmology Centres, including services delivered on an outreach basis when delivered as part of a provider network.

The NHS CB commissions the following specialist services, including emergency care:

- Orbital disorders (all major orbital pathology, lid tumours spreading to the orbit, exenteration, severe thyroid eye disease, provision of ocular prosthesis)
- Lacrimal disorders (complex lacrimal disorders or when there is co-morbidity)
- Oculoplastic surgery (complex surgery)
- Corneal disorders (severe anterior segment inflammation, high risk keratoplasty, endothelial keratoplasty, keratoprosthesis, collagen cross linking, excimer laser to treat corneal pathology)
- Eye banking
- Vitreoretinal surgery
- Medical retina services (to provide second opinions and management of uncommon conditions)

- Uveitis (the treatment of severe ocular disease requiring systemic or complex treatment)
- Complex surgical treatment of glaucoma
- Neuro-ophthalmology
- Eye movement recording facilities
- Ocular genetic disorders

Clinical Commissioning Groups (CCGs) commission all other ophthalmic services including cataracts, glaucoma not requiring complex surgery, strabismus (except when requiring eye movement recording facilities) and standard emergency ophthalmology care.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

14. Adult specialist orthopaedic services

[D10 – Specialised Orthopaedic Services]

Service summary
Adult specialist orthopaedic services include services provided by Adult Specialist Orthopaedic Centres including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex procedures only.

Other relevant services
- 89. Primary malignant bone tumours service (adults and adolescents)
- 121. Specialist orthopaedic surgery services for children and young people

About the condition/service
The majority of orthopaedic services are delivered in secondary care providers. Adult Specialist Orthopaedic Services are defined by any one or more of the following criteria:
- The rarity of the condition
- The complexity of the condition and the multi-disciplinary team required to treat it
- The expertise required to treat the condition.

How the service is organised
There are about 25-30 Adult Specialist Orthopaedic Centres. Some provide outreach clinics as part of a provider network.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist orthopaedic services from Adult Specialist Orthopaedic Centres including services delivered on an outreach basis as part of a provider network. The NHS CB commissions the following specialist services:
- **Hip** – secondary or tertiary referred revisions; primary revision (all stages); infected revision; replacement requiring modular prosthesis; massive acetabular defects requiring bone grafting or metal augmentation; complex femoral reconstructive segmental reconstruction
- **Knee** – partial knee replacement; infected joint replacement; all revision joint replacements; autologous transplant of the knee[9]; failed ligament reconstruction of the knee; failed osteotomy/complications of osteotomy; complex patella/femoral dysfunction
- **Foot and ankle** – ankle replacement and revision; revision fusion of the hint foot; complex post traumatic reconstruction requiring frames or multi-

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[9] NICE's current guidance, (Technology Appraisal 89), is that autologous chondrocyte implantation (ACI) is not recommended for the treatment of articular cartilage defects of the knee joint except in the context of ongoing or new clinical studies that are designed to generate robust and relevant outcome data, including the measurement of health-related quality of life and long term follow up. Patients should be fully informed of the uncertainties about the long term effectiveness and the potential adverse effects of this procedure NICE is expected to review and appraise more recent evidence later in 2012

disciplinary input; complex neurological deformity; tertiary element of an integrated diabetic foot system; tertiary complex reconstruction of a forefoot following failed surgery; revision or complex arthoscopic procedures, for example, coalition excision or revisions surgery for osteochondral lesions
- **Shoulder** – complex primary and revision shoulder replacement with or without a Computer Assisted Design or Computer Assisted Manufacture (CAD CAM) prosthesis; revision or complex arthoscopic procedures; deformity correction (congenital); scapulothoracic fusions; glenohumeral joint fusions; major tendon transfers around the shoulder; sternoclavicular joint arthroscopy and stabilisation
- **Elbow** – complex primary and revision elbow replacement; post traumatic elbow replacement; ligament reconstructions for elbow instability; complex fracture fixation at the elbow; revision fracture fixation surgery; treatment of post-traumatic elbow stiffness; allograft bone reconstruction for bone loss in upper limb; deformity correction; elbow arthroscopy
- **Hand** – complex microsurgical reconstruction including the thumb; tendon grafting; congenital hand deformity; radio-carpal wrist replacement; total distal radio-ulnar joint replacement; ulnar head replacement; novel small joint replacements; nerve reconstruction; complex soft tissue cover; trapezectomy; complex scaphoid reconstruction. It is recognised that, because of the highly specialist nature of hand surgery, some of these procedures take place in an Specialist Orthopaedic centre and others in a Plastic Surgery Centre.
- **Brachial plexus and peripheral nerve injury including both congenital and perinatal palsies in children**
- **Soft tissue sarcomas** [The NHS CB also commissions primary malignant bone tumour services[10]]

The NHS CB commissions the following devices: any associated specialist orthotics

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund autologous chondrocyte implantation in knees. Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission:
- **Knee** – primary soft tissue surgery; primary joint replacement, arthroscopy
- **Hip** – primary joint replacement; arthroscopy
- **Foot and ankle** – routine foot surgery; routine non-complex surgery of hind foot including fusions; arthroscopies
- **Shoulder** – most non-specialist arthroscopic procedures; routine rotated cuff repair; subacromial decompression; shoulder stabilisation; routine shoulder replacement
- **Elbow** – soft tissue procedures around the elbow; arthoscopic procedures
- **Hand** – non-specialist soft tissue surgery to facia and tendon; routine arthrodesis of joint and carpal tunnel release; routine joint replacement

Why the service is commissioned by the NHS Commissioning Board

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[10] See section 89

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is relatively small;
- the cost of providing the service is high because of the specialist interventions, specialist equipment and specialist prostheses involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

15. Adult specialist pulmonary hypertension services

[A11 – Pulmonary Hypertension]

Service summary
Adult specialist pulmonary hypertension services include all services provided by Adult Highly Specialist Pulmonary Hypertension Centres including outreach when delivered as part of a provider network.

Other relevant services

- 92. Pulmonary hypertension service for children
- 93. Pulmonary thromboendarterectomy service (adults and adolescents)

About the condition/service

Pulmonary hypertension is high pressure inside the pulmonary arteries, which are the vessels carrying blood from the right-hand side of the heart to the lungs. The condition results in damage to the right-hand side of the heart, making the heart less efficient at pumping blood around the body and getting oxygen to the muscles. This leads to symptoms such as:

- Shortness of breath
- Fatigue
- Feeling faint or dizzy

If it is not treated, pulmonary hypertension can cause heart failure, which is when the heart struggles to pump enough blood around the body. This can be fatal.

Most patients have idiopathic pulmonary hypertension, i.e. the cause is unknown, but it is also associated with a wide range of clinical conditions including connective tissue disease, congenital heart disease, chronic pulmonary thromboembolism, sickle cell disease and HIV infection.

It is estimated that pulmonary hypertension affects 15 to 50 people per million of the population each year. In 2011, the national audit identified that the six Adult Highly Specialist Pulmonary Hypertension Centres saw about 6,000 adult patients.

The severity of symptoms is used to provide a functional classification for each patient – Functional Classes I to IV:

- **Class I** – patients with pulmonary hypertension but without resulting limitation of physical activity. Ordinary physical activity does not cause undue dyspnoea or fatigue, chest pain or near syncope.
- **Class II** – patients with pulmonary hypertension resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity causes undue dyspnoea or fatigue, chest pain or near syncope.
- **Class III** – patients with pulmonary hypertension resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes undue dyspnoea or fatigue, chest pain or near syncope.
- **Class IV** - patients with pulmonary hypertension with inability to carry out any physical activity without symptoms. These patients manifest signs of right

heart failure. Dyspnoea and/or fatigue may even be present at rest. Discomfort is increased by any physical activity.

The specialist service focuses primarily on patients treated with targeted therapies in Functional Classes III and IV.

How the service is organised

The service is delivered from six Adult Highly Specialist Pulmonary Hypertension Centres. There are a number of formally recognised shared care units and outreach clinics linked to the centres.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all adult specialist pulmonary hypertension services from Adult Highly Specialist Pulmonary Hypertension Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs: sildenafil, tadalafil, bosentan, IV iloprost (including pump), nebulised iloprost, epoprostinil (including pump), treprostinil (including pump) in accordance with national clinical policy.

Clinical Commissioning Groups (CCGs) commission all services for patients with pulmonary hypertension not under the care of a Highly Specialist Pulmonary Hypertension Centre.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one patient from each GP practice is registered with an Adult Highly Specialist Pulmonary Hypertension Centre);
- the cost of providing the service is small because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Imperial College Healthcare NHS Trust (London)
- Papworth Hospital NHS Foundation Trust (Cambridge) (Cambridge)
- Royal Free London NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Royal Brompton & Harefield NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust

Review of the service commissioner

A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

16. Adult specialist renal services

[A6 – Renal Dialysis and D7 – Renal Transplant]

Service summary

Renal services

Adult specialist renal services include:

- All dialysis services (including plasma exchange for patients with acute kidney injury)
- Outpatient assessment and preparation for renal replacement at Adult Specialist Renal Centres including outreach as part of a provider network. The service includes procedures relating to establishing renal access prior to dialysis.
- All transplant-related care provided by Adult Specialist Renal Centres and all transplantation activity provided by Adult Renal Transplant Centres. This includes care delivered through outreach as part of a provider network.

Other relevant services

- 49. Encapsulating peritoneal sclerosis treatment service (adults)
- 82. Pancreas transplantation services (some kidney transplants are undertaken simultaneously with the pancreas)

About the condition/service

Each year, in England, about 5,500 people start treatment for kidney failure and there are currently about 43,000 people receiving treatment for kidney failure. Not treating or withdrawal of treatment leads to death in the majority of patients within three weeks. Of those affected:

- **about half are treated with a kidney transplant** either from a living or deceased donor
- **about four in 10 are treated with haemodialysis.** Haemodialysis involves circulation of blood through a machine that removes toxins and fluid returning the cleaned blood back into the body. This requires an initial surgical operation to join an artery and vein, or insertion of a tube into a large vein, usually in the neck, to create ‘vascular access’. Most people receive three treatment sessions a week, each lasting about four hours, which can be done at home after training or in a dialysis unit under the supervision of health care professionals.
- **about one in 10 are treated with peritoneal dialysis.** Peritoneal dialysis, which is carried out at home, involves using the peritoneum (a thin membrane that lines the inside of the abdomen) as a filter. This requires the initial insertion of a small flexible tube, known as a catheter, into the peritoneal cavity (the space that contains the bowels and other abdominal organs). A special dialysis fluid is run into the peritoneal cavity and waste products are filtered into this fluid before being drained out. This exchange of ‘used’ with ‘fresh’ dialysis fluid lasts roughly 35 minutes and is either repeated about four times each day or performed overnight. Most often the patients are trained to carry out these treatments themselves but some patients have this treatment with the supervision of healthcare professionals.

There were 2,800 kidney transplants undertaken in the UK in 2011/12, about 1,000 of which involved organs from living donors. Some deceased donor transplants were undertaken in conjunction with transplantation of other organs.

How the service is organised
There are 19 Adult Renal Transplant Centres and 52 Adult Specialist Renal Centres, all of which operate satellite haemodialysis units to reduce the distance patients have to travel to receive treatment.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist renal services from Adult Specialist Renal Centres and Adult Renal Transplant Centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions:

- All chronic dialysis services
- Intermittent haemodialysis and plasma exchange for patients with acute kidney injury of such severity that without treatment they would die
- Outpatient assessment and preparation for renal replacement at Adult Specialist Renal Centres; this includes Low Clearance Clinics and procedures relating to establishing renal access prior to dialysis, for example, creating arteriovenous fistulae or inserting peritoneal dialysis catheters
- All transplant-related care provided by Adult Specialist Renal Centres and Adult Renal Transplant Centres. Transplant-related care includes the work-up of potential living donors.
- All transplantation activity provided by Adult Renal Transplant Centres. This includes living donor nephrectomy for living donor transplantation.

The NHS Commissioning Board commissions the following drugs/devices: all drugs and devices used during dialysis treatment; immunosuppressive drugs prescribed following renal transplantation, cinacalcet, phosphate binders excluded from tariff, rituximab in ABO-incompatible kidney transplants

Clinical Commissioning Groups (CCGs) commission:

- Local inpatient and outpatient renal services for general nephrology (including services for acute kidney injury for patients not requiring dialysis or plasma exchange). The majority of general nephrology patients have chronic kidney disease, which is not so severe as to warrant treatment with either dialysis or transplantation.
- Transport for haemodialysis patients
- Continuous haemodialysis /filtrations treatments when used as a component of intensive and high dependency care, when the primary reasons for admission is NOT acute kidney injury

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one patient across two to three GP practices has a kidney transplant each year and about seven patients registered with each GP practice are on renal dialysis);

- the cost of providing the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating many patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

17. Adult specialist services for patients infected with HIV

[B6 – HIV]

Service summary
Adult specialist services for patients infected with HIV include inpatient care for HIV related conditions in Adult Specialist HIV Treatment Centres and outpatient care provided by these Specialist Centres including outreach when delivered as part of a provider network.

About the condition/service
Human immunodeficiency virus (HIV) is a virus that causes acquired immunodeficiency syndrome (AIDS), a condition in which progressive failure of the immune system allows life-threatening opportunistic infections and cancers to thrive. About 91,500 people were living with HIV in the UK at the end of 2010, of whom a quarter were unaware of their infection.

How the service is organised
There are currently over 50 providers of HIV services but it is anticipated that this will reduce over time and that consolidated networks of specialist care will be established. Affected individuals are concentrated in cities, particularly London.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions adult specialist services for patients infected with HIV from Adult Specialist HIV Centres. This includes the inpatient care provided by the Specialist Centres and outpatient care, which may be delivered on an outreach basis as part of a provider network.

The NHS Commissioning Board commissions the following drugs:

- All antiretroviral drugs listed in the British National Formulary (BNF) chapter 5.3.1, in line with national policy
- All drugs used to treat cytomegalovirus in the BNF chapter 5.3.2.2

For co-infected patients where the HIV service is the main provider of treatment:

- All drugs used to treat viral hepatitis in the BNF chapter 5.3.3 supported by NICE guidance
- All anti-fungal drugs listed in chapter 5.2, in line with national policy

Clinical Commissioning Groups (CCGs) commission promotion of opportunistic testing and treatment of sexually transmitted infections.

Local authorities commission testing of sexually transmitted infections, including HIV. They also commission sexual health advice, prevention and promotion.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because: the number of individuals requiring the service is relatively small; the cost of providing the service is high because of the specialist drugs involved; the number of doctors and other expert

staff trained to deliver the service is small; and the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

18. Adult thoracic surgery services

[Thoracic Surgery]

Service summary
Adult thoracic surgery services include all services provided by Adult Thoracic Surgery Centres including outreach when delivered as part of a provider network.

Other relevant services

- 105. Specialist cancer services (adults)

About the condition/service

Adult thoracic surgery involves the surgical assessment and operative treatment of all thoracic diseases. Although dominated by the management of lung cancer, about 50% of patients managed by thoracic surgeons are affected by other conditions. Data on thoracic surgical activity in the UK and Ireland collected on behalf of the Society for Cardiothoracic Surgery (SCTS) showed that for the year 2009/10 a total of 27,584 patients required thoracic surgery of which 17,406 were major operations.

How the service is organised

Because of the specific requirements for the care of patients, operative thoracic surgery has been carried out for many years in tertiary thoracic or cardiothoracic units. For the year 2010 the SCTS identified a total of 41 units in the whole of the UK and Ireland, of which 31 were located in England.

These units employ thoracic surgeons both for in-house thoracic surgery and to provide an outreach service to neighbouring hospitals for outpatient and cancer MDT work.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all adult thoracic surgery services from Adult Thoracic Surgery Centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about four patients from each GP practice needs access to the service each year);
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

19. Alkaptonuria service (adults)

Service summary
Alkaptonuria services include services provided by Highly Specialist Alkaptonuria centres. Services are provided directly to adults; there is a consultation service for children.

Other relevant services:

- 62. Highly specialist metabolic disorder services (all ages)

About the condition/service
Alkaptonuria (AKU) is a rare inherited disorder that causes considerable morbidity in the peak of adulthood due to severe premature destruction of the joints and spine. Disability, often severe, is the norm for those over 30 years of age. About 1 in 250,000 of the population has AKU.

How the service is organised
This service provides an inpatient-based assessment service for patients with AKU where patients are reviewed annually. It provides one-stop care to: assess and detect disease complications; prescribe and monitor drugs to arrest the progression of the disease; and formulate shared care management plans with local providers.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions alkaptonuria services for adult patients from Highly Specialist Alkaptonuria centres.

The NHS Commissioning Board commissions the following drug: nitisinone

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by the Highly Specialist Alkaptonuria Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small; and
- the number of expert doctors and other staff trained to deliver the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- The Royal Liverpool and Broadgreen University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

20. Alström syndrome service (adults and children)

Service summary
Alström services include services provided by Highly Specialist Alström Syndrome Centres. This applies to provision in adults and children.

Other relevant services:

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Alström is a rare genetic syndrome that usually presents with blindness in childhood. Patients go on to develop insulin-resistant diabetes, fibrosing cardiomyopathy (where abnormal tissue grows in the heart and stops it working effectively) and renal failure. They may also become deaf. There are thought to be about 200 families affected by Alström syndrome in the UK.

How the service is organised
Both the adult and paediatric services run two-day clinics that undertake assessment of all patients in a multi-disciplinary structure. Patients are assessed and reviewed by all the specialities appropriate to their needs during the two-day clinic.

Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress. Alström Syndrome UK support workers attend the clinic to provide advocacy and guidance on the social care aspects of living with the condition.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Alström syndrome services for adults and children from Highly Specialist Alström Syndrome Centres.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by the Highly Specialist Alström Syndrome Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals Birmingham NHS Foundation Trust (adults only)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

21. Ataxia telangiectasia service for children

Service summary
Ataxia telangiectasia services for children include services provided by Highly Specialist Children’s Ataxia Telangiectasia centres.

Other relevant services:

- 1. Adult ataxia telangiectasia
- 119. Specialist neuroscience services for children and young people

About the condition/service
Ataxia telangiectasia (AT) is a rare, neurodegenerative and progressive condition that starts in early childhood causing severe disability and premature death. It affects many parts of the body and a wheelchair is usually needed by the age of 10. The average life expectancy is 25 years. About 200 people in the UK have AT.

How the service is organised
This service provides outpatient clinics to patients with AT, which take place over two days with a multidisciplinary team of experts. Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress.

The service is restricted to those patients with a confirmed molecular diagnosis of AT (or AT-like disorder) or where there is a strong clinical indication of AT requiring diagnostic confirmation.

The Ataxia-Telangiectasia Society work jointly with the Highly Specialist Children’s Ataxia Telangiectasia Centres to organise and co-ordinate the multi-disciplinary clinics and to liaise with patients and their families regarding clinic appointments.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions ataxia telangiectasia services for children from Highly Specialist Children’s Ataxia Telangiectasia centres.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by Highly Specialist Children’s Ataxia Telangiectasia Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Nottingham University Hospitals NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

22. Autoimmune paediatric gut syndromes service

Service summary
Autoimmune paediatric gut syndromes services include services provided by Highly Specialist Autoimmune Paediatric Gut Syndromes Centres.

Other relevant services:

- 29. Blood and marrow transplantation services
- 100. Severe combined immunodeficiency and related disorders service
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders

About the condition/service
This service provides assessment, stem cell transplantation and follow up care to children with autoimmune gut disorders presenting with systemic immune dysregulation and severe gut and bowel inflammation.

How the service is organised
Children with these features require full immunological/gastroenterological and nutritional care in a centre with expertise in this condition. Decisions regarding therapy are complex and influenced by the spectrum of disease and clinical severity of the condition. Therapy may involve immunomodulation, parenteral nutrition, enteral feed modification, control of infection, treatment of a wide range of autoimmune conditions and human stem cell transplantation.

The service includes:

- Patient assessment and selection according to set criteria:
  - Child aged under 16
  - Severe refractory autoimmune gut disease as defined by indicative pathological findings with/without anti-enterocyte (intestinal absorption cells) antibodies
  - Evidence of systemic immune dysregulation including complex autoimmunity
- Assessment for human stem cell transplantation, the transplant itself and post-transplant care

The service stabilises about seven children each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services autoimmune paediatric gut syndrome services from Highly Specialist Autoimmune Paediatric Gut Syndromes Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist ward environment and specialist drugs involved; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

23. Autologous intestinal reconstruction in adults service

Service summary
Autologous intestinal reconstruction in adults services include services provided by Highly Specialist Autologous Intestinal Reconstruction in Adults Centres.

Other relevant services:

- 60. Highly specialist colorectal surgery services (all ages)

About the condition/service
Autologous intestinal reconstruction in adults (AuGIR) is a new surgical procedure in adult patients with short bowel syndromes who are on parenteral nutrition. Patients have insufficient bowel to take in enough food by mouth to provide adequate nutrition. The operation lengthens the bowel so that food can be taken normally. This is an established procedure in children.

How the service is organised
The service covers outpatient and inpatient assessment, surgery and lifelong follow up. The service undertakes about eight procedures each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions autologous intestinal reconstruction services for adults from Highly Specialist Autologous Intestinal Reconstruction in Adults Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of expert doctors and other staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Salford Royal NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

24. Bardet-Biedl syndrome service (adults and children)

Service summary
Bardet-Biedl syndrome services include services provided by Highly Specialist Bardet-Biedl Syndrome Centres. This applies to provision in adults and children.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Bardet-Biedl syndrome is a highly debilitating autosomal-recessive genetic disorder that causes early-onset blindness, renal failure, obesity, diabetes, Hirschsprung disease, urological problems and neurological deficits. About 1 in 100,000 babies are born each year with Bardet-Biedl syndrome, i.e. five or six each year in England.

How the service is organised
Both the adult and paediatric services run dedicated clinics that undertake assessment of all patients in a multi-disciplinary structure. Patients are assessed and reviewed by all the specialities appropriate to their needs during the clinic.

Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress. The Laurence-Moon-Bardet-Biedl Society co-ordinate the clinics at the Centres and provide advocacy and support to patients attending the clinics.

The service also includes a dedicated DNA diagnostic service to provide confirmation of diagnosis, carrier testing for relatives, pre-natal testing and genetic counselling.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Bardet-Biedl syndrome services for adults and children from Highly Specialist Bardet-Biedl Syndrome Centres.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by the Highly Specialist Bardet-Biedl Syndrome Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust (adults only)
- University Hospitals Birmingham NHS Foundation Trust (adults only)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

25. Barth syndrome service (male adults and children)

Service summary
Barth syndrome services include services provided by Highly Specialist Barth syndrome centres including outreach when delivered as part of a provider network. This applies to provision in adults and children. This condition only affects males.

Other relevant services

- 62. Highly specialist metabolic disorder services (all ages)

About the condition/service
Barth syndrome is an x-linked disorder of lipid metabolism presenting as cardiac/skeletal myopathy, neutropenia and growth retardation with a high infant mortality rate. Patients with Barth Syndrome present with frequent cardiac problems and, in two-thirds of patients, neutropenia (reduced white blood cell count leading to susceptibility to infection). When undiagnosed or treated by non-specialists, patients typically experience frequent hospital admissions for a range of diagnostic tests and treatment of severe infections. Infections are significantly reduced through protocol-driven prescription of granulocyte colony stimulating factor (G-CSF). Between 1 in 300,000 and 1 in 400,000 babies are born each year with Barth syndrome, i.e. two or three each year in England.

How the service is organised
The service provides diagnostic testing, which includes cardiolipin (a lipid essential for the optimal functioning of enzymes involved in energy metabolism) testing and genetic testing. It also provides post-mortem cardiolipin testing and familial gene testing. Care is provided through a multi-disciplinary team that: monitors cardiac function and other co-morbid factors; prescribes appropriate drugs; and develops management plans with local healthcare providers.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Barth syndrome services for male adults and children from Highly Specialist Barth Syndrome centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs: G-CSF

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by the Highly Specialist Barth Syndrome centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of expert doctors and other staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- University Hospitals Bristol NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

26. Beckwith-Wiedemann syndrome with macroglossia service (children)

Service summary
Beckwith-Wiedemann syndrome with macroglossia services include services provided by Highly Specialist Beckwith-Wiedemann Syndrome Centres.

Other relevant services

- 43. Craniofacial service (adults and children)

About the condition/service
Beckwith-Wiedemann syndrome is a disorder present at birth, characterised by an increased risk of childhood cancer and certain congenital features. One of the congenital features is macroglossia (significant enlargement of the tongue), which causes: drooling; feeding, speech, orthodontic and dental problems; and devastating psychosocial consequences. About 1 in 15,000 babies are born each year with Beckwith-Wiedemann syndrome but only about half have macroglossia, i.e. about 15-20 babies each year.

There is a risk of complication and poor surgical outcomes for patients treated outwith Specialist Centres.

How the service is organised
The service provides multi-disciplinary, centralised, expert clinical care for pre-operative assessment, surgical management and post-operative rehabilitation of this group of patients, including access to support and advice on the functional problems associated with the macroglossia.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Beckwith-Wiedemann syndrome with macroglossia services from Highly Specialist Beckwith-Wiedemann Syndrome Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of surgery and associated care for some patients can be very high.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

27. Behçet’s syndrome service (adults and adolescents)

Service summary
Behçet’s syndrome services include services provided by Highly Specialist Behçet’s Syndrome Centres. This applies to provision in adults and adolescents.

Other relevant services:

- 5. Adult highly specialist rheumatology services

About the condition/service
Behçet’s syndrome is a chronic, inflammatory, multi-systemic vasculitic disorder with a wide spectrum of clinical presentations that may include blindness, severe ulceration and cardiovascular problems. About 400-500 people in England have Behçet’s syndrome.

How the service is organised
The service provides multi-disciplinary, expert care for this group of patients.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with Behçet’s syndrome from Highly Specialist Behçet’s Syndrome Centres. Behçet’s Patients’ Centres Ltd provides a co-ordinating role in the service.

The NHS CB commissions the following biologic drugs:

- TNF alpha inhibitors (infliximab, etanercept, adalimumab)
- Interferons (interferon alpha, viraferon peg)
- CD20 depletor (rituximab)
- CD52 depletor (alemtuzumab)

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Aintree University Hospitals NHS Foundation Trust
- Barts Health NHS Trust
- Sandwell and West Birmingham Hospitals NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

28. Bladder exstrophy service (children)

Service summary
Bladder exstrophy services include services provided by Highly Specialist Bladder Exstrophy centres. This applies to provision in children.

Other relevant services

- 136. Specialist urology services for children and young people

About the condition/service
This NHS Service provides diagnostic, management advice and treatment for children with bladder exstrophy, primary epispadias, cloacal exstrophy and all variants. Expert management and appropriate surgical reconstruction can provide a child suffering from bladder exstrophy with a near normal lifestyle. The goals of exstrophy reconstruction are:

- Anatomic reconstruction of the bladder/urethra, bony pelvis, abdominal wall and external genitalia
- Creation of urinary continence with preservation of renal function
- Healthy psychological adjustment and adaptation to the condition throughout life
- Support during adolescence

Between 1 in 30,000 and 1 in 50,000 babies are born each year with bladder exstrophy, i.e. about 10-15 babies each year in England.

How the service is organised
The service is provided by a multi-disciplinary team including dedicated psychologists, clinical nurse specialists, input from nephrology and urodynamics and a specialist urology ward. One of the centres provides dedicated orthopaedic surgical input to address bony pelvis abnormalities.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for children with bladder exstrophy, primary epispadias, cloacal exstrophy (and all variants) from Highly Specialist Bladder Exstrophy centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist interventions involved; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Central Manchester University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

29. Blood and marrow transplantation services (all ages)

[B4 – Blood and Marrow Transplantation]

Service summary
Blood and marrow transplantation services include all care provided by Specialist Transplantation Centres including preparatory care, donation, transplant, aftercare and subsequent treatment. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services:

- 22. Autoimmune paediatric gut syndromes service
- 100. Severe combined immunodeficiency and related disorders service
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders

About the condition/service
Haematopoietic stem cell transplantation (HSCT), also known as blood and marrow transplantation (BMT) is used to treat a wide spectrum of haematological and, increasingly, non-haematological, disorders. The most common clinical indications for HSCT are leukaemias, lymphomas and myeloma. Transplants are broadly divided into two main types: allogeneic and autologous transplantation.

Allogeneic transplantation involves replacing the bone marrow stem cells of a patient with stem cells from a tissue-type matched or mismatched donor. Patients require extensive pre-transplant assessment and investigations to assess their clinical status and fitness to proceed to transplant. The transplant procedure begins with ‘conditioning’ therapy (chemotherapy with or without total body irradiation at a range of doses depending on the type and severity of disease being treated). The aim of conditioning is to:

- Kill leukaemia/tumour cells (in malignant diseases)
- Eradicate existing bone marrow tissue (in order to provide space for engraftment of transplanted donor stem cells)
- Suppress the patient’s immune system, so as to minimise the risk of graft rejection

Bone marrow, peripheral blood or umbilical cord blood stem cells may be used as donor stem cell sources.

Autologous transplantation uses the patient's own stem cells, which are harvested prior to high-dose therapy. It is performed as part of dose escalation therapy, mainly in patients with lymphoma and myeloma, although it is also used in certain autoimmune and oncology cases. It enables the patient to be treated with doses of chemotherapy which are higher than would be possible without subsequent replacement of the harvested cells, because the therapy destroys the patient’s remaining stem cell tissue.

Stem cell transplantation, particularly allogeneic transplantation, is a high cost and highly specialist procedure, performed by skilled and experienced transplant teams working in specialist centres. Allogeneic transplantation carries a relatively high morbidity and mortality, and these must be weighed against the potential longer-term survival benefits when considering a patient for transplantation. Rigorous patient selection is of paramount importance.

How the service is organised

Blood and Marrow Transplantation Services are provided by about 40 centres across England. All centres should have JACIE accreditation and be compliant with JACIE standards. Some centres have shared-care arrangements with their local referring hospitals for post-transplant care and follow up.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all Blood and Marrow Transplantation Services provided by Specialist Transplantation Centres, including preparatory care (including for patient who do not go on to have transplants), donation, transplant, aftercare and subsequent treatment. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children

The NHS CB commissions the following drugs/devices:

- Colony stimulating factors (G-CSFs)
- Defibrotide; plerixafor*
- Antibodies for graft versus host disease (GVHD) such as anti-tumour necrosis factors* (anti-TNFs)
- Anti-thymocyte globulin (ATG)
- Campath
- Antifungals

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one patient across two to three GP practices needs access to the service each year);
- the cost of providing the service is very high because of the specialist drugs and ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

30. Bone anchored hearing aid services (all ages)

[D9 – Specialised Ear Surgery]

Service summary
Bone anchored hearing aid services include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).This applies to provision in adults and children.

Other relevant services

- 36. Cochlear implantation services
- 75. Middle ear implantable hearing aid services (all ages)
- 108. Specialist ear, nose and throat services for children and young people

About the condition/service
Bone anchored hearing devices (BAHDs) are hearing aids which require surgical implantation to address either a specific type of hearing loss or to address hearing loss that cannot be corrected with conventional hearing aids.

About 60 hospitals implant about 900 devices each year. About 25% of centres implant very few devices.

How the service is organised
All patients are initially referred for general hearing assessment and see an audiologist and an ENT surgeon.

The assessment process for BAHDs is generally done by audiology. If BAHD is considered to be an option there is an additional requirement for the patient to trial the device.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions bone anchored hearing aid services. This includes the multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).

Clinical Commissioning Groups (CCGs) commission the initial general hearing assessment for patients who go on to have specialist assessment for BAHDs.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across seven GP practices requires access to the service each year);
- the cost of providing the service is high because of the specialist devices involved;
- the number of doctors and other expert staff able to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

31. Breast radiotherapy injury rehabilitation (a discrete cohort of adult females)

Service summary
Breast radiotherapy injury rehabilitation services include services provided by Highly Specialist Breast Radiotherapy Injury Rehabilitation Centres, including services delivered on an outreach basis as part of a provider network.

Other relevant services

- 4. Adult highly specialist pain management services

About the condition/service
This service is for a discrete cohort of about 225 women who have severe, chronic and complex conditions arising from radiation-induced injuries. The women received a treatment regime for breast cancer in the 1970s and 1980s that is now known to be associated with a particular risk of damage to the nerves of the brachial plexus.

How the service is organised
The service provides a specialist, multi-disciplinary rehabilitation service. The lead centre provides an inpatient service.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for a discrete group of women with breast radiotherapy injury from Highly Specialist Breast Radiotherapy Injury Rehabilitation Centres supported by three oncology centres as part of a provider network.

Clinical Commissioning Groups (CCGs) commission the local therapy recommended in the management plan developed by the Highly Specialist Breast Radiotherapy Centres.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Barts Health NHS Trust
- Royal National Hospital for Rheumatic Disease NHS Foundation Trust (lead centre)
- The Christie NHS Foundation Trust (Manchester)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

32. Tier 4 child and adolescent mental health services

[C6 – Tier 4 Child & Adolescent Mental Health Services]

Service summary
Tier 4 child and adolescent mental health services includes inpatient care and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Child and Adolescent Mental Health Centres. In addition, this includes associated non-admitted care including outreach when delivered as part of a provider network.

Other relevant services

- 9. Adult specialist eating disorder services
- 55. Gender identity development service for children and adolescents
- 74. Mental health service for Deaf children and adolescents
- 98. Secure forensic mental health service for young people
- 102. Severe obsessive compulsive disorder and body dysmorphic disorder service (adults and adolescents)

About the condition/service
Tier 4 Child and Adolescent mental health services (CAMHS) are highly specialist services with a primary purpose of the assessment and treatment of severe and complex mental health disorders in children. These services are part of a highly specialist pathway and provide for a level of complexity that cannot be provided for by comprehensive secondary, Tier 3 community services. It is generally the complexity and severity rather than the nature of the disorder that determines the need for specialist care.

About 2,500 children access the service each year.

How the service is organised
There are about 90 Specialist Child and Adolescent Mental Health Centres in England. Within the Tier 4 CAMHS estate, there is sub-specialisation so that there are about: 46 Tier 4 CAMHS General Adolescent Services; eight Tier 4 CAMHS General Children's Services; 11 Tier 4 CAMHS Eating Disorder Units; a small number of Tier 4 CAMHS Specialist Learning Disability inpatient Services; a small number of Tier 4 CAMHS Psychiatric Care Units; as well as a small number of Tier 4 CAMHS Low Secure Services.

Tier 4 CAMHS provision includes inpatient services, day-patient care (as an alternative to admission), outreach and some assessment/advice with the majority of referrals being for inpatient or day-patient care. The majority of services are in the form of inpatient units and are often provided across a broad geographical area although some offer day-patient care and increasingly offer outreach generally to more local/regional patients.

The four tier structure of CAMHS services means that referrals to CAMHS Tier 4 usually come from CAMHS Tier 3.

Tier 4 CAMHS also includes some outpatient provision including: services for children and young people with complex eating disorders; services for children and young people with severe psychosomatic disorders; specialist neuropsychiatry services; community adolescent forensic services and some assessment/treatment services for young sexual offenders; specialist autism spectrum disorder services; and services for families who may be involved in care proceedings or at risk of care proceedings and where parenting/family assessment is required and, if appropriate, treatment.

Packages of care from Tier 4 may be in the form of specialist assessment and outreach support for Tier 3 as well as treatment itself.

Admission to Tier 4 CAMHS inpatient or day-patient settings is usually for one or more of the following reasons:

- The child or young person's level of risk behaviour, thought to be a consequence of a psychiatric disorder, means they cannot be safely cared for in a community setting
- There is a need for an intensity of intervention, which cannot be provided in a community setting
- There is a need for more comprehensive assessment than can be provided in an outpatient/community setting

Factors leading to referral to Tier 4 are not only severity and complexity, but also lack of treatment response, unusual clinical features, difficulty in engaging in outpatient treatment, increased vulnerability due to personal circumstances (i.e. in local authority care, youth justice system).

As CAMHS is a multi-agency service there is a need for the NHS Commissioning Board and Clinical Commissioning Groups to liaise with Local Authority Children's Services (Social Care and Education), both of which are key to providing integrated CAMHS services. In addition both may play an important role in facilitating discharge and the provision of effective aftercare.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions Tier 4 Child and Adolescent Mental Health services includes inpatient care and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Child and Adolescent Mental Health Centres. In addition, this includes associated non-admitted care including outreach when delivered as part of a provider network.

Clinical Commissioning Groups (CCGs) commission CAMHS for children requiring care in Tier 1, Tier 2 or Tier 3 services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one child or adolescent across two to three GP practices requires inpatient access to the service each year);
- the cost of providing the service is high because of the specialist ward environment involved;

- the number of doctors and other staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

33. Choriocarcinoma service (adults and adolescents)

Service summary
Choriocarcinoma services include services provided by Highly Specialist Choriocarcinoma centres. This applies to provision in adults and adolescents.

Other relevant services

- 105. Specialist cancer services

About the condition/service
This service diagnoses and treats women with the different types of gestational trophoblastic disease including the following:

- Hydatidiform mole (also known as molar pregnancy): in this condition, the sperm and egg cells join together but a healthy foetus does not develop. The placenta grows to an abnormal size, requiring surgical evacuation of the uterus.
- Choriocarcinoma, which is an aggressive and malignant cancer that may spread from the uterus to other organs in the body, such as the lungs or brain. The incidence of choriocarcinoma in the UK is about one case in every 50,000 births, i.e. about 10 new cases each year in England.
- Placental site trophoblastic tumour, a rare variant of choriocarcinoma. This cancer is able to spread through the body via the lymphatic system.

How the service is organised
The service provides monitoring for all women who have a molar pregnancy through the regular measurement of hCG (human chorionic gonadotrophin). For those women who go on to develop gestational trophoblastic disease, the service provides a full inpatient and outpatient management service to treat the cancer.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with suspected and confirmed choriocarcinoma from Highly Specialist Choriocarcinoma centres.

The NHS CB commissions the following drugs: first line therapy for low risk patients is Methotrexate. High risk patients may be treated with a combination of EMA/CO (cyclophosphamide and vincristine) or MAE (mitozantrone, cytarabine and etoposide) chemotherapy. On rare occasions (one to two patients each year) patients do not respond to these therapies and may then be treated with a combination of high-cost chemotherapy (gemcitabine and pemetrexed) and/or bone marrow transplant.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;

- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Imperial College Healthcare NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

34. Chronic pulmonary aspergillosis service (adults)

Service summary
Chronic pulmonary aspergillosis services include services provided by Highly Specialist Chronic Pulmonary Aspergillosis centres. This applies to provision in adults.

Other relevant services

- 3. Adult highly specialist respiratory services

About the condition/service
Chronic pulmonary aspergillosis is a chronic, progressive infection of the lung with the fungus *Aspergillus fumigatus* that follows a lung insult (typically sarcoidosis, atypical TB or recurrent pneumothoraces) and occurs in those with one or more innate genetic defects.

How the service is organised
The service is an assessment and long term clinical management service. It enables the specific nature of any detected aspergillus infection to be classified and those patients confirmed to have chronic infection within the parameters of the service are offered clinically appropriate treatment options that may include:

- Anti-fungal drug therapy (itraconazole and voriconazole)
- Embolisation
- Surgery
- Physiotherapy advice
- Support provision of appropriate end of life care

The service sees about 250 patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commission services for adults with chronic pulmonary aspergillosis from Highly Specialist Chronic Pulmonary Aspergillosis centres.

The NHS CB commissions the following drugs: antifungals (itraconazole, voriconazole. Requests for posaconazole, micafungin and amphotericin A are considered on an individual funding request basis.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small, and

- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:
University Hospital of South Manchester NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

35. Cleft lip and palate services (all ages)

[D7 – Cleft Lip & Palate]

Service summary
Cleft lip and/or palate services include all specialist care delivered by Cleft Lip and Palate Centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

About the condition/service
A cleft is a gap or split in either the upper lip or the roof of the mouth (palate) or sometimes both. It occurs when separate areas of the face do not join together properly when a baby is developing during pregnancy.

About 75% of clefts of the lip can be detected during pregnancy at the routine 20-week scan with the majority of the remainder detected at birth. Clefts of the palate are rarely detected on ultrasound scans. Sub-mucous cleft, where the cleft is hidden in the lining of the roof of the mouth, are sometimes not detected for months or even years.

Between 1 in 600 and 1 in 700 babies is born with a cleft lip and/or palate.

The treatment of cleft lip and/or palate requires the multi-disciplinary involvement of many specialties throughout growth and development to the age of at least 20 years, as well as treatment of adults of any age. All centres providing CLP services also treat non-cleft velopharyngeal dysfunction.

How the service is organised
There are nine Cleft Lip and Palate Centres/Networks in England. Some elements of the specialist service are delivered in the Centres by the specialist team, some are delivered via outreach arrangements and others are provided locally but prescribed by the Centres.

The service in its entirety includes:

- Pre-natal and post-natal diagnosis
- Hospital paediatric care
- Pre- and peri-natal specialist cleft nursing, including support of newborn feeding and ongoing assessment and management
- Genetic assessment and chromosomal studies
- Multi-disciplinary pre-surgery assessment
- Initial lip and/or palate surgery and post-operative assessment
- Paediatric dentistry, including dental health education and oral health
- Alveolar cleft bone grafting and associated orthodontics
- Cleft-related dento-alveolar surgery
- Velopharyngeal dysfunction (VPD) investigations, therapy, surgery and/or prosthetics with follow up, including investigation and treatment of non-cleft velopharyngeal dysfunction
- Specialist speech and language assessment and therapy

- Audiology and otology assessment and treatment of hearing problems
- Orthodontics
- Restorative dentistry including implants and prosthetics
- Orthognathic surgery/distraction osteogenesis techniques to correct cleft-related jaw deformities, including associated orthodontics
- Rhinoplasty
- Cleft lip and/or palate revisions and fistula repair
- Psychological care for children, adults and families
- Revision treatment, including surgery where necessary, in adulthood
- Locally provided services (for example, health visitors, children's community services and community paediatric care, education, speech and language therapy, primary dental care) supported by the specialist team

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all cleft lip and palate services provided by Cleft Lip and Palate Centres, including services delivered on an outreach basis as part of a provider network. Cleft lip and palate services include specialist speech and language therapy services.

Clinical Commissioning Groups (CCGs) commission some services that support the specialist clinical pathway to ensure optimum outcomes and provide care closer to home. These services are: speech and language therapy, ENT, audiology and community paediatric care. The specialist team works collaboratively with these local delivered services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (there are about two patients aged 20 and under with a cleft lip and/or palate registered with each GP practice);
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

36. Cochlear implantation services (all ages)

[D9 – Specialised Ear Surgery]

Service summary
Cochlear implantation services include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children.

Other relevant services

- 30. Bone anchored hearing aid services (all ages)
- 75. Middle ear implantable hearing aid services (all ages)
- 76. Neurofibromatosis type 2 service (adults and children)
- 108. Specialist ear, nose and throat services for children and young people

About the condition/service
Cochlear implants are hearing devices that require surgical implantation to address either a specific type of hearing loss or to address hearing loss that cannot be corrected with conventional hearing aids.

About 14 hospitals implant about 900 devices each year.

How the service is organised
All patients are initially referred for general hearing assessment and see an audiologist and an ENT surgeon.

The assessment process for cochlear implants is generally led by audiology.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions cochlear implantation services. This includes the multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).

Clinical Commissioning Groups (CCGs) commission the initial general hearing assessment for patients who go on to have specialist assessment for cochlear implants.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across seven GP practices requires access to the service each year);
- the cost of providing the service is high because of the specialist devices involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

37. Complex childhood osteogenesis imperfecta service (children)

Service summary
Complex osteogenesis imperfecta services include services provided by Highly Specialist Complex Osteogenesis Imperfecta Centres including outreach when delivered as part of a provider network. This applies to provision in children.

Other relevant services

- 62. Highly specialist metabolic disorder services (all ages)

About the condition/service
Osteogenesis imperfecta (OI) is a genetic condition characterised by bones that break easily, often from little or no apparent cause. The condition can vary quite drastically from one person to another: a person can have just a few or as many as several hundred fractures in a lifetime. About 1 in 15,000 of the population has OI.

How the service is organised
The service provides care for children whose OI meets a service definition of ‘severe’, ‘atypical’ or ‘complex’. The service brings together surgery (opinion only), pharmacology, physiotherapy, occupational therapy, nursing and social work into a network model that aims to improve the diagnosis and management of under 16s who have this rare, genetic collagen deficiency.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for children with severe, atypical or complex OI from Highly Specialist Complex Osteogenesis Imperfecta Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Sheffield Children's NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

38. Complex Ehlers Danlos syndrome service (adults and children)

Service summary
Complex Ehlers Danlos services include diagnostic services (including specialist laboratory services) provided by Highly Specialist Ehlers Danlos Centres. This applies to provision in adults and children.

Other relevant services

- 5. Adult highly specialist rheumatology services
- 129. Specialist rheumatology services for children and young people

About the condition/service
Ehlers-Danlos syndrome (EDS) is a group of heritable disorders of connective tissue. The major clinical features are hyperextensible skin, hypermobile joints and tissue fragility. There are several types of EDS each with their own specific treatment. About 1 in 5,000 of the population has EDS but this service is focused on the rare types of the disorder.

How the service is organised
This service provides care for patients who have complex EDS. ‘Complex’ EDS is defined as either:

- Where the clinical diagnosis is not straightforward; OR
- Where the clinical diagnosis is confirmed as one of EDS but where laboratory testing has not confirmed the diagnosis and further clinical evaluation is necessary.

A management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions diagnostic services for adults and children with complex EDS from Highly Specialist Ehlers Danlos Centres.

Clinical Commissioning Groups (CCGs) commission diagnostic services for adults and children whose EDS does not meet the definition of ‘complex’. CCGs also commission treatment services for ALL patients with EDS, including patients with complex EDS.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- North West London Hospitals NHS Trust
- Sheffield Children's NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

39. Complex neurofibromatosis type 1 (adults and children)

Service summary
Complex neurofibromatosis type 1 services include services provided by Highly Specialist Complex Neurofibromatosis Type 1 Centres. This applies to provision in adults and children.

About the condition/service

Neurofibromatosis type 1 (NF1) is an inherited genetic disorder, characterised by formation of neurofibromas (tumours involving nerve tissue) in the skin, subcutaneous tissue, cranial nerves and spinal root nerve tissue. About 1 in 25,000 of the population has NF1. With *complex* NF1 there is a high risk of developing rare complications, which may affect most of the body systems.

Complex in NF1 is defined by the presence of other conditions that have the possibility of significant morbidity and mortality and which require integrated management by an expert team.

How the service is organised

The service includes:

- Specialist assessment of NF1 patients with suspected complex complications of the disease to provide accurate diagnosis of unusual phenotypes and other disease that can be mistaken for NF1. This is through genetic testing with support from genetic counselling
- Co-ordination of care by a specialist multi-disciplinary team when the NF1 complications mean the condition manifests differently to other NF1 patients
- Monitoring the risk of NF1-related malignancy and tumour progression
- Long-term monitoring to evaluate the need for surgery, for example, cervical cord compression

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions services for adults and children with complex NF1 from Highly Specialist Complex Neurofibromatosis Type 1 Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Central Manchester University Hospitals NHS Foundation Trust

- Guy's and St Thomas' NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

40. Complex spinal surgery services (all ages)

[D14 – Complex Spinal Surgery]

Service summary
For adults:
Complex spinal surgery services include a number of specified procedures when performed in Specialist Spinal Surgery Centres or as outreach when delivered as part of a provider network.

For children and young people:
Complex spinal surgery services include a number of specified procedures that should only be performed in Specialist Paediatric Spinal Surgery Centres.

About the condition/service
This service encompasses aspects of care provided by spinal surgeons from both orthopaedic and neurosurgery disciplines.

How the service is organised
There are about 30 Specialist Spinal Surgery Centres and a further 30 centres that deliver some specialist surgery.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions complex spinal surgery services for adults from Specialist Spinal Surgery Centres including services delivered on an outreach basis as part of a provider network. The NHS CB commissions complex spinal surgery services for children from Specialist Paediatric Spinal Surgery Centres.

The NHS CB commissions:
- All spinal deformity surgery (adults and children)
- All spinal reconstruction surgery (adults and children)
- Palliative or curative spinal oncology surgery (adults and children)
- Revision surgery for which the primary surgery is specialist, for example, revision surgery with instrumentation for over 2 levels
- All primary thoracic and primary anterior lumbar surgery
- Posterior cervical decompression surgery using instrumentation
- Cervical corpectomy

The NHS CB commissions the following devices: any associated specialist orthotics

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund spinal surgery for lower back pain. Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission:

- revision surgery for which the primary surgery is non-specialist, i.e. revision surgery with instrumentation for 2 levels or under
- posterior cervical decompression surgery without instrumentation
- anterior cervical decompression surgery (discectomy or fusion)
- all spinal injections
- primary lumbar decompression/discectomy
- posterior lumbar uninstrumented fusions
- lumbar instrumented fusion for 2 levels or less
- revision, instrumented lumbar fusion for 2 levels or less

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions and devices involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

41. Complex tracheal disease service (children)

Service summary
Complex tracheal disease services include services provided by Highly Specialist Complex Tracheal Disease centres. This applies to provision in children.

Other relevant services
- 85. Paediatric cardiac services

About the condition/service
The Complex Tracheal Disease Service assesses and treats children with severe and rare conditions affecting the trachea long segment tracheal stenosis. Patient selection is particularly complex.

How the service is organised
A range of surgical procedures is offered, including slide tracheoplasty.

There are about 60 new referrals to the service each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions complex tracheal disease services for children from Highly Specialist Complex Tracheal Disease centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:
- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the services is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:
- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

42. Congenital hyperinsulinism service (children)

Service summary
Congenital hyperinsulinism services include services provided by Highly Specialist Congenital Hyperinsulinism centres. This applies to provision in children.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Congenital hyperinsulinism (CHI) is a condition characterised by excess insulin production from the pancreas, resulting in hypoglycaemia. The clinical presentation and progress of CHI lies on a spectrum, varying between those with transient hypoglycaemia to those unresponsive to medical treatment and requiring pancreatectomy. In the absence of expert management, children who have prolonged or recurrent hyperinsulinaemic hypoglycaemia in infancy can suffer harm to their brains and may be developmentally delayed.

How the service is organised
There are about 110 new referrals to the service each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions congenital hyperinsulinism services for children from Highly Specialist Congenital Hyperinsulinism centres.

The NHS CB commissions the following drugs: diazoxide (initiation only), octreotide

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Central Manchester University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

43. Craniofacial service (adults and children)

Service summary
Craniofacial services include services provided by Highly Specialist Craniofacial Centres. This applies to provision in adults and children.

Other relevant services

- 26. Beckwith-Wiedemann syndrome with macroglossia service (children)
- 107. Specialist dentistry services for children and young people
- 108. Specialist ear, nose and throat services for children and young people
- 119. Specialist neuroscience services for children and young people

About the condition/service
This service provides assessment, surgical and non-surgical treatment and follow up of patients with severe congenital deformities of the skull and face.

How the service is organised
The core surgical specialties involved are plastic and maxillofacial surgery and neurosurgery, but input is also necessary from ear, nose and throat surgeons, orthodontists, ophthalmologists and anaesthetists with experience of treating complex craniofacial conditions.

A multi-disciplinary team of clinical psychologists, speech and language therapists, audiologists and nurses play an important role in supporting patients with congenital facial deformities. A molecular genetics service provides a diagnosis.

There are about 100 new referrals to the service each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions craniofacial services for adults and children from Highly Specialist Craniofacial Centres.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small; the number of expert doctors and other staff who can provide the service is very small; and
- the cost of surgery and associated care for individual patients can be very high.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Alder Hey Children's NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust

- Oxford University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

44. Cryopyrin associated periodic disorder (adults)

Service summary
Cryopyrin associated periodic syndrome services include services provided by Highly Specialist Cryopyrin Associated Periodic Syndrome centres. This applies to provision in adults.

About the condition/service
Cryopyrin associated periodic syndrome (CAPS), is a very rare lifelong inflammatory disease that interferes with growth and development that causes serious morbidity and is often fatal.

How the service is organised
The service assesses patients and makes or confirms a diagnosis. Treatment options for CAPS include Canakinumab and Anakinra.

The service treats a caseload of 40-50 patients.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adult patients with Cryopyrin associated periodic disorder from Highly Specialist Cryopyrin Associated Periodic Syndrome centres.

The NHS CB commissions the following drugs: canakinumab, anakinra

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist drug involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Royal Free London NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

45. Cystic fibrosis services (all ages)

[A1 – Cystic Fibrosis]

Service summary
For adults:
Cystic fibrosis services include all care provided by Adult Cystic Fibrosis Centres. This covers all specialist care including outreach when delivered as part of a provider network.

For children and young people:
Cystic fibrosis services include all care provided by Paediatric Cystic Fibrosis Centres. This covers all specialist care including outreach and shared care arrangements led by Paediatric Cystic Fibrosis Centres when delivered as part of a provider network.

About the condition/service
Cystic fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. CF affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. About 9,000 people in the UK are living with cystic fibrosis.

How the service is organised
CF services are delivered in about 20 Paediatric Cystic Fibrosis Centres and about 20 Adult Cystic Fibrosis Centres. Paediatric centres organise a shared care network approach so that some care can be delivered close to home by local paediatric teams under the supervision of the centre.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all cystic fibrosis services provided by Adult Cystic Fibrosis Centres and Paediatric Cystic Fibrosis Centres. This includes services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs: dornase, tobramycin, colistimethate sodium, aztreonam lysine in line with the national CF Commissioning Policy.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service. CCGs may prescribe some non-specialist drugs initiated by the Cystic Fibrosis Centre, for example, Salbutamol.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small (one or two patients with cystic fibrosis is registered at each GP practice);
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and

- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes ALL activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

46. Diagnostic service for amyloidosis (adults)

Service summary
Diagnostic services for amyloidosis include diagnostic services (including specialist laboratory services) provided by Highly Specialist Amyloidosis centres. This applies to provision in adults.

About the condition/service
Amyloidosis is a condition in which abnormal protein deposits accumulate in many different organs.

How the service is organised
The National Amyloidosis Centre provides diagnostic imaging (SAP scintigraphy – a technique for identifying amyloid deposits – and specialist echocardiography), histology and DNA analysis, genetic counselling, monitoring of amyloid proteins in the blood, recommendations for treatment, and supporting the evaluation of existing and new therapies.

The service provides a diagnostic service to about 700 new patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions a diagnostic service for patients with amyloidosis from Highly Specialist Amyloidosis centres.

Clinical Commissioning Groups (CCGs) commission the majority of treatment services for patients with amyloidosis with the exception of blood and marrow transplants, which are also commissioned by the NHS CB.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist equipment involved; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Royal Free London NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

47. Diagnostic service for primary ciliary dyskinesia (adults and children)

Service summary
Diagnostic services for primary ciliary dyskinesia management include diagnostic services (including specialist laboratory services) provided by Highly Specialist Primary Ciliary Dyskinesia Diagnostic Centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 3. Adult highly specialist respiratory services
- 88. Primary ciliary dyskinesia management service (children)
- 128. Specialist respiratory services for children and young people

About the condition/service

Primary ciliary dyskinesia is a genetic disorder of the air tubes of the lungs (the bronchi), which become infected and filled with pus due to abnormalities of the hair-like structure (cilia) of the cells lining the respiratory tract. This can lead to repeated infections and damage the lung, especially if the diagnosis is delayed. About 1 in 15,000 of the population has PCD, i.e. about 350-500 patients in England.

How the service is organised

This service provides a diagnostic and advice service to patients who are referred with suspected primary ciliary dyskinesia (PCD). It also supports and trains them in certain aspects of self-care treatment.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions diagnostic services for adults and children with PCD from Highly Specialist Primary Ciliary Dyskinesia Diagnostic Centres, including services provided on an outreach basis delivered as part of a provider network. The service includes full diagnostic assessment (nasal and, where necessary, bronchial biopsies).

Clinical Commissioning Groups (CCGs) commission management and treatment services for **adult** patients with PCD. The NHS CB Commissions management and treatment services for children with PCD[11].

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the cost of providing the facility is high because of the specialist diagnostic equipment involved; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

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[11] See section 88

Activity is identified via local data flows, which apply to established designated centres only:

- Royal Brompton and Harefield NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- University Hospitals of Leicester NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

48. Diagnostic service for rare neuromuscular disorders (adults and children)

Service summary
Diagnostic services for rare neuromuscular disorders include diagnostic services (including specialist laboratory services) provided by Highly Specialist Rare Neuromuscular Disorders centres. This applies to provision in adults and children.

The service includes outreach when delivered as part of a provider network.

Other relevant services

- 12. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children and young people

About the condition/service
The aim of the service is to make a precise molecular or clinical diagnosis in patients with four rare neuromuscular conditions and to assess fully the extent of their disease:

- Limb girdle muscular dystrophies
- Congenital muscular dystrophies
- Congenital myasthenic syndromes
- Muscle channelopathies (also known as periodic paralysis)

How the service is organised
This service provides a diagnostic, advisory and clinical service for patients with four groups of very rare inherited neuromuscular disorders. These conditions are all inherited, and the definitive diagnosis for a patient is made by identifying the primary gene defect. Each disease group involves multiple genes, and the decision as to which gene to search first for DNA mutations is arrived at by using a disease-specific battery of techniques. These may include detailed clinical assessments, specialist neurophysiological tests, and immunological analyses on tissue biopsies.

There are about 1600 referrals to the service each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board commissions diagnostic services for adults and children with rare neuromuscular disorders from Highly Specialist Rare Neuromuscular Disorders Centres and treatment services for non-dystrophic myotonia.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist diagnostic equipment involved;

- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust (congenital muscular dystrophies and myopathies)
- Oxford University Hospitals NHS Trust (congenital myasthenic syndromes)
- The Newcastle upon Tyne Hospitals NHS Foundation Trust (limb girdle muscular dystrophies)
- University College London Hospitals NHS Foundation Trust (muscle channelopathies)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

49. Encapsulating peritoneal sclerosis treatment service (adults)

Service summary
Encapsulating sclerosing peritonitis surgical services include services provided by Highly Specialist Encapsulating Sclerosing Peritonitis Surgical Centres. This applies to provision in adults.

Other relevant services

- 16. Adult specialist renal services

About the condition/service
Encapsulating peritoneal sclerosis (EPS), also referred to as sclerosing peritonitis, is a complication arising from long term use of peritoneal dialysis. EPS is characterised by marked sclerotic thickening of the peritoneal membrane, leading to encapsulation of the gut and sub-acute or acute bowel obstruction. As a chronic fibrosing process, it leads to abdominal pain, nausea, vomiting, weight loss, fever, malnutrition, anaemia, ascites and finally surgical peritonitis and mortality.

How the service is organised
The service undertakes about 40 primary surgical procedures to treat EPS each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults with encapsulating peritoneal sclerosis from Highly Specialist Encapsulating Sclerosing Peritonitis Surgical Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

50. Epidermolysis bullosa service (adults and children)

Service summary
Epidermolysis bullosa services for adults include services provided by Highly Specialist Adult Epidermolysis Bullosa Centres.

Epidermolysis bullosa services for children include services provided by Highly Specialist Paediatric Epidermolysis Bullosa Centres including outreach when delivered as part of a provider network.

Other relevant services

- 61. Highly specialist dermatology services (all ages)

About the condition/service
Epidermolysis bullosa (EB) is the name given to a group of rare inherited disorders that cause lifelong blistering and ulceration of the skin and often the mucous membranes. Blistering is almost always apparent at or soon after birth, but the severity of the condition varies greatly, depending on the type of Epidermolysis bullosa present. There are thought to be 5,000 people with EB in the UK and about 1 in 17,000 babies are born with the condition each year.

How the service is organised
The service provides diagnosis and assessment of infants, adolescents and adults with suspected or known EB, together with treatment and long term support.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults with EB from Highly Specialist Adult Epidermolysis Bullosa Centres.

The NHS CB commissions services for children with EB from Highly Specialist Paediatric Epidermolysis Bullosa Centres, including services delivered on an outreach basis as part of a provider network.

Both services include:

- Outpatient clinics
- Multi-disciplinary day case reviews
- Day case reviews
- Inpatient admissions (emergency and elective)
- Outreach clinical nurse specialist visits

The NHS CB commissions the following drugs/devices: all consumables including dressings required in the Highly Specialist Centre outpatient and inpatient settings.

Clinical Commissioning Groups (CCGs) commission dressings that are required once patients have been returned to the care of local providers.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust (adults only)
- Heart of England NHS Foundation Trust (adults only)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

51. Extra corporeal membrane oxygenation for adults

Service summary
Extra corporeal membrane oxygenation (ECMO) services for adults with severe potentially reversible respiratory failure include services provided by Highly Specialist Adult ECMO Centres including outreach when delivered as part of a provider network.

Other relevant services

- 52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- 57. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support (adults and children)

About the condition/service
Extra corporeal membrane oxygenation (ECMO) supports adults with severe potentially reversible acute respiratory failure by oxygenating the blood through an artificial lung machine.

How the service is organised
The specialist centres function as a national network, working closely with their local Critical Care Networks. All centres provide a retrieval service that includes the capability to undertake ‘mobile’ ECMO when this is deemed clinically necessary. The service assesses about 550 patients for treatment each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions ECMO services for adults with severe potentially reversible acute respiratory failure from Highly Specialist Adult ECMO Centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission local non-specialist care once the patient has been discharged from intensive care.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist equipment and specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Guy's and St Thomas' NHS Foundation Trust

- Papworth Hospital NHS Foundation Trust (Cambridge)
- Royal Brompton and Harefield NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust
- University Hospitals of Leicester NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure

Service summary
Extra corporeal membrane oxygenation (ECMO) services for neonates, infants and children with respiratory failure include services provided by Highly Specialist ECMO centres including outreach when delivered as part of a provider network.

Other relevant services

- 51. Extra corporeal membrane oxygenation for adults
- 57. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support (adults and children)
- 85. Paediatric cardiac services
- 122. Specialist paediatric intensive care services

About the condition/service
Extra corporeal membrane oxygenation (ECMO) supports critically ill babies and children who have severe potentially reversible acute respiratory failure by oxygenating the blood through an artificial lung machine.

How the service is organised
The centres work closely with local neonatal networks and paediatric intensive care units. Some patients receive mobile ECMO. The service treats about 150 patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions ECMO services for neonates, infants and children with respiratory failure from Highly Specialist ECMO centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission local non-specialist care once the child has been discharged from paediatric intensive care or neonatal intensive care.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist equipment and highly specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- University Hospitals of Leicester NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

53. Ex-vivo partial nephrectomy service (adults)

Service summary
Ex-vivo partial nephrectomy services include services provided by Highly Specialist Ex-vivo Partial Nephrectomy Centres. This applies to provision in adults.

Other relevant services

- 105. Specialist cancer services (adults)

About the condition/service
Ex-vivo partial nephrectomy can be used to treat cancers in patients with a single kidney, and offers the possibility of cancer cure and avoiding a life of dialysis.

How the service is organised
This is a new service and it is anticipated that 10-20 patients will be treated each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions ex-vivo partial nephrectomy services for adult patients from Highly Specialist Ex-vivo Partial Nephrectomy Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Oxford University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

54. Fetal medicine services (adults and adolescents)

[E12 – Fetal Medicine]

Service summary
Fetal medicine services include all care provided by Fetal Medicine Centres including outreach when delivered as part of a provider network.

About the condition/service
Common fetal conditions (for example, minor malformations, late fetal growth restriction) are managed in local hospitals, but complex and rare conditions (for example, major/multiple malformations, complications of monochorionic twins and severe fetal growth restriction and those secondary to maternal disorders, for example, alloimmunisation (where fetal blood cells are destroyed by maternal antibodies transferred across the placenta) are managed in conjunction with a specialist fetal medicine centre.

How the service is organised
Specialist fetal medicine services are provided from about 16 centres in England; however, not all centres provide the full spectrum of fetal therapeutic interventions, for example, laser ablation of placental vascular anastomoses in twin-to-twin transfusion syndrome. Cases are typically assessed and managed on an outpatient basis by the specialist multi-disciplinary team, often involving other specialist consultants and/or specialist laboratory services. The Fetal Medicine Service works as part of a clinical pathway with colleagues in local hospitals to provide care for women with difficult or complex fetal disorders as near to their home as is possible. Care is shared with local providers on a network basis. For some women, delivery in the Fetal Medicine Centre is necessary to provide optimal care for the baby at delivery.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all fetal medicine services provided by Fetal Medicine Centres. These include services delivered on an outreach basis by a provider network.

Clinical Commissioning Groups (CCGs) commission those services for common fetal conditions that are provided by local hospitals.

The NHS CB commissions the following drugs:
- anti-arrhythmic drugs (for fetal arrhythmias)
- immunoglobulin (for fetal alloimmune thrombocytopenia)
- intraamniotic thyroxine and maternal antithyroid therapy (for fetal thyroid disorders)
- glucocorticoids (to enhance pulmonary maturity and for some fetal conditions, (for example, congenital adrenal hyperplasia, congenital pulmonary malformations)
- antibiotics (for congenital infection)
- prostaglandin synthesis inhibitors (for hydramnios)

- progesterone (to reduce the risk of preterm birth)

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes ALL activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

55. Gender identity development service for children and adolescents

Service summary
Gender identity development services include services provided by Highly Specialist Gender Identity Development Centres including outreach when delivered as part of a provider network.

Other relevant services

- 32. Tier 4 child and adolescent mental health services
- 56. Gender identity disorder services
- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
The gender identity development service is a Tier 4 specialist multidisciplinary mental health service that provides support and therapeutic input for children and adolescents who have social and psychological difficulties with the development of their gender identity. The service works with paediatric endocrinology clinics to prescribe and administer hormone therapy and early intervention (from 12 years onwards, depending on need).

How the service is organised
The service provides outreach support to patients and families across the country. This network model of management for children struggling with the development of their gender identity involves close collaboration between the national service in London and local Child and Adolescent Mental Health Services.

The service sees about 130 patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions gender identity development services for children and adolescents from Highly Specialist Gender Identity Development Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs/devices: hormone blocker therapy is initiated through joint endocrinology clinics

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- The Tavistock and Portman NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

56. Gender identity disorder services

[C4 – Gender Identity Disorder]

Service summary
Gender identity disorder services includes specialist assessment, non-surgical care packages, transgender surgery and associated after care provided by Specialist Gender Identity Disorder Clinic Centres. This applies to provision in adults and children.

Other relevant services

- 55. Gender identity development service for children and adolescents

About the condition/service
Gender dysphoria is a condition in which there is a psychological experience of oneself as a man or woman, which is incongruent with the individual's external sexual characteristics of the body. The individual's physical sex is not aligned to their gender identity.

Sometimes, the distress/discomfort is sufficiently intense that people undergo *transition* from one point on a notional gender continuum to another – most commonly from Male-to-Female (MtF) or Female-to-Male (FtM). This typically involves changes to social role and presentation, and may necessitate treatment with cross-sex hormones and/or having gender related surgery.

How the service is organised
The delivery of current clinical services for gender dysphoria (adults) falls into two main categories:

A. Gender identity clinic services (GICs) provide specialist assessment and treatment of gender dysphoria. Available treatments may include clinical consideration of: psychological therapies, speech and language therapy, endocrinology, referral for hair removal, referral for surgical procedures and aftercare. Services generally accept referrals of adults with gender dysphoria from GPs or local psychiatry services (after delineation of any mental illness diagnosis by a community mental health team, if indicated by primary care.

Patients referred to GICs are not required to have started living in their desired social gender role and it is not necessary for them to have undertaken psychotherapy prior to referral.

Discussions regarding fertility are part of the assessment within GICs and should take place before any treatment that potentially compromises fertility is initiated. Hormone therapy has the potential to disturb the production of eggs and sperm. Genital surgery causes irreversible loss of fertility. Consequently, it is advisable for patients with gender dysphoria to consider providing sperm specimens or undergoing treatment to procure eggs prior to starting hormone treatment. Storage of gametes is not usually funded within the NHS.

There are seven GICs in England.

B. Sex Reassignment Surgery (SRS) services offer surgical procedures as part of the gender dysphoria treatment pathway. Surgical procedures may include:

- FtM chest reconstruction surgery
- MtF breast augmentation surgery
- FtM genital reconstructive surgery
- MtF genital reconstructive surgery

There are four sex genital reconstructive surgery centres and seven centres that provide chest reconstruction and breast augmentation surgery.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions gender identity disorder services from Specialist Gender Identity Disorder Clinic Centres. This includes specialist assessment, non-surgical care packages, transgender surgery and associated aftercare.

In this context, commissioning includes deciding which treatments should be commissioned by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. Clinical Commissioning Groups (CCGs) do not commission any elements of this service, regardless of whether or the NHS CB funds them. CCGs should not accept requests to fund these treatments.

The NHS Commissioning Board commissions the following drugs: hormone treatments

CCGs are responsible for the initiation and ongoing prescribing of hormone therapy and for organising blood and other diagnostic tests as recommended by the Specialist Gender Identity Disorder Clinic Centres.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients can be high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

57. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support) (adults and children)

Service summary
Heart and lung transplantation services include services provided by Highly Specialist Heart and Lung Transplant Centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 51. Extra corporeal membrane oxygenation for adults
- 52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- 85. Paediatric cardiac services

About the condition/service
(a) Heart and lung transplant service
The heart and lung transplant service provides: assessment of patients who are eligible for a heart transplant; the transplant operation; and lifelong follow up.

(b) bridge to heart transplant using mechanical circulatory support (adults)
Ventricular assist devices (VADs) can be attached externally or implanted within the body to support the adult's failing heart until a donor heart becomes available for transplantation, a technique known as ‘bridge to transplant’.

VADs work by supporting the pumping action of the left ventricle, which is the main pumping chamber of the heart. They sometimes also need to be implanted in the right ventricle.

The implantation of a VAD is only considered in patients with advanced heart failure who are listed for a transplant and who are deemed to be deteriorating so rapidly that they would not survive long enough to receive a heart via the urgent allocation scheme. The nature of the VADs available for adults allows many patients to be at home whilst awaiting a donor heart.

Occasionally, a VAD enables the heart to recover sufficiently for the device to be removed (‘bridge to recovery’).

(c) bridge to heart transplant using mechanical circulatory support (children)
A small but increasing number of children requiring a heart transplant are supported with ventricular assist devices (VADs), mechanical devices that circulate blood outside the body to supports the failing heart. This is known as ‘bridge to transplant’ and supports the heart until a donor heart becomes available for transplantation. The nature of the VADs available for children requires them to remain in hospital whilst awaiting a donor heart.

The use of the VADs such as the ‘Berlin Heart’ has increased the opportunity for bridging to heart transplant for children less than 10kg in weight, for whom it often takes longer to be offered a suitable donor heart.

How the service is organised
In England in 2010/11, there were 78 heart and 140 lung transplants in adults and 33 heart and six lung transplants in children.

The service implants about 100 VADs in adults each year.

The service implants about 25 VADs in children each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions heart and lung transplant services and bridge to transplant services for adults and children from Highly Specialist Heart and Lung Transplant centres, including services delivered on an outreach basis as part of a provider network.

The NHS Commissioning Board commissions the following drugs/devices: immunosuppressants; VADs

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is very high, placing a potential risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust
- Papworth Hospital NHS Foundation Trust (Cambridge) (adults)
- Royal Brompton and Harefield NHS Foundation Trust (adults)
- Sheffield Teaching Hospitals NHS Foundation Trust (adult assessments only)
- The Newcastle upon Tyne Hospitals NHS Foundation Trust (adults and children)
- University Hospital of South Manchester NHS Foundation Trust (adults)
- University Hospitals Birmingham NHS Foundation Trust (adults)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

58. Highly specialist allergy services (all ages)

[B9 – Specialised Immunology and Allergy Services]

Service summary
Highly specialist allergy services include services provided by Highly Specialist Allergy Centres including outreach when delivered as part of a provider network. This includes management of patients with:

- Severe allergic conditions; and
- Common allergic conditions for which conventional management has failed and for whom specified specialist treatments are required.

Other relevant services

- 115. Specialist immunology services for patients with deficient immune systems (all ages)

About the condition/service
Allergic disease is defined as an immune-mediated adverse event resulting from an externally-delivered agent. Allergy specialists deal with allergic reactions, particularly anaphylactic reactions to drugs, venoms and foods, as well as angioedema (swelling under the skin), hypereosinophilic disorders (conditions in which there is a marked increase in a type of white blood cell called an eosinophil), mastocytosis (where the presence of a type of white blood cell called a mast call is increased) and urticaria (swelling in the upper layer if the skin).

Allergic disease is very common affecting up to 30% of adults and 40% of children at some point in their lives. This service provides care for the complex and/or rare subgroup of those allergic conditions. There are an estimated 20,000 new referrals of patients in England annually with adult allergic disease of sufficient complexity to require specialist opinion or management.

How the service is organised
Most allergy-related hospital activity takes place in an outpatient or day-case setting. Specialist services are currently delivered exclusively by adult or paediatric physicians trained in allergy or immunology or who have had long experience in the practice of allergy.

In England there are approximately 50 centres providing Specialist Allergy Services, 30 for adults and 18 for children.

Specialist allergy services work in multi-disciplinary teams with specialist allergy nurses and access to an allergy specialist dietician; they are actively involved in education and training within the hospital, within their catchment area and in supporting primary care.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Highly Specialist Allergy Services from Highly Specialist Allergy Centres for patients with severe allergic conditions or who have common allergic conditions for which conventional

management has failed and for whom specified specialist treatments are required. This includes services delivered on an outreach basis as part of a provider network.

The NHS CB commissions services (including procedures and treatments) for patients with:

- **Complex drug allergy** – investigation including drug challenges, and desensitisation (antibiotics, analgesics (NSAID/aspirin/opiates), anaesthetics, contrast media, biologics)
- **Bee and wasp venom allergy requiring specific immunotherapy**
- **Vaccine allergy**
- **Anaphylaxis** which is recurrent, idiopathic or if there are multiple triggers
- **Systemic mast cell disorders (predominantly adults)**
- **Severe rhinitis/sinusitis** – when referred from another specialist because of inability to control the disease or requirement for specific immunotherapy (subcutaneous or sublingual)
- **Hereditary angioedema**
- **Severe atopic dermatitis** – when referred from another specialist because of inability to control the disease or requirement for complex dietary manipulation
- **Severe allergic asthma** – when referred from another specialist because of inability to control the disease or requirement for complex allergy tests or biologic therapy
- **Hypereosinophilic disorders** – managed predominantly in a subset of the specialist centres

The NHS CB commissions the following specialist treatments:

- **Specialist allergy testing techniques** – using drugs, foods or venom (skin prick/intradermal not available elsewhere)
- **High risk allergen challenge/provocation testing** – both high risk individuals and provocation to rare allergens when other procedures have failed to diagnose allergy using foods/venom/latex/aeroallergenics and drug challenges including aspirin, NSAIDs, penicillins and other antibiotics (oral, injected, subcutaneous, inhaled, nasal)
- **Immunotherapy** – the most severe patients requiring hospital-based injected allergen and home-based treatment via oral immunotherapy according to criteria laid out in National British Society for Allergy and Clinical Immunology guidelines
- **Multi-disciplinary team management of the complex patient** – including ENT, respiratory medicine, immunology and dermatology with specialist allergy nurses, allergy dietician, social care and laboratory diagnostic support providing comprehensive management
- **Drug allergy investigation and de-sensitisation (oral or injected)** – high risk desensitisation procedures for antibiotics and biologics
- **Monoclonal anti-IgE biological therapy for severe allergic asthma**, for example, Omalizumab – in patients with multiple hospital admissions

The NHS CB commissions the following drugs, some of which may be delivered in the patient's home: C1 inhibitor, bradykinin receptor antagonists, biological agents*, cytokines*, colony stimulating factors

Clinical Commissioning Groups (CCGs) commission all other allergy services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about three patients in each GP practice require access to specialist allergy services per annum);
- the cost of providing the service is high because of the specialist interventions and drugs involved;
- the number of doctors and other expert staff able to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

59. Highly specialist adult urinary and gynaecological surgery services (adults)

[E10 – Complex Gynaecological Services]

Service summary
Highly specialist adult urinary and gynaecological surgery services include complex procedures provided by Highly Specialist Urinary and Gynaecological Surgery Centres.

A. MANAGEMENT OF RECURRENT URINARY INCONTINENCE/FAILED PRIMARY SURGICAL TREATMENT and

MANAGEMENT OF RECURRENT PELVIC ORGAN PROLAPSE/FAILED PRIMARY SURGICAL TREATMENT and

MANAGEMENT OF COMPLICATIONS OF PROLAPSE OR INCONTINENCE SURGERY

About the condition/service
Primary surgical treatment of urinary incontinence (approximately 15,000 operations each year) is performed by gynaecologists and urologists who have a special interest in female urinary incontinence. The investigation and management of women whose primary surgery for stress incontinence has failed or who have complications such as mesh exposure following insertion of a tape is more complex and needs specialist intervention.

Primary surgery for stress urinary incontinence is performed by gynaecologists or urologists with a special interest in female urinary incontinence. In 10-20% of cases, the primary surgery fails and there is also a risk or recurrence of stress incontinence over time. These women require specialist expertise as the surgery can be technically challenging and alternative techniques may be needed.

Primary surgery for pelvic organ prolapse is usually performed by gynaecologists who have received additional training in uro-gynaecology. When primary surgery fails or there is a recurrence of prolapse, there are often associated bladder, bowel and sexual dysfunction. Further surgery is technically more difficult and may require techniques involving implant materials.

How the service is organised
There are about 30 centres that treat patients with these conditions.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions highly specialist adult urinary and gynaecological surgery services from Highly Specialist Urinary and Gynaecological Surgery Centres.

The NHS CB commissions:

- The investigation and management of women whose primary surgery for urinary incontinence has failed or who have complications such as mesh exposure following insertion of a tape
- The investigation and management of women whose primary surgery for stress urinary incontinence has failed or who have recurrence of the condition
- The investigation and management of women whose primary surgery for pelvic organ prolapse has failed or who have recurrence of the condition

Clinical Commissioning Groups (CCGs) commission primary surgical treatment for urinary incontinence, primary surgery for stress urinary incontinence and primary surgery for pelvic organ prolapse.

B. MANAGEMENT OF LOWER URINARY TRACT/URETHRAL FISTULAE

About the condition/service

Lower urinary tract fistulae are most commonly caused by pelvic surgery. There are about 120 cases each year in England and Wales.

How the service is organised

There are about 120 cases each year; each centre should treat at least 20 cases.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist adult urinary and gynaecological surgery services from Highly Specialist Urinary and Gynaecological Surgery Centres.

The NHS CB commissions services for the management of low urinary tract fistulae.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

C. WOMEN WITH URINARY AND FAECAL INCONTINENCE and

WOMEN WITH GENITAL AND ANORECTAL PROLAPSE

About the condition/service

Although primary surgery for urinary or faecal incontinence and for genital or anorectal prolapse are carried out by gynaecologists, uro-gynaecologists and colorectal surgeons, women who have a combination of both urinary incontinence and anorectal incontinence or whose primary surgery has failed need specialist interventions.

How the service is organised

There are about 30 centres that treat patients with these conditions.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist adult urinary and gynaecological surgery services from Highly Specialist Urinary and Gynaecological Surgery Centres.

The NHS CB commissions:

- assessment and treatment of combined urinary and faecal incontinence
- Assessment and surgical treatment of combined genital and anorectal prolapse
- incontinence combined with major prolapsed, for example, grade 2 or 3 uterine descent with grade 2 or 3 cystocele
- incontinence associated with voiding difficulties
- incontinence due to a combination of significant detrusor over activity, with sphincter incompetence
- assessment and treatment of surgical complications of treatments for urinary and faecal incontinence and genital prolapse, for example, first repeat surgery
- assessment and surgical treatment of rectovaginal fistula
- incontinence associated with neurological conditions such as paraplegia or multiple sclerosis, and / or has more than one cause simultaneously
- intractable incontinence requiring urinary or faecal diversion procedures or sacral nerve neuromodulation
- assessment and treatment of surgical complications of treatments for urinary and faecal incontinence and genital prolapse, for example, second or more repeat surgery, significant mesh complications
- repeat surgery for urinary and faecal incontinence and genital prolapse requires more expertise because the procedures are generally more complex than the initial procedure and the potential for damaging complications is considerably increased by the consequences of previous surgery

Clinical Commissioning Groups (CCGs) commission primary surgical treatment for urinary and faecal incontinence and for genital and anorectal prolapse.

D. MANAGEMENT OF SEVERE ENDOMETRIOSIS

About the condition/service

Medical and surgical treatment of non-severe endometriosis is undertaken by gynaecologists with a special interest. Severe endometriosis requires additional laparoscopic expertise and often multi-disciplinary surgery with urologists and colorectal surgeons involved.

Fewer than 30 centres treat patients with this condition.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist adult urinary and gynaecological surgery services from Highly Specialist Urinary and Gynaecological Surgery Centres.

The NHS CB commissions services for patients with severe endometriosis, for example, that requiring multi-disciplinary surgery with urologists and colorectal surgeons.

Clinical Commissioning Groups (CCGs) commission medical and primary surgical treatment of non-severe endometriosis.

E. MANAGEMENT OF CONGENITAL GYNAECOLOGICAL ANOMALIES

About the condition/service

Patients with congenital gynaecological anomalies, who fall into two groups:

- those diagnosed in childhood, who are transferring from paediatric care to adult care services; the diagnosis may have been made at birth with genital ambiguity or during childhood and adolescence with early or delayed puberty and growth, or virilisation; in addition, the diagnosis may have arisen from genetic testing because of an affected family member; and
- those who present for the first time in adolescence or adulthood; presentation may be with delayed puberty, virilisation, primary amenorrhoea or obstructed menstruation.

Conditions include disorders of sex development and Mullerian anomalies.

How the service is organised

Up to five centres treat patients with these conditions.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist adult urinary and gynaecological surgery services from Highly Specialist Urinary and Gynaecological Surgery Centres.

The NHS CB commissions services for patients with congenital gynaecological anomalies, who fall into two groups:

- those diagnosed in childhood, who are transferring from paediatric care to adult care services; the diagnosis may have been made at birth with genital ambiguity or during childhood and adolescence with early or delayed puberty and growth, or virilisation; in addition, the diagnosis may have arisen from genetic testing because of an affected family member;
- those who present for the first time in adolescence or adulthood; presentation may be with delayed puberty, virilisation, primary amenorrhoea or obstructed menstruation.

Conditions include disorders of sex development and Mullerian anomalies.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

F. ALL HIGHLY SPECIALIST ADULT URINARY AND GYNAECOLOGICAL SURGERY SERVICES

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the services is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

60. Highly specialist colorectal surgery services (all ages)

[A8 – Specialised Colorectal Services]

Service summary
Highly specialist colorectal surgery services include the following services when provided by Highly Specialist Colorectal Surgery Centres:

- Surgical management for complex inflammatory bowel disease
- Complex surgical interventions for faecal incontinence

This applies to provision in adults and children.

Other relevant services

- 23. Autologous intestinal reconstruction in adults service
- 91. Pseudomyxoma peritonei service (adults)
- 103. Small bowel transplantation service (adults and children)
- 105. Specialist cancer services (adults)

About the condition/service
Specialist colorectal services require a critical mass of expertise in surgery, medicine, radiology, pathology and nursing. This is possible only in units large enough to allow specialisation in all of these disciplines and it is only in units receiving referrals from a wide geographical area that sufficient experience is gained in dealing with the more difficult and complex cases.

How the service is organised
Services are currently provided at Highly Specialist Colorectal Surgery Centres only with networks under development.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions the following highly specialist colorectal surgery services from Highly Specialist Colorectal Surgery Centres:

- distal sacrectomy for advanced or recurrent cancer (a procedure in which bowel tumours that involve the sacrum (the bone at the base of the spine) are removed
- surgery for complex inflammatory bowel disease: excision of ileoanal pouch (pouches that have been constructed for people who have had their large intestine surgically removed due to disease or injury), revisional pouch surgery
- complex surgical interventions for faecal incontinence: sacral nerve stimulation (a procedure that involves the implantation of a programmable stimulator to control faecal incontinence)[12]; graciloplasty (the creation of a new anal sphincter), implantable sphincters
- transanal endoscopic microsurgery (TEMS) (a minimally invasive technique for the treatment of rectal neoplasia) and other trans anal techniques

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[12] Commissioning policy under development

- cytoreductive surgery and heated intra peritoneal chemotherapy (HIPEC) for peritoneal carcinoma from colorectal origin

Clinical Commissioning Groups (CCGs) commission all other colorectal surgery services, including primary ileoanal pouch procedures.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the facility is high because of the specialist interventions and devices involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

61. Highly specialist dermatology services (all ages)

[A4B – Specialised Dermatology]

Service summary
Highly specialist dermatology services include services provided by Highly Specialist Dermatology Centres for patients with rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 50. Epidermolysis bullosa service (adults and children)
- 143. Xeroderma pigmentosum service (adults and children)

About the condition/service

It is estimated that about 10% of patients requiring dermatology services (about 10,000 each year) need care from Highly Specialist Dermatology Centres.

Adult dermatology services are provided in local hospitals and deal with a wide range of conditions. Specialist adult dermatology services include the diagnosis, investigation and treatment of rare diseases and the management of severe diseases not suitable for, or not responding to, conventional treatment available in local dermatology departments. These cases usually require multidisciplinary input (for example, surgery, radiology, haematology, immunology, oncology, ophthalmology, nephrology, respiratory, cardiology and genetics), which may be delivered in a multidisciplinary clinic.

Similarly, paediatric dermatology services are available in most local hospitals and include a wide range of conditions. All dermatologists are trained in both adult and paediatric dermatology. Paediatric dermatology services are usually provided by dermatologists in local hospitals often with support from paediatricians. Specialist paediatric dermatology services incorporate any skin condition affecting a child, which a general dermatologist or paediatrician has been unable to diagnose or manage because it is atypical, severe, or complicated by other paediatric, medical or social factors.

How the service is organised

There are 25-30 Specialist Dermatology Centres, each of which is a Highly Specialist Dermatology Centre for the treatment of one or more rare conditions or specified common conditions with complex needs. There are three Highly Specialist Dermatology Centres for children.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist dermatology services from Highly Specialist Dermatology Centres. For adults, this is the diagnosis, investigation and treatment of rare diseases and the management of severe diseases not suitable for, or not responding to, conventional treatment available in local dermatology departments. For children, it is those services for children with conditions that general dermatologists or paediatricians have been unable to diagnose or manage because they are atypical, severe or complicated.

Clinical Commissioning Groups (CCGs) commission all other dermatology services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (one to two patients registered at each GP practice requires access to the service each year);
- the cost of providing the service is high because of the specialist drugs and interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

62. Highly specialist metabolic disorder services (all ages)

[E6 – Metabolic Disorders]

Service summary
Highly specialist metabolic disorder services include services provided by Highly Specialist Metabolic Disorder Centres for patients with specified conditions. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services:

- 19. Alkaptonuria service (adults)
- 25. Barth syndrome service (male adults and children)
- 37. Complex childhood osteogenesis imperfecta service (children)
- 71. Lysosomal storage disorder service (adults and children)
- 99. Severe acute porphyria service (adults and children)

About the condition/service
Specialist inherited metabolic disorders (IMDs) cover a diverse range of over 600 conditions, some of which are extremely rare.

Although varying widely in their presentation and management according to which body systems are affected, IMDs are caused by a disruption in normal biochemical processes. Conditions are lifelong and most are due to single enzyme deficiencies that lead to severe disturbance of metabolic processes in the body, resulting in either a deficiency of products essential for health or an accumulation of unwanted or toxic products. This can cause disease or damage in many organ systems, leading to severe learning or physical disability and death at an early age. Some disorders do not manifest symptoms for many years, and mature patients are referred frequently for investigation in other specialties, for example, nephrology, cardiology. This can lead to misdiagnosis, delayed diagnosis or multiple investigations.

About 10-12,000 people attend Highly Specialist Metabolic Disorder Centres.

How the service is organised
The NHS Commissioning Board commissions services from about 12 paediatric and adult Highly Specialist Metabolic Disorder Centres. These are units that have the following attributes:

- Provision of 24/7 clinical and laboratory cover
- Expertise in individual IMD syndromes
- Managed links to pharmaceutical industry including research, orphan drugs, etc.
- Care delivered by multi-disciplinary teams
- Co-location with other specialist services to treat multi-systemic conditions
- Provision of complex and expensive therapies

IMD patients may present initially to primary or secondary care services with varied and often nonspecific signs and symptoms. The specialist centre provides accurate clinical and laboratory diagnosis with confirmatory tests; identifies newborns through population screening programmes (PKU, MCADD); and identifies other at-risk family members. Centres provide inpatient facilities for patient observation and stabilisation and input from other specialties, for example, neurology, cardiology may be required.

Inpatient care includes planned admissions for investigations, initiation of and monitoring ongoing treatment, and routine assessments as well as emergency admissions for patients with acute metabolic decompensation. In addition to core MDT members, close liaison with healthcare professionals from other specialist services may be needed to provide comprehensive patient care, respite and appropriate end-of-life care.

Outpatient or shared-care services, led by an IMD consultant or specialist nurse/dietician, allow patients to be treated at home or in local facilities.

The Centres provide a number of outreach clinics and shared care with local hospitals is encouraged to enable patients to receive care as close to their homes as possible. All Centres work co-operatively to share expertise in individual syndromes.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions highly specialist metabolic disorder services for patients with IMDs from Highly Specialist Metabolic Disorder Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs for registered IMD patients:

- Betaine
- Cholesterol
- Chenodeoxycholic acid
- Copper histidine
- Dichloroacetate
- G-CSF
- Glycine
- Haem arginate
- Hydroxycobalamin
- 5-hydroxytryptophan
- L-arginine
- Laronidase
- L-carnitine
- L-citrulline
- L-lysine
- L-serine
- L-tryptophan
- Mannose
- N-carbamoylglutamate
- NTBC
- Penicillamine
- Pyrdoxine
- Pyridoxine phosphate

- Sapropterin
- Sodium benzoate
- Sodium phenylbutyrate
- Tetrahydrobiopterin
- Triethylene tetramine
- Triheptanoin
- Ubiquinone
- Uridine
- Vitamin E

In addition, the NHS CB commissions a number of specialist dietary products for the treatment of IMD patient with certain disorders, for example, aminoacidopathies, urea cycle disorders, organic acidaemia, fat oxidation disorders, galactosaemia

Clinical Commissioning Groups (CCGs) commission generic services for patients with IMDs at local hospitals. CCGs commission services general metabolic conditions such as diabetes or common IMD conditions such as familial hypercholesterolaemia in adults.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of patients requiring the service is small (about one to two patients in each GP practice needs access to the service);
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high (particularly if family members are affected), placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

63. Highly specialist pain management services for children and young people

[E3 – Paediatric Medicine]

Service summary
Highly specialist pain management services for children and young people include services provided by Highly Specialist Paediatric Pain Management Centres. The service includes:

- Multi-disciplinary assessment of childhood complex chronic pain (disease- and non-disease related) and pain-associated disability
- Specified inter-disciplinary interventions including intensive inpatient, residential and outpatient management programmes

This includes outreach when delivered as part of a provider network.

Other relevant services:

- 4. Adult highly specialist pain management services

About the condition/service
Chronic pain in children and young people (CAYP) is recurrent or persistent pain that persists beyond the usual course of an acute disease or which is associated with an underlying chronic condition. Traditionally, chronic pain in CAYP is pain that has been present after a period of three months. However, there are specific chronic pain conditions, such as complex regional pain syndrome and some cancer pains, which manifest before this period has elapsed. A small, significant cohort of children has such overwhelming pain (disease- and non-disease related) and pain-associated disability that they are unable to re-integrate into developmentally appropriate activities (including school, family life, independent social activity, physical activities). Family life can disintegrate and healthcare usage markedly increases. These children, and their families, require highly specialist, interdisciplinary input to manage their pain and support their physical and psychosocial rehabilitation.

The prevalence of chronic pain in children, as currently defined, is reported as between 6-25%. As stated previously, the majority of these CAYP are managed and rehabilitated effectively in primary, secondary and non-specialist tertiary centres. Based on current service activity figures, it is estimated that there are approximately 2,000 patients nationally who would benefit from referral to Highly Specialist Paediatric Management Services.

How the service is organised
There are five Highly Specialist Paediatric Pain Management Centres in England. Three of these centres provide intensive inpatient or residential pain management programmes for the most severely disabled patients.

The service is delivered via a networked approach similar to that provided by other specialist paediatric services, and is closely linked with existing major centres for adult chronic pain to allow easy transition to these services. Management of complex chronic pain in children is provided by a multidisciplinary team involving pain specialists, specialist paediatric anaesthetists, clinical psychologists, nurses, occupational therapists and physiotherapists. Highly specialist paediatric pain management services need to link in with other specialist paediatric services: rheumatology, gastroenterology, anaesthesia, neurology, orthopaedic surgery, general surgery, urology, dentistry, neurosurgery, plastic surgery, ENT surgery, oncology, psychology, mental health services and interventional radiology.

The Specialist Centre links to social services, primary care (GPs and community nursing) and educational services. Links to adult chronic care services are essential to ensure robust transitional arrangements are in place. Very occasionally, a child or young person requires interventional management that is provided only in Adult Highly Specialist Pain Management Centres. Chronic pain management is generally given to children and their families, rather than neonates or infants, and may be delivered in outpatient, day case, residential or inpatient settings.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions the following highly specialist pain management services for children and young people from Highly Specialist Paediatric Pain Management Centres:

- Multi-disciplinary team review for chronic pain
- Administration of pain-relieving blocks under anaesthesia
- Specialist pain management services for children referred from other pain management or paediatric services.

This includes services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission the majority of pain management services for children and young people, including services from secondary care providers.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one child across every three GP practices needs access to the service each year);
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients can be very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

64. Highly specialist palliative care services for children and young people

[E3 – Paediatric Medicine]

Service summary
Highly specialist palliative care services for children and young people include services provided by Highly Specialist Paediatric Palliative Care Centres including outreach when delivered as part of a provider network.

About the condition/service
Palliative care for children and young people with life threatening and life shortening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

How the service is organised
There are about six Highly Specialist Paediatric Palliative Care Centres in England.

Highly specialist paediatric palliative care services can be provided in the following ways:

- Direct support through an individual or joint consultation (involving other professionals) with the child and family in any care setting
- Direct support through provision of Specialist Inpatient Paediatric Palliative Care in a children’s hospice
- Direct support through facilitation and leadership of a multidisciplinary team, including multi-disciplinary team meetings
- Indirect advice provided to other professionals, including other providers of paediatric palliative care and other providers of health, social care or education by telephone, in writing or by participation in a multidisciplinary team meeting
- Support for other professionals through palliative care education and training. This may be generic education and training or specific teaching to facilitate support of an individual child and family (for example, training of a community nursing team to use a syringe driver for continuous infusion of medication to facilitate symptom management and end of life care at home).
- Education and training of patient or family (for example, relaxation techniques to control breathlessness or teaching how to administer medication for pain and symptom management) [This is also an aspect of other palliative care services for children.]
- Ongoing direct and indirect support through a formal or informal shared care arrangement

Although all paediatric palliative care services are able to deliver many interventions, generally speaking, the more complex the child’s problems, particularly where multiple problems are interacting with each other and the greater the number of interventions required, the greater the requirement for support from Specialist Paediatric Palliative Care Services.

Interventions that may be provided by Specialist Paediatric Palliative Care Services include:

- Complex interventions that exceed those that can be provided by the child's usual (condition specific) specialist service, core palliative care services or universal services, for example, end-stage osteosarcoma and complex pain and psychological symptoms, requiring interventions for pain management including an epidural and/or the use of specialist palliative care drug management techniques.

The Highly Specialist Paediatric Palliative Care Centres link with the eight Children's Palliative Care Networks across England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist palliative care services for children and young people from Highly Specialist Paediatric Palliative Care Centres. These services have the following features:

- Delivered by a consultant-led multi-professional specialist palliative care team
- Providing a clinical leadership role in planning delivery and evaluation of children's palliative care services across a managed clinical network
- Led by a medical consultant working at Paediatric Palliative Care Competency Level 4
- Providing the full range of specialist paediatric palliative care interventions including use of alternative opioids
- Able to treat all children and young people, regardless of their age

This includes services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission:

- Children's community nursing teams
- Specialist short break services/respite
- Routine care delivered by a children's hospice service that is not a Highly Specialist Paediatric Palliative Care Centre
- Carers and care packages
- Local, community-based palliative care services

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating individual patients can be very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

65. Highly specialist services for adults with infectious diseases

[B7 – Infectious Diseases]

Service summary
Highly specialist services for adults with infectious diseases includes:

- Patients affected by specified organisms provided by Specialist Adult Infectious Disease Centres
- High Secure Infectious Disease Units
- Tropical Disease Centres
- Highly Specialist Bone and Joint Infection Centres
- Human T-cell Lymphotropic Virus Centres

Other relevant services

- 130. Specialist services for children and young people with infectious diseases
- 131. Specialist services for complex liver, biliary and pancreatic disease (adults)

About the condition/service
Infectious diseases are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; the diseases can be spread, directly or indirectly, from one person to another. Zoonotic diseases are infectious diseases of animals that can cause disease when transmitted to humans. Infectious diseases can cause a range of symptoms, which in some cases can be life threatening.

How the service is organised
Although most hospitals treat patients with infectious diseases, about 20 specialist centres provide services to patients affected by rare organisms. Such centres have specialist infectious disease facilities such as isolation units.

There are also some highly specialist centres that provide care to patients (including children and young people) with very rare conditions:

- High Secure Infectious Disease Units (two centres)
- Tropical Disease Centres (two centres)
- Highly Specialist Bone and Joint Infection Centres (one centre)
- Human T-cell Lymphotropic Virus Centres (four centres)

The multi-disciplinary specialist infectious disease team co-ordinates a rapid and effective evaluation of the infection and its risk of transmission and provides appropriate diagnostic and medical management on a 24-hour basis. Some conditions require special isolation facilities with appropriate air handling and air filtration systems. Such facilities are serviced by teams of doctors with specialist training in infectious disease and microbiology, with support from their colleagues in nursing, radiology and pharmacology.

The specialist infectious disease team also provides telephone advice on patients being treated in local hospitals.

About 25,000 patients each year require access to highly specialist services for adults with infectious diseases.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions highly specialist services for adults with infectious diseases. The NHS CB commissions services for patients with suspected and confirmed:

- Viral haemorrhagic fevers
- Rabies
- HTLV-1 and HTLV-2 viral infection
- Meliodosis
- Leprosy
- Brucellosis
- Anthrax
- Leishmaniasis
- Trypanosomiasis – African and South American (Chagas)
- Malaria with complications, although non-complex malaria may still need specialist support
- Unusual imported invasive fungal infections, for example, Blastomycosis, cocciodomycosis, paracoccidiodomycosis, histoplasmosis, chromomycosis, sporotrichosis, zygomycoses, mycetoma
- Systemic helminthic infections – hydatid (echinococcus), neurocystercicosis, filariasis, loa loa, oncocerciasis schistosomiasis, various intestinal and biliary flukes, paragonimiasis, disseminated stronglyloidiasis, dracunculiasis, sparganosis, mansonellosis, trichinellosis
- Multi-drug resistant tuberculosis
- Systemic rickettsial infections
- Whipple’s disease
- Ehrlichiosis
- Tularaemia
- Borrelial relapsing fevers
- Endemic spirochaetoses
- Babesioisis
- Plague
- Non-pulmonary non-tuberculous mycobacteria
- Dengue haemorrhagic fever

The NHS CB also commissions specialist input to more complex cases of more common infections such as falciparum malaria, tuberculosis (especially CNS and bone), viral hepatitis (chronic) and bone and joint infections.

The NHS CB commissions all infectious disease services from:

- High Secure Infectious Disease Units
- Tropical Disease Centres
- Highly Specialist Bone and Joint Infection Centres
- Human T-cell Lymphotropic Virus Centres

The NHS CB commissions the following drugs: anti-tuberculosis drugs; anti-virals for Hepatitis C, antifungals

Clinical Commissioning Groups (CCGs) commission the non-complex elements of this service along with any services for infectious diseases provided outside of the specialist centres.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of patients requiring the service is small (about four patients from each GP practice require access to the service each year;
- the cost of providing the service is very high because of the specialist drugs and ward environment (including isolation facilities) involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at: High Secure Infectious Disease Units, Tropical Disease Centres, Highly Specialist Bone and Joint Infection Centres and Human T-cell Lymphotropic Virus Centres.

For all other highly specialist services for adults with infectious diseases, this service includes specified activity.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

66. Hyperbaric oxygen treatment services (all ages)

[D11 – Hyperbaric Oxygen Therapy]

Service summary
Hyperbaric oxygen treatment services include provision of this treatment in specified centres for specified conditions. This applies to provision in adults and children.

About this service
Hyperbaric oxygen treatment (HBOT) involves delivery of oxygen inside a treatment chamber at a partial pressure greater than 100 kPa. It is typically administered at a partial pressure substantially higher than 100 kPa and seldom less than 200 kPa. In certain circumstances, divers require prolonged exposure to ambient pressure in excess of 100 kPa but the partial pressure of oxygen is reduced to 50 kPa or less in order to avoid pulmonary toxicity. Whilst this is technically not HBOT, it is included in the scope of service as a necessary adjunct to HBOT.

Hyperbaric centres are classified depending on the availability of medical facilities, suitability for different types of patients and whether they use mono- or multi-place chambers. Mono-place chambers are less costly and may be portable. Multi-place chambers allow an attendant or nurse to care for the patient or to deal with emergencies in the chamber. Patients in a multi-place chamber typically inhale oxygen or a therapeutic mixture of gases via a hood or a mask. Standard treatment for decompression illness takes five hours but many diving casualties require longer treatment depending on severity of injury and response to treatment. For other conditions, treatment usually lasts up to two hours, although the number of sessions required is highly variable.

HBOT is widely accepted as standard clinical care for the emergency treatment of the following conditions:

- Decompression illness
- Air and gas embolism

HBOT is also used as a treatment for other conditions for which there is limited clinical and cost effectiveness data.

How the service is organised
In England, there are 10 hyperbaric oxygen centres that offer treatment commissioned by the NHS.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions hyperbaric oxygen treatment services for specified conditions from specified centres. In this context, commissioning includes deciding which treatments should be commissioned by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. Clinical Commissioning Groups (CCGs) do not commission any elements of this service, regardless of whether or the NHS CB funds them. CCG should not accept requests to fund these treatments.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (no more than 400 diving casualties, who make up the majority of patients accessing the service, are treated each year;
- the cost of providing the service is very high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

67. Insulin-resistant diabetes service (adults and children)

Service summary
Insulin-resistant diabetes services include services provided by Highly Specialist Insulin-resistant Diabetes Centres. This provision applies to adults and children.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Insulin resistant diabetes occurs because of either a genetic condition or because the individual has developed antibodies to insulin. In addition to the usual complications of diabetes (renal failure, stroke, etc) the condition can also affect the liver and can result in pancreatitis.

How the service is organised
The service is primarily outpatient based with a small amount of inpatient activity. Patients receive multi-disciplinary assessment and management that covers drug therapy and dietary advice. Additionally the service manages a number of patients on Leptin, which is currently under end-stage trials. In the event that the trial is successful, the drug will be considered for funding in a subgroup of the patients.

The service sees about 30 new patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions insulin-resistant diabetes services for adults and children from Highly Specialist Insulin-resistant Diabetes Centres.

The NHS CB commissions the following drugs: U500 insulin, recombinant human IGF-1, immunosuppression therapy, GPL-1 agonists (liraglutide, exenatide)

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Cambridge University Hospitals NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

68. Islet transplantation service (adults)

Service summary
Islet transplantation services include services provided by Highly Specialist Islet Transplantation and Laboratory Centres. This provision applies to adults.

About the condition/service
Islet transplantation is of proven benefit for patients with Type 1 diabetes who suffer from recurrent episodes of severe hypoglycaemia. Successful transplantation can abolish episodes of hypoglycaemia unawareness and improve the quality of life of recipients, whilst also improving overall metabolic control. Patients who are already immunosuppressed for a kidney transplant may also benefit from islet transplantation through the improved metabolic control afforded by an islet after kidney transplant.

How the service is organised
Two centres isolate and transplant patients and a further four centres undertake transplantation only. There were 13 islet cell transplants in 2010/11.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions islet transplantation services for adults from Highly Specialist Islet Transplantation and Laboratory Centres.

The NHS Commissioning Board commissions the following drugs/devices: immunosuppressants

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- King's College Hospital NHS Foundation Trust (cell separation and implantation)
- Oxford University Hospitals NHS Trust (cell separation and implantation)

- Royal Free London NHS Foundation Trust (implantation only)

- Central Manchester University Hospitals NHS Foundation Trust (implantation only)
- North Bristol NHS Trust (implantation only)
- The Newcastle upon Tyne Hospitals NHS Foundation Trust (implantation only)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

69. Liver transplantation service (adults and children)

Service summary
Liver transplantation services include services provided by Highly Specialist Liver Transplant centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 131. Specialist services for complex liver, biliary and pancreatic disease

About the condition/service
This service provides assessment, transplantation and lifelong follow up for patients requiring liver transplant surgery. The three main conditions for liver transplantations are primary and secondary biliary cirrhosis, chronic hepatitis and fulminant hepatic failure.

How the service is organised
There were 613 liver transplants in England in 2011/12 (20 from living donors).

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions liver transplantation services for adults and children from Highly Specialist Liver Transplant Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs/devices: immunosuppressants

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust (adults)
- King's College Hospital NHS Foundation Trust (adults and children)
- Leeds Teaching Hospitals NHS Trust (adults and children)
- Royal Free London NHS Foundation Trust (adults)
- The Newcastle upon Tyne Hospitals NHS Foundation Trust (adults)

- University Hospitals Birmingham NHS Foundation Trust (adults)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

70. Lymphangioleiomyomatosis service (adults)

Service summary
Lymphangioleiomyomatosis services include services provided by Highly Specialist Lymphangioleiomyomatosis Centres. This provision applies to adults.

Other relevant services:

- 3. Adult highly specialist respiratory services

About the condition/service
Lymphangioleiomyomatosis (LAM) is a rare, progressive disease characterised by lung cysts, kidney tumours and lymphatic abnormalities. LAM occurs in a sporadic form, which affects only females, usually of childbearing age; LAM also occurs in patients who have tuberous sclerosis complex (TSC), a genetic condition that causes non-malignant tumours to grow in the brain and on other vital organs.

About 1 in a million of the female population has sporadic LAM, i.e. about 25 patients in England.

How the service is organised
The service is delivered through:

- **Outpatient assessment and management**
- **Inpatient care:** for management of complications and in some cases diagnostic workup
- **Evaluation of patients with TSC or suspected TSC**: support for a small number of patients who may require further genetics investigations including genotyping
- **Surgical treatment**: when clinically indicated, video assisted thorascopic lung biopsy is utilised. Liaison with surgical colleagues is also required for effective management of pneumothorax and pleural effusion
- **Management of renal angiomyolipoma (benign tumour of the kidney**): case discussion and surgery where appropriate [This service is provided outside of the Highly Specialist Lymphangioleiomyomatosis Centres as part of a sub contracting arrangement.]
- **Lung transplant referral**[13]

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions LAM services from Highly Specialist Lymphangioleiomyomatosis Centres.

The NHS CB commissions the following drugs/devices: rapamycin

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

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[13] See section 57

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Nottingham University Hospitals NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

71. Lysosomal storage disorder service (adults and children)

Service summary
Lysosomal storage disorder services include services provided by Highly Specialist Lysosomal Storage Disorder Centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 62. Highly specialist metabolic disorder services (all ages)

About the condition/service
Lysosomal storage disorders (LSDs) are a group of rare genetic storage disorders, characterised by specific lysosomal enzyme deficiencies. Some LSDs can be treated using enzyme replacement therapies (ERTs) or substrate reduction therapy (SRT).

There are licensed ERTs or SRTs for seven LSDs:

- Gaucher's disease
- Anderson-Fabry's disease
- Mucopolysaccharidosis type I (MPSI, which occurs as Hurler's syndrome, Hurler-Scheie syndrome and Scheie syndrome)
- Mucopolysaccharidosis type VI (MPSVI or Maroteaux Lamy syndrome)
- Pompe's disease
- Mucopolysaccharidosis type II (MPSII)
- Niemann Pick type C

How the service is organised
The service has a caseload of about 1,800 patients.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and children with lysosomal storage disorders from Highly Specialist Lysosomal Storage Disorder Centres, including services delivered on an outreach basis as part of a provider network.

The NHS Commissioning Board commissions the following drugs/devices:

- Laronidase (aldurazyme)
- Imiglucerase (cerezyme, Vpriv)
- Iduronase (elaprase)
- Agalsidase alfa (replagal) and beta (fabrazyme)
- Aglucosidase alpha (myozyme)
- Galsulfase (naglazyme)
- Miglustat (zavesca)

Some of these therapies are provided through home care mechanisms.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of enzyme replacement therapies and substrate replacement therapies is very high.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust (adults)
- Central Manchester University Hospitals NHS Foundation Trust (children)
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Royal Free London NHS Foundation Trust (adults)
- Salford Royal NHS Foundation Trust (adults)
- University College London Hospitals NHS Foundation Trust (adults and children)
- University Hospitals Birmingham NHS Foundation Trust (adults)

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

72. Major trauma services (all ages)

[D15 – Major Trauma]

Service summary
Major trauma services include all activity (except A&E) at Major Trauma Centres for patients with an Injury Severity Score of greater than eight. This applies to provision in adults and children.

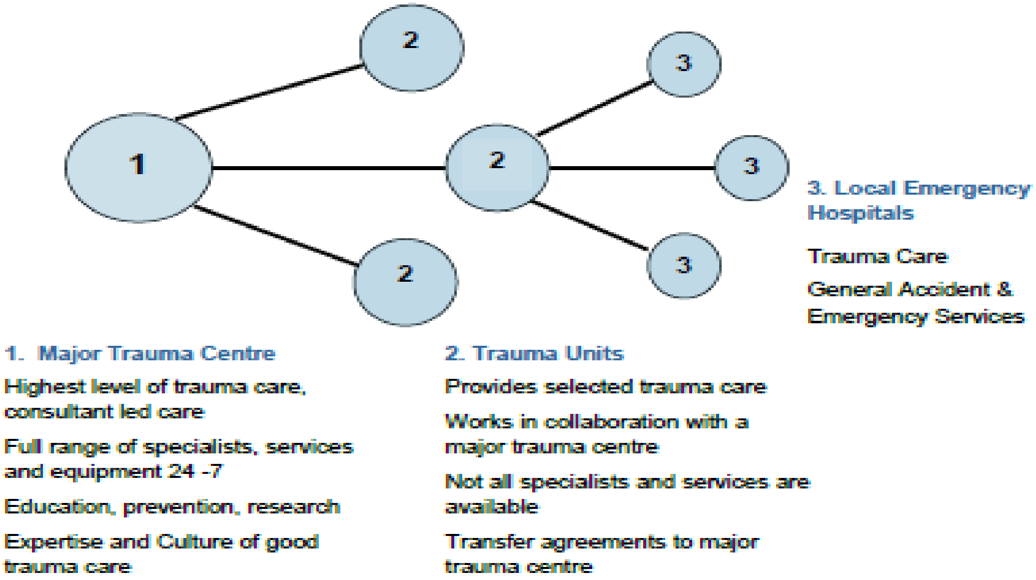
About the condition/service
Major trauma means multiple, serious injuries that could result in death or serious disability. These might include serious head injuries, severe gunshot wounds or road traffic accidents. These sorts of severe and complex injuries are quite rare: major trauma represents only 0.1% of total Accident & Emergency (A&E) activity, with the average Major Trauma Centre seeing on average one case per day. In 2010, the National Audit Office estimated that there are about 20,000 cases of major trauma each year in England.

As major trauma is so uncommon, it is not possible for all hospitals to have the equipment, onsite specialties and specialist doctors needed to treat it effectively. For this reason, patients with multiple, serious injuries should be taken directly to or transferred into a Major Trauma Centre. This is a hospital designed for the definitive care of seriously injured patients. On arrival they are immediately assessed by a specialist team led by a consultant 24/7. There is rapid access to diagnostic testing and surgery can be carried out immediately if required by a full range of trauma specialists.

How the service is organised
A Regional Trauma Network (RTN) is the name given to the collaboration between all providers of Trauma Care, from pre-hospital care through to rehabilitation. RTNs deliver trauma care services in a geographical area: at its heart is the ‘Major Trauma Centre’, linked through the network into other care providers such as ambulance services and local Trauma Units.

There are 26 Major Trauma Centres in England (adult only/standalone children’s and combined MTCs), which operate through Major Trauma Networks. Only these centres have the necessary onsite range of specialities, clinical expertise and major trauma services needed to deliver the care required to treat these severe and complex major trauma patients and their injuries.

Figure 1. Trauma Network



What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions major trauma services from Major Trauma Centres for patients taken to those centres with an Injury Severity Score (ISS) of greater than eight.

Clinical Commissioning Groups (CCGs) commission services from Major Trauma Centres for patients with an ISS of eight or less and trauma services and activity for all injured patients treated at local emergency hospitals and Trauma Units. CCGs also commission all A&E services regardless of whether this relates to patients with an ISS of more than eight.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the numbers of individuals requiring the service is small (about three patients from each GP practice require access to the service each year);
- the cost of providing the service is high because of the multi-specialist interventions involved, the intensity of the acute care and rehabilitation involved and the significant lengths of stay of some patients;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

73. McArdle's disease service (adults)

Service summary
McArdle’s services include services provided by Highly Specialist McArdle’s Disease Centres. This provision applies to adults.

Other relevant services

- 12. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children and young people

About the condition/service
McArdle's disease is a condition caused by an inborn deficiency of muscle phosphorylase resulting in an abnormal accumulation of glycogen in muscle tissue, characterised by exercise intolerance, muscular pain, fatigability and muscle cramping. Rhabdomyolosis leading to renal failure is a particularly severe complication of McArdle's disease. It is thought that there are about 150 patients in England with McArdle’s disease.

How the service is organised
The service provides an accurate diagnosis and outpatient management of the condition.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults with McArdle’s disease and related rare glycogenolytic disorders from Highly Specialist McArdle’s Disease Centres.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by Highly Specialist Adult McArdle’s Disease Centres.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is small; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- University College London Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

74. Mental health service for Deaf children and adolescents

Service summary
Mental health services for Deaf children and adolescents include services provided by Highly Specialist Deaf Child and Adolescent Mental Health centres including outreach when delivered as part of a provider network.

Other relevant services

- 32. Tier 4 child and adolescent mental health services
- 116. Specialist mental health services for Deaf adults

About the condition/service
The inpatient centre offers short-term admissions for young Deaf people with acute mental health problems, together with targeted assessment and intervention admissions for emotional and mixed disorders associated with language acquisition.

The community-based outreach service provides specialist advice, assessment and treatment in a network model with satellite clinics across the country.

How the service is organised
There are about 350 referrals to the service each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions mental health services for Deaf children and adolescents from Highly Specialist Deaf Child and Adolescent Mental Health centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) commission Tiers 1 to 3 mental health services for Deaf children and adolescents.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Dudley Primary Care Trust (outpatient and outreach)
- Leeds Partnerships NHS Foundation Trust (outpatient and outreach)
- Somerset Partnership NHS Foundation Trust (outpatient and outreach)
- South West London and St George's Mental Health NHS Trust (inpatient, outpatient and outreach)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

75. Middle ear implantable hearing aid services (all ages)

[D9 – Specialised Ear Surgery]

Service summary
Middle ear implantable hearing aid services include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).This applies to provision in adults and children.

Other relevant services

- 30. Bone anchored hearing aid services (all ages)
- 36. Cochlear implantation services (all ages)
- 108. Specialist ear, nose and throat services for children and young people

About the condition/service
Middle ear implantable hearing aid devices are hearing aids that require surgical implantation to address hearing loss that does not benefit from conventional hearing aids.

How the service is organised
Patients are referred for general hearing assessment and see an audiologist and an ENT surgeon. If middle ear implantation is considered to be an option there may be a requirement for additional CT and/or MRI scans. Those considered for middle ear implantation also have a Direct Drive Simulator test (an active trial of middle ear stimulation).

There are about eight providers that deliver a middle ear implantable hearing aid service. About 30 patients have a middle ear implant each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions middle ear implantable hearing aid services. This includes the multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance) of middle ear implantable hearing aid devices.

Commissioning includes deciding which treatments should be funded by the NHS CB – in the light of clinical and cost effectiveness information – and which should not. The NHS CB does not routinely fund middle ear implants. Clinical Commissioning Groups (CCGs) should not accept requests to fund these treatments.

CCGs commission the initial general hearing aid assessment for patients who go on to have specialist assessment for middle ear implantable hearing aids.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of patients requiring the services is very small (about one patient across 200 GP practices requires access to the service each year);

- the cost of providing the service is high because of the specialist devices involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

76. Neurofibromatosis type 2 service (adults and children)

Service summary
Neurofibromatosis type 2 services include services provided by Highly Specialist Neurofibromatosis Type 2 Centres including outreach when provided as part of a provider network. This applies to provision in adults and children.

Other relevant services

- 36. Cochlear implantation services (all ages)
- 105. Specialist cancer services
- 106. Specialist cancer services for young people

About the condition/service
Neurofibromatosis type 2 (NF2) is a genetic disorder characterised by the growth of non-cancerous tumours in the central nervous system. NF2 patients develop bilateral vestibular schwannomas (abnormal tissue growth originating in the cells of the sheath around the nerve), meningiomas (a type of benign brain tumour) and spinal tumours; usually causing deafness, balance problems, compression of the brain stem and premature death. About 1 in 60,000 of the population has NF2, i.e. about 80-100 patients in England.

How the service is organised

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and children with NF2 from Highly Specialist Neurofibromatosis Type 2 Centres, including services delivered on an outreach basis as part of a provider network. A small number of patients need an auditory brainstem implant.

The NHS CB commissions the following drugs/devices: bevacizumab, auditory brain stem implants, cochlear implants

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is being commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of providing drugs and/or auditory brainstem implants to some patients is high.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust

- Guy's and St Thomas' NHS Foundation Trust
- Oxford University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

77. Neuromyelitis optica service (adults and adolescents)

Service summary
Neuromyelitis optica services include services provided by Highly Specialist Neuromyelitis Optica Centres. This provision applies to adults and adolescents.

Other relevant services
- 12. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children and young people

About the condition/service
Neuromyelitis optica (NMO) (also known as Devic’s disease) is a rare inflammatory demyelinating disorder of the central nervous system that typically presents as severe optic neuritis and longitudinally extensive myelitis often followed by further severe attacks, which usually result in permanent disability (visual loss, limb weakness, respiratory muscle weakness). There are high mortality and morbidity rates associated with the condition. Fewer than 2 in 100,000 of the population have NMO, i.e. about 1,000 patients in England.

How the service is organised
The service provides an accurate diagnosis, inpatient or outpatient assessment and review. The service also prescribes Rituximab to appropriate patients.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with NMO from Highly Specialist Neuromyelitis Optica Centres.

The NHS CB commissions the following drugs/devices: rituximab

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by Highly Specialist Adult Ataxia Telangiectasia Centres (except for Rituximab as noted above) and care for acute relapses.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:
- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:
- Oxford University Hospitals NHS Trust
- The Walton Centre NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

78. Neuropsychiatry Services (al ages)

[D4 – Neurosciences]

Service summary

Neuropsychiatry services include services provided by Specialist Neuropsychiatry Centres. This includes assessment and treatment for patients with:

- Neurological diseases and associated severe psychiatric symptoms; or
- Severe and disabling neurological symptoms without identified neurological cause.

This applies to provision in adults and children.

Other relevant services

- 12. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children and young people

About the condition/service

Neuropsychiatry services work closely with other neuroscience and mental health services and have expertise provided by neither service alone. Neuropsychiatry services see patients with conditions such as young onset dementia including Huntington's disease, movement disorders, neuro-developmental disorders, epilepsy, sleep disorders, and acquired brain injury for example from head injury, cerebral tumours or a cerebrovascular accident. These patients are usually seen because of cognitive, behavioural or psychiatric symptoms.

Other patients are seen because of neurologically unexplained symptoms or altered states of conscious level or mental symptoms of uncertain aetiology.

How the service is organised

Neuropsychiatry Services are delivered by Specialist Neuropsychiatry Centres, which may be Neurosciences Centres (about 26 in number), Neurology Centres (about 10-15 in number) or Mental Health Centres. It is estimated that there are only about 20 neuropsychiatrists in the country. There is a National Centre for Neuropsychiatry with a 10-bedded inpatient unit.

Specialist neuropsychiatric activity includes:

- inpatient and outpatient assessment for complex conditions presenting with psychiatric symptoms
- access to clinical and nursing expertise, including neuropsychological assessment and brain scanning facilities and assessment of physical function
- intensive nursing care in specialist units and within community teams
- links with neuropathological centres
- access to detailed genetic investigations and counselling.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions neuropsychiatry services from Specialist Neuropsychiatry Centres, which may be Neurosciences Centres, Neurology Centres or Mental Health Centres. This includes assessment and treatment for patients with:

- Neurological diseases and associated psychiatric symptoms; or
- Severe and disabling neurological symptoms without identified neurological cause.

Clinical Commissioning Groups (CCGs) commission dementia services included within elderly care.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high; the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating individual patients can be high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

A review will be undertaken in two to three years to establish whether there are elements of this service that can be commissioned by CCG.

79. Ocular oncology service (adults)

Service summary
Ocular oncology services include services provided by Highly Specialist Ocular Oncology Centres. This applies to provision in adults.

Other relevant services

- 13. Adult specialist ophthalmology services
- 105. Specialist cancer services (adults)
- 90. Proton beam therapy service (adults and children)

About the condition/service
The ocular oncology service provides diagnosis, treatment and follow up of adults with suspected malignant tumours of the eye. Of the patients referred to the service about one third (about 670 each year) are confirmed as having eye cancer.

How the service is organised
There are a number of different treatment modalities:

- Surgery
- Radiotherapy
- Phototherapy
- Cryotherapy
- Chemotherapy

These eye cancer treatments can be used individually or in a combination and at present it is not clear if any particular approach has any advantages. The treatment aims, whenever possible, to preserve vision in the affected eye. Follow up care is provided for patients whose tumours recur or who have complications receive further treatment.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for patients with suspected and confirmed ocular oncology from Highly Specialist Ocular Oncology Centres.

The NHS CB commissions the following drugs/devices: radioactive plaques

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and

- the cost of treating some patients is high, placing a financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Barts Health NHS Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- The Royal Liverpool and Broadgreen University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

80. Ophthalmic pathology service (adults and children)

Service summary
Ophthalmic pathology services include diagnostic services Including specialist laboratory services) provided by Highly Specialist Ophthalmic Pathology Centres. This applies to provision in adults and children.

Other relevant services

- 13. Adult specialist ophthalmology services
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young people

About the condition/service

The National Specialist Ophthalmic Pathology Service (NSOPS) is the core national reference service for the specialist reporting of ophthalmic histopathology and cytology specimens.

How the service is organised

This service includes diagnosis and advice relevant to the clinical management of eye conditions. The service provides a comprehensive diagnostic service for malignant and non-malignant conditions for the following specimen types: eyelid, conjunctiva, cornea, aqueous and vitreous humour, iris, ciliary body, retina, choroid, sclera and orbit (including lacrimal gland and optic nerve).

The service receives about 6,000 cases each year.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions diagnostic ophthalmic pathology services from Highly Specialist Ophthalmic Pathology Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals (via their samples) requiring the service is small; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Central Manchester University Hospitals NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- The Royal Liverpool and Broadgreen University Hospitals NHS Trust
- University College London Institute of Ophthalmology, Department of Pathology

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

81. Osteo-odonto-keratoprosthesis service for corneal blindness (adults)

Service summary
Osteo-odonto-keratoprosthesis services for corneal blindness include services provided by Highly Specialist Osteo-odonto-keratoprosthesis Centres. This applies to provision in adults.

Other relevant services

- 13. Adult specialist ophthalmology services

About the condition/service
Osteo-odonto-keratoprosthesis (OOKP) surgery is a specialist surgical intervention that can restore meaningful vision to patients suffering from end stage corneal blindness, and for whom conventional corneal surgery is not possible for reasons such as severe ‘dry eyes’ that causes heavy scarring of the cornea. OOKP is only contemplated in patients where no other treatments would restore sight.

How the service is organised
During OOKP, patients are initially assessed by ophthalmic and maxillofacial consultants, involving examination of the eyes, teeth and mouth. OOKP is then a two-stage procedure that firstly involves the extraction of the patient’s own tooth and bone, which are then fashioned into a ‘bolt’ and placed within the eye for supporting a synthetic optical cylinder.

The second stage of the procedure is performed about four months after the first stage. Each surgical procedure lasts about six hours and patients require lifelong follow up.

The service sees about 10 patients each year for initial assessment.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions Osteo-odonto-keratoprosthesis services for adults from Highly Specialist Osteo-odonto-keratoprosthesis Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Brighton and Sussex University Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

82. Pancreas transplantation service (adults)

Service summary
Pancreas transplantation services include services provided by Highly Specialist Pancreas Transplant Centres. This applies to provision in adults.

Other relevant services

- 131. Specialist services for complex liver, biliary and pancreatic disease (adults)

About the condition/service
This service provides assessment, transplantation and one-year follow up for diabetic patients requiring pancreas transplant surgery.

How the service is organised
There were 178 pancreas transplants in England in 2011/12.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions pancreas transplantation services for adults from Highly Specialist pancreas transplant Centres.

The NHS CB commissions the following drugs/devices: immunosuppressants

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust
- Imperial College Healthcare NHS Trust
- Oxford University Hospitals NHS Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

83. Paroxysmal nocturnal haemoglobinuria service (adults and adolescents)

Service summary
Paroxysmal nocturnal haemoglobinuria services include services provided by Highly Specialist Paroxysmal Nocturnal Haemoglobinuria Centres including outreach when provided as part of a provider network. This provision applies to adults and adolescents.

About the condition/service
Paroxysmal nocturnal haemoglobinuria (PNH) is a rare disease in which red blood cells break down earlier than normal. Symptoms include abdominal pain, back pain, blood clots, dark urine, easy bruising or bleeding, headache and shortness of breath. About 300 patients in England suffer from PNH.

How the service is organised
This service provides diagnosis, clinical review and ongoing management for patients with the haemolytic form of paroxysmal nocturnal haemoglobinuria who are eligible for treatment with Eculizumab.

Outreach clinics are held in six locations outside of the designated hospitals.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with paroxysmal nocturnal haemoglobinuria from Highly Specialist Paroxysmal Nocturnal Haemoglobinuria Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs: eculizumab

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist drug involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- King's College Hospital NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

84. Paediatric and perinatal post mortem services

Service summary
Paediatric and perinatal post mortem services include all post mortems performed by Highly Specialist Paediatric Post Mortem Centres including examination of foetuses, babies, neonates and children.

About the condition/service
Although most cases of infant death are under the direction of the coroner, paediatricians commonly have an active involvement during attempted resuscitation and subsequent follow up with families. These cases are usually subject to a multidisciplinary review meeting between paediatrician, primary care, social care and the police, as part of the child death review process. Post mortem following neonatal death is more frequently performed for clinical reasons with parental consent.

How the service is organised
There are about TBC Highly Specialist Paediatric Post Mortem Centres in England.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions paediatric and perinatal post mortem services from Highly Specialist Paediatric Post Mortem Centres, including examination of foetuses, babies, neonates and children.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of interventions required with thin service is very small;
- the cost of providing the service is high because of the specialist facilities involved; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

85. Paediatric cardiac services

[E5 – Congenital Heart Services]

Service summary
Paediatric cardiac services include all activity provided by Specialist Surgical Centres and Children’s Cardiology Centres, including outreach when delivered as part of a provider network.

Other relevant services

- 2. Adult congenital cardiac services
- 41. Complex tracheal disease service (children)
- 52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- 57. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support (adults and children)
- 92. Pulmonary hypertension service for children

About the condition/service
Paediatric cardiac services include:

- Cardiac electrophysiology
- Inherited heart disorder services
- Congenital heart disease services
- Paediatric cardiac surgery and invasive cardiology services
- Specialist cardiovascular imaging
- Paediatric cardiac critical care
- Paediatric anaesthesia

About 3,600 heart surgery or interventional procedures are undertaken on children and young people each year.

How the service is organised
Services are delivered through seven Congenital Cardiac Heart Networks across England.

Children and young people who need heart surgery or interventional procedures are referred to a Specialist Surgical Centre. Children who live near these centres are assessed and receive follow up care there too. Some children who do not need surgery are treated in Children’s Cardiology Centres. These centres have experienced children’s cardiologists who can perform non-interventional procedures and provide ongoing management of children with congenital heart disease. Children’s Cardiac Centres team up with Specialist Surgical Centres to run combined clinics.

District Children’s Cardiac Services are available in some local hospitals. The team includes a consultant paediatrician with expertise in children’s cardiology. There is a named consultant paediatric cardiologist from the Children’s Cardiology Centre so that combined clinics are held regularly at the District Children’s Cardiac Service.

Children with suspected congenital heart disease are initially referred to the District Children's Cardiac Service where inpatient and outpatient treatment are performed. When a higher level of expertise is needed, children are referred to the Children's Cardiology Centre or the Specialist Surgical Centre.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all paediatric cardiac services from Specialist Surgical Centres and Children's Cardiology Centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one child across two GP practices requires heart surgery or a specialist interventional procedure each year);
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

86. Paediatric intestinal pseudo-obstructive disorders service

Service summary
Paediatric intestinal pseudo-obstructive disorder services include services provided by Highly Specialist Paediatric Intestinal Pseudo-obstructive Disorders Centres.

Other relevant services

- 110. Specialist gastroenterology, hepatology and nutritional support services for children and young people

About the condition/service

Chronic intestinal pseudo-obstruction is an intestinal motility disorder. Impaired intestinal motor activity causes recurrent symptoms of intestinal obstruction in the absence of mechanical occlusion. The service provides expert, multi-disciplinary diagnostic services for infants and children under five with congenital and acquired variations of the condition.

How the service is organised

This service provides a prompt and accurate diagnosis leading to rapid access to definitive treatment. There is evidence of unnecessary investigation without a definitive diagnosis. The service treats children under the age of five.

The service treats about 20 children each year.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions intestinal pseudo-obstructive disorder services for children from Highly Specialist Paediatric Intestinal Pseudo-obstructive Disorders Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

87. Positron emission tomography-computed tomography services (all ages)

[B2 – PET-CT]

Service summary
Positron emission tomography-computed tomography (PET-CT) services include all use of this diagnostic modality. This applies to provision in adults and children.

Other relevant services

- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young people

About the condition/service
A PET-CT scan combines a CT scan (anatomical) and a PET (metabolic) scan into one scan. A CT (computerised [axial] tomography) scan takes a series of x-rays and uses a computer to put them together. The CT machine takes pictures of your body from different angles and gives a series of cross sections or 'slices' through the part of the body being scanned. PET (positron emission tomography) uses a very small amount of an injected radioactive material (for example, glucose) to show where cells are active in the body.
A PET-CT scan can give important information about cancer and other diseases. It can help to

- Diagnose a cancer
- Stage a cancer
- Show whether a lump is cancer or not
- Show whether a cancer has spread to other parts of the body
- Help doctors decide on the best treatment for the cancer
- Show how well treatment is working
- Show the difference between scar tissue and active cancer tissue
- Alter the management strategy in selected patients in disease areas other than cancer, at the discretion of the lead clinician

Approximately 50,000 PET-CT scans are provided in England each year.

How the service is organised
There are approximately 25 providers of PET-CT scanning across England (usually Specialist Cancer Centres) plus two independent providers that deliver the majority of services to the NHS on both a mobile and static basis.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all PET-CT services.

Clinical Commissioning Groups (CCGs) do not commission any elements of the services.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is very high because of the specialist equipment required and the high level of regulatory and legislative requirements;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high in comparison to other diagnostic modalities, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

88. Primary ciliary dyskinesia management service (children)

Service summary
Primary ciliary dyskinesia management services include services provided by Highly Specialist Primary Ciliary Dyskinesia Management Centres including outreach when delivered as part of a provider network. This provision applies to children.

Other relevant services

- 47. Diagnostic service for primary ciliary dyskinesia (adults and children)
- 128. Specialist respiratory services for children and young people

About the condition/service
Primary ciliary dyskinesia (PCD) is a genetic disorder of the air tubes of the lungs (the bronchi), which become infected and filled with pus due to abnormalities of the hair-like structure (cilia) of the cells lining the respiratory tract. This can lead to repeated infections and damage the lung, especially if diagnosis is delayed. About 1 in 15,000 of the population has PCD.

How the service is organised
This service provides a multi-disciplinary (including respirology, ENT, audiology and physiotherapy) outpatient-based diagnostic, advice and management service to patients who are referred with suspected primary ciliary dyskinesia (PCD). It also supports and trains them in certain aspects of self-care treatment. The service also provides support to local Trusts when managing patients within an inpatient setting.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions management services for children with PCD from Highly Specialist Primary Ciliary Dyskinesia Management Centres, including services delivered on an outreach basis delivered as part of a provider network.

Clinical Commissioning Groups (CCGs) commission episodes of care for children with PCD from local providers.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Leeds University Hospitals NHS Trust
- Royal Brompton and Harefield NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- University Hospitals of Leicester NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

89. Primary malignant bone tumours service (adults and adolescents)

Service summary

Primary malignant bone tumours services include services provided by Highly Specialist Primary Malignant Bone Tumours Centres including outreach when provided as part of a provider network. This provision applies to adults and adolescents.

Other relevant services

- 14. Adult specialist orthopaedic services
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young people
- 121. Specialist orthopaedic surgery services for children and young people

About the condition/service

This service provides diagnosis and surgery for primary malignant bone cancers. Examples of conditions include osteosarcoma, chondrosarcoma and Ewing's sarcoma. The outlook is good with specialist care provided the cancer is detected early enough. One key aim is to avoid amputation if possible.

How the service is organised

The service receives about 1,000 referrals of suspected primary malignant bone tumours (PMBT) each year, of which about 300 are confirmed with PMBT.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with suspected and confirmed primary malignant bone tumours from Highly Specialist Primary Malignant Bone Tumours Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Oxford University Hospitals NHS Trust
- Royal National Orthopaedic Hospital NHS Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
- The Royal Orthopaedic Hospital NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

90. Proton beam therapy service (adults and children)

Service summary
Proton beam therapy services include services provided by Highly Specialist Proton Beam Therapy Centres. This provision applies to adults and children.

Other relevant services

- 79. Ocular oncology service (adults)
- 94. Radiotherapy services
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young people

About the condition/service
Proton beam therapy is a type of radiotherapy. It uses a high energy beam of protons rather than high energy X-rays to deliver a dose of radiotherapy for patients with cancer. It can be a more effective form of therapy because it directs the all important radiation treatment to precisely where it is needed with minimal damage to surrounding tissue. The treatment is therefore particularly suitable to complex childhood cancers.

How the service is organised
There is currently one centre in the UK that provides proton beam therapy but this can only treat patients who have eye tumours[14]. A national Proton Therapy Clinical Reference Panel considers cases, decides whether they are suitable for proton beam therapy and can therefore be referred overseas. Treatment takes 8-10 weeks.

The service treated 79 patients in 2011/12 but this number is expected to increase until 2017, when a proton beam therapy facility will be available in the UK.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions proton beam therapy services for adults and children from Highly Specialist Proton Beam Therapy Centres. This includes the patient’s travel overseas and their accommodation costs. The NHS CB also commissions any aspect of the oncology service that the patient receives prior to or after their proton beam therapy.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS Commissioning Board because:

- the number of individuals with the condition is very small;
- the cost of providing the specialist equipment is extremely high; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified

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[14] See section 79

Activity is identified via local data flows, which apply to established designated centres only:

- Paul Scherrer Institut, Villigen, Switzerland
- ProCure Proton Therapy Centre, Oklahoma, USA
- University of Florida Proton Therapy Institute, Florida, USA

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

91. Pseudomyxoma peritonei service (adults)

Service summary
Pseudomyxoma peritonei services include services provided by Highly Specialist Pseudomyxoma peritonei Centres. This provision applies to adults.

Other relevant services

- 60. Highly specialist colorectal surgery services (all ages)
- 105. Specialist cancer services (adults)

About the condition/service
Pseudomyxoma peritonei (PMP) is a rare, mucus-producing tumour, which spreads to compress the abdominal organs. PMP usually arises from a ruptured tumour of the appendix. The condition is of borderline malignancy in that it does not metastasise by the blood stream or through lymphatic spread in the early stages. The tumour spreads locally within the peritoneal cavity and eventually compresses the abdominal organs. The disease is slow growing and is considered a relatively benign condition. However, without specialist cancer treatment, the majority of patients die either from complications of repeated surgery or from compression of the small bowel with resulting malnutrition.

The symptoms of PMP are varied with most patients complaining of gradual abdominal swelling over a period of time affecting their ability to eat normally.

The incidence of PMP is between one and two per million of the population, i.e., 50-100 new patients each year in England.

How the service is organised
Treatment options include:

- Cyto-reduction and HIPEC (Hyperthermic Intraperitoneal Chemotherapy), known as the Sugarbaker technique
- Debaulking of the tumour is also an option.
- Draining of the abdomen as part of supportive care

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults with PMP from Highly Specialist Pseudomyxoma peritonei Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and

- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Hampshire Hospitals NHS Foundation Trust
- The Christie NHS Foundation Trust (Manchester)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

92. Pulmonary hypertension service for children

Service summary
Pulmonary hypertension services for children include services provided by Highly Specialist Pulmonary Hypertension centres including outreach when delivered as part of a provider network.

Other relevant services

- 15. Adult specialist pulmonary hypertension services
- 85. Paediatric cardiac services
- 93. Pulmonary thromboendarterectomy service (adults and adolescents)
- 128. Specialist respiratory services for children and young people

About the condition/service
Paediatric pulmonary hypertension is a high pressure in the circulation of blood hypertension (PH) service through the lungs, leading to progressive heart failure. The prognosis has improved with recently developed drugs. Some patients also need a lung (or heart and lung) transplant.

The service cares for about 250-300 children with PH.

How the service is organised
All patients are investigated, diagnosed, have their treatment for PH determined and their care package organised at the Highly Specialist Pulmonary Hypertension centre by a multi-disciplinary team.

The service provides care for patients with pulmonary hypertension including cardiac catheterisation, invasive radiology, echocardiography, non-invasive imaging (CT scanning, magnetic resonance imaging), exercise physiology and lung function testing. Patients may also need frequent access to microbiology, dental services, psychology, dietetics and other paediatric expertise.

Follow up care for patients recovering from paediatric pulmonary hypertension is undertaken at one of the seven satellite clinics across the UK, working through a network model.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions pulmonary hypertension services for children from Highly Specialist Hypertension Centres, including service delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs: sildenafil, bosetan, epoprostenol and equivalent drugs of the same therapeutic class.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

93. Pulmonary thromboendarterectomy service (adults and adolescents)

Service summary
Pulmonary thromboendarterectomy services include services provided by Highly Specialist Pulmonary Thromboendarterectomy Centres. This provision applies to adults and adolescents.

Other relevant services

- 8. Adult specialist cardiac services
- 15. Adult specialist pulmonary hypertension service
- 92. Pulmonary hypertension service for children

About the condition/service

Pulmonary thromboendarterectomy (PTE) is complex surgery to remove blood clots and related material from the pulmonary artery of people with chronic pulmonary thrombo-embolic disease (repeated episodes of blood clots travelling to the lung) that may cause life-threatening pulmonary hypertension (raised pressure in the artery that carries blood to the lung).

How the service is organised

The service assesses about 300 patients for surgery each year and undertakes about 150 surgical procedures.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions PTE services for adults and adolescents from Highly Specialist Pulmonary Thromboendarterectomy Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Papworth Hospital NHS Foundation Trust (Cambridge)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

94. Radiotherapy service (all ages)

[B1 – Radiotherapy]

Service summary
Radiotherapy services include all use of this treatment modality including brachytherapy and intra-operative radiotherapy and any associated outpatient activity. In addition, the service includes all provision of stereotactic radiosurgery. This applies to provision in adults and children.

Other relevant services

- 90. Proton beam therapy service (adults and children) [A highly specialist form of radiotherapy that uses protons instead of conventional x-rays.]
- 105. Specialist cancer services
- 106. Specialist cancer services for children and young people

About the condition/service
Radiotherapy, also known as radiation treatment, is the controlled use of high energy x-rays to treat many different types of cancer. About 40% of people with cancer have radiotherapy, although evidence suggests this should be about 50%. In a few cases, radiotherapy can also be used to treat benign (non-cancerous) tumours.
Radiotherapy may be used:

- to cure an illness – for example, by destroying a tumour (abnormal tissue)
- to control symptoms – for example, to relieve pain
- before surgery – to shrink a tumour to make it easier to remove
- after surgery – to destroy small amounts of tumour that may be left

How the service is organised
There are about 50 providers of radiotherapy for adults and 15-20 for children.

Radiotherapy can be given in two ways: it can be given from outside the body (external radiotherapy) or within the body (internal radiotherapy, also known as **brachytherapy**, which uses sealed sources) and molecular radiotherapy (unsealed sources/radiopharmaceuticals).

Radiotherapy is usually given as a course of treatment that lasts for a number of days or weeks. Radiation treatment is divided into a number of small doses called fractions, which are usually given over a number of weeks (up to seven). Fractions are used to reduce the side effects of a full dose of radiation. The number of fractions required depends on the type of cancer being treated.

Stereotactic radiosurgery/radiotherapy delivers a very precise dose of radiation to a tumour site. Stereotactic means locating a point using three-dimensional coordinates. This ensures that the maximum amount of radiation is aimed at the tumour and surrounding tissue is not exposed. It may be given as a single dose (radiosurgery) or delivered over several sessions (radiotherapy). The number of fractions is determined by type and extent of the cancer.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all radiotherapy services, including brachytherapy and stereotactic radiosurgery, in accordance with national commissioning policy.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is very high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

95. Rare mitochondrial disorders service (adults and children)

Service summary
Rare mitochondrial disorders services include diagnostic services provided by Highly Specialist Rare Mitochondrial Disorders Centres. This provision applies to adults and children.

About the condition/service
Mitochondria are small organelles – present in every cell in the body – whose function is to process the cell's energy. They contain their own genetic complement, the mitochondrial genome and their principal task is to provide the energy necessary for normal cell functioning and maintenance. Disruption of this energy supply can have devastating effects for the cell, organ and individual. One important consequence of mitochondrial involvement in all cell types is that mitochondrial disease can affect virtually any organ and present with a plethora of symptoms and signs to a variety of specialties. These genuinely multi-system diseases are associated with significant morbidity and mortality.

How the service is organised
The service provides diagnostic services for those patients with suspected rare mitochondrial disorders, which cannot be diagnosed by standard genetic tests available at Clinical Molecular Genetics Society-affiliated diagnostic laboratories.

The Highly Specialist Mitochondrial Disorders Centres provide:

- Specialist histochemical, biochemical and molecular genetics
- Multi-disciplinary outpatient assessment, including access to cardiology, ophthalmology, diabetology, neurology, genetics, physiotherapy, speech therapy

The service sees about 900 outpatients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions diagnostic services for adults and children with rare mitochondrial disorders from Highly Specialist Rare Mitochondrial Disorders Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Oxford University Hospitals NHS Trust

- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

96. Reconstructive surgery service for adolescents with congenital malformation of the female genital tract

Service summary
Reconstructive surgery services for adolescents with congenital malformation of the female genital tract include provision of this treatment in specified centres for specified conditions.

Other relevant services

- 112. Specialist gynaecology services for children and young people

About the condition/service
This service helps young women by providing assessment, inpatient care (including dilation therapy or surgical reconstruction), expert psychology input, outpatient support and follow up care after reconstructive surgery of female genital tract.

Conditions include:

- Congenital absence of the vagina and/or associated gynaecological structures
- Gynaecological outflow tract obstruction with primary amenorrhoea with cyclical abdominal pain and pelvis mass
- Occluded hemi-vagina
- Virilisation
- Abnormal anatomy requiring surgical reconstruction

How the service is organised
65 new patients were treated by the service in 2011/12.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions reconstructive surgery services for adolescents with congenital malformation of the female genital tract from specified centres for specified conditions.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small; and
- the number of doctors and other expert staff trained to deliver the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Imperial College Healthcare NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

97. Retinoblastoma service (children)

Service summary
Retinoblastoma services include services provided by Highly Specialist Retinoblastoma Centres. This provision applies to children.

Other relevant services

- 106. Specialist cancer services for children and young people

About the condition/service
Retinoblastoma is a malignant tumour of the retina and usually presents in children under the age of two. It is an aggressive eye cancer which can result in the loss of vision and in extreme cases, death. Between 40 and 50 children are diagnosed with retinoblastoma each year.

How the service is organised
The treatment is a combination of surgery, chemotherapy or radiotherapy dependent on the needs of the individual child. The service is effective and death from retinoblastoma in children is extremely rare.

The treatment modalities are as follows:

- Laser treatment – heat treatment to destroy the tumour
- Cryotherapy – freezing treatment to destroy the tumour
- Radiotherapy – external beam plaque brachytherapy to damage the tumour and control its growth
- Chemotherapy – to shrink the tumour (often combined with laser treatment)
- Enucleation – surgical removal of the eye in advanced cases

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for children with suspected and confirmed retinoblastoma from Highly Specialist Retinoblastoma Centres.

The NHS CB commissions the following drugs/devices: intra-arterial chemotherapy

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a financial risk on individual CCGs.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Barts Health NHS Trust
- Birmingham Children's Hospital NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

98. Secure forensic mental health service for young people

Service summary
Secure forensic mental health services for young people include services provided by Highly Specialist Secure Forensic Mental Health Service Centres for young people.

Other relevant services
- 7. Adult secure mental health services
- 32. Tier 4 child and adolescent mental health services

About the condition/service
This service provides highly specialist care in a medium secure environment, which is necessary for some young people with severe mental illness who are a danger to themselves and/or others and who may have committed criminal offences.

How the service is organised
The service treats about 140 young people each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions secure forensic mental health services for young people from Highly Specialist Secure Forensic Mental Health Services Centres for young people.

Clinical Commissioning Groups (CCGs) commission services for patients on the secure pathway who are stepping down from secure care, but who are assessed as not high risk.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:
- the number of individuals with the condition is very small;
- the cost of providing secure facilities is very high; the number of expert doctors and other staff who can provide the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:
- Birmingham and Solihull Mental Health NHS Foundation Trust
- Greater Manchester West Mental Health NHS Foundation Trust
- Hampshire Partnership NHS Foundation Trust
- Northumberland, Tyne and Wear NHS Foundation Trust
- South London and Maudsley NHS Foundation Trust
- St Andrew’s Healthcare
- West London Mental Health NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

99. Severe acute porphyria service (adults and children)

Service summary
Severe acute porphyria services include services provided by Highly Specialist Severe Acute Porphyria Centres. This provision applies to adults and children.

Other relevant services

- 62. Highly specialist metabolic disorder services (all ages)

About the condition/service
Acute porphyrias are a rare, inherited disorder, typically presenting in young adults. Acute attacks can be life-threatening. The condition can result in permanent disability and even death due to progressive motor neuropathy.

How the service is organised
The service comprises two elements:

- An acute support service to hospitals around the country. Advice is given on the treatment of the patient and the three centres also arrange for a stock of the drug, haem arginate, to be sent where appropriate
- A structured multi-disciplinary follow up service for patients after acute attacks and severely affected patients with recurrent attacks, often complicated by paralysis, and increased risk of kidney disease and hypertension

This is a new service and it is anticipated that 125-200 patients will be treated each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions severe acute porphyria services for adults and children from Highly Specialist Severe Acute Porphyria Centres.

The NHS CB commissions the following drugs: haem arginate

Clinical Commissioning Groups (CCGs) commission:

- All treatment of acute porphyria outside of the Highly Specialist Severe Acute Porphyria Centres (regardless of whether advice is given by the Specialist Centre or haem arginate prescribed by the Specialist Centre
- All treatment of acute porphyria that takes place at the Specialist Centres that does not meet the definition of ‘severe’

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the services is very small;
- the cost of providing the service is high because of the specialist investigations and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and

- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs:

- Cambridge University Hospitals NHS Foundation Trust
- Cardiff and Vale University Local Health Board
- King's College Hospital NHS Foundation Trust

100. Severe combined immunodeficiency and related disorders service (children)

Service summary
Severe combined immunodeficiency and related disorders services include services provided by Highly Specialist Severe Combined Immunodeficiency and Related Disorders Centres. This provision applies to children.

Other related services:

- 22. Autoimmune paediatric gut syndromes service
- 29. Blood and marrow transplantation services
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders

About the condition/service

Severe combined immunodeficiency disorders (SCID) is the term used to cover the most serious types of primary immunodeficiency where various components of the body's defence system are defective, leaving the child prone to unusual and/or frequent infections. In all forms of SCID, both T and B lymphocyte functions, the body's defence mechanisms, are defective from birth.

How the service is organised

Treatment is usually through a bone marrow or stem cell transplant to boost the immune system. In some cases, gene therapy or thymus transplantation is appropriate.

There are about 60 referrals to the service each year.

The service comprises:

- **Outpatient clinics**
- **Interventions:** screening for viruses, liver and kidney function, graft vs. host disease. Appropriate interventions are made if necessary including antibiotics, pre-transplant work-up and donor searches where applicable
- **Inpatient activity:** patients are admitted one to two weeks prior to their transplant for preparation and conditioning. Patients are re-admitted if there are complications following their discharge.
- **Follow up:** the follow up process runs for the period of time agreed with the referring clinician. A clinical review is required within three months post-transplant between referring and Specialist Centre clinicians to enhance communication, plan further treatment and agree on transfer arrangements.
- **Transplant:** bone marrow transplants, stem cell transplants, gene therapy, thymus transplants

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions services for children with severe combined immunodeficiency and related disorders from Highly Specialist Severe Combined Immunodeficiency and Related Disorders Centres.

The NHS CB commissions the following drugs/devices: pegadamase bovine

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the cost of the specialist facility is very high;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of the treatment and associated care including drugs is very high.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

101. Severe intestinal failure service (adults)

[A8 – Specialised Colorectal Services]

Service summary
Severe intestinal failure services include services provided by Highly Specialist Severe Intestinal Failure Centres. This provision applies to adults.

Other relevant services

- 11. Adult specialist intestinal failure services (adults)
- 103. Small bowel transplantation service (adults and children)

About the condition/service
The severe intestinal failure service treats patients with the most severe cases of intestinal failure. These patients are referred from general hospitals and teaching hospitals and have intestinal conditions that cannot be managed in a lower-intensity setting at local or regional intestinal failure units.

The major conditions covered by the service include:

- Severe and/or fistulating Crohn's disease
- Short bowel syndrome after massive intestinal resection for mesenteric vascular catastrophe
- Patients suffering from complications of severe pancreatitis
- The after-effects of therapy for malignancy
- Other conditions in which the intestine has ceased to function (for example, pseudo-obstruction)

How the service is organised
The service sees about 250 patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults with severe intestinal failure from Highly Specialist Severe Intestinal Failure Centres, including HPN.

Clinical Commissioning Groups (CCGs) commission care of patients with severe intestinal failure after discharge from hospital, including home parenteral nutrition.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- North West London Hospitals NHS Trust
- Salford Royal NHS Foundation Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

102. Severe obsessive compulsive disorder and body dysmorphic disorder service (adults and adolescents)

Service summary
Severe obsessive compulsive disorder and body dysmorphic services include services provided by Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder Centres. This applies to provision in adults and adolescents.

Other relevant services

- 32. Tier 4 child and adolescent mental health services

About the condition/service

This service offers inpatient and outpatient care for patients assessed as being at Level 6 (patients who are diagnosed as severe on a scale of 1-6) on the NICE guidelines for obsessive compulsive and body dysmorphic disorders.

How the service is organised

There are about 130 referrals to the service each year.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions services for adults and adolescents with severe obsessive compulsive disorder and body dysmorphic disorder from Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder Centres.

Clinical Commissioning Groups (CCGs) commission services for patients who are not diagnosed as severe, i.e. are on a scale of 1-5 as set out in the NICE guidelines.

Why the service is commissioned by the NHS Commissioning Board

This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the cost of providing highly specialist mental health services is very high;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

Activity is identified via local data flows, which apply to established designated centres only:

- Hertfordshire Partnership NHS Foundation Trust
- South London and Maudsley NHS Foundation Trust
- South West London and St George's Mental Health NHS Trust
- The Priory Hospital North London

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

103. Small bowel transplantation service (adults and children)

Service summary
Small bowel transplantation services include services provided by Highly Specialist Small Bowel Transplant Centres. This applies to provision in adults and children.

Other relevant services

- 11. Adult specialist intestinal failure services
- 60. Highly specialist colorectal surgery services (al ages)
- 101. Severe intestinal failure service (adults)
- 110. Specialist gastroenterology, hepatology and nutritional support services for children and young people

About the condition/service
This service provides assessment, transplantation and lifelong follow up of adult and paediatric patients requiring small bowel transplantation.

How the service is organised
There were eight adult and 11 paediatric transplants in 2010/11.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions small bowel transplantation services for adults and children from Highly Specialist Bowel Transplant Centres.

The NHS CB commissions the following drugs/devices: immunosuppressants

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust (adults)
- King's College Hospital NHS Foundation Trust (children)
- Oxford University Hospitals NHS Trust (adults)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

104. Specialist burn care services (all ages)

[D6 – Burn Care]

Service summary
Specialist burn care services include all burn care delivered by Burn Centres, Burn Units and Burn Facilities delivered as part of a provider network. This covers the whole pathway including:

- Specialist assessment
- Admission to a Centre, Unit or Facility and
- Rehabilitation and surgical reconstruction

This applies to provision in adults and children.

About the condition/service
Burn injuries range from the most minor, dealt with in the community, to the most severe and devastating, and affect all ages and social groups. In general terms, the definition of severity is based on the size and anatomical site of the injury, the depth of skin injury, the age of the patient and the presence of co-existing conditions.

Specialist burn care service activity is low volume and high cost, is driven by emergency admissions (although there is a very small number of elective cases) and requires multi-professional input and care delivered over a long period of time, involving acute, rehabilitation and community services.

Demand for burn care varies significantly across the country, especially for the more severe injuries.

How the service is organised
In England and Wales, specialist burn care services are organised using a tiered model of care (centre, unit and facility) whereby the most severely injured are cared for in services recognised as centres, those requiring less intensive clinical support are cared for in services recognised as units, and those with non-complex burn injuries are cared for in services recognised as facilities. A burn care service at a given level also provides a 'lower' level service to its local population (for example an adult burn centre also provides an adult unit and facility level service). The National Burn Care Referral Guidance (2012)[15] describes the injury severity thresholds for each level of service.

There are currently 24 NHS Trusts in England and Wales with a specialist burn care service.

Burn Facilities provide acute care for people with non complex burns. These services form part of a plastic surgery service. Burn Facilities refer patients to Burn Units and Centres for the treatment of more complex injuries (in line with national and local threshold guidance). Burn Facilities are an integral part of the patient pathway in the provision of a rehabilitation service for patients from their local area who have more

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[15] http://www.specialisedservices.nhs.uk/burncare/key-documents/national-burn-care-referral-guidance

complex injuries. Four services currently work at Facility level only (plans are in place to designate more facility-level services in a number of Networks where plastic surgery departments provide a service to non-complex burn inured patients but currently do so outside of Burn Care Networks). About 10,000 individuals require access to a Burn Facility each year.

Burn Units provide care for patients with a burn of moderate size and/or moderate complexity. These services treat patients across a wider area than Facilities and provide treatment for patients requiring critical care (such as care in a high dependency unit). There are 12 Unit level services (of which four are adult only, five child only and three both). These services deliver burn care at both Facility and Unit level. About 1,200 individuals require access to a Burn Unit each year.

Burn Centres provide care for patients with the most complex injuries and for those requiring the highest level of critical care. There are 12 services accepting patients at Centre level (of which six are adult care only, four child only and two both). These services provide burn care at Centre, Unit and Facility level. About 200 individuals require access to a Burn Centre each year.

The burn care pathway includes:

- Inpatient management of the acute burn by an extensive multi-disciplinary team focusing on intensive surgical care (including critical care if necessary), specialist nutritional care and therapy services, including physiotherapy, occupational therapy, psychology, speech and language therapy
- Discharge (from the acute service)
- Ongoing care, including outreach and rehabilitation

There are four Regional Networks of Specialist Burn Care Services across England and Wales.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all specialist burn care services provided by Burn Centres, Burn Units and Burn Facilities, delivered as part of a provider network. The NHS CB also commissions services for patients with toxic epidermal necrolysis, severe staphylococcal scalded skin syndrome and other similar conditions when they are treated in a Specialist Burn Care Centre.

Clinical Commissioning Groups (CCGs) commission burn care services from any providers that are not identified as Burns Centres, Burns Units or Burns Facilities.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small for Burn Facilities and very small for Burn Units and Centres;
- the cost of providing the facility is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

105. Specialist cancer services (adults)

[B3 – Specialised Cancer]

Service summary

Specialist cancer services include:

- All care provided by Specialist Cancer Centres for specified rare cancers*
- Complex surgery for specified common cancers provided by Specialist Cancer Centres (including assessment if performed at the Specialist Centre)
- Certain specified interventions provided by specified Specialist Cancer Centres (including assessment if performed at the Specialist Centre)
- Chemotherapy: for specified rare cancers, the procurement and delivery of chemotherapy including drug costs
- Chemotherapy: for common cancers, the drug costs, procurement and delivery of chemotherapy

‘All care’ includes cancer-related activity from referral to specialist centre to discharge including diagnostics, chemotherapy, surgery and any long term follow up. This includes outreach when delivered as part of a provider network. In addition, the service includes specialist palliative care and survivorship, when provided by a Specialist Cancer Centre.

Other relevant services

- 14. Adult specialist orthopaedic services
- 18. Adult thoracic surgery services
- 33. Choriocarcinoma service (adults and adolescents)
- 53. Ex-vivo partial nephrectomy service (adults)
- 60. Highly specialist colorectal surgery services (all ages)
- 76. Neurofibromatosis type 2 service (adults and children)
- 79. Ocular oncology service (adults)
- 80. Ophthalmic pathology service (adults and children)
- 87. Positron emission tomography-computed tomography services (all ages)
- 89. Primary malignant bone tumours service (adults and adolescents)
- 90. Proton beam therapy service (adults and children)
- 91. Pseudomyxoma peritonei service (adults)
- 94. Radiotherapy service (all ages)
- 106. Specialist cancer services for children and young people
- 131. Specialist services for complex liver, biliary and pancreatic disease (adults)

About the condition/service

Over 300,000 people are diagnosed with cancer each year and more than 1 in 3 people will develop cancer during their lifetime. There are over 200 types of cancer, of which about 50% are classified as ‘rare’.

How the service is organised

There are about 20 Specialist Cancer Centres that either treat specified rare cancers and/or provide specialist interventions for patients with more common cancers.

Some services are delivered on an outreach basis. In addition, a much larger number of Trusts (over 130) provide chemotherapy for patients with common cancers.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist cancer services for adults, including services delivered on an outreach basis as part of a provider network. Specialist cancer services include:

A. All care provided by Specialist Cancer Centres for specified rare cancers
  - Anal cancers
  - Brain/central nervous system cancers for all low and high grade tumours (linking with Specialist Neurosciences centres)
  - Endocrine cancers
  - Germ cell cancers (except initial diagnosis and treatment)
  - Gynaecological cancers (except early stage cervical and endometrial cancers and initial assessment of all gynaecological cancers)
  - Head and neck cancers
  - Mesothelioma (except malignant pleural mesothelioma)
  - Pituitary cancers (linking with Specialist Neurosciences Centres)
  - Sarcoma (except soft tissue sarcoma identified for local surgery)[16]
  - Skin cancers (patients with invasive skin cancer with a greater risk or rarity and patients with cutaneous skin lymphomas)
  - Upper gastro intestinal cancers
  - Urological cancers (testicular, penile)

B. All care provided to Teenagers and Young Adults by defined Specialist Teenage and Young Adult Cancer Centres

C. Certain complex surgery for more common cancers provided by specified Specialist Cancer Centres (including assessment if performed at the Specialist Centre):
  - Germ cell cancers (for example, gynaecological and testicular except initial diagnosis and non-complex surgery)
  - Gynaecological cancers (except early stage cervical and endometrial cancers and initial assessment of all gynaecological cancers)
  - Urological cancers (defined specialist surgery only for bladder, kidney and prostate cancers)

D. Certain specified interventions provided by defined Specialist Cancer Centres (including assessment if performed at the Specialist Centre) for more common cancers:

  - **Gastrointestinal cancer interventions:**
    - laparoscopic liver resection
    - thoracoscopically assisted oesophagectomy
    - preoperative high dose rate brachytherapy for rectal cancer
    - microwave ablation for hepatocellular carcinoma

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[16] See section 14

    - laparoscopic gastrectomy for cancer

- **Gynaecological cancer interventions:**
    - exenterative surgery for gynaecological cancer
    - high dose rate brachytherapy for carcinoma of the cervix

- **Lung cancer interventions:**
    - continuous hyperfractionated accelerated radiotherapy (CHART)) for non-small cell lung cancer
    - thoracic surgery for lung cancer
    - cryotherapy for malignant endobronchial obstruction

- **Skin cancer interventions:**
    - Mohs surgery
    - total skin electron beam radiotherapy (TSEB)
    - photopheresis for cutaneous (skin) T-cell lymphoma
    - immunocompromised patients at increased risk of developing skin cancers, for example, transplant patients

- **Urological cancer interventions:**
    - cryotherapy as a primary treatment for prostate cancer
    - cryotherapy for renal cancer

E. Chemotherapy: for specified rare cancers, the procurement and delivery of chemotherapy including drug costs and diagnostic testing for targeted medicine

F. Chemotherapy: for common cancers, the drug costs, procurement and delivery of chemotherapy including diagnostic testing for targeted medicine

Clinical Commissioning Groups (CCGs) commission services for patients with the following common cancers with the exception of radiotherapy, chemotherapy and the specialist interventions listed above:
- Bladder and kidney cancer (except specialist surgery)
- Breast cancer
- Germ cell cancer (initial diagnosis and treatment)
- Gynaecological cancers (Initial assessment of all cancers; treatment of early stage cervical and endometrial cancers)
- Haematological cancers and associated haemato-oncological pathology
- Lower gastrointestinal cancer
- Lung cancer (including pleural mesothelioma)
- Prostate cancer (except specialist surgery)
- Sarcoma (soft tissue where local surgery is appropriate)
- Skin cancer (except for patients with invasive skin cancer and those with cutaneous skin lymphomas)

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small (requiring a planning population of between one and six million depending on the cancer);

- the cost of providing the service is high because of the specialist interventions and drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

For rare cancers and all chemotherapy, this service includes ALL activity at specified centres.

For surgery and interventions, this service includes specified activity at specified centres.

Review of the service commissioner
There are plans to review chemotherapy for common cancers in terms of elements that could be commissioned by CCGs in the future.

106. Specialist cancer services for children and young people

[E4 – Paediatric Cancer Services]

Service summary
Specialist cancer services for children and young people include:

- All specialist care for children within children's Principal Treatment Centres (PTCs)
- All specialist care for teenagers and young adults within Teenage and Young Adult PTCs including transitional care
- All shared care overseen by PTCs
- All cancer chemotherapy and radiotherapy
- All specialist cancer palliative care services
- Planning after care (as part of the survivorship initiative)

Other relevant services

- 76. Neurofibromatosis type 2 service (adults and children)
- 80. Ophthalmic pathology service (adults and children)
- 87. Positron emission tomography-computed tomography services (all ages)
- 89. Primary malignant bone tumours service (adults and adolescents)
- 90. Proton beam therapy service (adults and children)
- 94. Radiotherapy service (all ages)
- 97. Retinoblastoma service (children)
- 105. Specialist cancer services (adults)

About the condition/service
Each year, about 1,200 children aged 0 to 14 years and 500 teenagers aged 15 to 18 years are newly diagnosed with cancer. In addition 1,300 young adults aged 19 to 24 are also diagnosed with cancer. Paediatric cancer is rare with about one in 600 children being diagnosed with a cancer by the age of 15.

How the service is organised
Children are treated primarily in 13 Children's Principal Treatment Centres (PTCs) and teenagers at either the Children's PTCs or one of the 13 Teenage and Young Adult PTCs. In addition there are about 90 shared care centres.

So as to provide care as close to the child or young person's home as possible, the PTCs decide and direct which elements of specialist cancer care can be delivered in hospitals designated for cancer shared care. The PTCs are staffed by doctors and nurses with specialist qualifications and training in cancers in this age group, whereas the shared care sites for children are staffed by doctors with a special interest in cancer. The PTCs link with associated children's services such as education.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist cancer services for children and young people from Children's PTCs and Teenage and Young Adult PTCs. The NHS CB also commissions services delivered at about 90 shared care

centres through the 26 PTCs. Specialist cancer services for children and young people include:

- All cancer chemotherapy and radiotherapy
- Specialist palliative care services
- Survivorship
- Long-term follow up
- Specialist therapies and rehabilitation

The NHS CB commissions the following drugs/devices: chemotherapy drugs

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one child or teenager is diagnosed with cancer across four GP practices each year and one young adult across five GP practices);
- the cost of providing the service is very high because of the specialist interventions and drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

107. Specialist dentistry services for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist dentistry services for children and young people include services provided by Specialist Paediatric Dental Surgery Centres including outreach when delivered as part of a provider network. The service includes:

- Surgical management of rare or complex conditions
- Surgical management of more common conditions when the child or the procedure is high risk (including the need for PICU or Specialist Anaesthetic management)
- Provision of specified procedures

Other relevant services

- 43. Craniofacial service (adults and children)

About the condition/service

Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex; the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. For example, multiple dental extractions are normally a routine procedure but require specialist surgical and anaesthetic input when the child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

There are about 20 Specialist Paediatric Dental Surgery Centres in England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist dentistry services for children and young people from Specialist Paediatric Dental Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require

treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

The NHS CB also commissions all other dental services through its dental contracts.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

108. Specialist ear, nose and throat services for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist ear, nose and throat services for children and young people include services provided by Specialist Ear, Nose and Throat Paediatric Surgery Centres including outreach when delivered as part of a provider network. The service includes:

- Surgical management of rare conditions
- Surgical management of more common conditions when the child or the procedure is high risk (including the need for PICU or Specialist Anaesthetic management)
- Provision of specified procedures

In addition, this service includes Specialist Audiology Services.

Other relevant services

- 30. Bone anchored hearing aid services (all ages)
- 36. Cochlear implantation services (all ages)
- 43. Craniofacial service (adults and children)
- 75. Middle ear implantable hearing aid services (all ages)

A. SPECIALIST EAR, NOSE AND THROAT SURGERY

About the condition/service
Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex (for example, total thyroidectomy); the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. For example, adenotonsillectomy is normally a routine procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

The specialist service links to associated children's services such as education.

How the service is organised
There are about 20 Specialist Ear, Nose and Throat Paediatric Surgery Centres in England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist ear, nose and throat services for children and young people from Specialist Ear, Nose and Throat Paediatric Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

Clinical Commissioning Groups (CCGs) commission routine ENT surgical management when the child or the procedure is not high risk, including:

- Tonsillectomy
- Adenoidectomy
- Insertion of grommets

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

B. SPECIALIST AUDIOLOGY SERVICES

About the service/condition

About 700 children are identified with bilateral hearing loss each year, 50-100 due to acquired hearing loss. About 12,000 children and young people require access to Specialist Audiology Services.

How the service is organised

To be added

What the NHS Commissioning Board commissions

The NHS CB commissions Specialist Audiology Services. Specialist Audiology Services are those audiological services that are part of a paediatric hearing aid service and include:

- Differential audiological diagnosis
- Etiological investigations (including radiology and genetics) and medical assessment (including vestibular assessment)
- Hearing aid and frequency modulated hearing aid provision
- Cochlear implant assessment and provision of cochlear implants[17]
- Transitional arrangements to adult services
- Outreach support to education

Clinical Commissioning Groups (CCGs) commission all other children's audiology services, including: services for children with unilateral hearing loss, glue ear and auditory neuropathy spectrum disorder; and assessment of children referred for professional concern or following a school screen.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions and specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

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[17] See section 36

109. Specialist endocrinology and diabetes services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist endocrinology and diabetes services for children and young people include:

- care for complex endocrine conditions provided by Paediatric Endocrine Centres (PECs)
- care for complex conditions related to diabetes provided by Paediatric Diabetes Centres, usually co-located with PECs

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant services

- 10. Adult specialist endocrinology services
- 20. Alström syndrome service (adults and children)
- 24. Bardet-Biedl syndrome service (adults and children)
- 42. Congenital hyperinsulinism service (children)
- 55. Gender identity development service for children and adolescents
- 67. Insulin-resistant diabetes service (adults and children)
- 117. Specialist morbid obesity services
- 142. Wolfram syndrome service (adults and children)

About the condition/service
Common paediatric endocrinology conditions are managed in local hospitals or primary care settings, but complex and rare endocrine conditions are managed in conjunction with Paediatric Endocrine Centres and Paediatric Diabetes Centres.

The incidence of these conditions varies from 1 in 1,000 where specialist endocrine input is required for some with the condition at a certain point in their lives (for example, puberty), through 1 in 5,000-10,000 where the condition requires a higher level of endocrine input (in some cases lifelong), through to rare (<1 in 10,000) endocrine conditions that require intensive input at various stages during childhood and adolescence, including lifelong endocrine input.

How the service is organised
There are about 18 Paediatric Endocrine/Paediatric Diabetes Centres in England.

Specialist Endocrinology and Diabetes Services for children and young people are provided in conjunction with other specialist paediatric services (including neonatal/paediatric Intensive and High dependency care, oncology, neurosurgery, endocrine surgery, biochemistry, genetics, imaging, histopathology, pharmacy, dietetics, physio/occupational therapy) and provide on-call cover for their region. The majority of children are assessed and treated on an outpatient or day case basis by the specialist multi-disciplinary team; these teams may focus on one set of conditions, for example, bone disorders. Treatment and follow up are lifelong and planned transition to adult services takes place via joint and/or hand-over clinics.

Outreach clinics led by the specialist endocrine and diabetes teams from the centres may take place in more local settings. These may include assessment of new patients referred from local paediatricians and review of existing patients through shared care arrangements.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist endocrinology and diabetes services for children and young people from Paediatric Endocrine/Paediatric Diabetes Centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions services for the following conditions:

(a) Endocrinology:

- complex growth problems including Turner syndrome and growth hormone deficiency; puberty disorders including precocious, delayed or absent puberty
- pituitary disease including hypopituitarism, pituitary and peri-pituitary tumours
- complex fluid balance problems (for example, in neurosurgery)
- thyroid and parathyroid associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease, for example, care of endocrine problems in cancer survivors, cystic fibrosis related diabetes, growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
- severe or repeated hypoglycaemia
- disorders of bone and calcium metabolism
- multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- DSD (disorders of sex development)
- morbid obesity

(b) Diabetes:

- diabetes complications in childhood (for example, nephropathy, complex compliance problems such as eating disorders)
- Type 2 or rare forms of diabetes (for example, neonatal diabetes, maturity onset diabetes of the young – MODY)
- Insulin resistance syndromes
- diabetes associated with chronic disease (for example, cystic fibrosis or high dose steroid usage in the treatment of some cancers)
- morbid obesity associated with Type 2 diabetes

The NHS CB commissions the following drugs/devices:

- Insulin-like growth factor-I
- Gonadotrophin releasing hormone analogues
- Anabolic and sex steroids
- Insulin sensitisers

- Insulin pumps

Clinical Commissioning Groups (CCGs) commission all other paediatric endocrine and diabetes activity.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

110. Specialist gastroenterology, hepatology and nutritional support (GHNS) services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist gastroenterology, hepatology and nutritional support (GHNS) Services for children and young people include:

- care for complex conditions provided by Paediatric Specialist GHNS Centres
- care for more common conditions requiring support from Paediatric Specialist GHNS Centres

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant services

- 86. Paediatric intestinal pseudo-obstructive disorders service
- 103. Small bowel transplantation service (adults and children)
- 123. Specialist paediatric liver disease service

About the condition/service
Specialist Gastroenterology, Hepatology and Nutritional Support (GHNS) Services for children and young people focus on the investigation and management of rare disorders and on complex or atypical cases of more common disorders. In some cases the role of the specialist gastroenterology, hepatology and nutrition centre may be to provide advice to a local clinical service and in many cases the centre shares clinical management with the local hospital but some patients require the intensive involvement of the specialist centre, particularly during periods of illness or for diagnostic evaluation including endoscopy, gastrointestinal imaging, manometry or liver biopsy.

How the service is organised
There are about 20 Paediatric Specialist GHNS Centres in England.

Specialist GHNS Services for children and young people perform colonoscopy and have a service for gastrointestinal bleeding and are co-located with paediatric surgery. A smaller number of centres in England provide comprehensive out of hours cover for Gastroenterology 365 days per year. GHNS Services for children and young people are delivered as part of a clinical network in order to provide the best patient care, facilitate optimal use of resources and maximise local access for patients.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist GHNS services for children and young people from Paediatric Specialist GHNS centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions services for the following conditions:

- Inflammatory bowel disease

- Intestinal failure
- Chronic diarrhoea/malabsorption
- Gastrointestinal polyps and polyposis syndromes
- Eosinophilic disorders
- Gastrointestinal motility disorders
- Exocrine pancreatic insufficiency and pancreatic disorders including pancreatitis
- Acute and chronic liver disorders
- Gastrointestinal bleeding
- Specialist nutritional support

The NHS CB commissions the following specialist investigations:

- upper gastrointestinal endoscopy (diagnostic and therapeutic)
- ileo-colonoscopy (diagnostic and therapeutic)
- video-capsule endoscopy
- endoscopic ultrasonography (EUS)
- endoscopic retrograde cholangiopancreatography (ERCP) (diagnostic and therapeutic)
- oesophageal pH and impedance monitoring
- diagnostic breath tests including hydrogen breath tests
- pancreatic function intestinal intubation tests
- gastrointestinal motility investigations (including oesophageal and gastrointestinal manometry, electrogastrography)
- enteroscopy

Clinical Commissioning Groups (CCGs) commission services for patients with these conditions once they have been discharged to local follow up following input from the specialist centre at presentation. These conditions can be managed by a local hospital initially as secondary care and then be referred for specialist care:

- Coeliac disease
- Peptic ulcer disease including *H. Pylori* gastritis
- Fabricated and induced illness presenting with gut symptoms
- Multiple food intolerances (actual and perceived) part of a network including allergist and local paediatrician.

The NHS CB commissions services for patients with these common conditions only when referral to the specialist centre is required

- Gastro oesophageal reflux disease
- Constipation
- Gastrointestinal functional disorders

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and

- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

111. Specialist genetic services (all ages)

[E1 – Medical Genetics]

Service summary
Specialist genetic services include services provided by Regional Clinical Genetics Centres, including outreach clinics when delivered as part of a provider network and specialist laboratory services. This applies to provision in adults and children. This service includes the provision of Pre-implantation Genetic Diagnosis and associated In-vitro Fertilisation services.

About the condition/service
Medical Genetics can be divided into to two main service areas both covering children and adults:

- Clinical Genetics
- Laboratory Genetics (consisting of molecular and cytogenetic tests and, in some Regional centres, specialist Biochemistry tests or other specialist tests).

Diseases with a genetic component are estimated to affect at least 5-6% of the population.

Clinical Genetics Departments provide diagnostic and genetic counselling services and, in some multi-system disorders, co-ordination of management and follow up for individuals and families with, or at risk of, conditions which have, or may have, a genetic basis.

Laboratory Genetics services provide either or both molecular and cytogenetic testing and, in some centres, Specialist Biochemistry tests. This covers diagnostic testing, carrier testing, prenatal and pre-symptomatic testing for a range of conditions. Laboratory Genetics Services provide tests for many referrers, including General Practitioners, a range of medical and surgical secondary and tertiary specialists as well as Clinical Geneticists and Genetic Counsellors.

How the service is organised
There are 17 Specialist Clinical Genetics Services in England.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist genetic services provided by Specialist Clinical Genetics Centres including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions tests ordered by Clinical Geneticists and Genetic Counsellors.

The NHS CB commissions the provision of Pre-Implantation Genetic Diagnosis and associated in-vitro fertilisation services.

Where genetic tests are ordered by a clinician other than a clinical geneticist or genetic counsellor, the test forms part of the pathway for the referring specialty. The commissioning responsibility is as follows:

- Where the referrer is referring as part of another service commissioned by the NHS CB, the NHS CB commissions the genetic test
- Where the referrer is a primary care or secondary/tertiary care clinician referring from a service that is not commissioned by the NHS CB, **Clinical Commissioning Groups (CCGs)** commission the genetic test

CCGs commission all in-vitro fertilisation services, except those associated with Pre-Implantation Genetic Diagnosis and those for members of the armed forces and some veterans.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

112. Specialist gynaecology services for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist gynaecology services for children and young people include all activity provided by Highly Specialist Paediatric Gynaecology Centres including outreach when delivered as part of a provider network.

Other relevant services

- 96. Reconstructive surgery service for adolescents with congenital malformation of the female genital tract

About the condition/service
Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex (for example, total thyroidectomy); the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

Congenital abnormalities of the genital tract are rare and include disorders of sex development (DSD) and Mullerian anomalies. Children with congenital abnormalities of the genital tract fall into two groups. The first group consists of those who are diagnosed at birth or during childhood before puberty. The diagnosis may have been made at birth with genital ambiguity or during childhood with precocious puberty, virilisation or with an inguinal hernia found to contain a testis. Genetic testing can lead to diagnosis because of an affected family member. These children usually have a DSD. The second group consists of those who present for the first time in adolescence. Presentation may be with delayed puberty, virilisation, primary amenorrhoea or obstructed menstruation. This may be due to a DSD or Mullerian anomaly.

How the service is organised
There are about TBC Highly Specialist Paediatric Gynaecology Centres in England.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist gynaecology services for children and young people from Highly Specialist Paediatric Gynaecology Centres, including services delivered on an outreach basis as part of a provider network.

The NHS Commissioning Board (NHS CB) commissions specialist ear, nose and throat services for children and young people from Specialist Ear, Nose and Throat Paediatric Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

Clinical Commissioning Groups (CCGs) commission routine surgery for children over 60 weeks post-conceptual age who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Examination under anaesthetic/swab taking in the event of suspected child abuse

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

113. Specialist haematology services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist haematology services for children and young people include services provided by Specialist Paediatric Haematology Centres including outreach when delivered as part of a provider network.

About the condition/service
The majority of care for children with haematological disorders can be provided by their local hospital. Some of the most common acute complications involve treatment of infections and many conditions require the regular transfusion of blood products; both of these services are better delivered locally. With the exception of children who have self-limited conditions or who are at low risk of complications, the diagnosis should be confirmed and a management plan formulated and regularly reviewed by a Specialist Paediatric Haematology Centre.

How the service is organised
There are about 17 Specialist Paediatric Haematology Centres in England.

Specialist Paediatric Haematology Specialist Centres provide:
- 24/7 access to care by a consultant paediatric haematologist
- Access to a paediatric haematology clinical nurse specialist, paediatric clinical psychologist and haematology laboratory scientist

Many of the specialist centres deliver outreach clinics, which have an important role in (a) the diagnosis of conditions with limited complexity and (b) follow up of patients.

Outreach services are delivered as part of a provider network and involve:
- A paediatric haematologist from the specialist centre
- A paediatric haematology clinical nurse specialist
- A local general paediatrician
- A local clinical nurse specialist (in some cases)
- A local haematologist (in some cases)

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist haematology services for children and young people from Specialist Paediatric Haematology Centres, including services delivered on an outreach basis as part of a provider network.

The NHS CB commissions services for the following conditions:
- Vitamin B_{12}, iron and folate deficiency anaemia
- Anaemia due to enzyme disorders
- Hereditary haemolytic anaemia
- Acquired haemolytic anaemia
- Acquired pure red cell aplasia

- Aplastic anaemia
- Sideroblastic anaemia
- Congenital dyserythropoietic anaemia
- Methahaemoglobinaemia
- Neutropenia
- Functional disorders of neutrophils
- Other disorders of white cells
- Myeloproliferative disorders
- Myelodysplasia
- Haemophagocytic lymphohistiocytosis
- Asplenia
- Hereditary or acquired coagulation deficiencies
- Purpura and other haemorrhagic conditions
- Thrombosis

Clinical Commissioning Groups (CCGs) commission the following services:

- Vitamin B_{12}, iron and folate deficiency anaemia
  - Nutritional anaemia not presenting with pancytopenia
  - Monitoring of stable disease
- Anaemia due to enzyme disorders
  - Uncomplicated G6PD
- Hereditary haemolytic anaemia
  - Mild hereditary spherocytosis
  - Monitoring of anaemia

The NHS CB commissions the following investigations from Specialist Paediatric Haematology Centres:

- Blood films
- Bone marrow aspirate and trephine
- Special haematology investigations
- Interpretation of special transfusion investigations
- Factor assays and special coagulation investigations
- Insertion of central venous catheters
- Plasmapheresis
- MR techniques for iron load assessment
- Liver biopsies
- Genetic testing

CCGs commission the following investigations:

- Blood films
- Factor assays and special coagulation investigations
  - Clotting screen
- Iron, B12, folate and coagulation tests

The NHS CB commissions the following interventions from Specialist Paediatric Haematology Centres:

- Initiation and monitoring of anticoagulation
- Initiation and monitoring of immunomodulatory therapy

- Combination of immunomodulatory therapy
- Monoclonal antibodies
- Initiation of anabolic steroids
- Initiation of chelation treatment
- Combination of chelation treatment
- Growth factors
- Initiation of hydroxycarbamide treatment
- Transfusions
- Treatment of all infections including invasive fungal infections and viral reactivations

CCGs commission the following interventions:

- Monitoring of anticoagulation
- Monitoring of single immunomodulatory therapy
- Monitoring of chelation treatment
- Monitoring of hydroxycarbamide treatment
- Transfusions
- Treatment of infections

The NHS CB commissions the following drugs/devices: immunomodulatory therapies, monoclonal antibodies, chelation treatments, growth factors, hydroxycarbamide, immunoglobulins

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

114. Specialist haemoglobinopathy services (all ages)

[B8 – Haemoglobinopathies]

Service summary
Specialist haemoglobinopathy services include all care provided by specialist haemoglobinopathy centres including inpatient care where the cause of admission is related to haemoglobinopathy. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

About the condition/service
There are about 1,000 patients with thalassaemia and 15,000 with Sickle Cell Disease (SCD) living in England at present, a large number of whom are under 19 years of age. The disorders occur predominantly but not exclusively in ethnic minority communities. SCD is the most common inherited condition in England; about 350 babies are born in England each year with SCD compared with 20-30 babies with thalassaemia. 60% of patients with SCD live in Greater London with the majority of the others within other inner city areas.

How the service is organised
About 120 Trusts deliver services to patients with haemoglobinopathies of which about 20 are Specialist Haemoglobinopathy Centres. A key element in the organisation of these services is the leadership responsibility of the Specialist Centres to support other Trusts in delivering high quality equitable care across an agreed geographic area.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all care provided by Specialist Haemoglobinopathy Centres where the cause of the admission is related to haemoglobinopathy. This includes services delivered on an outreach basis as part of a provider network.

The NHS CB commissions the following drugs/devices: red-cell transfusion, iron chelation.

Clinical Commissioning Groups (CCGs) commission services for patients with haemoglobinopathies outside of Specialist Haemoglobinopathy Centres where care is not provided on an outreach basis from the Specialist Haemoglobinopathy Centre as part of a provider network.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (there are two to three patients with a haemoglobinopathy registered at each GP practice although this varies widely around the country);
- the cost of providing the service is high because of the specialist drugs involved and the significant lengths of stay of some patients;
- the number of doctors and other expert staff trained to deliver the service is small; and

- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

115. Specialist immunology services for patients with deficient immune systems (all ages)

[B9 – Specialised Immunology and Allergy Services, E3 – Paediatric Medicine]

Service summary
Specialist immunology services include:
(a) Services provided by Highly Specialist Immunology Centres, including outreach when delivered as part of a provider network, for the following:

- All primary immunodeficiencies
- Autoimmune and autoinflammatory disease where there is associated immunodeficiency
- Complex autoimmune and vasculitic conditions as shared care
- Autoinflammatory syndromes

Services include provision of cytokines and other immunomodulatory therapies for the above conditions.

Other relevant services

- 58. Highly specialist allergy services (all ages)

About the condition/service
Primary immunodeficiencies are disorders in which part of the body's immune system is missing or does not function properly. Patients with primary immunodeficiencies have an increased susceptibility to recurrent, severe and/or unusual infections, which may be in any body system. Patients die from infections if not treated or can have recurrent health problems and may develop serious and debilitating illness. Primary immunodeficiencies may present not only with infections, but also with severe and often early onset autoimmune and autoinflammatory conditions, or infection-associated cancers such as lymphoma. Most primary immunodeficiencies are genetic disorders; the majority are diagnosed in young children, although milder forms may not be recognised until later childhood or adulthood. There are an estimated 6,000 people in England (adults and children) living with a primary immunodeficiency. This number includes patients with the condition hereditary angioedema (C1 inhibitor enzyme deficiency), which causes life-threatening swellings.

Following worldwide shortages of immunoglobulin in 2007, the Department of Health published a Demand Management Programme on Immunoglobulin Use to ensure that immunoglobulin was available and funded for all essential infusions to patients and to ensure that the most appropriate cases received supply in times of shortage. There is a national database onto which all immunoglobulin is recorded, regardless of the indication. Immunologists have a role in local immunoglobulin panels and as one of the major users of long term immunoglobulin replacement therapy.

How the service is organised

A. Adults

About 26 Highly Specialist Immunology Centres in England provide expert care to adults with primary immunodeficiencies. They incorporate the investigation, clinical assessment, treatment and holistic management of patients with suspected and established primary immunodeficiencies. The management of patients with primary immunodeficiencies requires either lifelong therapy with a limited and expensive blood product called immunoglobulin or with other biological agents such as interferons, C1 inhibitor concentrate, bradykinin receptor antagonists or colony stimulating factors.

All centres work through a multi-disciplinary team due to the complex nature of the conditions and heterogeneity of patient presentations; members include Specialist Nurses, dietitians, physiotherapists, genetic counsellors and social workers. Often, patients have shared care with other organ-based medical specialties.

Services are often delivered through network arrangements, including shared care and education for peripheral hospitals.

Immunology nurse specialists are essential to operate home therapy provision safely for patients, which is common for the administration of immunoglobulins. Access to a specialist diagnostic immunology laboratory is an integral component of the service.

A small number of centres provide specialist immunological management of complex autoimmune, autoinflammatory conditions and vasculitic conditions, including diagnosis and treatment. This is often undertaken in collaboration with rheumatology, respiratory and neurology services.

B. Children

About 13 Highly Specialist Immunology Centres provide expert care to children with primary immunodeficiencies. These centres co-ordinate provider networks over large geographical areas.

Adult and paediatric services are usually separate but work closely together and are often co-located. Transition arrangements for seamless transfer between paediatric and adult services is essential to ensure that young people take responsibility for their condition, its treatment and what they can do to minimise the risks to their health.

Highly Specialist Immunology Centres incorporate the investigation, clinical assessment, treatment and holistic management of patients with suspected and established primary immunodeficiencies. The management of patients with primary immunodeficiencies requires either lifelong therapy with a limited and expensive blood product called immunoglobulin or with other biological agents such as interferons or colony stimulating factors.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist immunology services for adults and children with deficient immune systems from Highly Specialist Immunology Centres, including services delivered on an outreach/shared care basis as part of a provider network. The NHS CB commissions services for the following conditions:

- All suspected and confirmed primary immunodeficiencies including functional disorders of polymorphonuclear neutrophils, hyposplenism, immunodeficiency with predominantly antibody defects, combined immunodeficiencies, immunodeficiency associated with other major defects, common variable immunodeficiency, other immunodeficiencies, for example, infection-induced cancers, ataxia telangiectasia

The NHS CB commissions the following drugs, some of which may be delivered in the patient’s home

- intravenous and subcutaneous immunoglobulins
- interferons
- colony stimulating factors
- C1 inhibitor
- other immune modulating drugs
- bradykinin receptor antagonists

Clinical Commissioning Groups (CCGs) may commission local immunology diagnostic laboratory support or clinical services.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS Commissioning Board because:

- the number of patients requiring the service is small (there is about one patient with a primary immunodeficiency registered at each GP practice);
- the cost of providing the service is high because of the specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

116. Specialist mental health services for Deaf adults

[C3 – Specialised Mental Health services for the Deaf]

Service summary
Specialist mental health services for Deaf adults includes inpatient and non-admitted care including assessment and treatment services for Deaf people provided by Specialist Centres. In addition, the service includes advice to general mental health services on the management and treatment of the Deaf person’s mental illness.

Other relevant services

- 74. Mental health service for Deaf children and adolescents

About the condition/service
Specialist Mental Health Services for Deaf Adults are services for those patients who cannot be effectively managed and treated in an acute mental health service ward. This is usually because of communication difficulties, which can impact significantly on the person’s mental health and wellbeing and the lack in availability of staff who are proficient in British Sign Language and other communication skills, have knowledge of Deaf culture **as well as** having experience in the care and treatment of Deaf people with mental illness. Specialist mental health and Deaf services have environments specifically adapted to the needs of the patient group and are staffed by mental health professionals who are expert in assessing and addressing the needs of people who are Deaf and experience mental ill health.

About seven per 10,000 people in the general population have severe or profound Deafness where onset was before language was established. About 50% of these individuals experience mental health difficulties at some time in their lives, ranging between mild depression and psychosis.

How the service is organised
The service includes inpatient, outpatient and community services including assessment and treatment services for Deaf people and advice to general mental health services on the management and treatment of Deaf people with mental illness.

There are three Specialist Centres covering England and a small number of linked specialist community services.

What the NHS Commissioning Board commissions
The NHS Commissioning Board commissions specialist mental health services for Deaf adults from Specialist Centres. This includes inpatient and non-admitted care including assessment and treatment services. In addition, the service includes advice to general mental health services on the management and treatment of the Deaf person’s mental illness.

Clinical Commissioning Groups (CCGs) commission inpatient, outpatient and community mental health and learning disability teams, which work closely with the specialist inpatient and specialist community Deaf services to ensure Deaf patients have access to local services including crisis teams and home treatment teams. Unless specifically agreed otherwise – and where a patient has a very high level of complexity – community mental health and learning disability teams hold the care co-ordination responsibility for patients. CCGs ensure that multidisciplinary adult mental health services have access to appropriate interpreting services and technology to ensure that they are able to implement their Equality Duty (Equality Act 2010) with due regard to people who are Deaf. CCGs commission primary care based psychological services such as IAPT (Improving Access to Psychological Therapies), which are accessible by Deaf patients either via providing appropriate interpreting services and technology (to implement their Equality Duty (Equality Act 2010)) or via commissioning services specifically designed for Deaf patients.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high;
- the number of doctors and other expert staff trained to deliver the service is very small (in particular, they need to: be fluent in sign language and be able to adapt their sign language to meet the needs of Deaf people who have language dysfluency; have an understanding of Deaf culture; have an ability to adapt their approach to meet the needs of Deaf blind patients; have knowledge of the Equality Act 2010 with due regard to patients who are Deaf);
- and the cost of treating some patients can be very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

117. Specialist morbid obesity services (all ages)

[A5 – Morbid Obesity Surgery]

Service summary
Specialist morbid obesity services include services provided by Specialist Morbid Obesity Centres. The service includes all bariatric surgical procedures and the associated care, as well as medical care provided by these centres for complex patients unsuitable for or not requiring surgery. This applies to provision in adults and children.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Currently, secondary prevention treatments for obesity include behaviour modification interventions such as diet: exercise and life style; referral to specialist weight-loss clinics; drug therapy; low and very low calorie diets; and behaviour modification therapies. Surgery to aid weight reduction may be considered when all other non invasive measures have been tried but have failed and the patient has been adequately counselled and prepared for surgery.

Bariatric surgery is one component of the multimodality lifetime treatment pathway of Severe and Complex Obesity which consists of multidisciplinary medical assessment and management of co-morbidities, lifestyle and dietary improvements, nutritional replacement, and lifelong follow up care.

How the service is organised
There are about 50 NHS providers of morbid obesity surgery, although some only operate on relatively small numbers of patients. There are also a number of private sector providers. About 10,000 operations are performed each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist morbid obesity services from Specialist Morbid Obesity Centres. This includes all bariatric surgery and associated care delivered by the Specialist Centre, including medical care and specialist weight management care for patients unsuitable for or not requiring surgery.

Clinical Commissioning Groups (CCGs) commission local weight management services.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is small (one to two patients from each GP practice requires access to the service each year);
- the number of doctors and other expert staff trained to deliver the service is small; and

- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

118. Specialist neonatal care services

[E8 – Neonatal Intensive Care]

Service summary
Specialist neonatal care services include all activity undertaken by Neonatal Intensive Care Units, Local Neonatal Units and Special Care Units including associated retrieval services. This includes transitional care and any associated outpatient services.

Other relevant services

- 122. Specialist paediatric intensive care services

About the condition/service
Much of the care of newborn babies, either healthy or with lesser problems, is carried out at the district hospital where they are born. Complex and intensive care, particularly of the very preterm, is carried out in tertiary centres for the most part. Tertiary centres provide care for both complex cases on a regional basis as well as services for the local population that may not be complex.

How the service is organised
In order to facilitate the newborn access to appropriate care as near to home as possible and to reduce the need for long transfers for intensive care, groups of hospitals providing various levels of care locally are organised into 22 clinical neonatal networks in England. There are three levels of neonatal care:

- Special Care Units (SCUs) (about 40 in number)
- Local Neonatal Units (LNUs) (about 80 in number)
- Neonatal Intensive Care Units (NICUs) (about 50 in number)

SCUs are expected to provide some high dependency care and to be able to stabilise a sick infant prior to transfer for critical care. LNUs have their own catchment population for which they provide all categories of care, but transfer the sickest or most complex cases to a network NICU. LNUs mostly keep those infants of more than 27 weeks gestation, and may, using pre-agreed protocols, accept infants from other network units. NICUs operate alongside specialist obstetric units and Fetal Medicine Centres taking high-risk cases. They provide the full range of care for their local population and accept network referrals of critically ill and complex cases.

Neonatal critical care services include:

- Neonatal transport team
- Respiratory support including high frequency oscillation and nitric oxide therapy
- Therapeutic hypothermia for hypoxic-ischaemic encephalopathy
- Total parenteral nutrition (including expert pharmacy support)
- Access to neonatal surgery service (this is covered under the individual paediatric surgery sections)
- Availability of peritoneal dialysis service

- Access to clinical imaging services (cardiac, general and cranial ultrasound scanning and magnetic resonance imaging and computerised tomography)
- Access to specialist paediatric services and advice, for example, neurology, metabolic/endocrine, cardiology, microbiology (infection control), clinical genetics

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist neonatal care services through 22 Neonatal Care Networks, with services delivered in Intensive Care Units, Local Neonatal Units and Special Care Units. This includes associated retrieval services, transitional care (i.e. where the baby needs some medical care but is well enough to receive this at their mother's bedside) and associated outpatient services.

Clinical Commissioning Groups (CCGs) do not commission any element of specialist neonatal care services except normal care.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes ALL activity at specified centres, with the exception of normal care.

Review of the service commissioner

A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

119. Specialist neuroscience services for children and young people

[E9 – Paediatric Neurosciences}

Service summary
Specialist neuroscience services for children and young people include all services provided by Specialist Paediatric Neurosciences Centres including:

- Neurosurgery (including paediatric neuro critical care)
- Neurology
- Neurophysiology
- Neuroradiology
- Neuropsychology and neuropsychiatry
- Neurodisability and neurorehabilitation
- Neuroanaesthesia

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant services:

- 12. Adult specialist neurosciences services
- 21. Ataxia telangiectasia services for children
- 43. Craniofacial service (adults and children)
- 48. Diagnostic service for rare neuromuscular disorders (adults and children)
- 73. McArdle's disease service (adults)
- 78. Neuropsychiatry services (adults and children)
- 77. Neuromyelitis optica service (adults and adolescents)
- 140. Vein of Galen malformation service (adults and children)

About the condition/service
Children with neurological disease require a sustained and integrated network of care involving a variety of organisations, professionals and equipment, often over a prolonged period of time. Services operate within managed networks to provide care that revolves around the individual child’s needs.

About 4,500 children each year have neurosurgical interventions.

How the service is organised
There are about 17 Specialist Paediatric Neurosciences Centres in England that provide specialist paediatric neurosciences services through a multi-disciplinary approach to the diagnosis and management of a range of neurological disorders. Services are both centrally-based (inpatient and outpatient) and outreach to local hospitals where the Centre staff work in partnership with local paediatricians and therapy teams to facilitate care as close to a child’s home as possible.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions the following specialist neuroscience services for children and young people from Specialist Paediatric

Neurosciences centres, including services provided on an outreach basis when delivered as part of a provider network:

- All paediatric neurosurgery, neurology, neuropsychology, neuropsychiatry, neurodisability and neurorehabilitation
- Complex paediatric neuroradiology (for example, detailed MRI for subtle antenatal or postnatal malformations, evaluation of non-accidental injury or whether a tumour has remained stable, angiography, interventional procedures, MRI spectroscopy, SPECT/PET scans)
- Complex paediatric neurophysiology (for example, video-EEG, brainstem and visual evoked potentials, nerve and muscle studies) and neuro-ophthalmology

In addition there are a very small number of specialist centres that provide brain injury and Neurorehabilitation services outside the tertiary care setting.

The NHS CB commissions the following drugs/devices: shunts, immunoglobulins, any associated specialist orthotics

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one child across one to two GP practices requires access to the service each year);
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

120. Specialist ophthalmology services for children and young people

[D12 – Specialised Ophthalmology Services]

Service summary
Specialist ophthalmology services for children and young people include services provided by Specialist Paediatric Ophthalmology Centres including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex or high risk procedures only.

Other relevant services

- 13. Specialist ophthalmology services

About the condition/service
Specialist ophthalmology services for children and young people encompass the investigation and management of visual, ocular and ocular adnexal disorders.

A large proportion of the paediatric ophthalmic workload comprises the investigation and treatment of amblyopia (‘lazy eye’) and strabismus (squint) and much of the day to day management of these conditions is delegated to orthoptists in local hospitals. The remainder of the workload consists of a wide variety of ocular, ocular adnexal and visual conditions, many specific to children and most not specialist.

There are 20,000 bilaterally visually impaired children in England. The most common cause of visual impairment in children is visual pathway damage and paediatric ophthalmologists are involved in the visual assessment and rehabilitation of such children. Other common causes of visual impairment in children include congenital eye anomalies (for example, congenital cataract, glaucoma and optic nerve disorders); retinopathy of prematurity; inherited retinal dystrophies and uveitis. Management of these conditions requires access to comprehensive paediatric and genetic services, including neonatology and anaesthesia.

How the service is organised
Specialist ophthalmology services for children are routinely delivered by both paediatric ophthalmologists and adult ophthalmologists (the latter in environments that meet national guidelines for the care of children). The service is provided within operational delivery networks, the networks comprising of a group of providers working together within the patient pathway.

What the NHS Commissioning Board commissions
The NHS Commissioning Board commissions the following specialist ophthalmology services for children and young people from Specialist Paediatric Ophthalmology Centres in England, including emergency care:

- Orbital disorders (with the exception of minor surgery and orbital cellulitis)
- Oculoplastic and lacrimal surgery (with the exception of routine syringe and probing and minor lid surgery)

- Cataract and lens disorders for younger children (< 2 years of age, but the age limit remains under review)
- Glaucoma
- Corneal disorders (except emergency corneal repair)
- Eye banking
- Vitreoretinal surgery
- Treatment of retinopathy of prematurity
- Medical retina services (to provide second opinions and management of uncommon conditions.
- Uveitis (the treatment of severe ocular disease requiring systemic or complex treatment)
- Ocular genetics disorders
- Neuro-ophthalmology (including multidisciplinary developmental paediatric clinics for sight impaired children and/or a clinic with a specialist interest in cerebral visual impairment led by a paediatric neuro-ophthalmologist or paediatric ophthalmologist)
- Eye movement recording facilities.

Clinical Commissioning Groups (CCGs) commission all other paediatric ophthalmology services including strabismus and amblyopia.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS Commissioning Board because:

- the number of individuals requiring the service is very small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

121. Specialist orthopaedic surgery services for children and young people

[E2 – Paediatric Surgery]

Service summary

Specialist orthopaedic surgery services for children and young people include services provided by Specialist Paediatric Orthopaedic Centres including outreach when delivered as part of a provider network. The service includes:

- Surgical management of rare conditions
- Provision of specified procedures
- Surgical management of more common conditions when the child or the procedure is high risk

Other relevant services

- 14. Adult specialist orthopaedic services
- 89. Primary malignant bone tumours service (adults and adolescents)

About the condition/service

Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex (for example, correction of congenital deformity); the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. For example, simple hand or foot surgery is normally a routine procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

There are about TBC Specialist Paediatric Orthopaedic Centres in England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist plastic surgery services for children and young people from Specialist Paediatric Plastic Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often

congenital with a genetic or developmental cause and who may require treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

The NHS CB commissions the following devices: any associated specialist orthotics

Clinical Commissioning Groups (CCGs) commission routine surgery for children over 60 weeks post-conceptual age who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:
- Removal of metalwork from wrist

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

122. Specialist paediatric intensive care services

[E7 – Paediatric Intensive Care]

Service summary
Specialist paediatric intensive care services include all activity undertaken by Paediatric Intensive Care Units and associated retrieval services.

Other relevant services

- 52. Extra corporeal membrane oxygenation services for neonates, infants and children with respiratory failure
- 118. Specialist neonatal care services

About the condition/service
Specialist paediatric intensive care services provide a care pathway for the sick child from recognition and stabilisation, through retrieval (if necessary), to delivery of care in an appropriate paediatric critical care facility be that in a paediatric intensive care unit (PICU) or in a Paediatric High Dependency Unit (PHDU). The service is provided to ensure, as far as possible, that the same standard of care is delivered to all critically ill children, regardless of their location. PIC is also an intimate part of some other Specialist Paediatric Services (for example, paediatric cardiac, general surgery and neurosurgery) and has a number of significant interdependencies (for example, paediatric anaesthesia, ENT, nephrology).

High dependency care is provided in tertiary centres, both to their local populations and to specialist tertiary services. It is also provided, at varying levels, by most local hospitals. Almost every local hospital can provide basic level PHDU care, for example, to children with diabetic ketoacidosis or acute exacerbations of asthma.

In England, 1.4 children per 100,000 of the population are admitted to a PICU each year, a total of 14-15,000 children of whom around 5,000 are admitted for HDU care. The majority of patients admitted are aged 0-15 years old. It is estimated that there are a further 6,000 children admitted to PHDUs.

How the service is organised
There are about 26 PICUs in 24 providers. The number of PHDUs is thought to be similar.

Paediatric critical care is configured with lead centres serving a network of referring hospitals, in a network model, supported by retrieval services. The referring hospitals have responsibility for the initial management and stabilisation of critically ill children.

Levels of care described as 1 to 4 are used to define paediatric critical care activity [expected nurse: patient ratio]:

- Level 1: high dependency care [one nurse to two patients]
- Level 2: intensive care (simple) [one nurse to one patient]
- Level 3: intensive care (complex) [one and a half nurses to one patient]
- Level 4: highly specialist intensive [two nurses to one patient]

The transfer of children in referring hospitals into the PICU (and/or PHDU) is performed by a retrieval service, which also performs bed location and provides clinical advice. There is overlap with neonatal transfer services.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist paediatric intensive care services from PICUs and PHDUs, including associated retrieval services.

The NHS CB commissions the following drugs: synergis

The NHS CB does not commission:

- Inpatient services:
    - PIC provided in a general paediatric ward or an adult intensive care unit
    - PHD level care provided in a general paediatric ward or an adult intensive care unit

Clinical Commissioning Groups (CCGs) commission:

- Inpatient services:
    - Children with a PICU and/or PHDU stay of less than four hours
    - Children stable on long term ventilation for more than 90 days
- Retrieval services:
    - General ambulance transfer to or from a PICU or designated PHDU (not by a dedicated specialist critical care transport team)

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

123. Specialist paediatric liver disease service

Service summary
Specialist paediatric liver disease services include services provided by Highly Specialist Paediatric Liver Disease Centres including outreach when provided as part of a provider networks.

Other relevant services

- 110. Specialist gastroenterology , hepatology and nutritional support services for children and young people

About the condition/service
This service provides a diagnostic, assessment and treatment service for paediatric liver disease. The major conditions covered by the service are:

- Acute liver failure
- Biliary atresia
- Chronic liver disease
- Hepatitis A,B and C
- Metabolic liver disease
- Neonatal hepatitis

How the service is organised
The service sees about 1,100 new patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board commissions specialist paediatric liver disease services from Highly Specialist Paediatric Liver Disease Centres, including services delivered on an outreach basis as part of a provider network.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the number of expert doctors and other staff who can provide the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- King's College Hospital NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

124. Specialist perinatal mental health services

[C5 – Perinatal Mental Health]

Service summary
Specialist perinatal mental health services are provided by Specialist Mother and Baby Units. Services include inpatients and associated non-admitted care including outreach provided by these units when delivered as part of a provider network. This applies to provision in adults and young people.

About the condition/service
Specialist perinatal mental health services provide a safe and secure environment for the care of seriously mentally ill women and their infants. These psychiatric units are separate from other acute mental health admission facilities. They provide care for women with serious mental illness including postpartum psychosis, schizophrenia, bipolar illness and other serious affective disorders and those with complex needs. They provide expert psychiatric care for the mother whilst at the same time ensuring the care of the infant and avoiding unnecessary separation of mother and baby.

Based on the known epidemiology of postpartum psychosis (2 per 1,000 live births) and the rate of admission for other serious and complex disorders (a further 2 per 1,000 live births), about 2,750 women need access to Specialist Mother and Baby Units each year.

How the service is organised
There are 17 Specialist Mother and Baby Units in England, 12 of which have integrated community teams.

Specialist Mother and Baby Units provide assessment of mother-infant care, attachment and interaction. They provide supervision, support, assistance and guidance in the care of the infant whilst the mother is ill, ensuring that the emotional needs of both mother and infant are met. They offer timely and equitable access so that mothers are not admitted to general adult psychiatric wards without their babies.

Specialist Perinatal Psychiatric (Outreach) Teams assess and manage women with serious mental illness or complex disorders in the community who would otherwise be admitted to the unit or who are in the transition phase from being an inpatient. Patients usually meet the following criteria:

- Women with acute serious mental illness in late pregnancy and the postpartum year
- Women discharged from Inpatient Mother and Baby Units
- Women for whom close collaborative working with the mother and baby unit is essential to avoid admission or promote early discharge
- Women with serious mental illness in pregnancy who require close collaborative working with Maternity Services and/or Adult Mental Health Services
- Women with pre-existing serious mental illness, particularly bipolar disorder and other serious affective disorders, who are at high risk of developing

postpartum illness and require preventative and therapeutic interventions in pregnancy and the postpartum period
- Women who require high intensity of specialist community input on a weekly or more frequent basis

Specialist Perinatal Psychiatric (Outreach) Teams also offer preconception counselling to women with pre-existing serious mental health disorders and those who are well but at high risk of a postpartum condition.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist perinatal mental health services from Specialist Mother and Baby Units. Services include inpatients and associated non-admitted care including outreach provided by these units when delivered as part of a provider network.

The NHS CB also commissions Specialist Perinatal Psychiatric Outreach Teams where these are provided by or through a Specialist Mother and Baby Unit.

Clinical Commissioning Groups (CCGs) commission activity from those perinatal community teams that are not provided by or through Specialist Mother and Baby Units. CCGs commission all perinatal mental health services for women with non-psychotic conditions who are either not admission vulnerable or do not require such a high level of intensity.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across 14 GP practices needs access to the service each year);
- the cost of providing the service is high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients can be high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

125. Specialist plastic surgery services for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist plastic surgery services for children and young people include services provided by Specialist Paediatric Plastic Surgery Centres including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex or high risk procedures only.

About the condition/service

Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex; the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

There are about TBC Specialist Plastic Surgery Centres in England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist plastic surgery services for children and young people from Specialist Paediatric Plastic Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and

require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

Clinical Commissioning Groups (CCGs) commission routine surgery for children over 60 weeks post-conceptual age who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Surgery on prominent ears

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

126. Specialist renal services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist renal services for children and young people include services provided by Specialist Paediatric Renal Centres including outreach when delivered as part of a provider network.

About the condition/service
Specialist Renal Services provide care for a wide variety of conditions. Many children with uncomplicated general nephrological conditions, for example, simple urinary tract infection or steroid responsive nephrotic syndrome, may be managed by general paediatricians in local hospitals without reference to a specialist paediatric nephrologist at the specialist renal centre. Some children develop complications of common conditions or have rare conditions benefiting from specialist expertise whilst others require specialist diagnostic and therapeutic procedures including dialysis and transplantation that can only be provided by a Specialist Paediatric Renal Centre. About 900 children in the UK have established renal failure.

How the service is organised
Children requiring more complex paediatric nephrology services are treated at about 10 Specialist Paediatric Renal Centres, all of which provide chronic dialysis and most of which also provide paediatric renal transplantation.

Children with renal disease often have multi-system problems and require co-location with other specialties. The aim is to care for children as close to home as possible with the local hospital providing as much of the care as possible. This is achieved by creating clinical networks. Each local hospital within the clinical network has at least one general paediatrician with a special interest in nephrology; the specialist renal centre provides support to the local hospital clinician where appropriate.

Specialist renal services may be delivered in the following ways:

- care within a specialist paediatric renal unit (both inpatient and outpatient)
- expert advice from a paediatric nephrologist to other paediatric specialists within a referral centre, for example, paediatric intensive care, oncology, endocrinology, cardiology
- outreach clinics with the specialist and the general paediatrician in the local hospital
- expert advice from a paediatric nephrologist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP
- expert advice from non-medical multidisciplinary renal team members to other healthcare providers, for example, specialist paediatric renal nurses, dieticians, psychologists, pharmacists, etc
- visits from members of the multi-disciplinary team to the patient's home and school to provide training and support to the child, family and other carers.
- specialist antenatal counselling

- managed transition to adult services

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist renal services for children and young people from Specialist Paediatric Renal Centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions services for the following conditions:

- acute kidney injury including those requiring haemodialysis (HD) or peritoneal dialysis (PD)
- moderate and severe chronic kidney disease (i.e. chronic kidney disease KDOQI categories 3-5)
- complicated nephrotic syndrome
- severe or chronic glomerular disease
- vasculitis(except mild Henoch-Schönlein purpura)
- tubulointerstitial disorders including renal tubular transport disorders that are primary or secondary to acquired or metabolic disease
- complex/severe hypertension
- nephrolithiasis
- complex neuropathic bladder particularly those requiring other specialist services

The NHS CB commissions the following specialist interventions:

- hospital dialysis (i.e. HD and peritoneal dialysis) for acute kidney injury and chronic kidney disease
- training for home peritoneal dialysis (and more rarely for home HD) for chronic kidney disease
- access surgery for dialysis
- paediatric urology
- plasmapheresis
- renal transplantation (including tissue typing)
- renal biopsy
- urodynamics
- specialist and interventional radiology
- visits from members of the multidisciplinary team to the patient’s home to provide training and support to the child and the family/carers

The NHS Commissioning Board commissions the following drugs/devices:

- Immunosuppressants (tacrolimus, cyclosporin, mycophenolate, azathioprine
- Steroids, sirolimus, basiliximab, rituximab, infliximab)
- Erythropoietin

For the following common conditions, **Clinical Commissioning Groups (CCGs)** commission services for patients when specialist input is NOT required and the NHS CB commissions the services when specialist input IS required:

- uncomplicated urinary tract infection
- nocturnal enuresis
- daytime enuresis
- antenatal hydronephrosis

- chronic kidney disease (mild-moderate CKD 1-2) not requiring dialysis
- acute kidney injury not requiring dialysis (if mild and uncomplicated)
- uncomplicated nephrotic/nephritic syndrome
- haematuria
- proteinuria
- mild/moderate renal hypertension

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the facility is very high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

127. Specialist rehabilitation services (all ages)

[D2 – Brain Injury Rehabilitation]

Service summary
Specialist rehabilitation services for patients with highly complex needs includes tertiary specialist rehabilitation for patients whose rehabilitation needs fall into Category A following brain injury or with other disabling conditions. These may be provided in designated Level 1 or 2a facilities. This applies to provision in adults and children.

About the condition/service
Rehabilitation is a process of assessment, treatment and management by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition.

Following illness or injury, the majority of patients have category C or D needs and progress satisfactorily down the care pathway with the help of their local non-specialist (Level 3) rehabilitation services. Some patients with more complex needs (Category B) may require referral to local specialist rehabilitation services (Level 2b). A small number of patients with highly complex needs (Category A) require tertiary specialist rehabilitation in centres that have the requisite staff expertise and facilities to manage their needs.

Tertiary specialist rehabilitation is the total active care of patients with any disabling condition who have highly complex (Category A) needs for rehabilitation that are beyond the scope of their local general and specialist services.

The rehabilitation is provided:

- Under the care of a consultant trained and accredited in rehabilitation medicine, neuropsychiatry or paediatric neurodisability, depending on the nature of the programme;
- By a multi-professional team who have undergone recognised specialist training in rehabilitation; and
- In designated tertiary (Level 1) services or in Level 2a services in parts of the country where there is insufficient coverage/capacity with the Level 1 services and have the requisite staff expertise and facilities to manage a highly complex caseload.

Programmes fall broadly into four categories:

- Programmes for people with profound and complex physical disability
- Cognitive/behavioural rehabilitation programmes for people who are independently mobile but have severe cognitive/behavioural/neuropsychiatric needs
- Specialist community integration/transitional living/vocational rehabilitation programmes

- Programmes for children, adolescents and young adults (16-25 years) who require tertiary specialist rehabilitation in the context of schooling or on-going education. These integrate into school and preparation for Statement of Special Educational Needs, and incorporate both the physical as well as cognitive requirements.

Tertiary specialist rehabilitation commissioned under this definition may be provided along three main pathways:

- *Restoring function* (for example, following a 'sudden onset' or 'intermittent' condition)
- *Managing disability* (for those with stable or progressive conditions)
- *'Neuro-palliative rehabilitation'* at the interface between rehabilitation and palliative care
- It is delivered in time-limited, goal-orientated programmes – usually up to six months (with extension where appropriate subject to negotiation). Activity under this definition does not include long term care or slow stream rehabilitation programmes with an expected time-course of >12 months.
- It is largely milieu-based (i.e., residential/inpatient/day-rehab and associated outreach / community activity). There are benefits to patients and their families if patients are managed within a peer group of people facing a similar level of challenge. It does not include rehabilitation delivered solely in the community, as it is rarely practical to provide such support from a distance compatible with the extended catchment (>1m population) of tertiary specialist services.

It is estimated that about 2,500 individuals each year need access to tertiary specialist rehabilitation services.

How the service is organised

Currently, there are about 40 units (Levels 1 and 2a) that provide services to Category A patients (adults and children).

Confirmation of eligibility for Level 1/2a status requires that tertiary specialist rehabilitation services have the expertise and facilities to meet the demands of a highly complex caseload:

- All services must be registered with the UK Rehabilitation Outcomes Collaborative (UKROC) database and must submit the full UKROC dataset for each case episode;
- UKROC is a national clinical database set up with Department of Health funding to collate the NHS Information Centre's inpatient rehabilitation dataset; and
- It provides the commissioning dataset for specialist rehabilitation services and national benchmarking on needs for rehabilitation, inputs and outcomes.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions tertiary specialist rehabilitation services for patients with Category A needs in specified centres that meet the criteria for Level 1/2a services.[18]

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[18] http://www.bsrm.co.uk/ClinicalGuidance/Levels_of_specialisation_in_rehabilitation_services5.pdf

Clinical Commissioning Groups (CCGs) commission rehabilitation services for patients with Category B needs and non-specialist rehabilitation for patients with C and D needs. They also commission long term care and slow stream rehabilitation programmes with an expected time-course of >12 months; and rehabilitation delivered solely in the community.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small (about one patient across two to three GP practices requires access to the service each year);
- the cost of providing the service is very high because of the specialist ward environment involved and the significant lengths of stay of some patients;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

When patients are transferred to a tertiary specialist rehabilitation service, the sole purpose of admission is for rehabilitation. This activity is therefore quite separate from rehabilitation in the context of acute care services:

- Activity is identified through the UKROC database, which is also the commissioning vehicle through which the multi-level weighted bed-day tariff for these services is operated
- Category A patients are identified using a Patient Categorization tool and complexity of needs are identified using the Rehabilitation Complexity Scale

Review of the service commissioner
A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

The NHS CB commissions both Level 1 and Level 2a services to ensure geographical equity of access for Category A patients. Expansion is anticipated in Level 2 services. There will be mandated tariffs for all levels of services from 2014/15 so commissioning of Level 2a facilities could transfer to CCGs in 2015/16.

128. Specialist respiratory services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist respiratory services for children and young people include services provided by Specialist Paediatric Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network.

Other relevant services

- 3. Adult highly specialist respiratory services
- 47. Diagnostic service for primary ciliary dyskinesia (adults and children)
- 88. Primary ciliary dyskinesia management service (children)
- 92. Pulmonary hypertension service for children

About the condition/service
Common paediatric respiratory conditions are managed in local hospitals or primary care settings, but complex and rare conditions are managed in conjunction with a Specialist Paediatric Respiratory Centre. About 11,000 children require access to Specialist Paediatric Respiratory Centres each year.

How the service is organised
There are about 20 Specialist Paediatric Respiratory Centres in England.

Children are assessed treated on an outpatient, inpatient and day case basis by the specialist multidisciplinary team. Treatment and follow up of many of these conditions are lifelong and planned transition to adult services takes place via joint and/or hand-over clinics. The Specialist Respiratory Service works as part of a clinical pathway with colleagues in local hospitals to provide care for children with difficult or complex respiratory disorders as near to their home as is possible. Much of the work is done on an ambulatory basis with an outpatient and diagnostic service for patients whose care is shared with secondary providers and inpatient services often working closely with other tertiary paediatric specialists. Support via outreach services is often needed for children with complex respiratory disorders, typically those requiring respiratory support from a portable ventilator and those with artificial airways (either tracheostomy or nasopharyngeal tubes).

Outreach work by members of the specialist team extends to

- shared care outpatient clinics in local hospitals
- support for ward staff in local hospitals and community staff as appropriate
- support to patients and staff in palliative care facilities
- support to patients and carers and families in the home
- education and support to secondary care multidisciplinary teams

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist respiratory services for children and young people, including services delivered on an outreach

basis as part of a provider network. The NHS CB commissions services for the following conditions:

- difficult to control asthma
- congenital lung and airway disease
- rare lung disease
- empyema, parapneumonic effusion and pneumothorax
- bronchiectasis and obliterative bronchiolitis
- chronic cough
- chronic neonatal lung disease with co-morbidity
- lung disease associated with primary and secondary immunodeficiency
- complicated pulmonary tuberculosis
- restrictive and chronic lung disease associated with thoracic dystrophy, severe scoliosis and neuromuscular disease
- sleep disordered breathing
- acute and chronic airway problems
- home respiratory support

The NHS CB commissions the following interventions and investigations from Specialist Paediatric Respiratory Centres as part of a specialist respiratory service for children and young people:

- flexible bronchoscopy and bronchography
- complex pulmonary function testing
- sleep studies
- nasal ciliary brushings
- exhaled and nasal nitric oxide
- sweat testing
- high resolution CT and other complex respiratory imaging.
- investigation of pulmonary hypertension
- lung biopsy
- chest drain insertion and management
- access to rigid bronchoscopy and airway intervention
- training in the use of assistive technologies such as use of cough assist machines, invasive and non-invasive ventilators, etc

The NHS CB commissions the following devices, whose use should be initiated and monitored by the specialist respiratory team:

- ventilators for use at home via tracheostomy
- ventilators for use at home via mask (non invasive ventilation)
- cough-assist devices for use at home

The NHS CB commissions the following drugs: omalizumab (for children aged 12 and above), cyclosporin and other immunosuppressive treatment in chronic severe asthma, pulsed methylprednisolone, immunoglobulins in inflammatory lung disease

Clinical Commissioning Groups (CCGs) commission:

- Non-specialist work undertaken in local hospitals
- Non-specialist work undertaken in specialist centres

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions and specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

129. Specialist rheumatology services for children and young people

[E3 – Paediatric Medicine]

Service summary
Specialist rheumatology services for children and young people include care provided by Specialist Paediatric Rheumatology Centres for complex conditions. The service includes outreach when delivered as part of a provider network.

Other relevant services

- 38. Complex Ehlers Danlos syndrome service (adults and children)

About the condition/service
Paediatric rheumatology spans all ages from neonates into late adolescence, encompassing a broad spectrum of conditions, many of which are rare/complex and often chronic. Many conditions require specialist care, co-dependency with paediatric sub-specialities and often complex/expensive interventions and treatments. Rapid access to a variety of specialist diagnostic services to underpin the clinical services, laboratory and radiological investigations and often requiring expert interpretation, is crucial in excluding alternative diagnoses, monitoring response to treatment and emphasises the co-dependencies of the service with other paediatric sub-specialties.

How the service is organised
There are about 13 Specialist Paediatric Rheumatology Centres in England.

Most specialist rheumatology services are delivered in an ambulatory setting. The multi-disciplinary teams at the Specialist Paediatric Rheumatology Centres work within networks delivering outreach and shared care with local hospitals.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist rheumatology services for children and young people from Specialist Paediatric Rheumatology Centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions services for the following conditions:

- Inflammatory and non-inflammatory rheumatic conditions
- Pain syndromes
- Unexplained fevers
- Complex multisystem disease
- Uveitis

The NHS CB commissions specialist investigations and interventions, including all drugs initiated, prescribed, delivered and monitored in specialist care.

The NHS CB commissions the following drugs:

- disease-modifying anti-rheumatic drugs (for example, methotrexate, immunosuppressive agents)
- biologicals/monoclonals/novel therapies

- joint injections of steroids
- IV steroids, immunoglobulins, plasma exchange or IV bisphosphonates
- home delivery of methotrexate or biologics

Clinical Commissioning Groups (CCGs) do not commission any elements of this service. CCGs may prescribe some non-specialist drugs initiated by the Specialist Paediatric Rheumatology Centre, for example, pain killers.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions and specialist drugs involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

130. Specialist services for children and young people with infectious diseases

[B6 – HIV, B7 – Infectious Diseases, E3 – Paediatric Medicine]

Service summary
Specialist services for children and young people with infectious diseases include services provided by Specialist Infectious Diseases Paediatric Centres. This includes management of:

- Overwhelming bacterial septicaemia/sepsis
- Severe and life-threatening viral infections
- Severe, complicated and drug-resistant tuberculosis
- Unusual or severe fungal infections
- HIV infection
- Tropical infections and infections in returning travellers
- Common infections in the immunocompromised host
- Specialist advice on infections in children treated by other (paediatric and adult) sub-specialties including those requiring intensive care for medical and surgical management and trauma and those receiving immunomodulatory medications
- Bloodstream healthcare associated infections in children
- Congenital infections (babies infected *in utero* with viruses, bacteria or parasites)

These include inpatient, day case and outpatient services including outreach (including telephone advice) when delivered as part of a provider network.

Other relevant services
65. Highly specialist services for adults with infectious diseases

About the condition/service
Infectious diseases are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; the diseases can be spread, directly or indirectly, from one person to another. Zoonotic diseases are infectious diseases of animals that can cause disease when transmitted to humans. Infectious diseases can cause of range of symptoms, which in some cases can be life threatening. There are approximately 1,500 cases each year of healthcare associated bloodstream infections in children. The increasing use of immunosuppressive and immunomodulatory treatments has increased the numbers of children developing complex infectious problems.

How the service is organised
Most infections in children are treated in primary care or by paediatricians in secondary care settings. However, children who have complex needs that require management in specialist centres are often more prone to severe or unusually complicated infections. Even though their day-to-day management is co-ordinated by their specialist team, advice is required from a Paediatric Immunology and Infectious Disease (PIID) Team for optimal management of their infection.

The multi-disciplinary specialist paediatric infectious disease team co-ordinates a rapid and effective evaluation of the infection and its risk of transmission and provides appropriate diagnostic and medical management on a 24-hour basis.

PIID Teams provide high quality guidelines, advice and consultation services to more common infections in children looked after by other teams. The specialist team also provides telephone advice on patients being treated in local hospitals.

PIID Teams provide specialist paediatric antimicrobial stewardship advice and infection prevention support to all tertiary children's services (along with clinical microbiologists).

As in the case of adult infections, some conditions require special isolation facilities with appropriate air handling and air filtration systems available at a limited number of centres. Children are treated in these units by PIID Teams and a paediatric multi-disciplinary team.

There are about 13 Specialist Infectious Diseases Paediatric Centres that co-ordinate clinical networks across wide geographic areas.

Services for children with HIV are organised in six regional networks, with each of the networks linked to one of three specialist centres, all of which are based in London.

Very rarely, children are treated in highly specialist infectious disease centres, which provide care to patients with very rare conditions:

- High secure infectious disease units (two centres)
- Highly Specialist Bone and Joint Infection Centres (one centre)
- Human T-cell Lymphotropic virus centres (four centres)

Details about these centres are included in section 65.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist services for children and young people with infectious disease from Specialist Infectious Diseases Paediatric Centres, including services delivered on an outreach basis as part of a provider network. The NHS CB commissions services for patients with suspected and confirmed:

- 'common' (severe) infections in the immunocompromised host
- recurrent infections (investigation and management of)
- opportunistic infections secondary to: immunodeficiency of unknown aetiology, immunodeficiency due to malignancy, chemotherapeutic drugs, viruses
- severe paediatric infections including those requiring intensive care
    - meningococcal disease
    - staphylococcal/streptococcal sepsis and toxic shock syndromes
    - bacterial meningitis
    - encephalitis
    - brain abscess
    - sinusitis

    - mastoiditis
    - ophthalmic infections and inflammatory conditions
    - empyema
    - endocarditis
    - abdominal sepsis and gastrointestinal infections
    - viral hepatitis
    - complicated urinary tract infections
    - complex musculo-skeletal infection
    - complex skin infections
- severe healthcare associated infections
- fever of unknown origin (greater than two weeks duration)
- nosocomial infections / healthcare associated infection (central line infections, ventilator-associated pneumonia, methicillin resistant *Staphylococcus aureus*, complicated *C difficile* infection and multi-antibiotic resistant bacterial infection)
- serious post-operative infections and post traumatic infections
- Tuberculosis (TB) (congenital, central nervous system, extra-pulmonary disease, complicated pulmonary disease, drug-resistant TB)
- HIV (all care of HIV-infected children/adolescents)
- complex and unusual manifestations of neonatal infections (for example, candida, multi-resistant organisms, pertussis)
- congenital infections (for example, HIV, Hepatitis, toxoplasmosis, cytomegalovirus, syphilis, rubella, herpes simplex virus, varicella, chlamydia)
- prevention of perinatal infection (for example, HIV, hepatitis, toxoplasmosis)
- persistent cervical lymphadenopathy and atypical/non-tuberculous mycobacterial infection
- sexually transmitted infections in children
- infections with unusual patterns of antimicrobial resistance (bacterial, fungal and viral)
- complex vaccine advice for passive and active immunisation (non-response, failures, immunocompromised)
- rare, imported and emerging paediatric infections, (for example, Lyme disease, brucellosis, leptospirosis), slow infections of the CNS (SSPE, spongiform encephalopathies), worldwide emerging new infections (dengue, SARS, influenza, chikungunya), imported infections (severe and complicated malaria, typhoid fever, visceral and cutaneous leishmaniasis).
- zoonosis (for example, coxiella, bartonella, brucella, toxoplasmosis, psittacosis)

Clinical Commissioning Groups (CCGs) commission services for infectious diseases provided outside of Specialist Infectious Diseases Paediatric Centres.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of patients requiring the service is very small (there is about one child with HIV registered across three GP practices);
- the cost of providing the service is high because of the specialist ward environment (including isolation facilities) involved;

- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

131. Specialist services for complex liver, biliary and pancreatic disease (adults)

[A2 – Hepatobiliary and Pancreas]

Service summary
Specialist services for complex liver, biliary and pancreatic diseases in adults include treatment of a defined list of conditions and a defined list of procedures provided by Specialist Hepatobiliary Centres including outreach when delivered as part of a provider network.

Other relevant services

- 10. Adult specialist endocrinology services
- 65. Highly specialist services for adults with infectious diseases
- 69. Liver transplantation service (adults and children)
- 82. Pancreas transplantation service (adults)
- 105. Specialist cancer services (adults)

About the condition/service
Hepato-pancreato-biliary (HPB) services treat patients who have disorders of the liver, bile ducts and pancreas. A large volume of HPB services are delivered in local hospitals but, because of the complexity and high cost of care, delivery in conjunction with or at specialist tertiary centres may be necessary. Such conditions include hepatitis C (about 2,000 cases each year), serious complications of cirrhosis (about 3,000 cases each year) and complex liver, biliary and pancreatic surgery (about 5,000 cases each year).

How the service is organised
Surgical HPB services are provided in 20-25 Specialist Hepatobiliary Centres; medical HPB services are provided in 25-30. Some services are delivered through outreach arrangements in more local hospitals.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions the following specialist services for complex liver, biliary and pancreatic disease from Specialist Hepatobiliary Centres, including services delivered on an outreach basis as part of a provider network:

- Treatment with curative intent for all tumours (malignant and benign) involving the liver, bile ducts and pancreas
- Acute or chronic liver failure requiring escalation to Level 2 dependency care
- Management of complex portal hypertension requiring TIPSS (transjugular intrahepatic portosystemic stent shunting) insertion
- All strictures (narrowing) of the bile ducts and pancreatic ducts of any aetiology requiring surgery
- Biliary manometry
- Patients with chronic hepatitis C viral infection requiring treatment that necessitates specialist input. This includes patients with genotype 1 infection requiring protease inhibitors, patients co-infected with HIV, presence of

haemophilia, chronic kidney disease 3-6 and/or cirrhosis. Similar considerations will apply for the expected and imminent new therapies for non-1 genotypes and further therapies for genotype 1 chronic viral hepatitis
- Complications of acute pancreatitis requiring surgical intervention
- Chronic pancreatitis requiring surgery
- Liver, biliary and pancreas trauma, including iatrogenic bile duct injuries following laparoscopic cholecystectomy
- Clinical genetics services for patients with benign and malignant hereditary HPB disorders

The NHS Commissioning Board commissions the following drugs: a range of drugs including protease inhibitors for patients with complex Hepatitis C

Clinical Commissioning Groups (CCGs) commission:
- Management, monitoring and surveillance of cirrhosis, alcoholic liver disease, NASH (non-alcoholic steatohepatitis), NAFLD (non-alcoholic fatty liver disease) not requiring intervention
- Prevention, identification and treatment of viral hepatitis B
- Prevention, identification and treatment of viral hepatitis C, other than complex cases outlined above
- Simple gallstone disease without suspicion of gallbladder cancer
- Acute and chronic pancreatitis not requiring surgery
- Initial diagnostic investigations of suspected HPB cancers under the direction of the designated HPB specialist MDT
- Diagnosis and initial assessment of jaundice
- Identification and surveillance of populations at risk of HPB cancers

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist drugs and interventions involved and the need to provide 24/7 cover for patients with these complex conditions;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

132. Specialist services for haemophilia and other related bleeding disorders (all ages)

[B5 – Haemophilia and other bleeding disorders]

Service summary
Specialist services for haemophilia and other related bleeding disorders include all care provided by Specialist Haemophilia Centres including inpatient care where the cause of admission is related to a bleeding disorder. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

About this condition
Bleeding disorders are medical conditions in which the blood fails to clot properly. These conditions are rare in the general population, affecting about 24,000 people in the UK. Most are genetically inherited.

Bleeding disorders include:

- Haemophilia A and B (classified as mild, moderate or severe)
- Von Willebrand disease (classified as Type 1, Type 2 and Type 3, with Type 3 being severe)
- Factor deficiencies I, II, V, VII, X, XI and XIII
- Platelet disorders
- Acquired (non-inherited) haemophilia

There are two main forms of haemophilia – A and B – both of which are inherited in such a way that they mainly affect males. The most common is haemophilia A (deficiency of clotting factor VIII), which affects between 1 in 5,000 and 1 in 10,000 males. Haemophilia B (deficiency of clotting factor Ix) is less common and affects about 1 in 40,000 males.

Von Willebrand disease is a deficiency or a defect of the coagulation protein, von Willebrand factor, it is more common that haemophilia but usually a less severe bleeding disorder. It affects at least 1 in 1,000 of both sexes.

Bleeding disorders are treated by replacing the missing clotting factor. Various clotting factor concentrates are available, but where there is no factor replacement available for a particular condition, fresh frozen plasma may be used. Replacement may be given ‘on demand’ to treat a bleeding episode, or for more severe disorders may be given prophylactically to prevent bleeding.

Women with bleeding disorders need very specialist care when they give birth to prevent excessive bleeding. Where it is known that a woman is going to give birth to a baby with a bleeding disorder, the obstetrician, midwife and haemophilia team work together to minimise any risks to the mother and baby, for example by avoiding forceps delivery.

How the service is organised

The standard service model for haemophilia services was set out in the Health Service Guidance HSG(93)30 ‘Provision of Haemophilia Treatment and Care’. This stated that there should be two different levels of haemophilia provision:

- Comprehensive Care Centres provide specialist diagnosis and care
- Haemophilia Centres provide a local, shared care service

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist services for haemophilia and other related bleeding disorders from both Comprehensive Care Centres and Haemophilia Centres where the cause of admission is the bleeding disorder. This includes services delivered on an outreach basis as part of a provider network.

The NHS Commissioning Board commissions the following drugs and blood products for the treatment of haemophilia, some of which may be delivered in the patient’s home:

- FVIII concentrate
- FVIII/VwF concentrate
- VwF concentrate
- FIX concentrate
- Recombinant FVIIa
- Factor Eight Inhibitor Bypassing Activity concentrate (FEIBA)
- Prothrombin Complex Concentrate (PCC)
- FXIII concentrate
- FXI concentrate
- Factor VII concentrate
- Porcine FVIII
- Cryoprecipitate
- Fresh frozen plasma
- Octaplas
- Fibrinogen concentrate
- Topical thrombin
- Platelets
- Rituximab*
- Tranexamic acid

Clinical Commissioning Groups (CCGs) commission all other activity for patients with bleeding disorders. For example, if an adult patient needs a hip replacement, the CCG commissions the hip replacement and the NHS CB commissions any blood products needed to support haemostasis. The NHS CB commissions all surgery for children with bleeding disorders.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS Commissioning Board because:

- the number of individuals with the condition is very small (there are about four patients with bleeding disorders registered at each GP practice);
- the cost of providing the service is very high because of the specialist drugs and blood products involved;

- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

133. Specialist services for severe personality disorder in adults

[Personality disorders]

Service summary
Specialist services for severe personality disorder in adults includes inpatients and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Centres. In addition, the service includes associated non-admitted care including outreach when delivered as part of a provider network.

About the condition/service
Personality disorders are "... deeply ingrained and enduring behaviour patterns, manifesting as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels and, particularly, relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance."

About 450 individuals each year need access to this service.

How the service is organised
There are about eight Specialist Centres in England.

The Specialist Centres provide intensive 'wrap around' interventions (24 hours a day, seven days a week) that ensure therapeutic assessment, engagement, containment, treatment and step down for adults with personality disorders (PDs). The decision to refer a patient to a Tier 4 PD Service is made on the basis of severity of their condition quantified by using an instrument developed by the National Personality Disorder Development Programme, which measures factors associated with diagnosis, pervasiveness, complexity, risk and unmanageability of PD. Patients who score 7, 8, 9 or 10 on the 10 point scale on the instrument are considered appropriate for referral to Tier 4. Interventions can be on an inpatient basis or through a bespoke care package. The Specialist Centres also provide access to or provision of expert specialist treatments for presenting co-morbidities, for example, eating disorders; substance misuse, etc.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist services (Tier 4 services) for severe personality disorder in adults from Specialist Centres. This includes inpatients and bespoke packages of care for intensive day care services (as an alternative to admission). In addition, the service includes associated non-admitted care including outreach when delivered as part of a provider network.

Clinical Commissioning Groups (CCGs) commission personality disorder services for patients requiring care in Tier 1, Tier 2 or Tier 3 services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is very small (about one patient across 14 GP practices needs access to the service each year);
- the cost of providing the service is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients can be very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

A review will be undertaken in two to three years to establish whether there are elements of this service that should be commissioned by CCGs.

134. Specialist services to support patients with complex physical disabilities (all ages)

[D1 – Complex Disability Equipment]

Service summary
Specialist services to support patients with complex physical disabilities (including those with a combination of physical, sensory, intellectual, learning or cognitive disabilities) include the specialist assessment for, and provision of (if indicated):

- Prosthetics (limb and artificial eyes)
- Specialist wheelchairs (including complex postural seating and powered wheelchair controls)
- Specialist augmentative and alternative communication aids
- Specialist environmental controls

This applies to provision in adults and children.

A. PROSTHETICS (LIMB AND ARTIFICIAL EYES)

About the condition/service
Prosthetics is a specialist service for all major upper and lower limb amputees and people with congenital limb deficiencies, who have a potential to use prostheses to help them mobilise or improve upper limb function.

The number of amputee and limb deficient people in England is about 45,000. Each year about 4,000 major lower limb amputations, 200 upper limb amputations and 150 congenital upper and lower limb amputations are referred to about 30 specialist centres.

The service provides lifelong care to people with a congenital limb deficiency or who have had major limb amputations. Pre-amputation, re-amputation and antenatal consultations are also provided as required.

The **National Artificial Eye Service** provides a manufacturing and fitting service for the supply of ocular prostheses to all eligible patients throughout England. The service sees about 1,000 new patients each year.

How the service is organised
Prosthetic services are provided by about 30 specialist centres across England and include workshops and manufacturing facilities. Some services are provided by satellite centres with all satellite centres being linked to a specialist centre.

Specialist centres provide:

- Specialist assessment and review
- Prescription, provision and maintenance of prosthetic limbs
- High tech prosthetic components, for example, microprocessor units and silicone cosmeses
- Specialist gait re-education and gait analysis

- Combined clinics with surgeons
- Pain management and psychological support including antenatal consultations
- Educational, vocational, leisure, mobility and driving advice

Assessments are carried out in specialist centres by a multi-disciplinary team that includes: a
rehabilitation physician specialising in prosthetics, prosthetists, physiotherapists, occupational therapists, nurses, psychologists, counsellors and any other specialist that may be appropriate for any specific case.

There are different arrangements for veterans requiring prosthetics services.

The **National Artificial Eye Service is** administrated centrally through one NHS Trust, has clinics in 16 locations and outreach services in 48 locations.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions all prosthetics services, including the National Artificial Eye Service.

Clinical Commissioning Groups (CCGs) commission any standard therapies (for example, physiotherapy, occupational therapy) required by the patient that take place outside the prosthetics service.

The NHS CB commissions the following pieces of equipment: all prosthetic devices (including microprocessor knee units, high definition silicon cosmoses), artificial eyes

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of prostheses and the infrastructure involved to manufacture them can be very high;
- the number of doctors and other expert staff trained to deliver the service is small (especially in the case of patients who have upper limb loss, congenital limb deficiencies and/or require high tech prostheses); and
- the cost of treating some patients can be very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

B. SPECIALIST WHEELCHAIRS (INCLUDING COMPLEX POSTURAL SEATING AND POWERED WHEELCHAIR CONTROLS)

About the condition/service

There are estimated to be about 500,000 wheelchair users in England but with only about 5% (about 25,000) requiring specialist services. These are patients who have the most profound disabilities and/or an unstable medical condition, who can only function adequately in a wheelchair with unique personalised modifications, often incorporating bespoke manufactured items. All aspects of provision (assessment, objective setting, specification, prescription, design, manufacture, commissioning, on-going support and maintenance) require greater knowledge and expertise than is available in most local wheelchair services. The specialist service addresses postural needs (facilitating comfort and function) as well as mobility**.**

People (adults and children) requiring specialist wheelchair services have a complex and /or fluctuating medical condition and multiple disabilities, which may include physical, cognitive, sensory and learning aspects. The most common diagnoses that need specialist wheelchair services are: cerebral palsy, muscular dystrophy, multiple sclerosis, brain Injury, motor neurone disease, high level spinal cord Injuries (with/without ventilation support).

How the service is organised

Although there are about 150 providers of wheelchair services in England, only about 30 of these are able to provide specialist services.

The specialist assessment team consists of a doctor specialising in rehabilitation medicine, a specialist therapist, a clinical engineer and a clinical scientist, all of whom have appropriate skills and experience. The specialist team works closely with the individual, their families/carers, other medical and surgical teams, local therapy staff (including speech and language therapists) as well as staff from social services, community nursing and education /employment. The specialist team also liaises with external suppliers of equipment.

Specialist centres are equipped with appropriate equipment for physical examinations, driving assessments and pressure measurement plus suitable facilities for moving and handling. Trial wheelchair/seating equipment is also available. Alternatively, individuals may be seen in other environments such as child development centres/schools for children or familiar/non-threatening surroundings such as homes for people with cognitive or learning difficulties.

Each prescription is individually formulated following a detailed assessment of the disabled person's needs and lifestyle, using a standardised assessment procedure. A specification is drawn up in conjunction with the disabled person, and his/her carers if appropriate, and based on his/her goals. The prescription most likely to meet the specification may comprise off-the-shelf components, bespoke manufactured items or any combination of these. Advice may be given about other aspects of mobility/postural management such as use in vehicles, static seating, standing frames, etc.

Specialist centres are equipped with technological and engineering facilities for assembly/set-up of the prescribed equipment and for customisation/modifications often necessary to complete an episode of care successfully.

Regular reviews are critical to the ongoing success of the prescription for these individuals as their needs may change at irregular intervals due to their medical conditions. Access to engineering facilities ensures that changes can be managed in a timely manner.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist wheelchair services for individuals who meet the following criteria:

- Have posture or mobility needs that can only be met with a high level of specific design input
- Are ‘active’ individuals requiring special expertise
- Have the ability to control a powered wheelchair but are unable to use standard joystick controls
- Require multiple items of integrated equipment

The NHS CB commissions the following drugs/devices: specialist wheelchair packages, special seating packages

Clinical Commissioning Groups (CCGs) commission services for those wheelchair users who do not meet the criteria for specialist wheelchair services.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS Commissioning Board because:

- the number of patients requiring the services is relatively small;
- the cost of providing the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

C. SPECIALIST AUGMENTATIVE AND ALTERNATIVE COMMUNICATION AIDS

About the condition/service

The Office of the Communication Champion estimates that approximately 6,000 children and adults require assessment and provision by specialist communication services each year.

Communication is fundamental to independence, achievement and quality of life. A communication system enables people who have lost, or never had speech or language to interact with their world, often allowing them to engage and be successful in education, vocation and work.

Augmentative and alternative communication (AAC) equipment allows for:

- Output of synthesised (artificial) voice, digitised (recorded) voice or text
- A vast array of ways in which vocabulary is organised and selected by the user
- Many different means of accessing and controlling the equipment

People requiring specialist AAC assessment have a combination of physical, sensory, intellectual, learning or cognitive disabilities. This includes children and adults born with a communication impairment (for example, cerebral palsy, developmental disorders, learning disabilities and other disorders such as autism) and children and adults who become communication impaired (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson’s, Alzheimer’s, multiple sclerosis or motor neurone disease).

How the service is organised

There are 10-12 specialist centres in England, either NHS or voluntary sector (funded via NHS or education sources). Assessment models and the services offered vary but most provide:

- A multi-disciplinary team including specialist speech and language therapists, clinical scientists and technologists, occupational therapists, specialist teachers and access to physiotherapists, psychologists and others
- Technological and engineering facilities for customisation and modification to the individual
- An assessment and loan bank of possible technologies offering a diverse range of solutions
- An extremely wide range of software, vocabulary packages and resources
- Expertise in procurement and equipment management
- An ability to issue, monitor, maintain, recall and refurbish equipment
- An ability to manage, aggregate and analyse user information to enhance the service and streamline day to day operations
- An ability to integrate services and equipment with other assistive technologies such as environmental controls
- An ability to educate and train a wide range of stakeholders from the user, families, spoke service members and local team members
- An ability to take account of co-morbidity issues such as postural support needs

Referrals for an AAC needs assessment originate from local services, including health care professionals in the community and acute medical settings, staff within the education sector, staff within the social care sector and specialist and local rehabilitation teams.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions services for patients that require specialist assessment for AAC aids:

- Where there is a severe/complex communication difficulty associated with a range of physical and/or cognitive, learning and sensory deficits.
- Where goals are achieved by the input of a multi-disciplinary team to include speech and language therapists, clinical scientists, occupational therapists and education professionals (as a minimum), with specific competencies and access to a wide range of specialist equipment.
- Where individuals require multiple assistive technologies, integrated into a single means of access and functionality (for example communication, environmental control, computer access and/or powered wheelchair control)
- Where communication solutions are dependent upon special engineering and adaptation.

The NHS CB commissions the following drugs/devices: specialist AAC aids

Clinical Commissioning Groups (CCGs) commission AAC aids for those patients who do not meet the criteria for specialist AAC aids.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of patients requiring the services is small (about one patient registered at each GP practice requires access to the service);
- the cost of the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCG.

D. SPECIALIST ENVIRONMENTAL CONTROLS

About the condition/service
There are about 6,000 users of environmental control systems (ECS) in England. These systems enable people with profound physical disability to gain a degree of personal independence, often enabling them to continue living in their own homes with carer support and relying on their ECS to achieve single switch access to operate multiple functions such as:

- Summoning help in an emergency or calling a carer
- making and receiving telephone calls
- controlling door access for visitors and the EC user
- adjusting room temperature, ventilation and lighting
- adjusting position in riser/recliner chair or profiling bed
- operating electrical appliances in home (television, satellite, audio visual equipment)

- computer control and access method

A significant proportion of users make use of these technologies to provide safety and security, gain remunerative employment, maintain social contacts and access information and services. The current EC equipment has a modular format with systems prescribed and assembled to meet individual need. However, they are only available from specialist suppliers and may require a customised means of access to accommodate the individual's functional abilities.

Most people requiring ECS have significant upper limb impairments that mean they are unable to use standard controls, for example remote-control handsets or telephones. Many are neurological conditions resulting in tetra-paresis, often with a progressive component varying from moderate to rapid and combined with fatigue. The commonest diagnoses are: multiple sclerosis, spinal cord injury (level C5/6 & above), motor neurone disease, cerebral palsy, muscular dystrophy, severe arthritis and acquired brain injury. Besides having severe physical impairments, some of the users may also have co-existing cognitive and communicative impairment.

How the service is organised

There are about 20-25 providers of ECS, with over 70% of the population being covered by 12 major service providers.

The specialist centres providing ECS: conduct assessment of the individual's needs, usually in their place of residence; prescribe equipment solutions to meet these needs; and undertake or oversee their installation. A stock of relevant equipment is available to demonstrate ECS and computer access to patients and carers and, if needed, a trial can be arranged.

The services are also responsible for: on-going support of the equipment, including initial tuition; clinical review with additions and modifications to suit changing needs; equipment maintenance; and service support, including emergencies.

Specialist ECS services achieve the required medical and technical competencies through the multi-disciplinary approach of clinical scientists, clinical technologists, specialist occupational therapists and input from medical personnel (most commonly rehabilitation medicine consultants). They work closely with the community and other specialist teams who may be involved with individual patients. Thus is especially needed for patients who require multiple assistive technologies that need integration into a single means of access (for example, environmental control, computer access, communication aid and/or powered wheelchair control).

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist environmental controls.

The NHS CB commissions the following drugs/devices: specialist environmental control devices

Clinical Commissioning Groups (CCGs) do not commission any services relating to a patient's specialist environmental control but commission any general health services required by that individual. Local authorities commission non-specialist environmental controls.

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of patients requiring the services is small (about one patient in each GP practice requires access to the service);
- the cost of providing the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified

This service includes specified activity.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

135. Specialist surgery for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist surgery for children and young people include services provided by Specialist Paediatric Surgery Centres including outreach when delivered as part of a provider network. The service includes:

- All surgery on neonates
- Surgical management of rare conditions
- Surgical management of more common conditions when the child or the procedure is high risk (including the need for PICU or Specialist Anaesthetic and acute pain management)
- Provision of specified procedures

About the condition/service
Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex (for example, total thyroidectomy); the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. For example, adenotonsillectomy is normally a routine procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

Congenital abnormalities are uncommon. About 3% of newborns have a major physical abnormality. Many of these do not require surgical intervention. Individual congenital conditions requiring intervention in the neonatal period are rare (for example, gastroschisis, one of the commonest abnormalities, in which an infant's intestines stick out of the body through a defect on one side of the umbilical cord, has an incidence of about 1 in 2,500). Less severe abnormalities are more common (for example, inguinal hernias have an incidence of about 1%) but do not always require specialist care unless the child has a significant co-morbidity.

Further specialist anaesthesia is required in a number of children undergoing diagnostic or interventional radiological procedures, for example, brain MRI in neonates, small infants or those with complex co-morbidity (for example, cystic fibrosis); percutaneous CT or ultrasound guided drainage of obstructed kidneys or difficult central venous cannulation; angiography; angioplasty; embolisation and thrombolysis; percutaneous cholangiography; nephrostomy.

How the service is organised
There are about 20 Specialist Paediatric Surgery Centres in England.

What the NHS Commissioning Board commissions

The NHS Commissioning Board (NHS CB) commissions specialist surgery for children and young people from Specialist Paediatric Surgery Centres in England, including services delivered on an outreach basis as part of a provider network. The service includes:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require treatment by more than one surgical specialty.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre, even for minor surgery, such as surgery to remove a soft tissue lump, if their co-morbidity is serious.

Clinical Commissioning Groups (CCGs) commission routine surgery for children over 60 weeks post-conceptual age who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Inguinal hernias
- Circumcision
- Undescended testis

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified

This service includes specified activity at specified centres.

Review of the service commissioner

There are no plans to review whether this service should be commissioned by CCGs.

136. Specialist urology services for children and young people

[E2 – Paediatric Surgery]

Service summary
Specialist urology services for children and young people include services provided by Specialist Paediatric Urology Centres including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex or high risk procedures only.

About the condition/service
Most children and young people who require routine surgical procedures can be cared for by their local children's surgical service.

Specialist surgical care for patients under the age of 18 is required when: the surgery is complex; the patient is very young (neonates and babies who have been born prematurely and are up to 60 weeks post-conceptual age); and/or when the baby or child has complex co-morbidity. In these circumstances, specialist paediatric anaesthesia and/or pain relief are also required. In addition, all babies and children already under the care of a neonatal or paediatric intensive care unit, and who require surgery, are managed by specialist paediatric surgeons and anaesthetists. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised
There are about 20 Specialist Paediatric Urology Centres in England.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist urology services for children and young people from Specialist Paediatric Urology Centres, including services delivered on an outreach basis as part of a provider network:

- All surgery performed on neonates and infants who have been born prematurely who are still under 60 weeks post-conceptual age
- The surgical and radiological management of infants and children who are very seriously ill and/or have rare conditions that require specialist expertise (including all babies and children already receiving care in a neonatal or paediatric intensive care unit). These children have conditions that are often congenital with a genetic or developmental cause and who may require treatment by more than one surgical or medical speciality, as well as specialist anaesthesia and acute pain control.
- The management of children who have complex co-morbidities or are at significant risk of peri-operative complications. Some children have other medical problems/co-morbidities that might complicate surgery or anaesthesia and make it more hazardous, such as complex airway abnormalities or severe uncorrected heart problems. These patients are regarded as specialist and require referral to a specialist centre providing specialist anaesthesia and acute pain services even for minor surgery.

Clinical Commissioning Groups (CCGs) commission routine surgery for children over 60 weeks post-conceptual age who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Circumcision

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

- the number of individuals requiring the service is small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individuals CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

137. Spinal cord injury services (all ages)

[D13 – Spinal Cord Injury]

Service summary
Spinal cord injury services include services provided by Spinal Cord Injury Centres. This applies to provision in adults and children.

About the condition/service
A spinal cord injury (SCI) is an injury to the spinal cord resulting from trauma, disease or infection. Complete injuries result in tetraplegia or paraplegia below the level of the injury and incomplete injuries result in neurological impairment affecting mobility, bladder and bowels. Patients with high-level injuries may require long term ventilation.

The incidence of SCI in the UK is estimated at between 12 and 16 per million with the majority of cases caused by trauma.

The aim of the service is to:

- Provide acute management and rehabilitation of people with SCI
- Provide ongoing management of people with SCI
- Promote optimal outcomes, leading to reduced mortality and morbidity
- Support patients to maximise their potential for independent living and for return to employment or education, hobbies and activities of daily living
- Optimise autonomy and health in people with SCI

How the service is organised
Spinal cord injury services are provided by eight Spinal Cord Injury Centres (SCICs) in England. Most services are delivered directly on site at the centres but provision may also include:

- Acute outreach, both face to face and by telephone, to newly injured patients and those caring for them
- Visits to the patient’s home, local area and local services, as part of planning for reintegration
- Outreach clinics in suitable locations

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all activity for Spinal Cord Injury patients provided by the SCIC’s host provider, including:

- any part of the initial admission to the SCIC’s host provider following injury, wherever in the provider the patient is situated
- any part of the initial admission to the SCIC’s host provider following injury, even if the patient is treated for another related or non-related condition during that spell (for example, hand injury, epilepsy). Occasionally the initial admission may be interrupted by a temporary transfer to another setting.
- any further admission or attendance for SCI-related care, wherever the treatment is located in the SCIC’s host provider (for example, cystoscopy,

tendon transfer), where a SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint care arrangement
- any further admission of the SCI patient for non-SCI-related care, if an SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint care arrangement

Clinical Commissioning Groups (CCGs) commission:
- Services for patients treated in or by SCI Centres who do not have a spinal cord injury as defined above, except where this service is defined elsewhere as a service commissioned by the NHS CB. Examples of services commissioned by CCGs might include patients with multiple sclerosis, patients without SCI having treatment for pressure sores.
- Patients admitted to SCICs with injury to the spinal column but intact neurology (with the exception of up to two nerve roots)
- Patients with progressive disease, except where this is covered by a service defined elsewhere as a service that is commissioned by the NHS CB, for example, patients with spinal tumours. However, if spinal cord dysfunction has arisen from the effects of a benign tumour that has been primarily managed by an appropriate specialty, or from a tumour that has been adequately treated and is now deemed to have a benign course, or if the patient has a significant life expectancy, the patient may transfer to the SCIC for rehabilitation and lifelong follow up. At this point, the NHS CB commissions the patient's care.
- A&E attendance following spinal cord injury up until a decision to admit
- Assisted conception services and sperm storage, with the exception of electro-ejaculation, which is part of the specialist SCI service
- Any further admission or attendance of a person with SCI for non-SCI-related care when the patient is treated by a clinician who is not an SCI clinician and there is no shared care agreement, except where the service is defined elsewhere as a service commissioned by the NHS CB
- People with SCI treated in centres (specialist or non-specialist) that are not recognised SCICs, except where formal sub-contract arrangements have been put in place with an SCIC or the service is defined elsewhere as being commissioned by the NHS CB
- Delivery (obstetrics) and care of the new-born
- Patients who remain in a SCIC after they are clinically fit for discharge
- Care in the community, including the provision, maintenance and replacement of equipment required to support the patient in the community, except where this is defined as a service commissioned by the NHS CB
- The provision of disability equipment, except where this is defined as a service commissioned by the NHS CB

Why the service is commissioned by the NHS Commissioning Board

This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small (about one patient across nine GP practices has a SCI each year);
- the cost of providing the service is very high because of the specialist interventions involved and the because of the significant lengths of stay of some patients;

- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)

Service summary
Stem cell transplantation services for juvenile idiopathic arthritis and related connective tissue include services provided by Highly Specialist Stem Cell Transplant Centres for juvenile idiopathic arthritis and related connective tissue. This provision applies to children.

Other related services:

- 22. Autoimmune paediatric gut syndromes service
- 29. Blood and marrow transplantation services
- 100. Severe combined immunodeficiency and related disorders service

About the condition/service
Juvenile idiopathic arthritis is an autoimmune disorder.

The service is participating in a European study evaluating the clinical effectiveness of stem cell transplant services for this disease as a treatment option when other more conventional treatment options have been exhausted. The increased use of monoclonal antibody therapies as a treatment for juvenile idiopathic arthritis has resulted in fewer patients being referred for stem cell transplantation.

How the service is organised
The service treats about one child each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions stem cell transplantation services for children with juvenile idiopathic arthritis and related connective tissue disorders from Highly Specialist Stem Cell Transplant Centres for juvenile idiopathic arthritis and related connective tissue**.**

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is very high because of the specialist ward environment involved;
- the number of doctors and other expert staff trained to deliver the service is very small; and
- the cost of treating patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

139. Stickler syndrome diagnostic service (adults and children)

Service summary
Stickler syndrome diagnostic services include diagnostic services provided by Highly Specialist Stickler Syndrome Centres (including specialist laboratory services). This provision applies to adults and children.

About the condition/service
Stickler syndrome is an inherited disorder of connective tissue associated with cleft palate, deafness and arthropathy. It is the commonest inherited cause of rhegmatogenous retinal detachment in children (where fluid passes into the space between the retina and the retinal pigment layer). Although the systemic features are widespread, the sight-threatening complications are generally the most serious, particularly the risk of giant retinal tear, which is frequently bilateral and, if untreated, can lead to blindness.

How the service is organised
The service is an outpatient diagnostic service that focuses on genetic testing to establish the patient’s sub-classification of the disease. It is a new service and it is anticipated that about 100 new index patients will be seen each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board Commissions (NHS CB) diagnostic services for patients with Stickler syndrome from Highly Specialist Stickler Syndrome Centres.

Clinical Commissioning Groups (CCGs) commission treatment of patients with Stickler syndrome.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals requiring the service is very small;
- the cost of providing the service is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Cambridge University Hospitals NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

140. Vein of Galen malformation service (adults and children)

Service summary
Vein of Galen malformation services include services provided by Highly Specialist Vein of Galen Malformation Centres. This provision applies to adults and children.

Other relevant services

- 119. Specialist neuroscience services for children and young people

About the condition/service
Vein of Galen Malformations (VGMs) are extremely rare abnormalities in the blood vessels in the brain. They usually occur in new-born children and often result in cardiac problems, although sometimes these problems do not occur until later in life.

How the service is organised
Treatment for VGMs in children involves injecting acrylate or placing a coil into the blood vessels to restore arteriovenous equilibrium.

The service treats about 10 new babies and children each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and children with vein of Galen malformations from Highly Specialist Vein of Galen Malformation Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Great Ormond Street Hospital for Children NHS Foundation Trust
- Acute Services Division, NHS Greater Glasgow and Clyde

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

141. Veterans’ post-traumatic stress disorder programme

Service summary
Veterans’ post-traumatic stress disorder services include services provided by Highly Specialist Veterans’ Post-traumatic Stress Disorder Centres.

About the condition/service
The veterans’ post-traumatic stress disorder programme provides inpatient treatment for service veterans who have complex post-traumatic stress disorder as a result of multiple traumas whilst in service.

How the service is organised
This is a new service that expects to treat about 240 patients each year.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions post-traumatic stress disorder services for veterans from Highly Specialist Veteran’s Post-Traumatic Stress Disorder Centres.

Clinical Commissioning Groups (CCGs) commission mental health services for veterans once they have been discharged from the Highly Specialist Veterans’ Post-traumatic Stress Disorder Centres.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small;
- the cost of the specialist mental health facility is very high; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Tyrwhitt House, Leatherhead, Surrey (expanding to Audley Court, Newport, Shropshire and Hollybush House, Ayr

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

142. Wolfram syndrome service (adults and children)

Service summary
Wolfram syndrome services include services provided by Highly Specialist Wolfram Syndrome Centres. This provision applies to adults and children.

Other relevant services

- 109. Specialist endocrinology and diabetes services for children and young people

About the condition/service
Wolfram syndrome is a very rare inherited disorder with an estimated prevalence in the UK of 1 in 770,000 adults, i.e. about 770 patients in England. It is a progressive neurodegenerative disorder with a debilitating and life threatening association of diabetes, blindness, deafness and brain disease.

How the service is organised
Both the adult and paediatric services run clinics that undertake assessment of all patients in a multi-disciplinary structure. Patients are assessed and reviewed by all the specialities appropriate to their needs during the clinic.

Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress.

Some clinics are run on an outreach basis in partnership with a doctor, nurse and dietician at a local hospital.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and children with Wolfram syndrome from Highly Specialist Wolfram Syndrome Centres.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

Clinical Commissioning Groups (CCGs) commission the local care recommended in the management plan developed by the Highly Specialist Wolfram Syndrome Centres.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals Birmingham NHS Foundation Trust (adults only)

Review of the service commissioner

There are no plans to review whether this service should be commissioned by Clinical Commissioning Groups.

143. Xeroderma pigmentosum service (adults and children)

Service summary
Xeroderma pigmentosum services include services provided by Highly Specialist Xeroderma Pigmentosum Centres. This applies to provision in adults and children.

Other relevant services

- 61. Highly specialist dermatology services

About the condition/service
Xeroderma pigmentosum is a life-threatening inherited disorder affecting skin, eyes and nervous system. A defect in the process of repairing ultraviolet-induced DNA damage results in: severe sunburn-type reactions to daylight; skin cancers in exposed skin from early childhood; eye disease; and progressive neurological degeneration in 20-30% of patients. There are thought to be about 100 people with the condition in the UK.

How the service is organised
The service is organised as follows:

- **One stop multidisciplinary clinic** over a one- or two-day period with consultations in neurology (paediatric and adult), dermatology, ophthalmology, psychotherapy, dermatological surgery, including specialist investigations
- **Laboratory diagnostic service**

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for adults and children with Xeroderma pigmentosum from Highly Specialist Xeroderma Pigmentosum Centres.

Clinical Commissioning Groups (CCGs) do not commission any elements of this service.

Why the service is commissioned by the NHS Commissioning Board
This service is being commissioned by the NHS CB because:

- the number of individuals with the condition is very small; and
- the number of expert doctors and other staff who can provide the service is very small.

How the activity for this service is identified
Activity is identified via local data flows, which apply to established designated centres only:

- Guy's and St Thomas' NHS Foundation Trust

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

First published Date
Published to Name, in electronic format only.