



**Gateway Reference: 17981**

**Clinical Advisory Group for Prescribed Services  
Final Recommendations**

June 2012

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## **Foreword**

The NHS has always sought to give the responsibility for planning and commissioning services to local health bodies. But there is a potential tension between local determination and the need to plan for larger populations when for example a condition is rare or a service is provided in a small number of centres.

In the recent past these have been called Specialised Regional Services, Specialised Services and, for very rare conditions, National Specialised Services.

As part of the changes to the NHS outlined in Equity and Excellence: Liberating the NHS, and subsequently included in the Health and Social Care Act 2012; commissioning of NHS services will be the responsibility of Clinical Commissioning Groups (CCGs) except where the service is prescribed in legislation. Prescribed services will be commissioned by the NHS Commissioning Board (NHSCB).

The prescribed services fall into two categories: those which are named on the face of the Act (see Page 9) - including services for members of the armed forces or their families; and those which are defined in regulations. For specialised services, it is envisaged that such prescription will have regard to the four factors:

- (a) the number of individuals who require the provision of the service or facility;
- (b) the cost of providing the service or facility;
- (c) the number of persons able to provide the service or facility;
- (d) the financial implications for clinical commissioning groups if they were required to arrange for the provision of the service or facility.

The Clinical Advisory Group for Prescribed Services (CAG) was established to offer advice on the initial list of such services. In the first instance, ministers asked that services within the current list of Specialised Services (the Specialised Services National Definition Set, SSNDS) and those removed in the most recent revision, be considered against the four factors.

## **The process**

I was asked to Chair the CAG and I worked with SHA Medical Directors to identify members from General Practice and Providers. We invited suggestions for members from Specialised Commissioning Group (SCG) teams and looked to include a diverse membership in terms of geography, size of provider and areas of expertise.

On initial review of the SSNDS, the CAG agreed to the establishment of two sub-groups to offer advice on Mental Health services and Services for children and young people. Again, we looked for a diverse membership, including representation from commissioning GPs.

Once CAG had agreed an initial view on services, we were tasked with asking the SCG teams (through the national Transitional Oversight Group, TOG) to

advise on the practical implications of prescription. The Health and Social Care Act requires ministers to consult with the NHSCB before prescribing services- but as this had not been established we sought views from the current commissioners.

CAG and its sub-groups received detailed responses on all services. Throughout the process, CAG asked for views from National Clinical Directors and DH Policy leads, as well as other appropriate experts.

The final version of the initial recommendations was agreed by all members of the CAG and its sub-groups. They were shared with DH Policy leads and NHS commissioner representatives.

### **Initial findings**

Overall, the SSNDS describes a consensus view of those services which are best planned at a population of greater than one million. The definitions offer a detailed description of such services together with some form of list of clinical codes to help identify and therefore commission the activity.

CAG's initial recommendation was to prescribe services based on the existing definition for around half of the services.

However, the definitions were written for a different purpose. Where services are part of a wider pathway the definition may not set out precise limits on the elements of service to be defined as specialised. We were struck by the difficulties which arise when an attempt is made to translate the consensus definition into contractual terms.

Consequently, some of the definitions, if used to prescribe a service, would not enable separate and direct commissioning by the NHSCB.

This is not to say that the service is not specialised. Nor that it should not be prescribed- in fact CAG members supported the inclusion of all services in the current SSNDS in the list of prescribed services. Rather, CAG advised that further work was needed to define specialised elements in a way that commissioners, clinicians, patients and the public can be clear on the split of responsibility for commissioning.

### **Further consideration**

We shared our initial recommendations with ministers in December 2011. Ministers agreed to further advice being sought where further clarity was required. This report presents CAG's final recommendations following receipt of this additional information.

The additional advice was provided by around 60 Clinical Reference Groups (CRGs). These groups were established to support the transition of specialised services commissioning from the current arrangements to the NHSCB. The CRGs' primary role is to develop the 'products' of specialised services commissioning, for example, service specifications and policies. They have a broad membership that includes clinicians, commissioners,

public health colleagues and patients. The chairs are all leading clinicians in their fields.

An assurance process was established for the more substantial CRG responses which included clinical, financial and public/ patient scrutiny. This process resulted in a comprehensive review of those services where the current definition made separate and direct commissioning difficult.

### **Key findings**

The final recommendations propose prescription of virtually all those services that have been commissioned through specialised commissioning groups. In addition to services included in the third edition of the SSNDS, several recommendations reflect inclusion of services removed from the SSNDS between versions 2 and 3.

The additional work, completed by CRGs, has resulted in a much clearer description of the services which would be appropriate for the NHSCB to commission. These now fall into three patterns:

1. Services where the entire patient pathway is to be prescribed- for example, Haemophilia and Cystic Fibrosis.
2. Services where care provided by Specialist and Highly Specialist Centres is to be prescribed- for example Complex Spinal Surgery and Highly Specialist Allergy Services.
3. Services where procedures or facilities are prescribed- for example Radiotherapy Services and Hyperbaric Oxygen Treatment Services.

CAG members were aware of widespread evidence that specialised services are often accessed disproportionately by patients living close to a specialist centre. Where appropriate, CAG has included in the description to accompany the proposed regulation services provided outside the Specialist Centre- in the form of managed out-reach. This is in acknowledgement that, where possible, services should be provided as 'close to home' as is safe.

### **Other issues**

CAG members were struck by the need for commissioners to work together where a patient pathway crossed between CCG and NHSCB responsibility. There were potential risks in creating a commissioning "boundary"- especially where separate budgets will apply.

For instance, our proposals recommend that general nephrology should be commissioned by CCGs but that specialist assessment for renal replacement therapy should be commissioned by the NHSCB. There is an identifiable risk that activity could migrate towards one or the other if the criteria for referral to such a clinic were not clearly laid out.

On the other hand, prescribing Morbid Obesity Services to be commissioned by the NHSCB separates the prevention from the outcome. Local Authorities (LAs) and CCGs will be responsible for weight management policy and weight management services. A successful programme to reduce the number of

people requiring surgery would lead to a reduced cost to the NHSCB based on expenditure by CCGs and LAs. Conversely, the absence of a weight management programme could lead to increased cost to the NHSCB but the investment required in prevention would sit within a separate budget.

CAG took the view that these risks were identifiable but should not preclude prescription of a service. As such, the NHSCB will need to develop systems to “join-up” commissioning for these services.

In addition, there are key service “boundary” issues which need to be tackled by the new commissioning system:

- Transition from children, to young adults and on into the adult service
- Return to maintenance and local care following specialist intervention
- Shared care arrangements (especially for children)

Finally, for some services CAG members were aware that the treatment and management of conditions will not remain static. For some services, we were advised that consistent national commissioning would lead to a reduction in providers- this was especially true of observed occasional practice in paediatric specialist services. For others there was a sense that, once established, CCGs would be better able to commission elements of the service. We have marked such services “for early review”.

### **National services**

We were not asked to review the list of services currently included in regulations and commissioned by the National Specialised Commissioning Team. We have included mention of these where they appear in definitions but accept that the inclusion in regulations as a highly specialised service can be taken to mean the service will be prescribed. The full list of the current regulations, together with a proposed description is included on Page 28.

### **Final reflection**

To consider the breadth of Specialised Services available across the NHS in England was a massive task. The Clinical Advisory Group has frequently been faced with reports of more than 200 pages in length- and one which was more than 500 pages. I am deeply grateful to all members- and especially the core members who have supported the process to completion.

The work this year has involved more than 500 clinicians in the various Clinical Reference Groups- I am grateful to James Palmer and Fiona Marley for the considerable success they have achieved in real national engagement.

Finally, I want to thank the Secretariat, led by Kev Smith and spanning the Department of Health and the NHS Commissioning Board Authority. They have made my task as Chair both more productive and more satisfying.

Dr Kathy McLean  
Chair

## **Extract from the Health and Social Care Act 2012**

### **15 Power to require Board to commission certain health services**

After section 3A of the National Health Service Act 2006 insert—

#### **“3B Secretary of State’s power to require Board to commission services**

(1) Regulations may require the Board to arrange, to such extent as it considers necessary to meet all reasonable requirements, for the provision as part of the health service of—

- (a) dental services of a prescribed description;
- (b) services or facilities for members of the armed forces or their families;
- (c) services or facilities for persons who are detained in a prison or in other accommodation of a prescribed description;
- (d) such other services or facilities as may be prescribed.

(2) A service or facility may be prescribed under subsection (1)(d) only if the Secretary of State considers that it would be appropriate for the Board (rather than clinical commissioning groups) to arrange for its provision as part of the health service.

(3) In deciding whether it would be so appropriate, the Secretary of State must have regard to—

- (a) the number of individuals who require the provision of the service or facility;
- (b) the cost of providing the service or facility;
- (c) the number of persons able to provide the service or facility;
- (d) the financial implications for clinical commissioning groups if they were required to arrange for the provision of the service or facility.

(4) Before deciding whether to make regulations under this section, the Secretary of State must—

- (a) obtain advice appropriate for that purpose, and
- (b) consult the Board.

(5) The reference in subsection (1)(b) to members of the armed forces is a reference to persons who are members of—

- (a) the regular forces within the meaning of the Armed Forces Act 2006, or
- (b) the reserve forces within the meaning of that Act.”

## Summary of recommendations

<b>SSNDS</b>	<b>Suggested text for regulation</b>	<b>Suggested Description</b>
1	Specialist Cancer Services	<p>Specialist Cancer Services include:</p> <ul style="list-style-type: none"><li>All care provided by Specialist Cancer Centres for specified rare cancers</li><li>All care provided to Teenagers and Young Adults by defined Specialist Teenage and Young Adult Cancer Centres</li><li>Certain specified interventions provided by defined Specialist Cancer Centres (including assessment if performed at the Specialist Centre)</li><li>The provision of chemotherapy drugs for all cancers (including diagnostic testing for targeted medicine)</li></ul> <p>“All care” includes cancer related activity from referral to specialist centre to discharge including diagnostics, chemotherapy, surgery and any long term follow-up. This will include out-reach when delivered as part of a provider network. In addition, the service will include Specialist Palliative Care and Survivorship when provided by a Specialist Cancer Centre.</p>
1	Radiotherapy services	<p>Radiotherapy services will include all use of this treatment modality including Brachytherapy and Intra-operative radiotherapy and any associated outpatient activity. In addition, the service will include all provision of Stereotactic Radiosurgery.</p>
1	Positron Emission Tomography – Computed Tomography services	<p>Positron Emission Tomography – Computed Tomography services will include all use of this diagnostic modality. This applies to provision in adults and children.</p>
2	Blood and Marrow Transplantation Services	<p>Blood and Marrow Transplantation Services include all care provided by Specialist Transplantation Centres including preparatory care, donation, transplant, aftercare and subsequent treatment. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.</p>

3	Specialist Services for Haemophilia and other related bleeding disorders	Specialist Services for Haemophilia and other related bleeding disorders include all care provided by Specialist Haemophilia Centres including in-patient care where the cause of admission is related to a bleeding disorder. The service will include out-reach when delivered as part of a provider network This applies to provision in adults and children.
4a	Highly Specialist Adult Urinary and Gynaecological Surgery Services	Highly Specialist Adult Urinary and Gynaecological Surgery Services will include specified complex procedures provided by Highly Specialist Urinary and Gynaecological Surgery Centres.
4b	Fetal Medicine Services	Fetal Medicine Services include all care provided by Fetal Medicine Centres including out-reach when delivered as part of a provider network.
4b	Maternal Medicine	Specialist elements included within Specialist Service regulations. For early review.
5	Specialist Services to support patients with complex physical disabilities	<p>Specialist Services to support patients with complex physical disabilities will include the specialist assessment for, and provision of (if indicated):</p> <ul style="list-style-type: none"> <li>Prosthetics (limb and artificial eyes)</li> <li>Specialist wheelchairs (including complex postural seating and powered wheelchair controls)</li> <li>Specialist Augmentative and Alternative Communication Aids</li> <li>Environmental Controls</li> </ul> <p>This applies to patients with complex physical disabilities. This applies to provision in adults and children.</p>
6a	Spinal Cord Injury Services	Spinal Cord Injury Services will include services provided by Spinal Cord Injury Centres including out-reach when delivered as part of a provider network. This applies to provision in adults and children.

6b	Complex Spinal Surgery Services	<p>For adults: Complex Spinal Surgery Services will include a number of specified procedures when performed in Specialist Spinal Surgery Centres or as out-reach when delivered as part of a provider network.</p> <p>For children and young people: Complex Spinal Surgery Services will include a number of specified procedures which should only be performed in Specialist Paediatric Spinal Surgery Centres.</p>
7	Specialist Rehabilitation Services for patients with Highly Complex Needs	<p>Specialist Rehabilitation Services for patients with Highly Complex needs will include all specialist rehabilitation for patients whose rehabilitation needs fall into Category A following brain injury or with other disabling conditions. These may be provided in Level 1 or 2a facilities. This applies to provision in adults and children. For early review.</p>
8	Adult Specialist Neurosciences Services	<p>Adult Specialist Neurosciences Services will include services provided by Adult Neurosciences or Neurology Centres. This will include:</p> <ul style="list-style-type: none"> <li>○ All Neurosurgery activity</li> <li>○ All Interventional procedures within neuroradiology</li> <li>○ In-patient neurology</li> <li>○ Specialist diagnostics (including neurophysiology, neuroradiology,)</li> <li>○ Associated services (Neuropsychology, Neuropsychiatry, Neurorehabilitation, Neuro Critical Care)</li> <li>○ Neurology Out-patients</li> </ul> <p>The service will include out-reach when delivered as part of a provider network.</p>

- 9 Specialist Burn Care Services Specialist Burn Care Services will include all care delivered by Burns Centres, Burns Units and Burns 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.
- 10 Cystic Fibrosis Services For adults:  
Cystic Fibrosis Services will be provided by Adult Cystic Fibrosis Centres. This covers all specialist care including out-reach when delivered as part of a provider network.
- For children and young people  
Cystic Fibrosis Services will be 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.
- 11 Adult Specialist Renal Services (a) Renal Services  
Adult Specialist Renal Services will include  
all dialysis services (including plasma exchange for patients with Acute Kidney Injury)  
Out-patient assessment and preparation for renal replacement at Adult Specialist Renal Centres including out-reach as part of a provider network. The service will include procedures relating to establishing renal access prior to dialysis.

- 11 Adult Specialist Renal Services (b) Transplantation  
Adult Specialist Renal Services will include all transplant related care provided by Adult Specialist Renal Centres and all transplantation activity undertaken by Adult Renal Transplant Centres. This will include care provided through out-reach as part of a provider network.
- 12 Adult Specialist Intestinal Failure Services  
Adult Specialist Intestinal Failure Services will include management of patients with Intestinal Failure Type II and III (including the provision of home parenteral nutrition). Severe Type II Intestinal Failure will be provided by Highly Specialist Intestinal Failure Centres.
- 13a,b,d Adult Specialist Cardiac Services  
Adult Specialist Cardiac Services will include services provided by Adult Specialist Cardiac Centres including out-reach when delivered as part of a provider network. The service will include:  
  - All Cardiac Surgery activity
  - Complex cardiac electrophysiology services
  - Provision of complex device therapy
  - Inherited Heart Disease Services
  - Complex invasive cardiology services
  - Primary PCI services
  - Provision of Cardiac MRI
For early review.
- 13c Adult Congenital Heart Disease Services  
Adult Congenital Heart Disease Services will include all activity provided by Highly Specialised Adult Congenital Heart Disease Centres including out-reach when delivered as part of a provider network.

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| 13e | Adult Specialist Pulmonary Hypertension Services                          | Adult Specialist Pulmonary Hypertension Services will include services provided by Highly Specialised Pulmonary Hypertension Centres including out-reach when delivered as part of a provider network. For early review.   |
| 14  | Adult Specialist Services for patients infected with HIV                  | Adult Specialist Services for patients infected with HIV will include in-patient care for HIV related conditions in Adult Specialist HIV Treatment Centres and out-patient care provided by these Specialist Centres including out-reach when delivered as part of a provider network.   |
| 15  | Cleft Lip and Palate Services   | Cleft Lip and Palate Services will include all specialist care delivered by Cleft Lip and Palate Centres including out-reach when delivered as part of a provider network. This applies to provision in adults and children.   |
| 16  | Specialist Immunology Services for patients with deficient immune systems | <p>Specialist Immunology Services will include</p> <p>(a) services provided by Highly Specialist Immunology Centres, including out-reach when delivered as part of a provider network, for the following:</p> <ul style="list-style-type: none"> <li>all primary immunodeficiencies</li> <li>autoimmune and autoinflammatory disease where there is associated immunodeficiency</li> <li>complex autoimmune and vasculitic conditions as shared care</li> </ul> <p>Services will include provision of cytokines and other immunomodulatory therapies for the above conditions. This applies to provision in adults and children.</p> <p>(b) the provision of Intravenous Immunoglobulins for all indications<br/>This applies to provision in adults and children.</p> |

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| 17  | Highly Specialist Allergy Services   | <p>Highly Specialist Allergy Services will include services provided by Highly Specialist Allergy Centres including out-reach when delivered as part of a provider network. This will include management of patients with:</p> <ul style="list-style-type: none"> <li>severe allergic conditions and</li> <li>common allergic conditions for whom conventional management has failed and for whom specified specialist treatments are required.</li> </ul> <p>This applies to provision in adults and children.</p>   |
| 18a | Highly Specialist Services for adults with infectious diseases             | <p>Highly Specialist Services for adults with infectious diseases will include</p> <ul style="list-style-type: none"> <li>Patients affected by specified organisms</li> <li>High secure infectious disease units</li> <li>Tropical disease centres</li> <li>Highly Specialist Bone and joint infection centres</li> <li>Human T-cell Lymphotropic virus centres</li> </ul>  |
| 18b | Specialist Services for children and young people with infectious diseases | <p>Specialist Services for children and young people with infectious diseases will include services provided by Specialist Infectious Diseases Paediatric Centres. This will include the management of</p> <ul style="list-style-type: none"> <li>Primary immunodeficiency</li> <li>Overwhelming septicaemia</li> <li>Severe Tuberculosis</li> <li>Unusual fungal infections</li> <li>HIV infection</li> <li>Tropical infections</li> <li>Common infections in the immunocompromised hosts</li> </ul> <p>These should include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.</p> |

19	Specialist Services for complex liver, biliary and pancreatic diseases in adults	Specialist Services for complex liver, biliary and pancreatic diseases in adults will include treatment of a defined list of conditions and a defined list of procedures provided by Specialist Hepatobiliary centres including out-reach when delivered as part of a provider network.
20	Specialist Genetic Services	Specialist Genetic Services will include services provided by Specialist Clinical Genetics Services (including specialist laboratory services) including out-reach when delivered as part of a provider network. This applies to provision in adults and children. This service includes the provision of Pre-implantation Genetic Diagnosis and associated In-vitro Fertilisation services.
22.1	Adult Specialist Eating Disorder Services	Adult Specialist Eating Disorder Services will include in-patients and bespoke packages of care for intensive day care (as an alternative to admission) services provided by Specialist Adult Eating Disorder Centres. The service will include associated non-admitted care including outreach when delivered as part of a provider network. For early review.
22.2	Adult Secure Mental Health Services	Adult Secure Mental Health Services will include high, medium and low secure in-patient care and associated non-admitted care including outreach when delivered as part of a provider network.
22.3	Specialist Mental Health Services for Deaf Adults	Specialist Mental Health Services for Deaf Adults will include in-patient and non-admitted care including assessment and treatment services for deaf people provided by Specialist Centres. In addition, the service will include advice to general mental health services on the management and treatment of the deaf person's mental illness.
22.4	Gender Identity Disorder Services	Gender Identity Disorder Services will include specialist assessment, non-surgical care packages, transgender surgery and associated after care provided by Specialist Gender Identity Disorder Centres. This applies to provision in adults and

children.

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| 22.5 | Specialist Perinatal Mental Health Services  | Specialist Perinatal Mental Health Services are provided by Specialist Mother and baby Units. Services will include in-patients 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.  |
| 22.6 | Complex and/or refractory disorder service   | Incorporated in national service regulations.  |
| 22.7 | Specialised Services for Asperger Syndrome and Autism Spectrum Disorder (AS and ASD) | Children's elements included in 22.10 below. Adult service not recommended for prescription at this time. For early review.  |
| 22.8 | Specialist Services for Severe Personality Disorder in Adults                        | Specialist Services for Severe Personality Disorder in Adults will include in-patients and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Centres. In addition, the service will include associated non-admitted care including out-reach when delivered as part of a provider network. For early review.  |
| 22.9 | Neuropsychiatry Services   | Neuropsychiatry Services will include services provided by Specialist Neuropsychiatry Centres. This will include assessment and treatment for patients with:<br><ul style="list-style-type: none"><li>Neurological diseases and associated severe psychiatric symptoms</li><li>or</li><li>Severe and disabling neurological symptoms without identified neurological cause</li></ul> This applies to provision in adults and children. For early review. |

22.10	Tier 4 Child and Adolescent Mental Health services	Tier 4 Child and Adolescent Mental Health services will include in-patients 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 will include associated non-admitted care including out-reach when delivered as part of a provider network.
23	Highly Specialist Palliative Care Services for Children and Young People	Highly Specialist Palliative Care Services for Children and Young People will include services provided by Highly Specialist Paediatric Palliative Care Services including out-reach when delivered as part of a provider network.
23.1	Highly Specialist Pain Management Services for children and young people	<p>Highly Specialist Pain Management Services for children and young people will include services provided by Highly Specialist Paediatric Pain Management Centres. The service will include</p> <ul style="list-style-type: none"> <li>Multi-disciplinary assessment of chronic pain</li> <li>Certain specified interventions including intensive in-patient or residential management programmes</li> </ul> <p>This will include out-reach when delivered as part of a provider network.</p>
23.1	Specialist Paediatric Anaesthesia	Other elements of this definition have been included in the separate proposed regulations for surgical and critical care.

23.2	Specialist Cancer Services for children and young people	<p>Specialist Cancer Services for children and young people will include:</p> <ul style="list-style-type: none"> <li>All specialist care for children within children's Principal Treatment Centres (PTCs)</li> <li>All specialist care for teenagers and young adults within Teenage and Young Adult PTCs including transitional care</li> <li>All shared care overseen by PTCs</li> <li>All cancer chemotherapy and radiotherapy</li> <li>All specialist cancer palliative care</li> <li>Planning after care (as part of the survivorship initiative)</li> </ul>
23.3	Paediatric Cardiac Services	<p>Paediatric Cardiac Services will include all activity provided by Highly Specialised Paediatric Cardiac Centres including out-reach when delivered as part of a provider network.</p>
23.4	Specialist Dentistry Services for Children and Young People	<p>Specialist Dentistry Services for Children and Young People will include services provided by Specialist Paediatric Dental Surgery Centres including out-reach when delivered as part of a provider network. The service will include:</p> <ul style="list-style-type: none"> <li>Surgical management of rare or complex conditions</li> <li>Surgical management of more common conditions when the child or the procedure is high risk (including the need for PICU or Specialist Anaesthetic management)</li> <li>Provision of specified procedures</li> </ul>

- 23.5 Specialist Ear, Nose and Throat Services for Children and Young People  
Specialist Ear, Nose and Throat Services for Children and Young People will include services provided by Specialist Ear, Nose and Throat Paediatric Surgery Centres including out-reach when delivered as part of a provider network. The service will include:
- 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.
- 23.6 Specialist Endocrinology and Diabetes Services for children and young people  
Specialist Endocrinology and Diabetes Services for children and young people will include
- care for complex endocrine conditions provided by Paediatric Endocrine Centres
  - care for complex conditions related to diabetes provided by Paediatric Diabetes Centres
- The service will include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.
- 23.7 Specialist Gastroenterology, Hepatology and Nutritional Support Services for children and young people  
Specialist Gastroenterology, Hepatology and Nutritional Support (GHNS) Services for children and young people will 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 will include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.

23.8	Specialist Gynaecology Services for Children and Young People	Specialist Gynaecology Services for Children and Young People will include all activity provided by Highly Specialised Paediatric Gynaecology Centres including out-reach when delivered as part of a provider network.
23.9	Specialist Haematology Services for children and young people	Specialist Haematology Services for children and young people will include services provided by Specialist Paediatric Haematology Centres including out-reach when delivered as part of a provider network.
23.10	Specialist Paediatric Intensive Care Services	Specialist Paediatric Intensive Care Services will include all activity undertaken by Paediatric Intensive Care Units and associated retrieval services.
23.11	Specialist Paediatric Mental Health	See 22.10 above.
23.12	Specialist Neonatal Care Services	Specialist Neonatal Care Services will include all activity undertaken by Neonatal Intensive Care Units, Local Neonatal Units and Special Care Units including associated retrieval services. This will include transitional care and any associated out-patient services. For early review.
23.13	Specialist Neuroscience Services for children and young people	<p>Specialist Neuroscience Services for children and young people will include services provided by Specialist Paediatric Neurosciences centres including:</p> <ul style="list-style-type: none"> <li>Neurosurgery (including Paediatric Neuro Critical care)</li> <li>Neurology</li> <li>Neurophysiology</li> <li>Neuroradiology</li> <li>Neuropsychology and Neuropsychiatry</li> <li>Neurodisability and Neurorehabilitation</li> </ul> <p>The service will include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.</p>

23.14	Specialist Ophthalmology Services for Children and Young People	Specialist Ophthalmology Services for Children and Young People will include services provided by Specialist Paediatric Ophthalmology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.
23.15	Specialist Paediatric Oral and Maxillofacial Surgery Services	Services included in this section are recommended for prescription elsewhere.
23.16	Specialist Orthopaedic Surgery Services for Children and Young People	Specialist Orthopaedic Surgery Services for Children and Young People will include services provided by Specialist Paediatric Orthopaedic Centres including out-reach when delivered as part of a provider network. The service will include: Surgical management of rare conditions Provision of specified procedures Surgical management of more common conditions when the child or the procedure is high risk
23.17	Specialist Plastic Surgery Services for Children and Young People	Specialist Plastic Surgery Services for Children and Young People will include services provided by Specialist Paediatric Plastic Surgery Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.
23.18	Paediatric and Perinatal Post Mortem Services	Paediatric and Perinatal Post Mortem Services will include all Post Mortems performed by Highly Specialised Paediatric Post Mortem Centres including examination of foetuses, babies, neonates and children.
23.19	Specialist Renal Services for children and young people	Specialist Renal Services for children and young people will include services provided by Specialist Paediatric Renal Centres including out-reach when delivered as part of a provider network.

23.20	Specialist Respiratory Services for children and young people	Specialist Respiratory Services for children and young people will include services provided by Specialist Paediatric Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network.
23.21	Specialist Rheumatology Services for children and young people	Specialist Rheumatology Services for children and young people will include care provided by Specialist Paediatric Rheumatology Centres for complex conditions. The service will include out-reach when delivered as part of a provider network.
23.22	Specialist Surgery for children and young people	<p>Specialist Surgery for children and young people will include services provided by Specialist Paediatric Surgery Centres including out-reach when delivered as part of a provider network. The service will include:</p> <ul style="list-style-type: none"> <li>All surgery on neonates</li> <li>Surgical management of rare conditions</li> <li>Surgical management of more common conditions when the child or the procedure is high risk (including the need for PICU or Specialist Anaesthetic management)</li> <li>Provision of specified procedures</li> </ul>
23.23	Specialist Urology Services for Children and Young People	Specialist Urology Services for Children and Young People will include services provided by Specialist Paediatric Urology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.
24	Highly Specialist Dermatology Services	Highly Specialist Dermatology Services will include services provided by Highly Specialist Dermatology Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

26	Adult Highly Specialist Rheumatology Services	Adult Highly Specialist Rheumatology Services will include services provided by Adult Highly Specialist Rheumatology Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network.
27	Adult Specialist Endocrinology Services	Adult Specialist Endocrinology Services will include services provided by Adult Specialist Endocrinology Centres for specified conditions. The service will include out-reach when delivered as part of a provider network.
28	Hyperbaric Oxygen Treatment Services	Hyperbaric Oxygen Treatment Services will include provision of this treatment in specified centres for specified conditions. This applies to provision in adults and children.
29	Adult Highly Specialist Respiratory Services	Adult Highly Specialist Respiratory Services will include services provided by Highly Specialist Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network.
29	Adult Thoracic Surgery Services	Adult Thoracic Surgery Services will include services provided by Adult Thoracic Surgery Centres including out-reach when delivered as part of a provider network.
30	Adult Specialist Vascular Services	Adult Specialist Vascular Services will include all vascular surgery and vascular interventional radiology services excluding the treatment of varicose veins. The service will include out-reach when delivered as part of a provider network.
31	Adult Highly Specialist Pain Management Services	Adult Highly Specialist Pain Management Services will include services provided by Adult Highly Specialist Pain Management Centres. The service will include multidisciplinary assessment including out-reach when delivered as part of a provider network. For specified interventions, the service will include procedure costs (including devices), follow-up and rehabilitation.

32a	Cochlear Implantation Services	Cochlear Implantation Services will include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children.
32b	Bone Anchored Hearing Aid Services	Bone Anchored Hearing Aid Services will include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children. For early review.
32c	Auditory Brainstem Implantation Service	Incorporated in national service regulations.
32d	Middle Ear Implantable Hearing Aid Services	Middle Ear Implantable Hearing Aid Services will include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children.
32e	Other Specialised Ear Surgery	The surgical aspects are reflected elsewhere. The Plastic surgery element is included within the proposed regulation on Specialist Plastic Surgery for Children and Young People.
33	Highly Specialist Colorectal Surgery Services	Highly Specialist Colorectal Surgery Services will include the following services when provided by Highly Specialist Colorectal Surgery Centres: Surgical management for complex inflammatory bowel disease Complex surgical interventions for incontinence This applies to provision in adults and children.
34a	Adult Specialist Orthopaedic Services	Adult Specialist Orthopaedic Services will include services provided by Adult Specialist Orthopaedic Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex procedures only.

34b	Major Trauma Services	Major Trauma Services will include all activity at Major Trauma Centres with an ISS of greater than 8. This applies to provision in adults and children.
35	Specialist Morbid Obesity Services	Specialist Morbid Obesity Services will include service provided by Specialist Morbid Obesity Centres. The service will include 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. For early review.
36	Highly Specialist Metabolic Disorder Services	Highly Specialist Metabolic Disorder Services will include services provided by Highly Specialist Metabolic Disorder Centres for patients with specified conditions. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.
37	Adult Specialist Ophthalmology Services	Adult Specialist Ophthalmology Services will include services provided by Adult Specialist Ophthalmology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex procedures only.
38	Specialist Haemoglobinopathy Services	Specialist Haemoglobinopathy Services will include all care provided by Specialist Haemoglobinopathy Centres including in-patient care where the cause of admission is related to haemoglobinopathy. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## Existing Regulations

The National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) (Amendment) Regulations 2012 [Statutory Instrument 2012 No. 417] contain the list of services specified by the secretary of state to be commissioned nationally. CAG proposes that these services transfer to the new regulations in the first instance.

<b>Service</b>	<b>Description</b>
Adult ataxia telangiectasia service	Adult ataxia telangiectasia services will include services provided by Highly Specialist Adult Ataxia centres.
Alkaptonuria service	Alkaptonuria services will include services provided by Highly Specialist Alkaptonuria centres. This applies to provision in adults.
Alström syndrome service	Alström services will include services provided by Highly Specialist Alström centres. This applies to provision in adults and children.
Ataxia telangiectasia service for children	Ataxia telangiectasia services for children will include services provided by Highly Specialist Children's Ataxia Telangiectasia centres.
Autoimmune paediatric gut syndromes service	Autoimmune paediatric gut syndromes services will include services provided by Highly Specialist Autoimmune Paediatric Gut Syndromes centres.
Autologous intestinal reconstruction in adults service	Autologous intestinal reconstruction in adults services will include services provided by Highly Specialist Autologous Intestinal Reconstruction in Adults centres.
Bardet-Biedl syndrome service	Bardet-Biedl syndrome services will include services provided by Highly Specialist Bardet-Biedl syndrome centres. This applies to provision in adults and children.
Barth syndrome service	Barth syndrome services will include services provided by Highly Specialist Barth syndrome centres including outreach when provided as part of a managed clinical network. This applies to provision in adults and children.
Beckwith-Wiedemann syndrome with macroglossia service	Beckwith-Wiedemann syndrome services will include services provided by Highly Specialist Beckwith-Wiedemann syndrome centres. This applies to provision in children.
Behçet's syndrome service	Behçet's syndrome services will include services provided by Highly Specialist Behçet's syndrome centres. This applies to provision in adults and adolescents.
Breast radiotherapy injury rehabilitation service	Breast radiotherapy injury rehabilitation services will include services provided by Highly Specialist Breast Radiotherapy Injury Rehabilitation centres.

<b>Service</b>	<b>Description</b>
Bladder exstrophy service	Bladder exstrophy services will include services provided by Highly Specialist Bladder Exstrophy centres. This applies to provision in children.
Choriocarcinoma service	Choriocarcinoma services will include services provided by Highly Specialist Choriocarcinoma centres. This applies to provision in adults and adolescents.
Chronic pulmonary aspergillosis service	Chronic pulmonary aspergillosis services will include services provided by Highly Specialist Chronic Pulmonary Aspergillosis centres. This applies to provision in adults.
Complex childhood osteogenesis imperfecta service	Complex osteogenesis imperfecta services will 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.
Complex Ehlers Danlos syndrome service	Complex Ehlers Danlos services will include diagnostic services (including specialist laboratory services) provided by Highly Specialist Ehlers Danlos centres. This applies to provision in adults and children.
Complex neurofibromatosis type 1 service	Complex neurofibromatosis type 1 services will include services provided by Highly Specialist Complex Neurofibromatosis Type 1 centres. This applies to provision in adults and children.
Complex tracheal disease service	Complex tracheal disease services will include services provided by Highly Specialist Complex Tracheal Disease centres. This applies to provision in children.
Congenital hyperinsulinism service	Congenital hyperinsulinism services will include services provided by Highly Specialist Congenital Hyperinsulinism centres. This applies to provision in children.
Craniofacial service	Craniofacial services will include services provided by Highly Specialist Craniofacial centres. This applies to provision in adults and children.
Cryopyrin associated periodic syndrome service	Cryopyrin associated periodic syndrome services will include services provided by Highly Specialist Cryopyrin Associated Periodic Syndrome centres. This applies to provision in adults.
Diagnostic service for amyloidosis	Diagnostic services for amyloidosis will include diagnostic services (including specialist laboratory services) provided by Highly Specialist amyloidosis centres. This applies to provision in adults.

<b>Service</b>	<b>Description</b>
Diagnostic service for primary ciliary dyskinesia	Diagnostic services for primary ciliary dyskinesia will include diagnostic services (including specialist laboratory services) provided by Highly Specialist Primary Ciliary Dyskinesia centres. This applies to provision in adults and children.
Diagnostic service for rare neuromuscular disorders service	Diagnostic services for rare neuromuscular disorders will include diagnostic services (including specialist laboratory services) provided by Highly Specialist Rare Neuromuscular Disorders centres. This applies to provision in adults and children.
Encapsulating sclerosing peritonitis surgical service	Encapsulating sclerosing peritonitis surgical services will include services provided by Highly Specialist Encapsulating Sclerosing Peritonitis Surgical centres. This applies to provision in adults.
Epidermolysis bullosa service	Epidermolysis bullosa services for children will include services provided by Highly Specialist Paediatric Epidermolysis Bullosa centres including outreach when delivered as part of a provider network.
Extra corporeal membrane oxygenation service for adults	Epidermolysis bullosa services for adults will include services provided by Highly Specialist Adult Epidermolysis Bullosa centres. ECMO services for adults will include provision of ECMO treatment in specified centres for specified conditions including outreach when delivered as part of a provider network
Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure	ECMO services for neonates, infants and children with respiratory failure will include services provided by Highly Specialist ECMO centres including outreach when delivered as part of a provider network
Ex-vivo partial nephrectomy service	Ex-vivo partial nephrectomy services will include services provided by Highly Specialist Ex-vivo Partial Nephrectomy centres. This applies to provision in adults.
Gender identity development service for children and adolescents	Gender identity development services include services provided by Highly Specialist Gender Identity Development centres including outreach when delivered as part of a provider network.
Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support)	Heart and lung transplantation services will 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.

<b>Service</b>	<b>Description</b>
Insulin-resistant diabetes service	Insulin-resistant diabetes services will include services provided by Highly Specialist Insulin-resistant Diabetes centres. This provision applies to adults and children.
Islet transplantation service	Islet transplantation services will include services provided by Highly Specialist Islet Transplantation and Laboratory centres. This provision applies to adults.
Liver transplantation service	Liver transplantation services will 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.
Lymphangiomyomatosis service	Lymphangiomyomatosis services will include services provided by Highly Specialist lymphangiomyomatosis centres. This provision applies to adults.
Lysosomal storage disorder service	Lysosomal storage disorder services will include services provided by Highly Specialist Lysosomal Storage Disorder centres including outreach when delivered as part of a provider networks. This applies to provision in adults and children.
McArdle's disease service	McArdle's services will include services provided by Highly Specialist McArdle's centres. This provision applies to adults.
Mental health service for deaf children and adolescents	Mental health services for Deaf children and adolescents will include services provided by Highly Specialist Deaf Child and Adolescent Mental Health centres including outreach when delivered as part of a provider network.
Neurofibromatosis type 2 service	Neurofibromatosis type 2 services will 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.
Neuromyelitis optica service	Neuromyelitis optica services will include services provided by Highly Specialist Neuromyelitis Optica centres. This provision applies to adults and adolescents.
Ocular oncology service	Ocular oncology services will include services provided by Highly Specialist Ocular Oncology centres. This applies to provision in adults.
Ophthalmic pathology service	Ophthalmic pathology services will include diagnostic services (including specialist laboratory services) provided by Highly Specialist Ophthalmic Pathology centres. This applies to provision in adults and children.

<b>Service</b>	<b>Description</b>
Osteo-odonto-keratoprosthesis service for corneal blindness	Osteo-odonto-keratoprosthesis services for corneal blindness will include services provided by Highly Specialist Osteo-odonto-keratoprosthesis centres. This applies to provision in adults.
Pancreas transplantation service	Pancreas transplantation services will include services provided by Highly Specialist pancreas transplant centres. This applies to provision in adults.
Paroxysmal nocturnal haemoglobinuria service	Paroxysmal nocturnal haemoglobinuria services will 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.
Paediatric intestinal pseudo-obstructive disorders service	Paediatric intestinal pseudo-obstructive disorders services will include services provided by Paediatric Intestinal Pseudo-obstructive Disorders centres.
Primary ciliary dyskinesia-management service	Primary ciliary dyskinesia management services will include services provided by Primary Ciliary Dyskinesia Management Centres including outreach when delivered as part of a provider network. This provision applies to children.
Primary malignant bone tumours service	Primary malignant bone tumours services will include services provided by Highly Specialist Primary Malignant Bone Tumours centres including outreach when provided as part of a provider network. This provision will include adults and adolescents.
Proton beam therapy service	Proton beam therapy services will include services provided by Highly Specialist Proton Beam Therapy centres. This provision applies to adults and children.
Pseudomyxoma peritonei service	Pseudomyxoma peritonei services will include services provided by Highly Specialist Pseudomyxoma peritonei centres. This provision applies to adults.
Pulmonary hypertension service for children	Pulmonary hypertension services for children will include services provided by Highly Specialist Pulmonary Hypertension centres including outreach when delivered as part of a provider network
Pulmonary thromboendarterectomy service	Pulmonary thromboendarterectomy services will include services provided by Highly Specialist Pulmonary thromboendarterectomy centres. This provision applies to adults and adolescents.

<b>Service</b>	<b>Description</b>
Rare mitochondrial disorders service	Rare mitochondrial disorders services will include services provided by Highly Specialist Rare Mitochondrial Disorders centres. This provision applies to adults and children.
Reconstructive surgery service for adolescents with congenital malformation of the female genital tract	Reconstructive surgery services for adolescents with congenital malformation of the female genital tract will include provision of this treatment in specified centres for specified conditions.
Retinoblastoma service	Retinoblastoma services will include services provided by Highly Specialist Retinoblastoma centres. This provision applies to children.
Secure forensic mental health service for young people	Secure forensic mental health services for young people will include services provided by Highly Specialist Secure Forensic Mental Health Service centres for young people.
Severe acute porphyria service	Severe acute porphyria services will include services provided by Highly Specialist Severe Acute Porphyria centres. This provision applies to adults and children.
Severe combined immunodeficiency and related disorders service	Severe combined immunodeficiency and related disorders services will include services provided by Highly Specialist Severe Combined Immunodeficiency and Related Disorders centres. This provision applies to children.
Severe intestinal failure service	Severe intestinal failure services will include services provided by Highly Specialist Severe Intestinal Failure centres. This provision applies to adults.
Severe obsessive compulsive disorder and body dysmorphic disorder service	Severe obsessive compulsive disorder and body dysmorphic services will include services provided by Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder centres. This applies to provision in adults and adolescents.
Small bowel transplantation service	Small bowel transplantation services will include services provided by Highly Specialist Small Bowel Transplant centres. This applies to provision in adults and children.
Specialist paediatric liver disease service	Specialist paediatric liver disease services will include services provided by Highly Specialist Paediatric Liver Disease centres including outreach when provided as part of a provider networks

<b>Service</b>	<b>Description</b>
Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders	Stem cell transplantation services for juvenile idiopathic arthritis and related connective tissue will include services provided by Highly Specialist Stem Cell Transplant centres for juvenile idiopathic arthritis and related connective tissue. This provision applies to children.
Stickler syndrome diagnostic service	Stickler syndrome diagnostic services will include diagnostic services provided by Highly Specialist Stickler syndrome centres (including specialist laboratory services). This provision applies to adults and children.
Vein of Galen malformation service	Vein of Galen malformation services will include services provided by Highly Specialist Vein of Galen Malformation centres. This provision applies to adults and children.
Veterans' post-traumatic stress disorder programme	Veterans' post-traumatic stress disorder services will include services provided by Highly Specialist Veterans' Post-traumatic Stress Disorder centres
Wolfram syndrome service	Wolfram syndrome services will include services provided by Highly Specialist Wolfram Syndrome centres. This provision applies to adults and children.
Xeroderma pigmentosum service	Xeroderma pigmentosum services will include services provided by Highly Specialist Xeroderma Pigmentosum centres. This applies to provision in adults and children.

## **1 Specialised Cancer Services (adults)<sup>1</sup>**

### **Services covered**

In general, Cancer services that require a planning population of over one million are regarded as specialised cancer services. Guidance issued by the Department of Health, and subsequently NICE, specifies the minimum planning population for a rare tumour type of highly specialised treatment. The definition sets out services for these rare cancers to be included in their entirety: anal cancer, brain/ CNS cancers, endocrine cancers, germ cell cancers, complex gynaecological cancers, haematological cancers, head and neck cancers, mesothelioma, penile cancers, pituitary cancers, sarcoma, skin cancers, upper GI cancers, urological cancers (this also includes Children and Young people's cancers- described elsewhere).

Also included are elements of services: treatment of liver metastases, surgery of the skull base and central nervous system, and thoracic surgery.

Further, some interventions are defined as specialised when used for any indication: photodynamic therapy, radiofrequency ablation, radionuclide therapy, and specialised radiotherapy.

In addition, the definition states:

Although chemotherapy and radiotherapy services have not been included in this definition it is important to note that two recent Department of Health publications refer to the need for radiotherapy services to be reviewed and organised at SHA/SCG level and for chemotherapy services to be organised at Cancer Network level, which accordingly brings them into the remit of this definition by virtue of the one million planning population criterion.

Finally, specialised imaging modalities used in the diagnosis of these cancers (PET scanning) is included in the definition.

Specialised cancers tend to be treated in less than 50 providers in England. Overall, each cancer tends to have an annual incidence of less than 200 new cases per million. Treatments are often high cost.

### **CAG's initial view**

There is a clear case for rare cancers and rare procedures (as set out in the definition) to be prescribed. These met the four factors.

There remained some questions regarding inclusion of radiotherapy, chemotherapy and PET scanning. The concern related to the broad provision of these services which would include patients with more common cancers.

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<sup>1</sup> CAG considered all adult cancer services within the SSNDS under this heading. Where cancer services appear elsewhere in the SSNDS- this recommendation covers those services.

Following discussion with DH Policy team, CAG were minded to recommend prescription of all services included in the most recent version of the definition including;

- All radiotherapy

- All PET CT scanning

- All chemotherapy drugs (plus the chemotherapy services associated with rare cancers)

It was felt that such a service description would meet the four factors.

### **View of TOG**

The main concern expressed related to separating activity included in the definition from other non-specialised cancer services. It was felt that the current definition was sufficiently robust but more work was required to allow separate and robust commissioning by the NHSCB.

### **CAG's review**

CAG agreed that the broadest interpretation of the definition was the most appropriate to meet the four factors. It was clear that further work would be needed to ensure appropriate commissioning of services at the boundary: 2-week wait clinics, initial diagnostics and generic chemotherapy services; some of which would be best commissioned through CCGs.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**, including all radiotherapy, PET CT scanning together with chemotherapy services for rare conditions and chemotherapy drugs for all cancers.

CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

### **Suggested text for regulation**

Specialist Cancer Services

### **Suggested Description**

Specialist Cancer Services include:

- All care provided by Specialist Cancer Centres for specified rare cancers

- All care provided to Teenagers and Young Adults by defined Specialist Cancer Centres

- Certain specified interventions provided by defined Specialist Cancer Centres (including assessment if performed at the Specialist Centre)

The provision of chemotherapy drugs for all cancers (including diagnostic testing for targeted medicine)

“All care” includes cancer related activity from referral to specialist centre to discharge including diagnostics, chemotherapy, surgery and any long term follow-up. This will include out-reach when delivered as part of a provider network. In addition, the service will include Specialist Palliative Care and Survivorship when provided by a Specialist Cancer Centre.

### **Suggested text for regulation**

Radiotherapy services

### **Suggested Description**

Radiotherapy services will include all use of this treatment modality including Brachytherapy and Intra-operative radiotherapy and any associated outpatient activity. In addition, the service will include all provision of Stereotactic Radiosurgery.

### **Suggested text for regulation**

Positron Emission Tomography – Computed Tomography services

### **Suggested Description**

Positron Emission Tomography – Computed Tomography services will include all use of this diagnostic modality. This applies to provision in adults and children.

## **2 Blood and Marrow Transplantation (all ages)**

### **Services covered**

All Blood and Marrow transplants are regarded as falling under specialised services. This includes preparatory care, donation, transplant, aftercare and subsequent treatment. For most patients this is a discrete part of their care pathway as part of the treatment of their condition. There are about 44 centres in England and less than 3000 procedures are performed across the whole of the UK each year. The cost ranges from around £30-120,000 depending on the form of transplant and availability of donor stem cells.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

The response noted that this service is commissioned regionally across England by SCGs. Since this treatment is not included in national tariff arrangements, local currencies and prices vary. However, it was felt that the current definition was sufficiently robust to allow separate and direct commissioning.

### **CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

### **Suggested text for regulation**

Blood and Marrow Transplantation Services

### **Suggested Description**

Blood and Marrow Transplantation Services include all care provided by Specialist Transplantation Centres including preparatory care, donation, transplant, aftercare and subsequent treatment. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

### **3 Haemophilia and other related bleeding disorders (all ages)**

#### **Services covered**

The two main inherited bleeding disorders, haemophilia A & B are rare and complex conditions. Acquired haemophilia is even rarer. Services to treat these patients are currently delivered through a two-tier structure.

Comprehensive Care Centres (CCCs) provide the highest level of care and function as tertiary referral centres. There are currently 20 of these in England. Haemophilia Centres (HCs) provide local routine care. There are around 51 of these in England. All services delivered by CCCs and HCs for haemophilia and related bleeding disorders are regarded as specialised services and included in this definition.

The main cost within this service relates to the blood products patients need to function normally. This represents 75% of the current spend. At an individual patient level, major surgery may necessitate additional blood product usage costing more than £500,000.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

The response noted that this service is commissioned regionally across England by most SCGs. The definition includes in-patient care where the cause of admission related to a bleeding disorder but excludes other hospital care. It was felt that the current definition was sufficiently robust to allow separate and direct commissioning.

#### **CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

#### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

#### **Suggested text for regulation**

Specialist Services for Haemophilia and other related bleeding disorders

#### **Suggested Description**

Specialist Services for Haemophilia and other related bleeding disorders include all care provided by Specialist Haemophilia Centres including in-patient care where the cause of admission is related to a bleeding disorder. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## **4 Specialised Services for Women's Health (adults)**

### **(a) Complex urinary and gynaecological surgery (adults)**

#### **Services covered**

This definition includes:

- complex urinary and faecal incontinence and genital prolapse
- complex gynaecological reconstruction services
- complex minimal access gynaecological surgery services.

Several of the listed procedures do not yet have a tariff. Some of the more complex procedures can require 2 or more surgeons and often multi-stage operations are required. Less than 10 centres provide complex gynaecological reconstruction services.

#### **CAG's initial view**

CAG agreed that there seemed to be a good case for these complex procedures (as set out in the definition) to be prescribed. These met the four factors.

There remained some questions regarding the specific list of procedures and how they would be identified. CAG asked that additional advice be sought from experts on the procedures currently included in the definition.

However, CAG were minded to recommend prescription of all procedures listed in the most recent version of the definition.

#### **View of TOG**

The response highlighted the difficulty of separately commissioning a procedure when it is "repeat" activity or "complex" as the current information systems may not capture this. Local data flows would be needed to commission these separately.

#### **CAG's review**

Following discussion with DH Policy team, CAG agreed that, although the definition did not give a precise description of what is included, it did identify activity which met the four factors. As such, if prescribed, further work would be needed to allow for identification of this activity.

#### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

#### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Highly Specialist Adult Urinary and Gynaecological Surgery Services

**Suggested Description**

Highly Specialist Adult Urinary and Gynaecological Surgery Services will include specified complex procedures provided by Highly Specialist Urinary and Gynaecological Surgery Centres.

## **4 Specialised Services for Women's Health (adults)**

### **(b) Specialised Maternal medicine services and Fetal medicine (adults)**

#### **Services covered**

Specialised maternal medicine includes two groups:

- the management of women with pre-existing long term conditions (eg respiratory, renal, cardiac, haematological, neurological, musculoskeletal, endocrine, transplanted etc)
- the management of pregnancy-related conditions (eg haemorrhage, eclampsia, acute psychoses, acute renal failure)

Such services are widespread and are often supported by clinicians working in specialised services.

Fetal medicine includes:

- General specialised fetal medicine services.
- Invasive diagnostic and therapeutic procedures
- Invasive procedures relating to termination of pregnancy
- Assessment and management of complicated twin pregnancies and multiple pregnancies (3 or more)

There are 12 fetal medicine centres. Approximately 5% of the pregnant population (30,000 women per annum in the UK) are offered a choice of invasive prenatal diagnostic tests. There were 153 multiple (3 or more babies) pregnancies in England in 2009. There were 135 terminations for fetal anomalies performed over 24 weeks gestation in England and Wales (2010).

#### **CAG's initial view**

CAG agreed that there seemed to be a good case for fetal medicine (as set out in the definition) to be prescribed. This service met the four factors. However, it was unclear how the most specialised level of maternal medicine could be separately identified.

However, CAG were minded to recommend prescription in line with the most recent version of the definition.

#### **View of TOG**

Maternal medicine tends to be coded as specialised, even when no other specialist is involved. If this service were prescribed a solution would be required to allow separate commissioning.

Fetal medicine can be identified but to best capture the meaning of the definition, restriction to specialised centres (the 12 referred to above) may be appropriate.

#### **CAG's review**

CAG agreed that, although the definition did not give a precise description of what is included, it did identify activity which met the four factors. As such, if

prescribed, further work would be needed to allow for identification of this activity.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of a Fetal Medicine service could be secured.

On review of the proposals for Maternal Medicine, it proved very difficult to define which such out-patient clinics should be prescribed. For the most part, the Specialist element of this activity - eg the Cystic Fibrosis consultant in a joint clinic- is prescribed elsewhere. At this stage, CAG recommends that no separate regulation be made of maternal medicine in light of the fact that Specialist elements should be included within Specialist Service regulations.

This approach should be subject to an early review.

**Suggested text for regulation**

Fetal Medicine Services

**Suggested Description**

Fetal Medicine Services include all care provided by Fetal Medicine Centres including out-reach when delivered as part of a provider network.

## **5 Assessment and provision of equipment for people with complex physical disability (all ages)**

### **Services covered**

Specialised services for assessment/provision of equipment for people with complex disability are those that provide bespoke/customised equipment to enable those with profound physical disability to live as independently as possible.

Specialised equipment services include

- 1) Amputee and Limb Deficiency services
- 2) Complex Orthotics
- 3) Specialist Wheelchairs
- 4) Communication Aids
- 5) Environmental Controls & Assistive Technologies
- 6) Specialised Telecare Services

Amputee & limb deficiency services are provided in 34 centres. Specialised wheelchair services are not currently well planned and are often provided alongside more generic wheelchair provision. Communication Aids are provided in 10 centres (of which 6 only provide assessment).

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that the most specialised elements of each of the 6 areas above may meet the four factors. However, it was unclear how these specialised elements could be separately identified. Further, members questioned the benefit of separating out the specialised element in terms of patient benefit.

CAG were minded to recommend prescription of based on the most recent version of the definition.

### **View of TOG**

This definition is challenging for commissioners. Service by service approaches would be needed as no national currency, prices or service specifications have been developed. Most contracting is under block arrangements and local links with social services and non-specialist services are vital.

### **CAG's review**

Following discussion with DH Policy team, CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG agreed that the most appropriate way to ensure the most complex orthotic devices were directly commissioned was to include their provision in the associated specialist pathway (Spinal surgery, paediatric neurology etc.). For the remaining elements, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

The term "Specialist Wheelchairs" here includes complex postural seating and powered wheelchair controls.

### **Suggested text for regulation**

Specialist Services to support patients with complex physical disabilities

### **Suggested Description**

Specialist Services to support patients with complex physical disabilities will 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  
Environmental Controls

This applies to patients with complex physical disabilities. This applies to provision in adults and children

## **6 Specialised spinal services (all ages)**

### **(a) Spinal cord injury**

#### **Services covered**

This part of the definition relates to activity undertaken within specialist spinal cord injury (SCI) centres. Other providers (i.e. major trauma centres, specialised spinal surgery centres, critical care units) handle significant spinal activity and early liaison and agreed protocols with SCI centres will ensure seamless care and the avoidance of unnecessary complications.

There are an estimated 40,000 people in the UK living with a traumatic SCI. About 800 patients are admitted to a SCI centres annually (16 per million). There are eight SCI centres in England. With long stays, multiple operations and prolonged recovery before transfer to rehabilitation, individual patient costs can be well over £100,000

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

This activity is already separately identified and commissioned by SCGs. Work is underway to develop consistent commissioning arrangements. It was felt that the current definition was sufficiently robust to allow separate and direct commissioning.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

#### **Suggested text for regulation**

Spinal Cord Injury Services

#### **Suggested Description**

Spinal Cord Injury Services will include services provided by Spinal Cord Injury Centres including out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## **6 Specialised spinal services (all ages)**

### **(b) Complex Spinal Surgery**

#### **Services covered**

This service encompasses aspects of care provided by spinal surgeons from both orthopaedic and neurosurgery disciplines. Increasingly these complex cases are treated with close collaboration between spinal surgeons from both disciplines. Some facets of this specialised service are essentially the sole province of one or other of these disciplines - e.g. intra-dural lesions (neurosurgery) or scoliosis (orthopaedic surgery).

There are six areas of complex spinal surgery:

- spinal deformity surgery
- spinal reconstruction surgery (trauma, tumour, infection);
- primary cervical, primary thoracic and primary anterior lumbar surgery
- revision surgery
- interventions for severe back pain
- palliative or curative spinal oncology surgery.

Specialised spinal services may be delivered by a single centre or, increasingly, by several hospitals working in a collaborative network. Networks allow resources and expertise to be shared, with common audit and governance arrangements, whereby complex surgery can be delivered *safely* by several providers within the network.

There are 27 neurosciences centres in England providing neurosurgery. It is not clear how many other centres would be defined as specialised for the purposes of complex spinal surgery.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. However, it was unclear how these specialised elements could be separately identified. There was some concern that separately commissioning specialised elements of the pathway could de-stabilise local elements.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

Although much of the activity could be identified, the definition relates to sub-groups relating to complexity and revision activity which is more difficult to pinpoint. Inclusion of all activity mentioned in the definition without this 'complexity' filter would involve activity in most (206) acute providers. Greater clarity on the specific elements of care which are to be included would be helpful.

#### **CAG's Review**

Following further input from the orthopaedic and trauma teams within DH, CAG agreed that, although there was likely to be specialised service elements

which met the four factors, the current definition failed to identify these in such a way as to allow separate commissioning.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Complex Spinal Surgery Services

### **Suggested Description**

For adults:

Complex Spinal Surgery Services will include a number of specified procedures when performed in Specialist Spinal Surgery Centres or as out-reach when delivered as part of a provider network.

For children and young people:

Complex Spinal Surgery Services will include a number of specified procedures which should only be performed in Specialist Paediatric Spinal Surgery Centres.

## **7 Specialised rehabilitation services for brain injury and complex disability (adult)**

### **Services covered**

Specialised rehabilitation services (i.e. Level 1 units) support patients with complex disability whose rehabilitation needs (i.e. Category A) are beyond the scope of their local rehabilitation services. These are normally provided in co-ordinated service networks planned over a regional population of 1-3 million. Many such units will provide services on an in-patient basis.

It is difficult to estimate the size of the population requiring level 1 care. The London consortium treats around 600 cases per annum (80 per million). The services included in this definition provide a vital support to services in definitions 5, 6 and 8. A study published in 2006 suggested initial costs ranged between £17-41,000. The mean cost within a major level 1 centre was calculated to be £52,000 for an average length of stay of 6 months. It is not uncommon for a total package to be in excess of £100,000. A recent study found 50 neuro-rehabilitation units, 45 brain-injury services (NHS) and 98 brain-injury services (non-NHS) in England.

### **CAG's initial view**

CAG agreed that there seemed to be a good case for care in Level 1 units to be prescribed. These met the four factors. However, it was not clear that the definition was sufficient to allow separate commissioning of the service.

Even so, CAG were minded to recommend prescription of this service as described in the most recent version of the definition.

### **View of TOG**

The current definition identifies the HRGs for non-specialist activity but there is little detail on the specialist activity. This makes separate and direct commissioning very challenging. There needs to be a clear distinction between the acute episode and the rehabilitation phase and this has not been developed. As outlined above, many providers offer services which could be seen to be included in this definition at present.

### **CAG's review**

Following discussion with DH Policy team, CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning. Once commissioned by the NHSCB this service should be reviewed within 2-3 years. At this time, CAG expected that elements of this service may be suitable for commissioning by CCGs.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service. Subject to further review in 2-3 years.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. CAG felt that this service should be subject to early review.

### **Suggested text for regulation**

Specialist Rehabilitation Services for patients with Highly Complex Needs

### **Suggested Description**

Specialist Rehabilitation Services for patients with Highly Complex needs will include all specialist rehabilitation for patients whose rehabilitation needs fall into Category A following brain injury or with other disabling conditions. These may be provided in Level 1 or 2a facilities. This applies to provision in adults and children. For early review.

## 8 Specialised Neurosciences services (adults)

### Services covered

This definition encompasses a range of disciplines and specialties that include:

- Neurosurgery,
- stroke diagnostic services for stroke of non atheroembolic origin and complex interventions;
- neuropathology;
- neurophysiology;
- neuroradiology;
- neurorehabilitation;
- neuropsychiatry;
- neurology out-patient services that are identified as specialised services and neurology inpatients services.

The clinical neurosciences services have undergone a period of great change. New drugs, surgical procedures and investigative techniques have changed the relationships between specialties, the use of facilities and the site at which treatment takes place.

In parallel with these developments stroke medicine has developed and includes practitioners from elderly care medicine, clinical pharmacology and neurology. Neurosurgery and neuroradiology services for stroke patients are specialised and therefore that aspect of stroke care is included in this definition. Routine stroke care, including 24 hour access to a stroke specialist, urgent brain imaging (with expert interpretation) and thrombolytic treatment, is not a specialised service.

Because of the interrelationships it is important to plan neurosciences services as a whole; a strategic plan for neurosurgery services will take into account plans for neurology services and consider the whole care pathway, including neuro-rehabilitation and key support services such as neuroradiology, neurophysiology and other cognate disciplines.

The second version of this definition, published in 2002, included *all* neurology out-patient activity despite the fact that much of this activity would be non-specialised (i.e. be provided from more than 50 neurology units in England). In the 2009 edition of the definition all *general* neurology out-patients activity, defined as all activity undertaken by a single neurologist, was excluded from specialised services. However, some neurology conditions which are treated in out-patients are particularly complex and/or uncommon and require a multidisciplinary approach; services for these conditions are regarded as specialised and are included in the 2009 edition.

There are 27 neurosciences centres in England providing neurosurgery and specialised neurology services and a further 9 neurosciences centres which do not provide neurosurgery but do provide specialised neurology services.

### **CAG's initial view**

CAG agreed that this service (as set out in the definition) met the four factors. However, it was unclear how well the current definition reflected the need for local services to support the neurosciences centres. This was a particular issue with regard to out-patient neurology. It was recognised that much of the more specialised care in neurology is delivered as an out-patient service and patients with rare conditions would be excluded unless specifically included in the out-patients definition.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

#### Neurosurgery (including some stroke services)

In-patients within neurosurgery centres can easily be identified. The accompanying out-patient work can also be captured. Activity which meets the definition but takes place outside of a specified centre will be difficult to capture. However, there is a strong case for neurosurgery activity (when accurately defined) only being commissioned from neurosciences centres.

#### Neuropathology

Most of the funding for this service comes from the tariff for the associated activity. It is not clear what additional benefit would come from separate commissioning of this element of pathology.

#### Neurophysiology

This element of care cannot be separately identified. If it is delivered out with one of the elements described here, it is unlikely it will be identified.

#### Neuroradiology

This can be identified within neurosciences centres but the same codes are used for non-specialised activity elsewhere.

#### Neurorehabilitation

This links to definitions 5 and 7 within the SSNDS. See response to definition7.

#### Neuropsychiatry

This is identifiable but often the care is just part of the care package for neurosurgery or neuro-rehabilitation patients.

#### Neurology services.

In-patient neurology can be identified but this activity may take place outside neuroscience centres. The current definition sets out diagnosis codes for neurology but all are flagged "maybe specialised". This results in activity being identified in most acute providers. Coding of out-patient visits is even less detailed and is not sufficient to allow identification of specialised activity.

### **CAG's review**

CAG took further views from the DH policy team. Overall, CAG agreed that although the definition was not ideal, it did identify activity which met the four factors. Work is needed on the detailed implementation of this definition, rather than the content. If prescribed, further work would be needed to allow for identification of this activity in such a way as to ensure clear separation between the “neuroscience centre” (to be commissioned by NHSCB) and the local services (to be commissioned by CCGs)- especially in relation to out-patient neurology.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG’s suggested description. Spinal surgery can be undertaken by neurosurgeons- this activity is included in the Complex Spinal Surgery Services (Page 47).

### **Suggested text for regulation**

Adult Specialist Neurosciences Services

### **Suggested Description**

Adult Specialist Neurosciences Services will include services provided by Adult Neurosciences or Neurology Centres. This will include:

- All Neurosurgery activity
- All Interventional procedures within neuroradiology
- In-patient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology,)
- Associated services (Neuropsychology, Neuropsychiatry, Neurorehabilitation, Neuro Critical Care)
- Neurology Out-patients

The service will include out-reach when delivered as part of a provider network.

## **9 Specialised Burn Care services (all ages)**

### **Services covered**

The specialised burn care service is divided into three levels: burns centres, units and facilities each clinically led by plastic surgeons. Burn care provision in local hospitals, including initial assessment in A&E departments, is not a specialised service. In this definition, specialised burn care services are based on the 2001 Burn Injury Referral Guidelines and include the whole pathway of care from injury to final discharge following rehabilitation and surgical reconstruction.

There are less than 30 specialist burns providers, ordered in three tiers of complexity with burns centres dealing with only the most complex cases.

Although much burn care activity is in the initial stages after the burn occurs, there is often a very long period of rehabilitation including multiple operations for reconstruction. Single case costs can be over £100,000 in a single year

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

It should be possible to identify a large volume of specialised burns activity and this can be confirmed by cross validation to the National Burns injury database. Most of this care is already commissioned by SCGs although burns facilities are often locally commissioned.

It was felt that the current definition was sufficiently robust to allow separate and direct commissioning.

### **CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

### **Suggested text for regulation**

Specialist Burn Care Services

### **Suggested Description**

Specialist Burn Care Services will include all care delivered by Burns Centres, Burns Units and Burns Facilities delivered as part of a provider network. This covers the whole pathway including

## RESTRICTED- POLICY

- specialist assessment
- admission to a Centre, Unit or Facility and
- rehabilitation and surgical reconstruction.

This applies to provision in adults and children.

## **10 Cystic Fibrosis services (all ages)**

### **Services covered**

CF care is provided at specialist CF centres by a multi-disciplinary team all of whom will be specialists in CF care. The majority of specialist CF centres for adult patients have an active caseload of over 150 patients. Care tends to be delivered at the centre but outreach is beginning to develop.

CF affects about 1 in 2500 live births. It is estimated that 60 adult cases per million is the current prevalence in England. There are a total of 55 CF centres, some providing care for children as well as adults. There will need to be good liaison with other hospital specialties particularly radiology, surgery, obstetrics, gastroenterology, hepatology, diabetology, endocrinology and rheumatology. This year, there is a mandatory currency for CF patients with annual payments based on clinical severity. Work published alongside the PBR guidance suggested that mean annual treatment costs varied between £5,000 for Band 1 patients to £48,000 for Band 5 patients. This includes high cost drug costs which can cost in excess of £6,000.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

CF services are identifiable through consistent national commissioning currencies supported by a centrally held database operated by the CF Trust. Work is in progress to develop financial flows to allow remote activity (shared-care, homecare/ delivery of drugs) to be funded through these same currencies.

It was felt that the current definition was sufficiently robust to allow separate and direct commissioning.

### **CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

### **Suggested text for regulation**

Cystic Fibrosis Services

## **Suggested Description**

For adults:

Cystic Fibrosis Services will be provided by Adult Cystic Fibrosis Centres. This covers all specialist care including out-reach when delivered as part of a provider network.

For children and young people

Cystic Fibrosis Services will be 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.

## **11 Specialised Renal Services (adult)**

### **(a) renal services**

#### **Services covered**

Renal services for patients with chronic kidney disease are largely delivered by renal specialists working in a specialist renal centre itself and on an outreach basis to surrounding local hospitals. With the growing prevalence of renal disease in the elderly population, there is an increasing need to provide care for pre-dialysis patients and low clearance renal patients receiving palliative care as close to home as possible; this can be done by increasing local hospital nephrology provision and improving community and primary care services.

Specialist renal centres also treat patients with acute kidney injury (AKI).

Kidney transplantation and desensitisation services are provided in 20 of approximately 50 specialist renal centres (see next section).

Specialist renal centre services include:

In-patient nephrology services

nephrology out-patient clinics on site and as an outreach service to local hospitals

dialysis for chronic kidney disease including

- haemodialysis services on site
- satellite haemodialysis services
- support to patients on peritoneal dialysis and home haemodialysis

anaemia management and specialist renal dietetic support

conservative management programmes for established renal failure

out-patient and in-patient services for acute kidney injury

transplantation services. (see next section)

39,476 patients in England receiving HD or PD (end of 2008) from the UK Renal Registry (767 per million population). There are annual changes in prevalence across HD, PD, but with an underlying growth overall, and with further variation at the regional and renal unit levels. Maintaining a patient with end-stage renal failure costs £17,500 per patient per year for a patient on peritoneal dialysis and £35,000 per patient per year for a patient on haemodialysis.

#### **CAG's initial view**

CAG considered that most activity within a Specialist Renal Centre meets the four factors. However, a significant amount of renal out-patients care was not thought to be specialised. Further, there was a question regarding the extent of AKI which required specialist renal support in the absence of a need for dialysis. At present it was thought that renal replacement therapy should be prescribed for national commissioning, but this should be reviewed as CCGs develop.

CAG were minded to recommend prescription of all services included in the most recent version of the definition, subject to further discussion.

### **View of TOG**

Recent developments in national currencies and tariffs should mean it is possible to identify dialysis activity. Out-patient services are more difficult to identify. Coding for Out-patients is such that clinic level separation is the only option. Overall, TOG proposed excluding Out-patient activity.

### **CAG's review**

After discussion with the DH policy team, CAG agreed that all dialysis activity (HD and PD) in-patient, chronic and home; should be prescribed. This would include those AKI patients whose condition necessitated dialysis and/ or plasma exchange. The case for Low Clearance Clinics to be prescribed was accepted and these should be the only out-patient activity included in the prescribed service. This would include establishing fistulae or Tenckhoff catheters for patients approaching dialysis. This would require further detailed work by commissioners.

This would leave a need for CCGs to commission a local renal service for general nephrology (including AKI not requiring dialysis/ plasma exchange) which would be best provided as part of a renal network incorporating Specialist Renal Centres.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. After further discussion with DH policy leads, CAG agreed a description which covered transplant and non-transplant activity.

### **Suggested text for regulation**

Adult Specialist Renal Services

### **Suggested Description**

#### **(a) Renal Services**

Adult Specialist Renal Services will include

- all dialysis services (including plasma exchange for patients with Acute Kidney Injury)
- Out-patient assessment and preparation for renal replacement at Adult Specialist Renal Centres including out-reach as part of

a provider network. The service will include procedures relating to establishing renal access prior to dialysis.

## **11 Specialised Renal Services (adult)**

### **(b) transplants**

#### **Services covered**

Kidney transplantation is the other form of renal replacement therapy (RRT) which treats very poor or absent kidney function. The kidney transplantation service is a specialised service carried out by specialist renal transplant centres of which there are around 20 centres in England.

The kidney transplantation service includes

(i) activities taking place at all specialist renal centres:

- assessment of patient need and suitability for transplantation
- organizing tissue typing and testing for anti – HLA antibodies
- registration of appropriate patients with NHS B&T
- live donor screening
- live donor workup
- post transplant follow up (for life)
- post transplant immunosuppressant drug therapy (for life). (NOTE: The GP often prescribes the drugs but the transplant centre or specialist renal centre remains responsible for all follow-up and changes in therapy)

(ii) activities only taking place at the 20 renal transplant centres:

- live donor organ retrieval
- cadaveric kidney transplant
- non heart-beating kidney transplant
- live donor kidney transplant
- desensitisation of potential transplant recipients who have high panel reactivity (by plasma exchange, infusion of human immunoglobulin, administration of immunosuppressive agents and other forms of extracorporeal blood circulation).

In 2008-09, 2,497 people received a kidney transplant (50 per million). The cost of a kidney transplant (excluding UK transplant costs) is £17,000 per patient per transplant. The immunosuppression required by a patient with a transplant costs £5,000 per patient per year.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

Most SCGs commission these services. The transplant operation is easily identifiable. The work-up activity could be separately identified if undertaken in specific clinics within identified renal centres. Immunosuppression funding

usually moves to GP prescribing (under specialist guidance) after the first year.

**CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

**Suggested text for regulation**

Adult Specialist Renal Services

**Suggested Description**

(b) Transplantation

Adult Specialist Renal Services will include all transplant related care provided by Adult Specialist Renal Centres and all transplantation activity undertaken by Adult Renal Transplant Centres. This will include care provided through out-reach as part of a provider network.

## **12 Specialised intestinal failure and home parenteral nutrition Services (adult)**

### **Services covered**

Intestinal Failure (IF) comprises a group of disorders with many different causes, but it is characterised by an inability to maintain adequate nutrition or fluid status via the intestines. Where IF persists for more than a few days intravenous delivery of nutrients and water, i.e. parenteral nutrition, will be required. There are three types of IF: Type 1 IF which would not on its own require a specialised service and Types II and III IF which do require specialised services.

This definition covers the specialised services needed for the management of prolonged IF, including services for patients requiring prolonged hospital or home parenteral nutrition (HPN). HPN services include the HPN training programme for patients and/or carers, the provision of homecare HPN packages (often provided by private sector organisations, homecare companies) and the HPN support services provided by hospital teams often in conjunction with the homecare company.

Services for severe cases of Type II IF have been nationally commissioned by the National Commissioning Group (NCG) since April 1998. In addition to the two nationally designated Severe Intestinal Failure units, there are approximately 15 hospitals looking after a significant caseload of these patients.

The annual incidence of Type II Intestinal Failure (requiring inpatient care) in England is thought to be approximately 1,500 cases per year. The prevalence of long-term (metabolically stable) Type III Intestinal Failure requiring Home Parenteral Nutrition is approximately 15 patients per million head of population. 2 new patients per million are initiated on Home Parenteral Nutrition each year. The cost per patient year for Home Parenteral Nutrition is £30-£40,000 per year rising to £55-£65,000 where nursing care is required

### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

Identification is problematical but proposals for a registry and formalising the 'flag' arrangements already in place should enable activity to be coded. There are likely to be between 15 and 20 providers.

**CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

**Suggested text for regulation**

Adult Specialist Intestinal Failure Services

**Suggested Description**

Adult Specialist Intestinal Failure Services will include management of patients with Intestinal Failure Type II and III (including the provision of home parenteral nutrition). Severe Type II Intestinal Failure will be provided by Highly Specialist Intestinal Failure Centres.

## **13 Specialised cardiology and cardiac surgery services (adult)**

### **(a) Cardiac electrophysiology services**

#### **Services covered**

Cardiac Electrophysiology (EP) is the evaluation and treatment of cardiac arrhythmias or abnormal rhythms. Interventions include:

- diagnostic electrophysiology study
- radiofrequency and other forms of cardiac ablation
- implantation, revision and renewal of cardiac defibrillator (OPCS K59)
- cardiac resynchronisation therapy (CRT) including:
  - biventricular cardiac pacemaker (OPCS K61.7)
  - CRT with pacing (CRTp) (OPCS K61.7)
  - CRT with defibrillator (CRTd) (OPCS K61.7 + K59)
- pacemaker lead extraction using special equipment
- 3 dimensional navigation system mapping catheters

There are around 42 providers of ICD of which 32 carry out ablation. ICD rates vary from 30 to 100 per million population; CRT rates vary from 25 to 110 per million population. The costs of inserting an ICD range between £10,000 and £25,000. For CRT the figure is closer to £6,000.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

It should be possible to identify the services set out in the definition. Commissioning the services only from defined centres will reduce the total number of contracts and prevent occasional practice. There will be a need to identify non-specialised activity in such providers so that this can be charged to CCGs.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

#### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG noted that a revised list approach to coding was proposed. CAG endorsed this approach.

## **Suggested text for regulation**

Adult Specialist Cardiac Services

## **Suggested Description**

Adult Specialist Cardiac Services will include services provided by Adult Specialist Cardiac Centres including out-reach when delivered as part of a provider network. The service will include:

- Complex cardiac electrophysiology services

- Provision of complex device therapy

For early review.

## **13 Specialised cardiology and cardiac surgery services (adult)**

### **(b) Inherited heart disorders**

#### **Services covered**

The management of most inherited cardiac conditions should be considered specialised services. These include:

- hypertrophic cardiomyopathy,
- dilated cardiomyopathy,
- arrhythmogenic RV cardiomyopathy,
- arrhythmogenic right ventricular dysplasia,
- other rarer cardiomyopathies (e.g. Fabry's disease, mitochondrial disease, cardiomyopathies associated with neuromuscular and other systemic disorders)
- ion channel disorders (e.g. Long QT and Brugada syndromes)
- inherited aortic diseases (e.g. Marfan syndrome, Ehlers Danlos, pseudoxanthoma elasticum and familial aortic aneurysm/dissection)
- ventricular arrhythmias associated with cardiomyopathies
- families afflicted by sudden arrhythmic death syndrome.

A national initiative for inherited heart disorders is underway which seeks to ensure, among other things, that care is only delivered by a few specialist centres.

It is planned that such centres offer an integrated inherited cardiovascular disease service. This is an emerging speciality and it is thought that less than 20 centres provide such a service. The cost of specific treatments is moderate but the need for a large multi-disciplinary team makes costs high for the provider- making a sufficient critical mass vital.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

There was some concern that Familial Hypercholesterolaemia can sometimes be included in the list of inherited cardiac conditions and members did not feel that this should be included in the service (it is not specifically mentioned in the definition).

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

It should be possible to identify the specific In-Patient activity by diagnostic codes. Defined out-patient clinics will also be commissioned.

**CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

Note- this service does not include the management of Familial Hypercholesterolaemia which will be commissioned by CCGs..

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG noted that a revised list approach to coding was proposed. CAG endorsed this approach.

The response from the CRG made a strong case for the inclusion of Familial Hypercholesterolaemia in this service. CAG were not convinced of the merits of such an approach- noting the need to retain management of FH in local cardiology services, rather than in the smaller number of specialised IHD providers.

**Suggested text for regulation**

Adult Specialist Cardiac Services

**Suggested Description**

Adult Specialist Cardiac Services will include services provided by Adult Specialist Cardiac Centres including out-reach when delivered as part of a provider network. The service will include:

Inherited Heart Disease Services

For early review.

## **13 Specialised cardiology and cardiac surgery services (adult)**

### **(c) adult congenital heart disease services**

#### **Services covered**

The success of diagnostic and treatment strategies over the last 20 years has resulted in most patients with congenital heart disease surviving to adulthood. The majority require ongoing follow up and treatment in adult life in a centre with expertise in adult congenital heart disease. The transition from paediatric to the adult congenital service is supported by joint clinics between the paediatric specialist centre and the adult specialist centre to ensure a smooth transition to adult care.

Adult congenital heart disease specialist centres provide diagnostic and interventional services for teenagers and adults with congenital heart disease which include:

- out-patient clinics
- expert imaging assessment (echo, MRI , CT and nuclear)
- diagnostic and interventional cardiac catheterisation
- corrective and palliative cardiac surgery
- device therapy
- radiofrequency ablation of arrhythmias following congenital heart disease surgery
- advice on pregnancy/delivery and family planning issues.

The Department of Health Adult Congenital Heart Disease Commissioning Guide (May 2006) suggests a hub and spoke service model, concentrating expertise in a small number of specialist centres and developing local centres which provide shared care under protocols agreed with the specialist centre. The Guide lists the facilities and skills needed at specialist and at local centres.

Since ACHD centres are ideally linked to surgical provision for congenital heart disease in children, there are a fewer than 20 centres that provide this service in England. The provision of ACHD is being reviewed alongside the review of Paediatric Cardiac Surgery.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

It is possible to separately identify specialised activity. If a hub and spoke model is commissioned, specialised input to 'spokes' would need to be identified separately.

**CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

**Suggested text for regulation**

Adult Congenital Heart Disease Services

**Suggested Description**

Adult Congenital Heart Disease Services include all activity provided by Highly Specialised Adult Congenital Heart Disease Centres including out-reach when delivered as part of a provider network.

## **13 Specialised cardiology and cardiac surgery services (adult)**

### **(d) Cardiac surgery, invasive cardiology and cardiac MRI**

#### **Services covered**

This section includes all activity within adult cardiac surgery (except specialised adult congenital heart disease – see 13d above and specific AGNSS services) and some invasive interventional cardiology procedures.

Adult cardiac surgery includes: All surgery on the structure of the heart, heart valves, ascending thoracic aorta and aortic root, coronary artery and septal defects (acquired). There are around 30 000 cardiac surgery procedures per year in England (500 per million) performed in about 30 centres.

Invasive interventional cardiology in this definition refers to percutaneous cardiovascular procedures which are therapeutic as opposed to diagnostic. This includes: closure of atrial septal defects, PFO closure, left atrial appendage, reduction of myocardial septum, valvuloplasty, and percutaneous aortic valve replacement. In the NHS, Invasive Cardiology is mostly angiography and angioplasty- excluding these leaves around 1500 cases a year of specialised procedures. Specialised Interventional Cardiology procedures are high cost due to the price of devices used which can be in the range £15-25,000. There are less than 30 providers which offer these procedures in England.

Primary percutaneous coronary intervention for ST-elevation myocardial infarction (STEMI), along with other revascularisation procedures was removed from the SSNDS between versions 2 and 3 as it is carried out in more than 50 hospitals. It requires an emergency 24 hours, 7 days a week, service and consequently the procedure cannot be performed in every hospital which carries out angioplasties. This relates to practicalities including the provision of 24 hour/7 days a week cover and having a large enough emergency workload to maintain operator experience.

Cardiovascular magnetic resonance (CMR) is a specialised service. There are around 20 centres in England currently providing CMR of which half have a relatively small workload.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors. There was a sense that some of the elements of this service may be suitable for CCG commissioning in the near future and so an early review (2-3 years) would be appropriate.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

Separate commissioning should be straightforward. Services would be commissioned from defined centres.

### **CAG's review**

Following discussion with DH Policy team, CAG noted that the commissioning of Primary PCI, although removed from the most recent version of the definition, did in fact meet the four factors. In view of this, CAG determined to recommend inclusion of PPCI in the initial list of services with an early review at 2-3 years. At this time, CAG expected that such services may be suitable for commissioning by CCGs.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

In addition, all Primary percutaneous coronary intervention for ST-elevation myocardial infarction, (PPCI) services should be prescribed, subject to review at 2-3 years.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG noted that a revised list approach to coding was proposed. CAG endorsed this approach.

### **Suggested text for regulation**

Adult Specialist Cardiac Services

### **Suggested Description**

Adult Specialist Cardiac Services will include services provided by Adult Specialist Cardiac Centres including out-reach when delivered as part of a provider network. The service will include:

- All Cardiac Surgery Activity
- Complex invasive cardiology services
- Primary PCI services
- Provision of Cardiac MRI

For early review

## **13 Specialised cardiology and cardiac surgery services (adult)**

### **(e) Pulmonary Hypertension Services**

#### **Services covered**

A diagnosis of pulmonary hypertension (PH) is usually established in a local hospital through echocardiography. Patients should be referred immediately, and before cardiac catheterisation, to one of the nationally designated specialist centre to establish the underlying cause of the condition and its severity in order to determine optimal treatment, which may be medical or surgical.

The six centres for pulmonary hypertension services for adults have been nationally designated since September 2001:

London: Hammersmith, Royal Brompton, Royal Free

Cambridge: Papworth

Sheffield: Royal Hallamshire

Newcastle: Freeman

A national commissioning policy is in place to ensure the availability of funding for high cost drugs for patients with severe PH (NYHA III or IV). These should only be prescribed by one of the centres. The service includes management of these patients and provision of medication (including home care services where appropriate).

Lack of systematic and often poor data collection prevents reliable estimation of incidence. The census of patients on treatment at 31 March 2007 identified 1500 patients UK wide. The number has doubled over 3 years. The pool of patients on treatment continues to grow and has not yet reached a 'steady state'. The main cost on provision of the sub-national services is drug treatment. Despite the use of home care arrangements annual drug costs range between £5-40,000 per year

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

It should be possible to identify all activity relating to the specialised centres. Where shared care is in place (usually linked to ACHD services) the PH specialised element will need to be identified.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription. This service should be reviewed in 2-3 years. At this time, CAG expected that some elements of this service may be suitable for commissioning by CCGs.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**  
Subject to review at 2-3 years.

**Suggested text for regulation**

Adult Specialist Pulmonary Hypertension Services

**Suggested Description**

Adult Specialist Pulmonary Hypertension Services will include services provided by Highly Specialised Pulmonary Hypertension Centres including out-reach when delivered as part of a provider network. For early review.

## **14 HIV/ AIDS treatment and care services (adults)**

### **Services covered**

This definition was removed from the 3rd edition as it was noted that around 100 providers offered out-patient HIV care. In-patient care is included in the definition on Infectious Diseases (18). HIV treatment is included in the list of services to be commissioned by Public Health England through an arrangement with NHSCB. Prescription of these services would mean such commissioning would be retained by the Board.

The professional societies recommend a network approach including the identification of Principal Treatment Centres for in-patient care and MDT oversight of complex cases. The link to ID units is more frequent outside London where the prevalence tends to be lower.

The main cost for HIV care is anti-retroviral drugs. The basic cost of a year of care including drug costs is around £10,000 but higher costs are incurred when patients have multi-drug resistant disease or co-infection- for example with TB

In 2009 about 60,000 people accessed care for HIV/ AIDS in England. Almost half of these are registered in the London area.

### **CAG's initial view**

CAG agreed that this service (as set out in the v2 of the SSNDS) meets the four factors.

CAG were minded to recommend prescription of this service as set out in the version 2 of the definition set- including elements still incorporated in v3 under definition 18 (Infectious Diseases).

### **View of TOG**

In-patient HIV activity in centres meeting the standards to be an HIV centre should be straightforward- although it will be important to identify only that activity relating to the condition. Only one SCG commissions all out-patient activity within their area. In addition, NHS Number is not collected for all of these services making activity based contracting a challenge. Some SCGs have used a census approach- paying for a year of care for patients 'registered' with a provider. There would need to be continued local commissioning of sexual health services including HIV prevention and testing.

### **CAG's review**

After discussion with the DH policy team, it was confirmed that HIV treatment will not be included in the remit of Public Health England. CAG agreed that this service should be prescribed.

**CAG recommended to prescribe as per 2<sup>nd</sup> and 3<sup>rd</sup> edition of SSNDS.**  
However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Adult Specialist Services for patients infected with HIV

### **Suggested Description**

Adult Specialist Services for patients infected with HIV will include in-patient care for HIV related conditions in Adult Specialist HIV Treatment Centres and out-patient care provided by these Specialist Centres including out-reach when delivered as part of a provider network.

## **15 Cleft Lip and Palate services (all ages)**

### **Services covered**

Cleft lip and/or palate (CL/P) is a congenital deformity with an incidence in the UK of between 1 in 600 and 1 in 700 live births and with a range of presentations from a unilateral incomplete cleft of the upper lip, cleft palate without lip involvement, through to a complete bilateral cleft of the lip and palate. Successful management of patients born with cleft lip and/or palate involves multidisciplinary, highly specialised treatment from birth to early adulthood. With antenatal diagnosis, contact with the specialist CL/P team often begins before birth. Some adults will also have problems later in life that arise as a result of their cleft lip and/or palate or treatment thereof.

The Clinical Standards Advisory Group (CSAG) report on cleft lip and/or palate (1998) endorsed in a Health Services Circular (HSC 1998/002) recommended that CL/P services be concentrated in a small number of designated centres throughout the UK. The implementation of the recommendations across the country was a complex process lasting seven years. A national overview group, the Cleft Development Group, continues to exist to ensure that the intended benefits of the CSAG recommendations are delivered and is also responsible for the national cleft CRANE database. There are 9 formally recognised CL/P centres in England; 6 centres carry out surgery on more than one site.

About 1000 children are born each year in England with some degree of cleft. The range of presentations is from a unilateral incomplete cleft of the upper lip through to bilateral cleft of the lip and palate. The patient pathway can span 15-20 years, with improvement in surgical techniques leading to revisions in adulthood. It is suspected that adult care accounts for less than 100 cases per year. The costs will vary according to the severity and needs of the individual child, but care of these children tends to be costly due to the ongoing surgery that can span into adulthood

Services for Cleft Lip and Palate (CLP) cover multidisciplinary care including prenatal and postnatal diagnosis, hospital and community paediatric care, corrective surgery, speech and language therapy, rhinoplasty, orthognathic surgery, audiology and supporting services such as psychology, genetics, and revision treatment.

The services also treat and follow-up patients with Velopharyngeal Dysfunction (VPD) through investigation, therapy, surgery and/or prosthetics

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

**View of TOG**

Most, if not all, SCGs commission these services at present. Identification of paediatric care is straightforward but coding for adults is more difficult. This could be facilitated through use of the CRANE database. There remain some difficulties regarding adult referral for newly diagnosed problems.

**CAG's review**

CAG agreed that the services within this definition would be suitable for prescription. This would include assessment of adults where necessary.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

**Further Consideration by CAG**

CAG agreed that this definition should include all specialist care delivered by centres including Speech and Language Therapy.

**Suggested text for regulation**

Cleft Lip and Palate Services

**Suggested Description**

Cleft Lip and Palate Services will include all specialist care delivered by Cleft Lip and Palate Centres including out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## **16 Specialised Immunology services (all ages)**

### **(a) specialised clinical immunology including Primary Immunodeficiency diseases**

#### **Services covered**

Specialised immunology services incorporate the investigation, clinical assessment, treatment and holistic management of patients with suspected and established primary (i.e. inherited) and secondary (i.e. acquired) immunodeficiencies requiring treatment with and monitoring of complex immunotherapies. Primary immunodeficiency (PID) is rare and affects approximately 1 in 30,000 of the population and requires life-long treatment. Early diagnosis and appropriate treatment is crucial for reducing both morbidity and mortality and with timely diagnosis and optimal treatment a normal lifespan is possible.

The national professional organisation, UK Primary Immunodeficiency Network (UKPIN) produces a range of national PID standards of care and accredits PID centres specialising in the care of immunodeficiency (other than HIV).

The management of patients with established PID requires either regular, life-long therapy with a limited and expensive blood product called immunoglobulin (which can be administered both intravenously (IVIg) and subcutaneously (SCIg)) or other biological agents such as interferons, colony stimulating factors, etc. These are low volume, high cost therapies.

In 2009 there were 55 consultant (adult) clinical immunologists working in 17 centres in England.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

Unfortunately, most of this service is provided in an out-patient setting where coding does not allow identification of PID patients within the general immunology clinic setting. If the definition is broadened to cover all specialised immunology clinics this will include significant amounts of non-specialised activity. There is considerable overlap with allergy services (see definition 17).

#### **CAG's review**

CAG accepted that further advice was needed to agree the extent of immunology services which are truly specialised.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Immunology Services for patients with deficient immune systems

### **Suggested Description**

Specialist Immunology Services will include  
(a) services provided by Highly Specialist Immunology Centres, including out-reach 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

The service will include provision of cytokines and other immunomodulatory therapies for the above conditions. This applies to provision in adults and children.

## **16 Specialised Immunology services (all ages)**

### **(b) Use of Immunoglobulins**

#### **Services covered**

Owing to world wide shortages of immunoglobulin in 2007 the Department of Health (DH) published a Demand Management Programme on Immunoglobulin Therapy Use, updated in 2008, to ensure that immunoglobulin is available and funded for all essential infusions to patients, regardless of geographical location and to ensure that the most appropriate cases receive the supply in times of shortage. The plan included a set of national Clinical Guidelines for immunoglobulin usage (updated in 2008) and the establishment of a national Clinical Database which went live in June 2008. The National Specialised Commissioning Group has agreed a national Model Commissioning Policy for Intravenous and Subcutaneous Immunoglobulin Therapy for its member Specialised Commissioning Groups.

Around 5000 patients received Immunoglobulins in England in a period between September 2008 and September 2009 according to the National Immunoglobulin Database (100 per million). This is likely to represent most of the use in the NHS. Almost every acute trust in England administers immunoglobulins with more than 160 submitting data to the national database. This accounts for around £80 million spend on immunoglobulins by the NHS annually in England.

Use of immunoglobulins include:

- patients with immunodeficiencies who are unable to make protective antibodies are treated with human immunoglobulin preparations harvested from blood donations and infused either intravenously or subcutaneously (i.e. replacement therapy)

- patients with a range of autoimmune and inflammatory disorders are treated with large doses of human immunoglobulin (usually given by intravenous infusion) over a short period (i.e. immunomodulatory therapy)

- home therapy programmes are increasingly used for patients receiving long-term or lifelong immunoglobulin treatment; such programmes involve training patients and carers in self-delivered, home-based infusion techniques underpinned by ongoing support of patients for life

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

Immunoglobulin usage can be identified through the National Clinical Database on Immunoglobulin therapy but almost every acute trust in England administers this treatment.

### **CAG's review**

CAG accepted that, the current definition- where all use of immunoglobulins was considered specialised- may not lend itself to separate and direct commissioning. This was felt to be especially the case when the immunoglobulin was used outside a specialised service. It was not clear how such widespread use could be successfully monitored by the NHSCB.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Immunology Services for patients with deficient immune systems

### **Suggested Description**

Specialist Immunology Services will include:

(b)

The provision of intravenous Immunoglobulins for all indications

This applies to provision in adults and children.

## 17 Specialised Allergy services (all ages)

### Services covered

Allergic disease is common and prevalence has increased 2-3 fold in the last 20 years. The bulk of allergic disease is treated by GPs in primary care.

The definition is primarily concerned with the diagnosis and treatment of allergic conditions irrespective of the specialty / specialties which deliver those specialised services. In the case of specialised services for allergic disease the bulk of the services are delivered by clinicians from the specialties of allergy and clinical immunology but other specialties may also be involved.

Conditions covered by a specialised allergy service will have some or all of the following attributes: severe, complex/multi-system, rare, carry a high-risk of severe reaction, have unclear diagnosis and are inadequately controlled by standard treatment approaches

The following conditions should only be seen or procedures performed in Specialist Allergy Centres:

- Anaphylaxis, general anaesthetic allergy, local anaesthetic allergy, severe or multiple drug allergy, aspirin/NSAID intolerance, opioid intolerance, multiple food allergy, bee and wasp allergy, hereditary angioedema, occupational allergy, severe latex allergy

- Excluding allergy as a cause of disease

- Patients who require allergen immunotherapy (desensitisation): initiation, until maintenance therapy, then supervision

- Any type of challenge testing

- When the diagnosis of allergy is in doubt, for example discordance between the history and objective skin/RAST tests

The pattern of provision of specialised services for allergic disease varies across the country. For adults there are around 25 departments of allergy and / or immunology in the UK providing specialised services for allergic disease. For children there are paediatric allergy consultants (0.5 WTE to 1.0 WTE) based at 8 hospitals in the UK (including 2 hospitals where paediatric allergic disease services are also delivered by paediatric immunologists working alongside paediatric allergists); there are a total of 11 paediatric allergy consultants in the UK.

Very large numbers of patients are seen in primary care with conditions that may be allergic in origin It is very conservatively estimated that 3 people per thousand would benefit from the skills of clinicians with specialist training in allergy.

Although individual care costs are low to moderate, the provision of a cohort of specialists within an MDT for a service which is mostly out-patient based creates significant challenges for providers.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. However, there was real concern that the current definition could lead to commissioning of secondary care allergy services from specialised centres and excluding specialised allergy work when performed elsewhere.

Even so, CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

A pilot, undertaken to test the implementation of this definition in the North West suggested it should be possible to identify activity within a specialist centre- but not when it takes place elsewhere. Most of the activity is in the out-patients setting where coding information is very poor and does not lend itself to differential commissioning at patient level. A pathway approach- which ensured non-specialised allergy care was not provided in the specialist clinics might offer a solution. The current definition fails to offer a useful tool to identify the specialised activity beyond "provided by a specialist".

### **CAG's review**

CAG accepted that, the current definition does not lend itself to separate and direct commissioning. There was confusion as to what elements of care would be the responsibility of CCGs to commission.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

CAG noted the concern that there is considerable variation in the provision of secondary care allergy services and this could be masking a significant unmet need.

### **Suggested text for regulation**

Highly Specialist Allergy Services

## **Suggested Description**

Highly Specialist Allergy Services will include services provided by Highly Specialist Allergy Centres including out-reach when delivered as part of a provider network. This will include management of patients with:

- severe allergic conditions and
- common allergic conditions for whom conventional management has failed and for whom specified specialist treatments are required.

This applies to provision in adults and children.

## **18 Specialised services for Infectious Diseases (all ages)**

### **(a) Adult care**

#### **Services covered**

Infectious diseases services are provided by multidisciplinary teams including Infectious Diseases (ID) consultants and clinical microbiologists as well as clinicians from many other organ-based and syndrome based specialities.

Specialised ID services, currently provided in around 20-25 specialist ID centres in England, deal with less common or more serious cases of ID requiring specialist diagnostic facilities and clinical expertise in infectious diseases. Some of the conditions also require special isolation facilities with appropriate air handling and air filtration systems. These facilities are serviced by teams of doctors with specialist training in ID and microbiology, with support from their colleagues in nursing, radiology and pharmacology. The multidisciplinary ID 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. There is some variability in the provision of specialist ID centres around the country.

Around a quarter of an ID physician's workload in a specialist ID centre and the majority of a laboratory-based clinical microbiologist's workload in any hospital entails providing diagnosis and management advice on patients under the care of other specialties in the hospital; this activity is not captured by current hospital statistics. A lesser amount of time is spent giving telephone advice on patients being treated in local hospitals who have exotic diseases and unusually severe or undiagnosed feverish conditions; again this is not recorded in any hospital statistics.

There were around 25,000 admissions to the ID specialty in England in 2009-10 (500 per million). Maintenance of an ID unit, with appropriate isolation facilities makes in-patient costs much higher than the standard.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors. However, it was noted that there were ID services provided outside of ID centres, and ID centres often provided secondary care level services to their local population.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

#### **View of TOG**

Although specialised ID consultant led services can be identified, there are other services which could be seen as specialised within this definition, which may be led by a different consultant- eg Hepatitis care or Tuberculosis. If prescribed based on the current definition, it would be difficult to identify all of the activity. Further, specialised ID units provide non-specialised care,

especially to local patients. A more precise definition of the extent of specialised activity is needed.

### **CAG's review**

CAG accepted that, the current definition does not lend itself to separate and direct commissioning. If this definition were used, it was unclear how CCGs could be sure of the services they were required to commission locally.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

It was noted that services for the treatment of infection with HIV, viral hepatitis and tuberculosis are recommended for prescription elsewhere in this report.

### **Suggested text for regulation**

Highly Specialist Services for adults with infectious diseases

### **Suggested Description**

Highly Specialist Services for adults with infectious diseases will include

- Patients affected by specified organisms
- High secure infectious disease units
- Tropical disease centres
- Highly Specialist Bone and joint infection centres
- Human T-cell Lymphotropic virus centres

## **18 Specialised services for Infectious Diseases (all ages)**

### **(b) Paediatric care**

#### **Services covered**

Most infections in children are treated by local paediatricians at local hospitals. Advice and treatment in a specialist ID centre is required where the infection is very serious, persistent, unusual or recurrent. Specialist paediatric ID centres tend to be co-located with paediatric intensive care units and specialised microbiology services. Currently provision of specialised paediatric ID services is very variable across the country; there are 11 hospital trusts in England that have at least 1-5 whole time equivalent paediatric ID specialist and / or paediatric immunology specialist and a further 2 hospitals that have less than one whole time equivalent paediatric ID / immunology specialist.

Generally the specialist paediatric ID centre works on a network basis providing specific specialised services as well as advice and support to primary care and local hospitals within its network.

The paediatric definition specifically includes all HIV treatment (whereas the adult definition only includes in-patients HIV care within Infectious Diseases services).

In 2008 there were 1309 children living in the UK diagnosed with HIV of whom 855 were living in London. However the number of children with HIV living outside London is increasing. There are currently no specialist paediatric HIV centres outside the three centres London but in 2005 the Children's HIV National Network (CHIINN), a regional network structure for paediatric and perinatal HIV, was established with 6 regional lead centres and the Direct London Linked Centres (around the M25).

Lead clinician/s and nurse are identified for each of the 6 regional networks, and each network is linked to one of the three London centres. Each network has a formal process for clinical governance including network meetings, training, collaborative audit and research. Regional multidisciplinary family HIV teams have been established including, doctors, nurses, midwives, psychologists, dieticians, pharmacists, allied health professionals and social work support.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) meets the four factors. However, it was noted that there were ID services provided outside of ID centres, and ID centres often provided secondary care level services to their local population.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

Similar comments apply as for adults. Children's HIV services were less of a concern as these tend to be separately identified services and are not widespread.

### **CAG's review**

CAG accepted that, the bulk of the current definition does not lend itself to separate and direct commissioning. It was unclear how CCGs would know which services they were responsible for commissioning. However, Paediatric HIV services met the four factors and should be prescribed.

### **CAG recommended to prescribe services within this definition relating to paediatric HIV as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **For other services within this definition, CAG agreed that the services described meet the factors on the face of the bill.**

Further advice should be sought to define these services in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

Primary immunodeficiency in children is also discussed elsewhere (Page 79).

### **Suggested text for regulation**

Specialist Services for children and young people with infectious diseases

### **Suggested Description**

Specialist Services for children and young people with infectious diseases will include services provided by Specialist Infectious Diseases Paediatric Centres. This will include the management of

- Primary immunodeficiency
- Overwhelming septicaemia
- Severe Tuberculosis
- Unusual fungal infections
- HIV infection
- Tropical infections
- Common infections in the immunocompromised hosts

These should include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.

## 19 Specialised services for liver, biliary and pancreatic medicine and surgery (adults)

### Services covered

The delivery of services to treat liver, biliary and pancreatic disease may take place in different locations:

Services for pancreatic cancer are delivered in line with the NICE Improving Outcomes Guidance for pancreatic cancer and, as such, pancreatic surgery takes place in centres serving a population of 2-4 million and is a specialised service.

For pancreatic disease there are 6 nationally designated centres for pancreatic transplant, all co-located with NICE Improving Outcomes Guidance-designated pancreatic surgery centres. Two of the pancreatic transplant centres are co-located with liver transplant centres.

For liver disease the six nationally designated (adult) liver transplant centres represent centres of expertise in liver and biliary medicine, radiology and surgery.

There are additional (non transplant) centres of expertise in liver and biliary medicine, radiology and surgery, which may be co-located with pancreatic centres or be separate.

There are also non-specialised services provided at local hospitals where gastroenterologists with extensive training in liver disease and hepatologists provide some medical liver and pancreatic services.

One particular difficulty in determining which medical liver conditions should be regarded as specialised is that it is often not the underlying diagnosis but the **severity** of the disease that governs whether expertise at a larger, specialist centre is required or not. The severity of liver disease is poorly identified in ICD10 and may be better identified by the existence of comorbidities, e.g. renal failure, bleeding and coma.

This definition includes:

- acute liver failure
- complicated chronic liver disease
- complicated viral hepatitis
- Primary cancers of the liver and biliary tree (hepatocellular carcinoma and cholangiocarcinoma)
- Secondary liver tumours - colorectal, neuroendocrine
- non-cancer related hepatobiliary surgery
- pancreatic cancer including neuroendocrine tumours and cystic neoplasms
- benign pancreatic disease including acute and chronic pancreatitis.

### Acute liver failure

The majority of care for acute liver failure is given in the local hospital. The severity of the liver disease and the rapidity of the onset (very rapid in the case of fulminant hepatic failure, for which there is no diagnostic code)

determines the clinical necessity for transfer to a liver centre or a liver transplant centre.

### **Complicated chronic liver disease**

Referral to a liver centre will largely be dependent upon disease severity. In addition, in many cases specialist input is needed to diagnose and treat uncommon liver diseases e.g. cases of primary sclerosing cholangitis, Budd Chiari syndrome, Wilson's disease and metabolic liver disease. While mild cases of many of these conditions are treated by hepatologists in local hospitals, it is the severity and need for specialist therapy that determines discussion with the centre and need for transfer.

### **Complicated viral hepatitis**

The bulk of this service relates to the provision of care for patients with chronic Hepatitis B and C. Most patients with chronic viral hepatitis are treated at local hospitals within clinical networks and according to national and local guidelines. Some patients with particular complications, e.g. co-infection with HIV, haemophilia, decompensated cirrhosis, drug-resistant hepatitis, patient with severe complications of therapy and multi-organ failure, are treated at a liver centre.

### **Primary cancers of the liver and biliary tree**

#### **Secondary liver tumours - colorectal, neuroendocrine**

These are considered under definition 1

### **Non-cancer related hepatobiliary surgery**

Virtually all hepatobiliary surgery is a specialised service. Non-cancer related hepatobiliary surgery includes liver trauma and bile duct damage (traumatic or iatrogenic). Liver trauma presents at local hospitals as an emergency and initial stabilization may take place there, before discussion of the case with a liver centre. Transfer to a liver centre is usually required for further imaging and a decision on surgery or interventional radiology. Where the acute liver damage is part of multi-organ trauma it is likely to be dealt with by the trauma centre itself, usually liaising with the liver centre depending on severity of the case.

### **Pancreatic cancer**

This is considered under definition 1

### **Benign pancreatic disease**

Benign pancreatic disease includes acute and chronic pancreatitis of varying aetiologies and varying severities and with various complications. Optimal care for benign pancreatic conditions is best provided within a clinical network with the local hospital managing the patient until specialist intervention is required. Increasingly patients with acute pancreatitis and chronic pancreatitis are discussed with the pancreatic centre and severe acute pancreatitis cases are often transferred urgently from the local hospital to the pancreatic centre.

Over the last 30 years liver disease mortality in the UK has increased at least six-fold and liver admissions and liver deaths are both rising at between 8-10% per year. About 400 cases of Acute Liver Failure are seen in the UK each year. The most severe are transferred to one of 25 major liver units. Complicated chronic liver disease estimated at 100 people per million.

In England there are an estimated 50-800 new cases of pancreatitis per million population. There are an estimated that 450 per million men and 120 per million women with chronic pancreatitis. As well as 6 national centres that deal with pancreatic transplants, there are around 20 further providers of specialised care.

### **CAG's initial view**

CAG agreed that this service (as set out in the definition) meets the four factors. However, it was noted that there were significant parts of the definition which relied on 'complexity' or 'severity' to determine inclusion in a specialised service.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

The current definition would incorporate 136 providers if not restricted to inpatient activity at liver centres. However, this would fail to capture much of the service defined- including a substantial amount of out-patient care. The current definition could be used if restricted to liver/ pancreatic units. However, this would include activity at those units which is not specialised since out-patient coding would not allow for a distinction between specialised and non-specialised diagnoses.

### **CAG's review**

Following discussion with the DH policy team, CAG agreed that although the current definition sets out the specialised elements of this service, it does not provide sufficient clarity to allow separate commissioning.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

The proposed scope includes  
patients with complex Hepatitis C

treatment of all cancers of the liver, pancreas and biliary tree  
Specialist liver units

**Suggested text for regulation**

Specialist Services for complex liver, biliary and pancreatic diseases in adults

**Suggested Description**

Specialist Services for complex liver, biliary and pancreatic diseases in adults will include treatment of a defined list of conditions and a defined list of procedures provided by Specialist Hepatobiliary centres including out-reach when delivered as part of a provider network..

## **20 Medical Genetic services (all ages)**

### **Services covered**

Medical genetics is the umbrella term describing clinical and laboratory activity relevant to the genetic aspects of disease. The clinically-led activity, comprising clinical consultation (clinical examination and diagnosis, pedigree interpretation and investigations) as well as interpretation of genetics laboratory results, risk estimation and genetic counselling, is provided to patients and their families by medical genetic centres. There are less than 20 medical genetics centres in England, and outreach clinics are an integral part of service provision.

This definition distinguishes between an integrated specialised medical genetics service (known in this document as 'core medical genetics service') and services provided by clinical geneticists and laboratory personnel in collaboration with specialties such as neurosciences, cardiac, cancer, etc.

The core medical genetics service is defined as a specialised clinical genetics service integrated with a laboratory service which is provided for individuals with / concerned about an inherited disorder with a significant genetic component, and their families. In some cases the genetic disorder may occur sporadically rather than being inherited.

This definition does not include the treatment of patients for their genetically determined condition.

Little of the costs of genetics services relate to clinical care or treatments. A significant proportion of the spend relates to genetic testing. Tests often cost up to £1000 but may be much higher for specific groups of tests. In much of the country the genetics team are the "gate keeper" for such tests.

Preimplantation genetic diagnosis (PGD) involves both specialist genetics services and specialist infertility services as it requires input from laboratory and genetic counselling services as well as close collaboration with specialised infertility services for medical management, gamete and embryo work.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

Genetics services are commissioned by SCGs for the most part. The precise method of separating the tests requested by geneticists and those requested by "collaborating" clinicians will differ by provider but should enable separate funding. "Mainstreaming" such tests will impact on other specialised services in the main but may also be a cost pressure on non-specialised providers.

**CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

**Suggested text for regulation**

Specialist Genetic Services

**Suggested Description**

Specialist Genetic Services will include services provided by Specialist Clinical Genetics Services (including specialist laboratory services) including out-reach when delivered as part of a provider network. This applies to provision in adults and children. This service includes the provision of Pre-implantation Genetic Diagnosis and associated In-vitro Fertilisation services.

## **21 Specialised Learning Disability Services**

This definition was removed from version 3 of the SSNDS with elements incorporated into other definitions- mainly 22.

## **22 Specialised Mental Health Services (all ages)**

### **Specialised Addiction Services**

This service was removed from version 3 of the SSNDS. In discussion with the policy leads within DH it has been confirmed that these services will now be commissioned through Public Health budgets held by Local Authorities and will not be included in the NHS.

## **22 Specialised Mental Health Services (all ages)**

### **Specialised Psychological therapies (inpatient and specialised outpatient services)**

This service was removed from version 3 of the SSNDS with elements incorporated into other sections of the definition.

## **22 Specialised Mental Health Services (all ages)**

### **22.1 Specialised Services for Eating Disorders**

#### **Services covered**

Patients with eating disorders are usually treated in primary or secondary care and services are provided in out-patient, daycase or 5-day/week facilities. This section covers the highly specialised service that is provided in an in-patient setting for people with very severe and intractable eating disorders, including those patients who are diagnosed late in the development of the condition. At this level of clinical management such cases can require specialist interventions, e.g. controlled feeding, plus clinical knowledge and expertise that is not routinely available from local services.

A specialised service for eating disorders provides comprehensive care including access to emergency and intensive in-patient treatment for complex cases, some out-patient services and community liaison services. A close working partnership with local mental health services to ensure the provision of intensive community-based intervention services will reduce the need for hospital admission or hospital length of stay if hospitalisation is unavoidable.

Both the NHS and the independent sector provide specialised services for eating disorders.

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors. There was concern regarding the exact point where this service took over from local services, and a concern that separation of the pathway could lead to issues regarding transfer between specialised and non-specialised care.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

#### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future. Further work is required to ensure comprehensive commissioning of all elements of the service as laid out in the definition.

#### **CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription. If prescribed, further work would be needed to allow for identification of this activity in such a way as to ensure clear separation between the specialised element (to be commissioned by NHSCB) and the local services (to be commissioned by CCGs)- especially in relation to day patient services and follow-up. This service should be reviewed at 2-3 years. At this time, CAG expected that some elements of this service may be suitable for commissioning by CCGs.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.  
Review at 2-3 years.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. CAG accepted the proposal that out-patient care “associated” with the in-patient service should also be prescribed.

**Suggested text for regulation**

Adult Specialist Eating Disorder Services

**Suggested Description**

Adult Specialist Eating Disorder Services will include in-patients and bespoke packages of care for intensive day care (as an alternative to admission) services provided by Specialist Adult Eating Disorder Centres. The service will include associated non-admitted care including outreach when delivered as part of a provider network. For early review.

## **22 Specialised Mental Health Services (all ages)**

### **22.2 Secure / Forensic Mental Health Services**

#### **Services covered**

Secure and forensic mental health services are provided for people who are mentally disordered, including those with personality disorder or learning disability and who require secure care. The majority of patients will be mentally disordered offenders or others with similar needs.

Secure and forensic mental health services include high, medium and low secure in-patient care as well as community and out-patient services. The services are part of the wider spectrum of mental health, learning disability and personality disorder services.

The following services are not included in this definition:

- prison, court and police diversion schemes
- in-reach services provided to prisons, young offender institutions, Local Authority managed secure care units, bail and probation hostels
- psychiatric intensive care services
- locked rehabilitation facilities.

#### High secure psychiatric care services for adults

Three NHS Trusts are designated by the Secretary of State under the 1999 NHS Act to provide high secure psychiatric care services to meet the needs of adults with a mental illness, a learning disability (who may require secure care but may not have mental illness comorbidity) or a personality disorder who also require care in conditions of maximum security.

Access to high secure care is through assessment in medium secure service settings or via the courts or prisons. People admitted to these settings must present as a grave and immediate danger to the public. The average length of stay is 7-8 years.

#### Medium secure psychiatric care services for adults

These services are delivered by NHS Trusts or independent sector providers which are specifically designed to meet the needs of adults with a mental illness, a learning disability (who may require secure care but may not have a mental illness co-morbidity) or a personality disorder who require care and treatment in a secure setting to ensure they are safely managed. Rehabilitation is a key part of the medium secure care service.

Access to medium secure care would normally be following a court appearance, referral from general mental health services, or transfer from the high secure care service. The average length of stay is 18-24 months.

Longer stay medium secure services provide care for adults who require longer periods of inpatient care, usually 2-5 years but sometimes longer; the

focus remains on rehabilitation for the person to the lowest level of security necessary to meet their needs.

#### Community and out-patient care services for adults

These services may be provided by specialised mental health services to former patients of high or medium secure care units who are now in low secure units or in the community including patients on Restriction Orders. Follow-up may be provided on a shared care basis with local services.

#### Low secure care services for adults

These services for adults are delivered by a specialist team drawing on expertise from rehabilitation and forensic specialists. Patients usually have a long-standing and complex problem with their mental health which requires longer term rehabilitation and support which cannot be safely or successfully delivered in open local mental health units. They also exhibit behaviour at a level of risk greater than general mental health services could safely address. Staff working in these settings will have experience in the provision of forensic or rehabilitation services and secure care.

Access to this service is usually from local mental health services (including psychiatric intensive care), from medium secure care services or from the criminal justice system.

Longer stay low secure services provide care for adults who require longer periods of inpatient care, usually 3-5 years but sometimes longer; the focus remains on rehabilitation for the person to the lowest level of security necessary to meet their needs.

#### Secure forensic mental health services for young people

This in-patient service has been nationally commissioned since April 2002. There are 7 nationally designated centres.

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

#### **View of TOG**

Activity is currently recorded locally through bespoke information systems. Contracting and payment for these services is largely straightforward, with most SCGs holding contracts directly with secure providers.

These secure services also provide additional functions such as follow-up in the community of high risk patients. Costs and activities are not separately monitored.

**CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription. If prescribed, further work would be needed to include all elements of community services for forensic patients which are not consistently commissioned at present.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service. This should include community services for forensic patients.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. CAG accepted the proposal that out-patient care “associated” with the in-patient service should also be prescribed.

**Suggested text for regulation**

Adult Secure Mental Health Services

**Suggested Description**

Adult Secure Mental Health Services will include high, medium and low secure in-patient care and associated non-admitted care including outreach when delivered as part of a provider network.

CAG were assured that the regulation relating to the existing national service for young people was sufficient (included here for completeness).

**Suggested text for regulation**

Secure forensic mental health service for young people

**Suggested Description**

Secure forensic mental health services for young people will include services provided by Highly Specialist Secure Forensic Mental Health Service centres for young people.

## **22 Specialised Mental Health Services (all ages)**

### **22.3 Specialised Mental Health Services for the Deaf**

#### **Services covered**

Specialised services for children and adults who are deaf and have a mental illness cover those patients who cannot be effectively managed and treated on a general acute admission ward usually because of the communication difficulties, including the impact of this on the patient's mental health, and the lack of health staff with signing and communication skills who have experience in the care and treatment of deaf people with mental illness.

The service includes specialised in-patient, out-patient and community services including assessment and treatment services for deaf people and advice to general mental health services on the management and treatment of the deaf person's mental illness.

#### Specialist centres

There are currently three main NHS centres in London, Manchester and Birmingham providing specialised mental health services for deaf adults. There is also a local specialised community service in Nottingham plus other independent organisations that provide specialised services in collaboration with the NHS centres.

The specialist centres have multi-disciplinary teams that are trained and experienced in the treatment and support of deaf people with mental illness and who understand the cultural and communication difficulties that affect deaf people. Team members are competent in British Sign Language (BSL) signing and other methods of communication with deaf people.

At the moment specialist centres provide a range of in-patient and out-patient services for people who are deaf and have mild, moderate and severe mental illness/problems including personality disorders. Out-patient services include psychotherapy and cognitive behavioural therapy.

#### Mental health service for deaf children and adolescents – in-patient service

This service has been nationally commissioned since April 1998. There is one nationally designated centre.

#### Mental health service for deaf children and adolescents – outreach service

Since April 2009, the NCG has commissioned an outreach service based at four nationally designated specialist centres across the country which provide a service for children and adolescents who have a mental health condition where referral to a specialist CAMHS is appropriate AND have either: severe or profound hearing loss OR British Sign Language as their preferred/first language OR a significant language impairment related to moderate to profound hearing loss.

### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors. It would be important to define the interface with locally commissioned services.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future.

The three national providers provide local services in addition to those defined as specialised here. The service model will need to accommodate this local access within the service specification.

### **CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

#### **Suggested text for regulation**

Specialist Mental Health Services for Deaf Adults

#### **Suggested Description**

Specialist Mental Health Services for Deaf Adults will include in-patient and non-admitted care including assessment and treatment services for deaf people provided by Specialist Centres. In addition, the service will include advice to general mental health services on the management and treatment of the deaf person's mental illness.

CAG were assured that the regulation relating to the existing national service for children and adolescents was sufficient (included here for completeness).

#### **Suggested text for regulation**

Mental health service for deaf children and adolescents

#### **Suggested Description**

Mental health services for Deaf children and adolescents will include services provided by Highly Specialist Deaf Child and Adolescent Mental Health centres including outreach when delivered as part of a provider network.

## **22 Specialised Mental Health Services (all ages)**

### **22.4 Gender Identity Disorder Services**

#### **Services covered**

Gender identity disorders can be described as a desire to live and be accepted as a member of the opposite sex, usually accompanied by a sense of discomfort with, or the inappropriateness of, the patient's anatomic sex. Patients may receive hormonal treatment and in some cases surgery to make the body as congruent as possible with the patient's preferred sex.

In the main this definition covers services for adults. It covers both the mental health services and the surgical services that may be required during the treatment programme as well as treatments post-surgery such as speech therapy or electrolysis.

The service is often provided by two separate health care provider organisations (providing the surgical and the mental health services respectively) working together to provide the full package of care.

All patients receive a first and second mental health assessment and each assessment is carried out by a psychiatrist who is a specialist in the area of gender dysphoria. If accepted onto the programme a care package is drawn up. Initial treatment includes hormone therapy for a period of two years, after which patients are re-assessed by two specialist psychiatrists for possible referral to one of the very few surgical units providing transgender surgery.

Prior to surgery a comprehensive evaluation is carried out which confirms the patient has met the eligibility and readiness criteria set out in the HBIQDA standards including undergoing a successful 'real life' experience for a minimum of two years. For men seeking female identity, this includes exclusive adoption of female dress, a female name and full-time employment as a female.

#### **Child and adolescent gender identity development service**

This service has been nationally commissioned since April 2009. There is one nationally designated centre.

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

#### **View of TOG**

There are a limited number of providers of the mental health elements of this service and very few for surgical interventions. Activity is currently recorded locally through bespoke information systems. It is expected that more

uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future.

There is some NHS funded surgery which takes place elsewhere in the EU.

**CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

**Further consideration by CAG**

It should be noted that the nationally commissioned Gender identity development service for children and adolescents does not cover surgery. As such, and for the avoidance of doubt, we have included children in the description for the proposed regulation.

**Suggested text for regulation**

Gender Identity Disorder Services

**Suggested Description**

Gender Identity Disorder Services will include specialist assessment, non-surgical care packages, transgender surgery and associated after care provided by Specialist Gender Identity Disorder Centres. This applies to provision in adults and children.

## **22 Specialised Mental Health Services (all ages)**

### **22.5 Perinatal Mental Health Services (Mother and Baby Units)**

#### **Services covered**

Psychiatric disorder following childbirth is common, treatable, sometimes predictable but often serious. Childbirth also poses a predictable risk to those women with past or current mental health problems who require pre-pregnancy advice on issues of medication and illness risk. It can also pose a severe risk to the health and safety of the baby. Information exists to identify some of those at risk of serious post partum illness and to draw up anticipatory management plans.

When women in the puerperium develop severe depression, mania or other psychoses it is often clinically desirable for them to be cared for with their babies so as to provide uninterrupted mother-baby interaction. Perinatal mental health in-patient units, or mother and baby units (MBUs) as they are often known, provide in-patient assessment and treatment for mothers with serious mental illness and their babies in an environment where it is possible to supervise the mother's care of the baby and work on the mother / baby relationship as well as the wider family relationships, particularly the father's. Mothers and babies are admitted to MBUs unless there are strong clinical reasons that they be separated.

MBUs are stand-alone units run by specially trained and dedicated staff with skills to address both the mental health needs of the mother and care of the baby. A separate area on an acute psychiatric ward is not regarded as a specialist unit. There are 10 MBUs in England.

Perinatal mental health in-patient unit services include:

- in-patient assessment and treatment of mothers with serious mental illness
- assessment of the quality of maternal care and supporting the development of parenting skills
- recommendations on whether to place the baby with the mother on discharge
- local out-patient follow-up or timely discharge planning and transfer of care to referring organisations and care co-ordinators
- community outreach services provided by the specialist unit (these include a multidisciplinary team with a caseload or specialist nurses advising and liaising with local health and social services personnel)
- facilities for patients at high risk of postnatal illness to be admitted prophylactically
- pre-pregnancy assessments of women with severe mental illness so as to advise on risks in relation to pregnancy (as recommended by the Confidential Enquiry into Maternal and Child Health)

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future.

Local communities need to develop robust partnership working and expertise to ensure mothers and families receive support within the community. Such services should be locally commissioned.

### **CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription. Further work is required to identify which out-reach services should be included within the service in line with the definition, and which should be locally commissioned.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. CAG accepted the proposal that out-reach “associated” with the in-patient service should also be prescribed.

### **Suggested text for regulation**

Specialist Perinatal Mental Health Services

### **Suggested Description**

Specialist Perinatal Mental Health Services are provided by Specialist Mother and baby Units. Services will include in-patients 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.

## 22 Specialised Mental Health Services (all ages)

### 22.6 Complex and/or Refractory Disorder Services

#### Services covered

Patients with complex and/or refractory disorders comprise a minority of patients with mental illness and require specialised in-patient and out-patient services. Such patients pose major therapeutic challenges and centres of expertise concentrate skills and experience to treat the relatively low number of patients.

There are no clear criteria for when it is appropriate for a patient to be managed at a specialist centre, but patients meeting one or more of the criteria below *in addition* to meeting disorder specific criteria are appropriate for referral to a specialist centre:

- a lack of diagnostic clarity hampering treatment
- a persistently high symptom burden on established scales of severity
- a significant degree of impact upon the individual's functioning, i.e. occupational, social and family
- the duration of functional incapacity and/or symptoms has persisted despite *adequate* treatment in excess of two years or a recurrent (or relapsing/ remitting) pattern of illness over a longer period or with limited inter-episode functioning
- multiple factors (three or more) that increase the likelihood of the disorder/episode becoming chronic or relapsing/recurring in the subsequent 12 months, e.g. co-morbid substance misuse; non-compliance with treatment; poor tolerance of routine treatments; multiple axis I and axis II diagnoses
- specialised treatments, e.g. specialised psychopharmacological combinations, vagus nerve stimulation (VNS) for depression, or in-patient exposure and response prevention for obsessive compulsive disorders (OCD) are being considered

or

- anyone who has been an in-patient for longer than 6-12 months (for whatever reason).

Severe obsessive compulsive disorder (level 6) and body dysmorphic disorder services for adults and adolescents.

Services for patients with severe (Level 6) Obsessive Compulsive Disorder (OCD) and Body Dysmorphic Disorder (BDD) have been nationally commissioned since April 2007. There are 4 nationally designated centres.

#### CAG's initial view

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors. However, apart from the nationally commissioned services, it was not clear that such specialised services exist.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Currently, there is only one known specialised service other than those nationally commissioned. This provides a local specialised service. Elsewhere, the more severe forms of mental health problems are treated within local services.

### **CAG's review**

CAG agreed that the nationally commissioned service included within this section of the definition would be suitable for prescription. Further, it is not clear that other specialised services have been developed which would meet the current definition.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that the appropriate services were covered by the regulation relating to the existing national service (included here for completeness).

### **Suggested text for regulation**

Severe obsessive compulsive disorder and body dysmorphic disorder service

### **Suggested Description**

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.

## **22 Specialised Mental Health Services (all ages)**

### **22.7 Specialised Services for Asperger Syndrome and Autism Spectrum Disorder (AS and ASD)**

#### **Services covered**

Autism spectrum disorder (ASD) is the collective diagnostic term used for autism and Asperger syndrome. People with this condition have lifelong deficits in social interaction, communication and imagination, although levels of intellectual functioning vary considerably.

Current estimates of the number of children with ASD in the UK suggest a prevalence of 116 per 10,000 population. Projected estimates of the numbers of adults with Asperger syndrome vary from 36-50 per 10,000.

Assessment of complex ASD is most often carried out on an ad hoc basis by adult mental health services or learning disability services and only very occasionally by a dedicated ASD service. Diagnosis is often delayed until adulthood. Transition services (from paediatric to adult services for those diagnosed early) are variable across the country.

The large majority of people with ASD have their mental health needs met by local mental health services. These include: multidisciplinary diagnostic assessment and management; advice to people with ASD and their carers/families; advice to social workers; advice to other health service providers (e.g. eating disorder services, drug and alcohol services, prison in reach services) about how to adapt their provision for people with ASD; and psychological therapies adapted to optimise effectiveness for people with ASD.

A small number of individuals with ASD will need more specialised services. Such patients include those:

- who have complex diagnostic problems
- who present with severe challenging behaviour
- who pose a serious risk to themselves and others
- who have complex or treatment resistant co-morbid psychiatric and neurological disorders.

Specialised services include:

- multi-disciplinary diagnosis, assessment and management advice for complex individuals
- where there is ongoing local diagnostic uncertainty
- advice and support to families and carers
- consultation and supervision for health and social care professionals
- in-patient facilities for ASD non-forensic patients, providing co-ordination and gatekeeping to ensure appropriate referral and facilitating discharge back to the local service.

Since the definition was completed, the first ever strategy for improving the lives of adults with autism in England was published on 3 March 2010.

### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors. It was noted that the definition was not fully in line with the national strategy.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future. All such commissioning is currently performed by PCTs with no SCG commissioning these services.

There is an expectation within the national strategy that every local community will put in place plans for local ADS/ AS teams including the ability to diagnose and assess all cases.

### **CAG's review**

It was not clear that the definition reflects the national strategy. Further, it is not clear that specialised services have been developed which would meet the current definition. A broad review of this area would allow for the identification of the specific elements that continued to require NHSCB commissioning. If prescribed, this should be again reviewed in 2013, alongside the national strategy.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service. Review in 2013, alongside the review of the national strategy.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were concerned that no service had been identified which met the four factors. Children's in-patient services and secure services are proposed for prescription elsewhere.

There was a strong sense that local commissioning would be a better option for the adult service- especially with the national focus on localism so clearly set out in the national strategy.

CAG agreed that this service should not be recommended for prescription in 2012 but that this should be reviewed in 2013.

## **22 Specialised Mental Health Services (all ages)**

### **22.8 Tier 4 Severe Personality Disorder Services (adults)**

#### **Services covered**

Services for complex and severe personality disorders (PD), described as 'Tier 4' PD services, are provided for adults who have:

- more severe and complex needs than can be met through local specialist service provision (described as 'Tier 3')
- and who need in-patient or other intensive services
- but who do not fall into the forensic category.

The diverse range of adults with complex and severe personality disorders necessitates the provision of flexible and complex packages of care, including gender specific services, to supplement the local services. This will be co-ordinated by dedicated PD team. The following three models of residential treatment integrate the necessary social and psychological interventions to provide intensive therapeutic treatment, social therapy, relational security and a rehabilitation ethos:

- residential adult units for patients at high risk of suicide, for those with very unstable lifestyles, and those who cannot be managed within Tier 3 services or with enhanced Tier 3 packages
- "step-down" units for men who are being discharged from Medium Secure Unit programmes for PD or have previously presented a high risk of harm to others
- specialist "vulnerable women's" residential units for those with severe PD who are in danger of moving to higher levels of security due to unmanageability at lower levels of security, for those who have longstanding emotional problems leading to petty criminality and danger of inappropriate imprisonment, for those who are moving to less secure provision or from prison (analogous to the men in model 2, above) and for those who have a severe and intractable history of self-harm which is unmanageable elsewhere.

All Tier 4 PD services provide:

- collaborative care pathway planning by working closely with local services to help clients maintain their links to the community, supporting the ownership and commitment of local services, and ensuring smooth transitions into recovery
- liaison support, including consultation, liaison and advice to local services to support workforce development and improve local responses and mainstream service access for PD clients.

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors. It was noted that the interface with local Tier 3 services was essential.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future. Out-reach and non-residential services are provided widely. It may be more appropriate for these to be commissioned alongside local services.

### **CAG's review**

The service model for provision of Personality Disorders services is developing rapidly. The current definition is difficult to use in the context of maintaining clear boundaries with local services, and maintaining specialised services where required. Further advice should be sought to improve the definition. If prescribed, this service should be subject to review at 2-3 years.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.  
Review at 2-3 years.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. For early review.

### **Suggested text for regulation**

Specialist Services for Severe Personality Disorder in Adults

### **Suggested Description**

Specialist Services for Severe Personality Disorder in Adults will include in-patients and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Centres. In addition, the service will include associated non-admitted care including out-reach when delivered as part of a provider network.  
For early review

## **22 Specialised Mental Health Services (all ages)**

### **22.9 Neuropsychiatry Services**

#### **Services covered**

These services are also included in Definition 8 and 23.13.

Neuropsychiatry services work closely with other neuroscience and mental health services. Neuropsychiatry services see patients with conditions such as young onset dementia including Huntington's disease, movement disorders, neurodevelopmental disorders, epilepsy, sleep disorders, and acquired brain injury. These patients will usually be seen because of cognitive, behavioural or psychiatric symptoms. Other patients are seen because of neurologically explained symptoms or altered states of consciousness or mental symptoms of uncertain aetiology.

The out-patient service is often delivered through cross-speciality (joint) clinics. Patients who require neuropsychiatric investigation and intervention may require support from neuropsychiatry or neurology services, depending on their needs and route of referral. Where a neuropsychiatrist and a neurologist provide joint out-patient clinics the activity could be attributed to either but should probably be attributed to the service to which the patient was originally referred unless different arrangements have been agreed locally.

Specialised neuropsychiatric activity includes:

- in-patient and out-patient assessment for complex conditions presenting with psychiatric symptoms
- access to necessary clinical and nursing expertise, including neuropsychological assessment and brain scanning facilities and assessment of physical function, where necessary
- intensive nursing care in specialist units and within community teams; links with neuropathological centres and access to detailed genetic investigations and counselling
- training for local services, particularly in the early detection of these mental disorders.

#### **CAG's initial view**

CAG, informed by the Mental Health Sub-Group, agreed that this service (as set out in the definition) meets the four factors.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

#### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future.

Most such services are integrated into neurosurgery or brain injury services. There are around 10 adult centres in England with less providing care to adolescents and children.

### **CAG's review**

Neuropsychiatry as a service meets the four factors and should be prescribed. However, the current definition does not make clear what service should be commissioned out with those commissioned within other services (eg neurosciences and rehabilitation following brain injury).

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.  
Review at 2-3 years.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. For early review.

### **Suggested text for regulation**

Neuropsychiatry Services

### **Suggested Description**

Neuropsychiatry Services will include services provided by Specialist Neuropsychiatry Centres. This will include 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. For early review.

## **22 Specialised Mental Health Services (all ages)**

### **22.10 Tier 4 Child and Adolescent Mental Health Services**

#### **Services covered**

In child and adolescent mental health services (CAMHS) it is generally the complexity and severity rather than the nature of the disorder that determines the need for specialist care. CAMHS Tier 4 is regarded as a specialised service; it involves input from a multidisciplinary perspective, including Education and Social Services, and deals with the most complex and severe mental health problems.

The four tier structure of CAMHS means that referrals to CAMHS Tier 4 usually come from CAMHS Tier 3. There is significant variation in Tier 3 services in terms of resources and expertise across England and this variation can have a knock-on effect on Tier 4 service provision. Most Tier 3 services would not be defined as a specialised service although confusingly they are often known as “specialist CAMHS”.

The majority of referrals to Tier 4 are for in-patient or day patient treatment. Factors leading to referral to Tier 4 are not only severity and complexity, but also lack of treatment response, unusual clinical features, breakdown in therapeutic relationships, unavailability of local treatment options, increased vulnerability due to personal circumstances (i.e. in local authority care, youth justice system) and patient choice. Both the NHS and the independent sector provide CAMHS Tier 4 in-patient services.

CAMHS Tier 4 also includes some out-patient provision including services for eating disorders, gender identity disorders, youth sexual offending, secure and forensic services and attachment disorders (where family assessment is required and, if appropriate treatment thereafter).

Input from Tier 4 out-patient services is being increasingly sought in the form of second opinions, supervision, and teaching and training to support Tier 3 services. Packages of care from Tier 4 may be in the form of specialist assessment and outreach support to Tier 3 as well as treatment itself.

NHS in-patient beds for children (up to age 19) are provided by approximately 50 units in England (a total of 500 beds).

Specialised mental health services include:

- in-patient units (largely 5 day units with 3-6 month lengths of stay) for children aged 5-13 and associated day and outreach services
- in-patient units (acute, medium stay and long stay) for adolescents aged 13-18 and associated day and outreach services
- in-patient care units (2 NHS units, remainder independent sector) and day patient, assessment/consultation and out-patient treatment services for children and adolescents with severe eating disorders (see also Section 22.1)

- in-patient care and specialist assessment for children and adolescents with severe learning disabilities and mental health problems
- forensic/secure in-patient care and forensic outreach services for children and adolescents (see also Section 22.2)
- neuropsychiatric/neuro-developmental services for children and adolescents including those with a dual diagnosis
- services for children and adolescents with severe sensory impairments (see also Section 22.3)
- gender identity disorder services for children and adolescents (see also Section 22.4)
- services for young sex offenders and for young substance mis-users (complex cases)
- residential family assessment for mentally ill parents and their children and adolescents
- assessment and treatment services for attachment disorders and where families are at risk of breakdown (with or without associated care proceedings)
- mental health liaison with specialised paediatric services.

The three services listed below involve joint working between CAMHS Tier 4 specialists and other paediatric specialties for the treatment of the most severe end of the spectrum. Less severe cases are treated by local services but not infrequently local services are relatively under-developed and CAMHS Tier 4 will treat the less severe cases as well as developing interventions for delivery by local services:

- assessment and treatment services for severe and chronic feeding disorders
- specialised services for assessment and treatment of childhood obesity including targeted psychological and behavioural interventions for those at high risk of obesity complications (not addressed under Definition No.35, Specialised Morbid Obesity Services)
- services for severe and complex chronic fatigue syndrome and related disorders.

### **CAG's initial view**

CAG, informed by the Mental Health and Children's Sub-Groups, agreed that this service (as set out in the definition) meets the four factors. However, there was concern that the pathway needed to be maintained with Tiers 1-3.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 22.

### **View of TOG**

Activity is currently recorded locally through bespoke information systems. It is expected that more uniformity will come from the Mental Health Minimum Data Set (MDS) in the near future.

There is an emerging service model known as Complex Home Treatment teams or T3.5. This should be commissioned alongside Tier 4. Similarly in-

patient Learning disabilities CAMHS should be included in this service in line with the current text of the definition.

There will need to be detailed work to identify packages of care which are subject to tri-partite or joint funding (Health, Social Care and Education).

### **CAG's review**

CAG agreed that the services within this section of the definition would be suitable for prescription. Further work is required to identify which services, beyond the standard in-patient beds, would be included in prescription in line with the text of the definition. This work should also consider the issue of joint funding and ensuring seamless transition to other levels of CAMHS care

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. This service should include Tier 4 provision to children with ASD and Asperger's.

### **Suggested text for regulation**

Tier 4 Child and Adolescent Mental Health services

### **Suggested Description**

Tier 4 Child and Adolescent Mental Health services will include in-patients 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 will include associated non-admitted care including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **Specialised Paediatric Palliative Care Services**

Extract from the Introduction to Definition 23 “Specialised Services for Children”

“Palliative care services will potentially be needed for all life-threatening conditions in children but in particular for critically-ill children on neonatal and paediatric intensive care units; children with cancer; children with severe congenital heart disease and cardiomyopathies; children with muscular dystrophies and spinal muscular atrophy; children with spastic quadriplegic cerebral palsy; children with severe inborn errors of metabolism; babies and children with multiple congenital malformations; babies and children with significant chromosomal anomalies; children with cystic fibrosis and technology-dependent children.

“Palliative care services for children encompass the active total care of the child’s body, mind and spirit plus support to the family; begin when illness is diagnosed and continue regardless of whether or not a child receives treatment directed at the disease; are based on a broad multi-disciplinary approach that includes the family; and are provided in the most appropriate setting for the child and family. Set out below are the three core elements of a comprehensive paediatric palliative care service which operates across organizational and geographical boundaries via a provider network.

- Consultant-led multidisciplinary specialist children’s palliative care teams serving a population of around 1.5 to 2 million provide advice and support on all aspects of symptom control and psychological support for the child and their family. Services are provided directly to the child and family and also indirectly by supporting other professionals involved in the child’s care (e.g. children’s community nurses, general paediatricians and paediatric specialists) through a provider network. Provision is very variable; currently there are only 4 such teams in England. These services are specialised services.
- Children’s community nursing teams with skills and training in children’s palliative care and resources provide a 24 hours a day, 7 days a week, call-out service supporting end of life care at home. These services are not considered to be specialised services.
- Specialist short break services, including children’s hospice services and care packages, provide carer support for children and their families in school and / or at home. Elements of these services (generally the non- health aspects) may be funded by the voluntary (charitable) sector or by local authorities. These services are not considered to be specialised services.

### **Consideration by CAG**

CAG received a detailed submission from the NHS providers and commissioners highlighting the need for these services to be prescribed. A

proposed scope was offered with Specialist Paediatric Palliative Care Services led by a Medical Consultant working at Paediatric Palliative Care Competency Level 4- there are thought to be just six such services in England. CAG endorsed the proposal to specifically prescribe these services.

**Suggested text for regulation**

Highly Specialist Palliative Care Services for Children and Young People

**Suggested Description**

Highly Specialist Palliative Care Services for Children and Young People will include services provided by Highly Specialist Paediatric Palliative Care Services including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.1 Specialised Paediatric Anaesthesia and Pain Management Services**

#### **Services covered**

Wherever and whenever children undergo anaesthesia, surgery and pain management services, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.

Conditions and situations requiring more specialised anaesthesia expertise concern neonates (0-28 days), infants (29 days to 12 months) and children; these patients often being treated in neonatal / paediatric intensive care and high dependency care units (see also 23.10 and 23.12).

The definition includes:

- All neonates requiring surgery / anaesthesia
- Anaesthesia for infants with significant co-morbidity (ASA 3 or more)
- Anaesthesia for other children with significant co-morbidity (ASA 3 or more)
- Anaesthesia for children requiring specialised surgery or procedures as set out in the Specialised Services National Definitions Set
- Peri-operative care for neonates, infants and children

Acute and chronic pain management is also included in this definition.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. There was some concern regarding the precise age boundary- with a sense that anaesthesia in younger children was increasingly specialised. There was concern at the inclusion of all chronic pain management.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 23.

#### **View of TOG**

In general, hospital activity which relates to this part of the definition will tend to code for the procedure. Provision of anaesthetic care will not be separately commissioned (except for critical care- see 23.10 and 23.12). At present, no acute activity is coded to this sub-section of the definition. The section on chronic pain management is problematic, since the out-patient management of chronic pain is unlikely to be in standalone clinics and coding of out-patients is rudimentary. As such, it is not possible to identify the specialised input the definition describes.

#### **CAG's review**

CAG noted that this definition was a statement of intent picked up in other parts of the SSNDS- since specialised anaesthetics is integral to the provision of so many specialised services- and not a separate service. It was felt that

the actual cut-off of specialised care may have changed. Further, the inclusion of chronic pain management as a standalone service would be problematic. CAG agreed that further advice should be sought to identify the elements of service not included elsewhere in the SSNDS but meeting the four factors.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Highly Specialist Pain Management Services for children and young people

### **Suggested Description**

Highly Specialist Pain Management Services for children and young people will include services provided by Highly Specialist Paediatric Pain Management Centres. The service will include

Multi-disciplinary assessment of chronic pain

Certain specified interventions including intensive in-patient or residential management programmes

This will include out-reach when delivered as part of a provider network.

Other elements of this definition have been included in the separate surgical sections.

## **23 Specialised Services for Children**

### **23.2 Specialised Paediatric Cancer Services (paediatric oncology, malignant haematology and cancer surgery services)**

#### **Services covered**

The medical treatment of cancers in children and young people comprises three main modalities: surgery, chemotherapy and radiotherapy. Less common modalities include stem cell transplantation. All these modalities are specialised services.

This definition set refers only to children with cancer but there has been increasing recognition of the specific needs of older teenagers and young adults with cancer and the need to provide age appropriate services.

Some specialised services for children with cancer (e.g. administration of chemotherapy; management of mucositis) may be undertaken outside the specialist cancer centre in designated 'shared care' centres.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. The sub-section focuses on paediatric care, but notes the need for transitional care to young adult services to be included.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 23.

#### **View of TOG**

There are 13 centres in England which treat children with cancer, but 159 providers offer some part of this service (usually through shared care). At one extreme, In-patient surgery can be easily identified but out-patient follow-up in non-specialised clinics will be difficult to differentiate from general paediatrics.

#### **CAG's review**

This is a very brief sub-section for such a wide-reaching service. It is not clear if the intention of the definition is to include all children's cancer activity or only that provided by specialist centres. CAG agreed that further advice should be sought to identify the elements of service which should be included in prescription, with thought being given to including services for young adults in this work.

#### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

## **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

## **Suggested text for regulation**

Specialist Cancer Services for children and young people

## **Suggested Description**

Specialist Cancer Services for children and young people will 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

Planning after care (as part of the survivorship initiative)

## **23 Specialised Services for Children**

### **23.3 Specialised Paediatric Cardiology and Cardiac Surgery Services**

#### **Services covered**

Activity defined as specialised in this sub-section is concentrated in relatively few specialist centres to ensure a sufficient volume of activity is undertaken to develop and maintain expertise. Currently, there are just 10 centres that provide the full range of these services (excluding those commissioned nationally).

This definition encompasses seven specialised service areas:

heart, lung and heart & lung transplantation services (including implantable ventricular assist devices and extra corporeal membrane oxygenation)

Commissioned nationally- AGNSS

cardiac electrophysiology services

This includes diagnostic electrophysiology, radiofrequency and other forms of cardiac ablation, implantation, revision and renewal of cardiac defibrillator, and the insertion of pacemakers.

inherited heart disorder services

See Definition 13b.

congenital heart disease services

See Definition 13c.

paediatric cardiac surgery and invasive cardiology services

All cardiac surgery and interventional cardiology procedures (both therapeutic and diagnostic) for children are specialised services. Specialised cardiac surgery services also include surgery of the thoracic aorta and aortic root (including aortic root replacement, replacement of ascending aorta, repair of thoracic aortic aneurysm, repair of coarctation of aorta (see table below) and surgical management of cardiac trauma.

specialist cardiovascular imaging (MR and cardiac CT)

pulmonary hypertension services

Commissioned nationally- AGNSS

complex tracheal disease.

Commissioned nationally- AGNSS

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. It was identified that transitional care to the adult service (ACHD- see Definition 13c) needed to be included. Most of the pathway is defined as specialised but careful thought needs to be given to local cardiac clinics which are the front line of this service.

CAG were minded to recommend prescription of all services included in this sub-section of the most recent version of definition 23.

### **View of TOG**

There are defined national centres for most of this service and coding and separate commissioning will be straightforward. Out-reach clinics could be included in the service definition.

### **CAG's review**

CAG agreed that the services within this definition would be suitable for prescription. However, it is not clear from the definition where the lower limit of specialised care should be set- only include services provided by the centre, include services offered as an out-reach, only include specialised services offered as an out-reach. The emerging model is to establish local experts linked to the specialised service, but this is not explicit in the definition. Commissioners will need to carefully specify which elements remain within CCG commissioning.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Suggested text for regulation**

Paediatric Cardiac Services

### **Suggested Description**

Paediatric Cardiac Services will include all activity provided by Highly Specialised Paediatric Cardiac Centres including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.4 Specialised Paediatric Dentistry Services**

#### **Services covered**

There are clearly identified dental services which can be classified as specialised in respect of the nature of the dental condition or the treatment a child may need. However, as with paediatric surgery, there will also be occasions where the need for referral to a specialist centre will not be determined by the precise dental condition but by the presence of comorbidity which requires a multidisciplinary approach to care, with support being needed from other paediatric specialised (medical, surgical or anaesthesia) services or paediatric high dependency / intensive care services to. Hence both the child's primary dental condition alone, or the presence of complex co-morbidity, will require specialised dental services.

Specific conditions and types of treatment include

- Management of complex dento-alveolar trauma

- Tooth auto-transplantation

- Management of specialised and relatively rare dental developmental problems

- Management of aggressive periodontal disease

- Dental services for children with complex co-morbidity

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

It is possible to identify this activity using a combination of procedure and diagnostic code. However, 159 providers report such activity at present. Restricting to defined specialised providers would mean inclusion of routine work in those providers, and exclusion of genuine complex work in other providers.

#### **CAG's review**

CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning.

The definition states:

“the same dental condition/treatment may require a non-specialised, local hospital, dental service if the patient is a healthy child but may require a specialised dental service if the child has a complex co-morbidity. For this reason the specialist paediatric dental centre and the local hospital will use some of the same diagnostic and treatment codes. Hence the codes listed do

not distinguish between specialised and non-specialised dental service activity.”

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

#### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

#### **Suggested text for regulation**

Specialist Dentistry Services for Children and Young People

#### **Suggested Description**

Specialist Dentistry Services for Children and Young People will include services provided by Specialist Paediatric Dental Surgery Centres including out-reach when delivered as part of a provider network. The service will include:

- 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

## **23 Specialised Services for Children**

### **23.5 Specialised Paediatric Ear, Nose and Throat Services**

#### **Services covered**

The majority of ENT surgical procedures in children are elective and routine, with many carried out as day cases in a local hospital setting. There is a small emergency workload delivered at both local hospitals and specialist paediatric ENT centres and a small proportion of highly specialised work only delivered at specialist paediatric ENT centres. Examples of complex paediatric ENT surgery include cochlear implantation, laryngotracheal reconstruction and surgery for congenital vascular malformations of the neck.

Some paediatric ENT activity which may not be specialised of itself cannot be delivered in a local hospital due to the need for specialised anaesthetic services, paediatric high dependency/intensive care facilities or the input of other specialised paediatric services. For example, a child with severe obstructive sleep apnoea having a routine ENT procedure such as a tonsillectomy would require care at a specialist paediatric ENT centre whereas the majority of children requiring a tonsillectomy could be managed in a local hospital setting. Co-morbidities such as cardiac, respiratory or developmental conditions might also require routine ENT surgery to be delivered in a hospital providing other specialised paediatric services so as to be able to manage the non-ENT condition.

Specialised audiology services consist of those audiological services which are part of a paediatric hearing aid service. In some cases specialised audiology services may not be co-located with specialised ENT surgery services.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

It is possible to describe this service using a combination of procedure and diagnostic codes. 148 providers offer services identified in this way. However, just 9 do a total of more than 50 procedures per year of which 4 do more than 100.

If only those services provided by the 4 major centres were prescribed- this would include some non-specialised activity provided to local residents. Conversely, some activity meeting this definition, taking place in other centres would not be included.

#### **CAG's review**

CAG agreed that more clarity was required to ensure CCGs were clear as to which elements they would continue to commission. The difficulty is in

defining ENT work which is performed in the specialist centre by necessity- and therefore should not be performed elsewhere.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Specialist Ear, Nose and Throat Services for Children and Young People

**Suggested Description**

Specialist Ear, Nose and Throat Services for Children and Young People will include services provided by Specialist Ear, Nose and Throat Paediatric Surgery Centres including out-reach when delivered as part of a provider network. The service will include:

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.

## **23 Specialised Services for Children**

### **23.6 Specialised Paediatric Endocrinology and Diabetes Services**

#### **Services covered**

Paediatric endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders including growth and puberty problems, which occur relatively commonly, and a range of other endocrine disorders, which occur relatively rarely. Common endocrine conditions are managed in local hospitals or primary care settings, but complex and rare conditions are managed in conjunction with a specialist paediatric endocrinology centre. Treatment and follow-up are life-long and planned transition to adult services takes place via joint and/or hand-over clinics.

Paediatric endocrinology includes some diagnoses not found in adult endocrinology practice. Those diagnoses which are also found in adults will require additional specialist management in childhood and adolescence because of the impact on growth, puberty, education, social interaction and potential for fertility.

#### **Diabetes**

Most diabetic services for children and adolescents are NOT specialised services. Children and adolescents with diabetes are managed by their local hospital by a multi-disciplinary team which includes a paediatrician with a special interest in diabetes (they may be a paediatric endocrinologist or a general paediatrician). The aim is to deliver as much care as possible in the community. Treatment and follow-up are life-long and planned transition to adult services takes place via joint and/or hand-over clinics.

The exceptions, where referral to a specialist paediatric endocrinology and diabetes centre may be required, concern:

- diabetes complications in childhood (e.g. nephropathy, complex compliance problems such as eating disorders)
- Type 2 or rare forms of diabetes (e.g. neonatal diabetes, maturity onset diabetes of the young - MODY)
- diabetes associated with chronic disease (e.g. cystic fibrosis or high dose steroid usage in the treatment of some cancers).
- morbid obesity associated with Type 2 diabetes Services for these conditions are specialised.

#### **Endocrine disease**

Paediatric endocrinology includes some diseases not found in adult endocrinology practice. Those diagnoses which are also found in adults will require additional specialist management in childhood and adolescence because of the impact on growth, puberty, education, social interaction and potential for fertility. Care for children with endocrine disease aims to optimise growth and puberty and to minimise disruption to family life and education.

Common paediatric endocrine conditions are managed in local hospitals or primary care settings, but complex and rare endocrine conditions are managed in conjunction with a specialist paediatric endocrinology centre. There are around 15-20 specialist paediatric endocrinology centres in England. The specialist centre's multidisciplinary team (i.e. paediatric endocrinologist, clinical nurse specialist, dietician, psychologist, clinical geneticist, pharmacist surgeon, diabetologist and gynaecologist) provide assessment and investigations (including uncommon biochemical tests) to confirm diagnoses of endocrine disease as well as patient management thereafter (including drug therapy, radio-iodine treatment and surgery). Paediatric endocrinology services are often delivered as part of a clinical network with the specialist centre providing support to a paediatrician with a special interest in endocrinology who works at the local hospital.

The following endocrine disorders are either managed by the specialist paediatric endocrinology centre, or, where appropriate, through outreach clinics run by the specialist centre team at local hospitals or on a shared care basis between the specialist centre and the local hospital:

- complex growth problems including Turner syndrome and growth hormone deficiency
- pituitary disease including hypopituitarism, pituitary and peripituitary tumours
- thyroid and parathyroid associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease e.g. 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 calcium metabolism
- multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- DSD (disorders of sex development)
- morbid obesity.

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. There was some concern on the precise elements of diabetes care which was included in the definition.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

The codes included in this definition make identification of in-patient care for rare conditions straightforward. However, this will not identify common conditions with complex co-morbidities, or where associated conditions makes the management complex. Most of this activity is delivered in an out-patient setting and the coding of clinics does not allow for identification of complex

cases- specialist centres will often provide the non-specialised care for local residents. There are around 20 paediatric endocrinology centres.

Data from diabetes clinics will not identify the complex cases envisaged by the definition. Such cases would need to be seen separately to allow for separate commissioning.

### **CAG's review**

The specialist paediatric endocrinology centres provide specialised services which should be prescribed but the current definition could encompass far more than this activity if it is not restricted to defined providers. Unfortunately, this would leave the problem of separating the routine service provided to local residents from the specialised service. The precise activity defined as specialised in the definition with respect to diabetes is unclear when an attempt is made to separately commission the service.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Endocrinology and Diabetes Services for children and young people

### **Suggested Description**

Specialist Endocrinology and Diabetes Services for children and young people will include

care for complex endocrine conditions provided by Paediatric Endocrine Centres

care for complex conditions related to diabetes provided by Paediatric Diabetes Centres

The service will include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.7 Specialised Paediatric Gastroenterology, Hepatology and Nutritional Support Services**

#### **Services covered**

Paediatric specialised gastroenterology, hepatology and nutritional support services 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 will share clinical management with the local hospital but some patients will require the intensive involvement of the specialist centre, particularly during periods of illness or for diagnostic evaluation including endoscopy, gastrointestinal manometry or liver biopsy.

The more complex and serious paediatric liver diseases and liver/small bowel transplantation services are restricted to the three nationally designated and funded centres.

#### Specialised gastroenterology services

These include services for the investigation and/or management of:

- protracted diarrhoea of infancy more than three weeks duration
- intestinal failure
- gastrointestinal inflammatory disorders including inflammatory bowel disease
- gastrointestinal motility disorders
- gastrointestinal bleeding
- multiple food intolerances (actual and perceived)
- gastrointestinal polyps and polyposis syndromes
- faltering growth and disorders associated with malabsorption (e.g., coeliac disease)
- pancreatic disorders including pancreatitis
- chronic, intractable constipation and soiling
- severe gastrointestinal functional disorders

#### Specialised nutrition services

These include services for the investigation and/or management of:

- special nutritional needs associated with acute and chronic illness
- parenteral nutrition for children with intestinal failure, including provision of home parenteral nutrition (HPN).

#### Specialised hepatology services

These include services for the investigation and/or management of:

- neonatal hepatitis
- chronic liver disease (including portal hypertension)
- autoimmune hepatitis
- hepatitis (viral) B and C

- acute liver failure
- metabolic conditions with hepatic involvement
- biliary atresia
- benign and malignant tumours of the liver and biliary tree
- congenital vascular anomalies such as porto-caval shunts
- liver and/or small bowel transplantation - AGNSS
- liver disease associated with intestinal failure and parenteral nutrition

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. Thought was required on transitional care for children moving to the adult service.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

In-patient admissions for the listed specialised causes will be easily identified. However, out-patient activity, especially shared care and out-reach, will be difficult to separately capture. Thought needs to be given to how best to identify this activity- and what elements of this should be prescribed.

### **CAG's review**

The three national liver units provide highly specialised care for a large population. This work clearly meets the four factors. However, much of the work undertaken by the 20 or so regional centres may relate to local secondary care as well as complex care for a broader population. The definition needs to be clear on where the cut off should lie to enable CCGs to commission local services which can support these centres.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Gastroenterology, Hepatology and Nutritional Support  
Services for children and young people

## **Suggested Description**

Specialist Gastroenterology, Hepatology and Nutritional Support (GHNS) Services for children and young people will include

- care for complex conditions provided by Paediatric Specialist GHNS Centres

- care for more common conditions requiring support from Paediatric Specialist GHNS Centres

These should include in-patient, day case and out-patient services including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.8 Paediatric Gynaecology Services**

#### **Services covered**

The clinical activity divides into those abnormalities concerned with childhood, which are primarily disorders of sex development, and disorders of puberty which relate to primary amenorrhoea.

Conditions presenting at birth include:

- ambiguous genitalia (e.g. congenital adrenal hyperplasia, partial androgen insensitivity syndrome, 5 alpha reductase deficiency)
- those associated with other major congenital anomalies (e.g. complex cloacal anomalies).

Conditions presenting during adolescence include:

- virilisation (i.e. secondary male sexual characteristics are acquired by a female)
- primary amenorrhoea (e.g. Mayer Rokitansky Kuster Hauser - MRKH - syndrome and androgen insensitivity).
- obstructive outflow tract disorders.

Clinical input in the newborn and in early childhood is predominantly provided by paediatric endocrinology and paediatric urology services. Gynaecological input becomes necessary prior to puberty and throughout adolescence. The aim of gynaecological input for these children is to ensure and preserve optimum potential for menstruation and future sexual relationships and, in some cases, fertility. Vaginoplasty may be required at puberty or beyond to prevent obstruction to menstrual flow. In other conditions treatment for vaginal agenesis can be deferred until late adolescence prior to sexual activity. Gonadectomy may be required and should be laparoscopic if appropriate.

There are around 23 paediatric gynaecology providers. Reconstructive surgery service for adolescents with congenital malformation of the female genital tract has been nationally commissioned since April 1998- AGNSS.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. The definition does not currently include management of genital trauma.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

The surgery elements of this definition are easily identified and were thought to be highly specialised. In fact 106 providers report activity in relation to this list of procedures- although with very small numbers of cases- only 8 trusts performed more than 9 procedures in 2010-11. The out-patients activity at the specialist centres could be included if separate clinics are identified.

**CAG's review**

If significant centralisation of these procedures is appropriate, separate commissioning from these defined centres would be possible. However, the current definition suggests all such activity, wherever provided should be included. Further consideration is needed to allow for separate and direct commissioning of this service. Thought should be given at the same time to including management of conditions with traumatic origin as well as congenital.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Specialist Gynaecology Services for Children and Young People

**Suggested Description**

Specialist Gynaecology Services for Children and Young People will include all activity provided by Highly Specialised Paediatric Gynaecology Centres including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.9 Specialised Paediatric Haematology Services (excluding malignant haematology, bleeding disorders and haemoglobinopathies)**

#### **Services covered**

Malignant Haematology is included in 23.2

Bleeding disorders is included in Definition 3

Haemoglobinopathies are included in Definition38

There are 41 paediatric haematologists based in 17 centres in England (2009). Clinical care of the children after diagnosis may be delivered by the paediatric haematologist in the specialist paediatric haematology centre itself or on an outreach basis at the local hospital. Alternatively care may be delivered by the paediatrician at the local hospital with advice and support from the paediatric haematologist at the specialist centre.

The general paediatrician at the local hospital will care for children with stable or self limiting haematological disorders. These services would generally not be regarded as specialised.

Paediatric haematological disorders may be primary or may be secondary to other disorders, in the latter case the paediatric haematologist at the specialist paediatric haematology centre plays a crucial role in diagnosis and thereafter acts as adviser to the treating clinician.

This definition refers only to children with haematological disease but there is increasing recognition of the specific needs of older teenagers and young adults particularly with regard to transition to adult services in those with life-long conditions.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

Where shared care is arranged between the local paediatrician and the specialist paediatric haematologist at a centre, this activity will be difficult to identify. Such care will be delivered in general local paediatric settings. Conversely, in centres where there are paediatric haematologists, even basic care may be provided for local residents within the specialist clinic. In-patient activity at a centre is easily identified- but this may include some local 'routine' admissions.

#### **CAG's review**

Local provision and shared care for many children with blood disorders should be encouraged. The definition needs to clearly set out which conditions

should only be managed by a specialist centre- which in turn will leave care for other conditions to be commissioned by CCGs.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Haematology Services for children and young people

### **Suggested Description**

Specialist Haematology Services for children and young people will include services provided by Specialist Paediatric Haematology Centres including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.10 Specialised Paediatric Intensive Care Services**

#### **Services covered**

Paediatric intensive care services are defined in “Paediatric Intensive Care, A Framework for the Future, a report from the National Coordinating Group on Paediatric Intensive Care to the Chief Executive of the NHS Executive”, January 1997.

There are four levels of paediatric intensive care (PIC):

1. high dependency care,
2. intensive care (simple),
3. intensive care (complex) and
4. intensive care (extra-corporal membrane oxygenation and extracorporeal life support).

Not all units offer all four levels of care. ECMO is nationally commissioned-AGNSS.

Level 1 (high dependency) care is usually part of the clinical escalation to intensive care and de-escalation from ventilatory support. A high dependency service may be considered a specialised service if it occurs as part of an intensive care unit service (i.e. a unit providing Levels 2-4 care) or is provided by a stand-alone HDU unit specifically recognised by commissioners (currently there are very few of these).

PIC Levels 2, 3, and 4 of care are always specialised services. There are a few hospitals that undertake neonatal surgery, neurosurgery or burns care that provide specialised HDU or PIC services.

Some PIC units act as Lead Centres with a fuller range of PIC services and capabilities whereas other units offer more limited levels of care in consultation with a Lead Centre. Local agreements may require patients to be retrieved to the Lead Centre if the expected length of intubation is more than 24 hours.

Specialised services for PIC also include retrieval services for critically ill children and paediatric burns cases.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

There are now around 33 PICUs (including level 2 services or above) in the UK. All elements of the service can be easily identified with most of this activity already within regional specialised commissioning.

**CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS****Suggested text for regulation**

Specialist Paediatric Intensive Care Services

**Suggested Description**

Specialist Paediatric Intensive Care Services will include all activity undertaken by Paediatric Intensive Care Units and associated retrieval services.

## 23 Specialised Services for Children

### 23.11 Specialised Paediatric Mental Health (Tier 4 CAMHS and Forensic) Services

See 22.10

## **23 Specialised Services for Children**

### **23.12 Specialised Neonatal Care Services**

#### **Services covered**

Neonatal services provide care for all babies who are generally (but not exclusively) less than 44 weeks post conceptual age (less than 28 days old, adjusted for prematurity). Neonatal care services are provided in a variety of settings dependent upon the interventions required and the stability of the baby.

The nationally accepted levels of care over and above "normal" are:

- Special Care (formerly known as Level 3 care)
- High Dependency Care (formerly known as Level 2 care)
- Intensive Care (formerly known as Level 1 care).

There are three types of unit:

- Special Care Units
- Local Neonatal Units
- Neonatal Intensive Care Units.

These units work closely together in 23 Managed Neonatal Networks.

The National Neonatal Taskforce (2009) 'Toolkit for Quality Neonatal Services' advises that optimal outcomes and quality of care for sick newborn babies and their families are most likely to be achieved if all neonatal care services (intensive care, high dependency care, special care, transfer and neonatal surgery) are commissioned together across the managed network as part of co-ordinated commissioning of maternity and neonatal services.

#### **Special Care Units (SCU)**

These units provide SC services for their own local population. They also provide, by agreement with their Managed Neonatal Network, some HDC services. In addition SCUs provide a stabilisation facility for a baby requiring transfer to a Neonatal Intensive Care Unit for IC or HDC and receive transfers from their other Network units for continuing SC. There are 43 SCUs in England (2009).

#### **Local Neonatal Units (LNU)**

These units provide SC and HDC services and transfer babies who require complex or longerterm intensive care to a Neonatal Intensive Care Unit. LNU's are not staffed to provide longerterm IC. The majority of babies over 27 weeks of gestation will usually receive their full care, including short periods of IC, within their LNU. Some Managed Neonatal Networks have agreed that their LNU will only manage babies requiring short periods of IC who are above a specific gestational age. LNU's provide SC and HDC services for their own catchment population. Some LNU's provide HDC and short periods of IC for their Network population. LNU's may receive transfers for care from other neonatal services in the network if the transfer is within their agreed work pattern. There are 86 LNU's in England (2009).

### Neonatal Intensive Care Unit (NICU)

These units are sited within Perinatal Centres and provide the whole range of medical neonatal care for their local population and additional care for babies and their families referred from the Managed Neonatal Network. Some Network NICUs in England additionally provide neonatal surgery services and other more specialised treatments. There are 51 NICUs in England, of these 19 units additionally provide neonatal surgery services and other specialised treatment (2009).

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. There was some concern about co-ordination of commissioning of high risk maternity, transport and neonatal critical care.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

All elements of the service can be easily identified with most of this activity already within regional specialised commissioning. The exception is standalone Special Care Units which are not consistently commissioned in this way. However, identifying this additional activity will not be difficult.

### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription. In view of the concerns regarding links with maternity services, this should be reviewed in 2-3 years.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

Subject to review in 2-3 years.

### **Suggested text for regulation**

Specialist Neonatal Care Services

### **Suggested Description**

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 will include transitional care and any associated out-patient services. For early review.

## **23 Specialised Services for Children**

### **23.13 Specialised Paediatric Neurosciences Services**

#### **Services covered**

Centres providing specialised paediatric neurosciences service (neurosurgery, neurology, neuroradiology, complex disability and rehabilitation, neuropsychiatry and neuropsychology services) adopt an integrated approach to the diagnosis and management of a large number of neurological diseases, many of which are individually uncommon or rare.

Most specialist paediatric neurosciences centres provision is a mixture of centrally-based (inpatient and out-patient) services and outreach (mainly out-patient) services to local hospitals where the centre staff work in partnership with the local paediatricians. This arrangement is then under-pinned by frequent phone consultation between specialist centres and local hospitals in and out of hours.

All paediatric neurosurgery, neuropsychiatry and neuropsychology services are specialised services.

Complex paediatric neuroradiology (e.g. detailed MRI for subtle malformations, evaluation of whether a tumour has remained stable, angiography, spectroscopy) is a specialised service. Other neuroradiology services such as MRI and CT brain and cord scanning is carried out by local hospitals and is not specialised although advice is frequently sought on appropriate imaging techniques and interpretation from the paediatric neurologists/neuroradiologists at the specialist paediatric neurosciences centre.

All paediatric neurology services delivered by paediatric neurologists are a specialised service, whether delivered at the specialist neurosciences centre itself or on an outreach basis at local hospitals.

A significant amount of the care of children with neurological problems is given at local hospital level both by paediatricians and by paediatric neurologists from the specialist neurosciences centre.

Paediatric epilepsy is the commonest neurological disorder, affecting about 0.7% of all children, and requires the provision of a network of care from primary care, local hospitals and the specialist centre. Specialist neurosciences centres provide diagnostic services, management advice and specialist treatment for intractable and complex epilepsy including epilepsy with regression and behaviour disorder.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. The provision of local services vary between all care being provided by the specialist centre specialists (usually

the case for the local residents) to all local care being delivered by a paediatrician with any specialist input requiring a referral to the main centre.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

If prescription is restricted to care provided by the specialist centre, this should be straightforward to commission separately. The issue with out-reach and shared care is that coding is poor in out-patients and would not allow for identification of the complexity of the care given.

### **CAG's review**

Local provision and shared care for children with neurological conditions is essential- especially for those with life long conditions. The definition needs to clearly set out which conditions should only be managed by a specialist centre- which in turn will leave care for other conditions to be commissioned by CCGs.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. It should be noted that Paediatric Neuropsychiatry is included elsewhere (22.9, Page 115) as is Specialised Rehabilitation for patients with Highly Complex needs (7, Page 49).

### **Suggested text for regulation**

Specialist Neuroscience Services for children and young people

### **Suggested Description**

Specialist Neuroscience Services for children and young people will include services provided by Specialist Paediatric Neurosciences centres including:

- Neurosurgery (including Paediatric Neuro Critical care)
- Neurology
- Neurophysiology
- Neuroradiology

- Neuropsychology and Neuropsychiatry
- Neurodisability and Neurorehabilitation

The service will include in-patient, day case and out-patient services including out-reach when delivered as part of provider networks.

## **23 Specialised Services for Children**

### **23.14 Specialised Paediatric Ophthalmology Services**

#### **Services covered**

Paediatric specialised ophthalmology services encompass the investigation and management of visual, ocular and ocular adnexal disorders in children and young people. Specialised ophthalmology services for children are provided by both paediatric and adult ophthalmologists.

Approximately 90% 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.

#### **Orbital disorders**

Orbital disorders are rare in children, and most significant paediatric orbital disorders are referred for specialist evaluation, either to a predominantly adult orbital service or to a specialist paediatric ophthalmology centre.

#### **Cataract and lens disorders**

Treatment for cataract and lens disorders where the condition requires surgical treatment within the first few weeks of life is a specialised service not least because of the anaesthetic requirements for these infants.

However not all congenital cataracts require surgery. Treatment for cataracts in older children (5-7 years+) can usually be managed using techniques common to adult cataract surgery and thus would not be regarded as a specialised service.

#### **Retinal detachment**

Retinal detachment is rare in children, sight threatening and more difficult to treat than in adults. Treatment should be regarded as a specialised service.

#### **Glaucoma**

Infantile and congenital glaucoma in children is rare; glaucoma caused by developmental abnormalities of ocular structure is the commonest cause. Treatment of glaucoma in children is a specialised service.

#### **Orbital and Oculoplastic Surgery**

In children, all orbital surgery (apart from minor surgery and enucleation) is a specialised service. Surgery on children may often be undertaken by an (adult) orbital surgeon (i.e. an adult ophthalmic surgeon sub-specialising in orbital surgery) rather than a paediatric ophthalmic surgeon.

Oculoplastic surgery, corneal surgery, glaucoma surgery, vitreoretinal surgery and lacrimal surgery on children is also a specialised service and may also be undertaken by an (adult) ophthalmic surgeon rather than a paediatric ophthalmic surgeon.

However probing/syringing of the nasolacrimal duct in children over 12 months, which is normally only carried out by paediatric ophthalmologists, is not a specialised service.

Services for children with retinoblastoma have been nationally commissioned by the since April 1990. There are 2 nationally designated centres.

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

The codes included in the definition identify 133 providers of this service. However, just 7 providers perform a total of more than 50 of the included procedures. Many of the codes do not differentiate between routine and complex care. The problem is mirrored in out-patients where clinics include a mix of routine and specialised patients. This is further complicated by the fact that much of these services are provided by adult ophthalmologists.

### **CAG's review**

Further work is needed to identify which procedures should only be performed in specialised centres- to enable separate and direct commissioning of the specialised elements of these pathways.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

### **Suggested text for regulation**

Specialist Ophthalmology Services for Children and Young People

### **Suggested Description**

Specialist Ophthalmology Services for Children and Young People will include services provided by Specialist Paediatric Ophthalmology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.

## **23 Specialised Services for Children**

### **23.15 Specialised Paediatric Oral and Maxillofacial Surgery Services**

#### **Services covered**

Oral and Maxillofacial Surgery is a major provider of paediatric services for children requiring surgery involving the mouth, face, head and neck. The majority of emergency and elective procedures are undertaken in otherwise healthy children in District General Hospitals.

Complex maxillofacial paediatric surgery is undertaken in specialist centres following referral from outlying units. This includes surgery for cleft lip and palate, craniofacial surgery, craniofacial trauma, paediatric head and neck oncology (including skull base surgery and management of complex vascular malformations). Children with significant co-morbidity requiring otherwise routine surgery may require referral to specialist centres where appropriate specialist paediatric services are available.

#### Cleft lip and palate

Covered in Definition No.15

#### Craniofacial surgery service for congenital conditions

This service has been nationally commissioned since April 1988- AGNSS. There are four nationally designated centres.

#### Craniofacial trauma

Paediatric patients with craniofacial injuries requiring neurosurgical input are managed in a regional neurosurgical unit and require multidisciplinary care from neurosurgeons and maxillofacial surgeons.

#### Paediatric head and neck malignancies

Malignant tumours of the head and neck in children are rare and present challenges not always encountered in the adult population. These include:

- mucosal head and neck cancer
- salivary gland malignancy
- midface and skull base malignancy
- free flap microvascular reconstruction
- cranio-orbital and mid-facial prosthetic rehabilitation.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

This activity is often identified to neurosurgery due to the nature of the condition. If craniofacial trauma is restricted to shared care with neurosurgery this reduces the number of providers considerably. Head and neck cancers

are considered specialised in adults and highly specialised in children. Even so the current list of codes for this definition are provided at 159 providers with more than fifty showing an activity of greater than 100 included procedures.

### **CAG's review**

CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning. This especially related to activity separate from neurosurgery centres.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. However, it was noted that all of the procedures would be prescribed under other proposed regulations- notably for Cleft lip and palate services, within Neurosurgery for cranial trauma, Paediatric cancers and in existing national services. It was agreed that no separate regulation would be recommended.

## 23 Specialised Services for Children

### 23.16 Specialised Paediatric Orthopaedic Surgery Services

#### Services covered

Paediatric orthopaedic services are increasingly provided on a hub and spoke basis so that as much treatment as is appropriate is provided in local hospitals close to the child's home but there is speedy access to specialist paediatric orthopaedic centres where the required service is specialised.

The specialised elements are defined by diagnosis or intervention.

The Primary malignant bone tumours service has been nationally commissioned since April 2005. There are seven nationally designated centres.

#### Specialised diagnoses

- Cerebral palsy

Many children with cerebral palsy (CP) will require specialist paediatric orthopaedic assessment and treatment. The major specialised surgical interventions for CP are: hip reconstruction, multilevel gait surgery and spinal surgery.

- Perthes' disease

This is a potent cause of hip deformity. In childhood treatment is directed towards maintaining the sphericity of the femoral head, and may involve femoral and/or pelvic osteotomies; these services are specialised services.

- Congenital dislocation/subluxation of the hip

Treatment for this condition constitutes a major workload in specialist paediatric orthopaedic centres and requires co-ordination with local neonatal and local paediatric services in order to identify cases as early as possible. In the early stages of treatment simple care such as splintage is provided in a local hospital care setting; if it is unsuccessful then surgical intervention at the specialist paediatric orthopaedic centre is required. All surgery for this condition is a specialised service.

- Congenital foot deformity

Whilst metatarsus varus and talipes calcaneovalgus self-limiting conditions requiring no intervention at all or treatment at a local hospital; congenital talipes equinovarus involves a considerable workload for specialist paediatric orthopaedic centres. Current treatment of this condition involves serial plastering which may take place at a local hospital under the supervision of a specialist paediatric orthopaedic surgeon, followed by operative interventions if necessary. All surgery for this condition is a specialised service. Treatment for fixed flat foot deformities is a specialised service.

- Congenital chest deformity

Congenital deformity of the sternocleidomastoid muscle is a specialist condition requiring physiotherapy in the first instance. Surgical intervention

may be performed by paediatric orthopaedic or paediatric general surgeons; always at a specialist paediatric centre. Deformities of the chest not involving the spine are generally treated by thoracic surgeons in specialist paediatric thoracic surgery centres.

#### Surgical interventions

Children undergoing major orthopaedic surgery, particularly spinal surgery and limb reconstruction, are likely to have postoperative pain which requires specialist pain management techniques e.g. epidural and regional nerve block infusions.

Surgical interventions include (those referred to above have been removed):

- treatment of congenital limb anomalies
- focal limb enlargement
- surgical management of metabolic bone disease
- fractures through pathological bone
- bone tumours (benign and malignant)
- management of limb discrepancy
- club foot surgery especially revisions
- surgery of juvenile rheumatoid arthritis
- surgery of osteogenesis imperfecta
- obstetric brachial plexus injuries
- sequelae growth plate injuries
- surgery for development dysplasia of the hip
- complex fracture and fracture complication
- complex cases of slipped upper Femoral epiphysis
- infections of the growth plate
- sequelae of bone and joint infections
- major trauma in children with multiple injuries
- rare conditions in children with syndromes
- adolescent hip dysplasia
- refractory bone and joint infections
- congenital hand deformities
- surgery for neuromuscular disorders (spina bifida and muscular dystrophy)
- amputation prosthetics
- some shoulder injuries
- skeletal dysplasia
- scoliosis surgery cervical spine disorders and torticollis

In addition:

#### Fracture treatment

Surgery is mainly undertaken at local hospitals by general orthopaedic surgeons or by specialist paediatric orthopaedic surgeons. All revision procedures on children's fractures are specialised services. Difficult primary procedures (due to the complexity of the fracture) are also specialised services.

#### Arthrography

This is an important treatment for children's hip conditions such as congenital dysplasia of the hip (CDH) and Perthes' disease and is considered a

specialised service as it is generally a planning operation for subsequent complex surgery.

#### Fixation of slipped upper femoral epiphysis

Slipped epiphysis is a hip condition associated with adolescence; incidence is approximately 2 per hundred thousand of the population. *Mild and moderate* forms are treated by stabilisation of the epiphysis with a single screw and this operation is performed successfully on adolescents at many local hospitals and as such is not a specialised orthopaedic surgery service. However, where the *severe* form occurs referral to a specialist paediatric orthopaedic centre for specialised orthopaedic surgery will always be required.

#### Bone grafting

All bone grafting is a specialised service for children.

#### Hand surgery

Peripheral nerve surgery is a specialised service and may be performed in specialist hand units.

#### Infusion of bisphosphonates

This is involved in the treatment of osteogenesis imperfecta and fibrous dysplasia; it is a specialised service normally undertaken under the care of paediatric endocrinologists.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

Although this definition appears to identify specialised activity in great detail, the coding is not capable of differentiating between primary and repeat activity, nor routine and complex. There are 162 providers with activity included in this definition- 51 performing more than 50 cases per year and 23 performing more than 100.

#### **CAG's review**

CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning.

The definition states:

“There are significant problems with the current ICD and OPCS codes for children's orthopaedics. Many codes inadequately describe conditions and operative interventions. Fixation of slipped upper femoral epiphysis is a case in point: OPCS codes currently do not adequately distinguish between interventions for mild/moderate cases and interventions for severe cases.”

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Specialist Orthopaedic Surgery Services for Children and Young People

**Suggested Description**

Specialist Orthopaedic Surgery Services for Children and Young People will include services provided by Specialist Paediatric Orthopaedic Centres including out-reach when delivered as part of a provider network. The service will include:

- Surgical management of rare conditions

- Provision of specified procedures

- Surgical management of more common conditions when the child or the procedure is high risk

## 23 Specialised Services for Children

### 23.17 Specialised Paediatric Plastic Surgery Services

#### Services covered

Paediatric plastic and reconstructive surgery is involved in a large number of conditions and ranges from the management of congenital deformities and abnormalities to complex problems relating to trauma and malignancies.

Congenital malformations

- Cleft lip and palate

Covered in Definition No.15

- Congenital malformation of the eye including: ptosis, ectropion, entropion, anophthalmos.
- Congenital malformations of the ear including: absence of ear, absence/atresia/stricture of auditory canal, macrotia, microtia, misshapen ear, misplaced ear.
- Congenital malformations of the sinus, tongue, mouth, pharynx including: Sinus/fistula/cyst of branchial cleft, preauricular sinus and cyst macrostomia, microstomia, macroglossia.
- Congenital malformations of the nose
- Congenital malformations of the skin and face bones including: craniosynostosis, craniofacial dysostosis including crouzons, hypertelorism, mandibulofacial dysostosis, oculomandibular dysostosis.
- Congenital malformation syndromes predominately affecting facial appearance including: acrocephhalosyndactyly, Goldenhar syndrome, Moebius syndrome, orofacial digital syndrome, Robin syndrome, Treacher-Collins syndrome.
- Congenital musculoskeletal deformities of the head, face, spine and chest including: facial asymmetry, compression facies, dolichocephaly, plagiocephaly, hemifacial atrophy, pectus excavatum, pectus carinatum.
- Congenital musculoskeletal deformities of the upper and lower limbs includes hand and toe including: polydactyly, syndactyly, reduction defects of upper limb, shoulder girdle, cleidocranial dysostosis, macrodactylia, radioulnar synostosis, triphalangeal thumb.
- Congenital malformations of female /male genital organs and indeterminate sex and pseudohermaphroditism including: congenital absence of vagina and vulva, fusion of labia hypospadias, congenital absence of penis. (See also 23.8)

- Congenital malformations of urinary system including: epispadias, extrosophy of the bladder.

#### Trauma

Plastic surgery for paediatric trauma covers a vast number of differing ICD-10 codes. The main ones are outlined below.

- Head and neck trauma
- Nerve injury at shoulder and upper arm (excluding brachial plexus)
- Hand and arm trauma
- Burn injury

#### Birth injury to peripheral nervous system

These include: Erb's injury, Klumpke's paralysis, other brachial plexus injury.

#### Skin lesions and conditions

- Skin malignancy
- Sarcoma

#### Craniofacial surgery service for congenital conditions

This service has been nationally commissioned since April 1988. There are four nationally designated centres.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

This is a very broad definition with in-patient activity identified as specialised taking place in 158 providers. There are 21 providers with more than 100 procedures per year.

#### **CAG's review**

CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning.

#### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Specialist Plastic Surgery Services for Children and Young People

**Suggested Description**

Specialist Plastic Surgery Services for Children and Young People will include services provided by Specialist Paediatric Plastic Surgery Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.

## **23 Specialised Services for Children**

### **23.18 Specialised Paediatric and Perinatal Post Mortem Services**

#### **Services covered**

The paediatric and perinatal pathology service comprises two main areas: the reporting of surgical biopsies taken from children and the post-mortem examination of fetuses, babies, neonates and unexpected paediatric deaths (e.g. cot deaths). This section covers post-mortem examination services only.

Although most cases of infant death are under the direction of the coroner, paediatricians will commonly have had an active involvement during attempted resuscitation and will subsequently follow-up the families. These cases will usually be 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.

At present examinations performed for HM Coroners are funded by the local authority. The payment varies and in some cases does not cover the full cost of the investigation, which is then borne by the hospital to which the pathologist is attached. Consented hospital post-mortem examinations on children dying in hospital are funded by the hospital concerned – these cases make up a tiny fraction of all paediatric post-mortems.

Funding for perinatal post-mortem examinations (i.e. those consented hospital post-mortems on fetuses, still births and neonatal deaths) differs across England. In some areas the cost is borne by the obstetric unit where the delivery occurs. In other areas, such as the West Midlands and London, the service is funded by the Specialised Commissioning Group on behalf of its PCTs.

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

This service can be separately commissioned.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

**Suggested text for regulation**

Paediatric and Perinatal Post Mortem Services

**Suggested Description**

Paediatric and Perinatal Post Mortem Services will include all Post Mortems performed by Highly Specialised Paediatric Post Mortem Centres including examination of fetuses, babies, neonates and children.

## 23 Specialised Services for Children

### 23.19 Specialised Paediatric Renal Services

#### Services covered

Specialised renal services provide care for a wide variety of conditions. Many children with uncomplicated general nephrological conditions - e.g. 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 renal centre.

Children requiring the more complex paediatric nephrology services are treated at the 10 specialist renal centres in England, 8 of which also carry out paediatric renal transplants.

Specialised renal services may be delivered in the following ways:

- care within a specialist paediatric renal unit (both in-patient and out-patient)
- expert advice from a paediatric nephrologist to other paediatric specialists within a referral centre - e.g. paediatric intensive care, oncology, endocrinology, cardiology
- outreach clinics held with 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 other multidisciplinary team members to other healthcare providers
- multi-disciplinary team visits to the patient's home and school to provide training and support to the child, family and other carers.

List 1 below lists the conditions which may require in-patient admission to a specialist renal centre (with subsequent care possibly including admission to a local hospital and out-patient follow-up at both) whereas List 2 lists the conditions that may be managed by a local hospital or by a local hospital under a shared care arrangement with the specialist renal centre.

#### List 1

- acute kidney injury including those requiring haemodialysis (HD) or peritoneal dialysis (PD)
- moderate and severe chronic kidney disease (i.e. chronic kidney disease categories 1 to 3)
- complicated nephrotic syndrome
- severe or chronic glomerular disease
- vasculitis(except mild Henoch-Schonlein purpura)
- tubulointerstitial disorders including renal tubular transport disorders that are primary or secondary to acquired or metabolic disease
- complex hypertension

- nephrolithiasis
- complex neuropathic bladder particularly those requiring other specialised services.

#### List 2

- uncomplicated urinary tract infection
- nocturnal enuresis
- daytime enuresis
- antenatal hydronephrosis
- chronic kidney disease (mild-moderate) not requiring dialysis
- acute renal failure not requiring dialysis (if mild and uncomplicated)
- uncomplicated nephrotic/nephritic syndrome
- haematuria
- proteinuria
- mild/moderate renal hypertension.

In addition, the following are a list of Interventions provided by a specialist renal centres and regarded as specialised:

- 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
- multi-disciplinary team visits

#### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

#### **View of TOG**

Procedures, including transplantation and dialysis are easily identified. Admissions to specialist centres can be identified but the severity of the diagnosis is not coded. This will therefore include 'routine' care at the centre for local residents and exclude complex care managed locally under advice from the centre. Out-patient paediatric nephrology can be identified but this is more difficult for out-reach.

#### **CAG's review**

The paediatric renal centres provide specialised services which should be prescribed. The current definition makes separate commissioning difficult unless a 'centres only' approach is adopted. Unfortunately, this may reduce

the incentive for centres to provide local out-reach: since in house clinics would be centrally funded whereas out-reach would need to be funded by CCGs. Further thought is needed on the appropriate cut off for this specialised service.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Renal Services for children and young people

### **Suggested Description**

Specialist Renal Services for children and young people will include services provided by Specialist Paediatric Renal Centres including out-reach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.20 Specialised Paediatric Respiratory Services**

#### **Services covered**

The majority of children's respiratory illnesses, being acute infections and mild asthma, are managed in local hospitals and primary care.

Specialised paediatric respiratory services encompass a range of services not provided at local hospitals because they require specialist expertise for most, or all, elements of care.

The following conditions are regarded as requiring specialised paediatric respiratory services:

- cystic fibrosis (see Definition No.10)
- severe chronic or life-threatening asthma (i.e. failure to respond to standard asthma therapy, or need for high dose inhaled corticosteroids, or need for period of ventilation for a severe exacerbation)
- chronic neonatal lung disease (bronchopulmonary dysplasia)
- congenital lung and airway disease (congenital cystic adenomatoid malformation, sequestration, congenital lobar emphysema, diaphragmatic hernia)
- rare lung disease e.g. chronic/obliterative bronchiolitis, other interstitial lung diseases, pulmonary haemosiderosis, pulmonary alveolar proteinosis
- children with recurrent lower respiratory tract infections (i.e. two or more chest radiograph confirmed pneumonias)
- empyema and parapneumonic effusions
- bronchiectasis
- chronic cough
- lung disease associated with primary and secondary immunodeficiency
- complicated pulmonary tuberculosis (in conjunction with infectious diseases specialist)
- restrictive and chronic lung disease associated with severe scoliosis and neuromuscular disease
- sleep disordered breathing (i.e. central apnoeas during sleep and obstructive sleep apnoea syndrome)
- congenital stridor (in conjunction with paediatric ENT specialist)
- home respiratory support i.e. non invasive ventilation and home oxygen
- nationally commissioned services including: complex tracheal disease; primary ciliary dyskinesia; pulmonary hypertension; heart lung/lung transplantation; ventricular assist devices; extra corporeal membrane oxygenation for respiratory failure- AGNSS.

Specialised investigations include:

- flexible bronchoscopy
- paediatric lung function testing including exercise testing and bronchodilator
- responsiveness (local hospitals will carry out standard peak flow measurement)

- sleep studies (full polysomnography and overnight O2 saturations/transcutaneous CO2)
- high resolution CT scanning
- 24-hour pH studies (this is also done at some local hospitals)
- nasal ciliary brushings
- exhaled and nasal nitric oxide

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

There are around 30 regional centres with out-reach and shared care. Much of this diagnosis related to out-patient activity where clinics will need to be identified as specialised to avoid inclusion of all activity within a centre. There is a converse risk of excluding specialised activity which takes place in local hospitals under advice from a centre.

### **CAG's review**

The paediatric respiratory centres provide specialised services which should be prescribed. However, exclusion of all activity not provided by the centre removes the incentive for centres to support out-reach and shared care. This also puts a risk on CCGs with local provision at a distance from the centre- with CCGs having to fund services which, if located closer to the centre, would be funded nationally.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Suggested text for regulation**

Specialist Respiratory Services for children and Young People

### **Suggested Description**

Specialist Respiratory Services for children and young people will include services provided by Specialist Paediatric Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service will include outreach when delivered as part of a provider network.

## **23 Specialised Services for Children**

### **23.21 Specialised Paediatric Rheumatology Services**

#### **Services covered**

Rheumatology services are concerned firstly, to establish the correct diagnosis and, secondly, to gain rapid control of disease activity; to preserve normal physical, social and emotional growth and development; to minimize chronic disability and deformity; and to achieve and maintain remission of disease. The diagnosis of rheumatological disorders can be difficult and delay in appropriate referral can affect outcomes, particularly for inflammatory arthritides and for inflammatory disorders in general.

Services are provided in a variety of ways for paediatric rheumatology around the country. All paediatric rheumatologists are trained paediatricians. Paediatric rheumatologists may be based in a specialist paediatric rheumatology centre or in a local hospital general paediatric service. If the service is not provided by a specialist paediatric rheumatology centre the service is likely to be part of a clinical network with the centre acting as the hub of the network.

There are around 12 specialist paediatric rheumatology centres in England; usually the centre has a minimum of 2 paediatric rheumatology posts. The specialist paediatric rheumatology centre takes referrals from local hospitals and also provides advice and support to local hospital paediatric and adult rheumatology services dealing with children thereby enabling children with less challenging rheumatic disease to be managed in a local hospital.

Many of the children seen by the specialist paediatric rheumatology centre will have challenging multi-systemic disease and when presenting with acute illness their management may be very complex, involving other paediatric specialities including intensive care.

In some instances, although therapies may be complex, ongoing management may successfully be devolved back to local hospitals.

Specific arrangements are required to manage the transfer of adolescents with chronic rheumatic disease from paediatric care to adult care; provision of transitional services is variable across the country.

Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders

Stem cell transplantation helps the very small number of patients who have very severe juvenile idiopathic arthritis (JIA) and related connective tissue disorders disease which is not responding to drug treatment. The stem cell transplantation service has been commissioned nationally since April 2000. There are two nationally designated centres.

Complex Ehlers Danlos service

Ehlers Danlos is a group of heritable disorders characterised by skin extensibility, joint hypermobility and tissue fragility. This service for patients with atypical and/or complex Ehlers Danlos syndrome has been commissioned nationally since April 2009. There are two nationally designated centres.

### **CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

Most of this work is delivered in an out-patient setting where coding is less well developed. The definition includes the following:

“The ICD-10 diagnostic and OPCS-4.5 interventions coding systems do not distinguish between complex cases of the more common rheumatological conditions being treated in specialist paediatric rheumatology centres and straight forward cases being treated in local hospitals e.g. longstanding inflammatory arthritis and chronic pain. It is therefore not possible to provide a list of clinical diagnoses/treatments which refer specifically to specialised paediatric rheumatology services, and further work is required on this subject.”

The network service model in place in parts of the country means that not all specialised activity takes place in a specialised centre. Shared care arrangements make this even more complicated.

### **CAG's review**

The paediatric rheumatology centres provide specialised services which should be prescribed. However, exclusion of all activity not provided by the centre removes the incentive for centres to support out-reach and shared care. This also puts a risk on CCGs with local provision at a distance from the centre- with CCGs having to fund services which, if located closer to the centre, would be funded nationally. Further thought needs to be given to the appropriate way to identify the specialised care in a service which is predominantly provided to out-patients.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of

this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

**Suggested text for regulation**

Specialist Rheumatology Services for children and young people

**Suggested Description**

Specialist Rheumatology Services for children and young people will include care provided by Specialist Paediatric Rheumatology Centres for complex conditions. The service will include out-reach when delivered as part of a provider network.

## 23 Specialised Services for Children

### 23.22 Specialised Paediatric Surgery Services

#### Services covered

Paediatric surgery is the only surgical specialty that is defined not by the nature of the disorder but by the age of the patient. There are clearly defined areas of paediatric surgery which can be classified as *specialised paediatric surgery* services and these form the bulk of the definition described below. *General paediatric surgery* is the surgical treatment of relatively common disorders that usually do not require the resources of a specialist surgery centre. This surgery may take place in a local hospital with appropriate resources or it may take place in a specialist paediatric surgery centre.

Specialised paediatric surgery services cover the following three areas:

1. neonatal surgery;
2. the management of infants and children with conditions requiring specialist surgical expertise
3. and the management of infants and children with relatively straightforward surgical conditions who have an associated disorder which requires management in a specialist centre

Currently there are 21 specialist paediatric surgery centres in England.

A specialised paediatric surgery service cannot operate without a specialised paediatric anaesthesia service on-site. Integral to this is provision of a comprehensive pain control service with facilities for epidural infusions in infants and children and patient/nurse controlled analgesia techniques.

#### 1. Neonatal surgery and follow-up

A neonate is defined as an infant less than 44 weeks post-conception. All neonatal surgery is considered a specialised service and is provided by paediatric surgeons in specialised paediatric surgery centres.

Some children with congenital malformations treated in the newborn period will require longterm follow-up throughout childhood, adolescence and adulthood (e.g. children with certain congenital anorectal malformations, Hirschsprung's disease). Follow-up care for adolescents is delivered by joint clinics run by the paediatric surgeon and the adult specialist concerned.

#### 2. Management of infants and children with complex medical conditions requiring specialist surgical expertise

Many children with complex medical problems develop surgical problems which are either related to the underlying condition or as a consequence of treatment. Surgical support will be necessary, to varying degrees, for all of the specialised paediatric medical services to operate safely. Successful surgical treatment invariably requires joint management in a centre where specialised paediatric medical and surgical services are available.

For many complex paediatric medical conditions follow-up is carried out in joint out-patient clinics run by the paediatric surgeon and the clinician providing the particular paediatric specialised service (e.g. children with inflammatory bowel disease or complex respiratory problems such as oesophageal atresia).

3. Management of infants and children with complex medical disorders requiring relatively straightforward surgery

Infants and children with relatively straightforward surgical conditions (eg inguinal hernia) who have an associated complex medical disorder which requires medical management in a specialist centre (e.g. congenital heart disease, metabolic disease, chronic renal failure) are treated by paediatric surgeons co-located in the specialist centre. Specialised anaesthetic services and the backup of a paediatric intensive care unit are necessary for the safe management of these children.

**CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

**View of TOG**

It is straightforward to include all paediatric surgery in specialised centres. However, these centres may also provide routine surgery for local residents. The definition contains codes which can be both specialised and non-specialised and coding does not allow for severity, complexity and co-morbidities to accurately identify the specialised surgery.

**CAG's review**

The specialised paediatric surgery centres provide specialised services which should be prescribed. Further thought needs to be given to the categories of surgery which are included in the specialised definition to enable separate and direct commissioning.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Suggested text for regulation**

Specialist Surgery for children and young people

**Suggested Description**

Specialist Surgery for children and young people will include services provided by Specialist Paediatric Surgery Centres including out-reach when delivered as part of a provider network. The service will include:

- 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 management)
- Provision of specified procedures

## **23 Specialised Services for Children**

### **23.23 Specialised Paediatric Urology Services**

#### **Services covered**

There are two facets to paediatric urology; non specialised services are provided in local hospitals mainly by adult urologists or general surgeons but also as an outreach service by paediatric surgeons or paediatric urologists.

There are 44 paediatric urologists providing specialised paediatric urology services in 22 centres in England. In addition a further 10 or more paediatric surgeons or “adult” urologists have a significant paediatric urological workload which will include some specialised surgery services (e.g. treatment for hypospadias and pyeloplasty). The majority of non-specialised urology surgery services for children (e.g. orchidopexy, circumcision, hernia repair) is provided by paediatric surgeons and general surgeons (adults) and urologists (adult).

Paediatric urology services include:

- prenatal counselling and postnatal management of urological anomalies detected by antenatal ultrasound investigation and management of urological conditions presenting postnatally
- investigation and management of urinary incontinence unresponsive to management in primary care and local hospital settings; or incontinence associated with urological or other (e.g. neurological) medical conditions
- provision of paediatric urodynamic services.

Specialised surgical interventions include the following:

- minimally invasive and robotic paediatric urology
- urological surgical support for specialist paediatric renal centres
- renal surgery
- bladder surgery including reconstruction
- surgery to the genitalia including hypospadias and surgery for disorders of sex development.

Bladder exstrophy service for children

This service has been nationally commissioned since April 2001. There are two nationally designated centres.

#### **CAG's initial view**

CAG, informed by the Children’s Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

There is considerable paediatric practice outside of the 22 specialised paediatric urology centres. Some of the codes included in the definition apply to activity taking place outside of the centres.

### **CAG's review**

The Specialised Paediatric Urology Centres provide specialised services which should be prescribed. It is not clear from the definition if all the activity described should only be commissioned from such centres- which would make separate commissioning more straightforward. However, this leaves the risk that routine non-specialised activity for patients locally resident to the centre would be included where the same activity taking place outside the centre would not. This needs to be tested with expert clinicians.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

### **Suggested text for regulation**

Specialist Urology Services for Children and Young People

### **Suggested Description**

Specialist Urology Services for Children and Young People will include services provided by Specialist Paediatric Urology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex or high risk procedures only.

## 24 Specialised Dermatology services (all ages)

### Services covered

Specialised dermatology services include the 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.

Many patients are diagnosed and assessed in the out-patient setting but more complex and / or severe cases are referred for further management to a specialised adult or paediatric dermatology service. Co-ordination of investigations and management is often required with other specialties. Combined clinics may be held with other specialties such as rheumatology or genetics. Some patients are managed as day cases e.g. intravenous methylprednisolone, skin surgery, phototherapy (ultraviolet B light (UVB) and psoralen plus ultraviolet A light (PUVA)). In-patient care is required for more severe dermatoses, complex skin cancers or complex vascular malformations. Telephone advice is given to carers, families and local hospital medical teams

(i) Severe inflammatory skin disease requiring non-conventional therapy  
This covers management of difficult cases of commoner diseases in children and in adults for which second or third line treatment or supportive care is not normally available in a local hospital.

(ii) Life threatening skin disease  
Specialised dermatology services for children and for adults treat a number of life threatening skin diseases including toxic epidermal necrolysis, toxic pustuloderma, staphylococcal scalded skin syndrome and other severe drug reactions.

(iii) Rarer skin cancers  
These are considered under definition 1

(iv) Genital dermatology  
Most paediatric and adult cases are managed in the local hospital but difficult cases and unusual disorders may require management by a specialist multidisciplinary team and liaison with child protection services where appropriate.

(v) Non-malignant lymphoedema  
Non-malignant lymphoedema may be dealt with by the hospice or the hospital service. There are a small number of specialist hospital units dealing with non-malignant lymphoedema including specialist dermatology centres.

(vi) Infectious diseases of the skin  
These are considered under definition 18

(vii) Hair and nail disease

Hair and nail problems requiring specialist diagnostic skills include genetic hair and nail disorders, hair and nail problems occurring in complex syndromes, and severe nail problems interfering with normal functioning and related to inflammatory skin disease.

(viii) Inherited skin disease

Many genetic dermatological disorders present in childhood requiring a multidisciplinary

approach to investigation and management including:

- ichthyosis
- xeroderma pigmentosum
- ectodermal dysplasias

(ix) Occupational dermatoses and contact dermatoses

Specialist dermatology centres provide diagnostic services for complex cases e.g. those involving outbreaks of allergic dermatitis in the workplace or wider community, multiple allergens, photo-allergy of unknown cause. It may involve factory or work place visits as well as specialist patch testing and specialist pharmacy services.

(x) Photo-investigation and specialised photo-dermatology

This includes the investigation and management of porphyrias and light induced skin disease e.g. chronic actinic dermatosis (adults only), photo allergy, light sensitive eczema, and actinic prurigo.

(xi) Specialised skin surgery

These are considered under definition 1

(xii) Laser treatment

Laser treatment is used for the removal of birthmarks, vascular and pigmented, and some iatrogenic lesions (e.g. minocycline and amiodarone pigmentation) and surgical/traumatic tattooing which produce psychological sensitivity problems for patients. This service is NOT a specialised dermatology service for adults but may be a specialised service for younger children requiring a general anaesthetic.

(xiii) Specialised dermatopathology

Some services are provided within the specialist dermatology centre although they may remain linked to pathology departments.

(xiv) Neonatal disorders

Specialised dermatology services for children include the treatment of severe neonatal dermatoses presenting in infants.

An estimated 10,000 cases fall into the range of specialised cases per year. This represents about 1% of the total new patient activity within dermatology.

A number of high cost treatments –both drug and emerging technologies- have arisen in dermatology. These are now widely available but annual costs of £9500 per year make these a high risk for CCGs.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that there seemed to be a case for certain elements of the dermatology service to be prescribed. The specialised elements would certainly meet the four factors. However, it was not clear that the specialised service could be separated from the secondary care service in many hospitals. Further, with so much of the care being provided in the out-patient setting, it was not obvious how such services could be differentiated from routine care in the same provider.

However, CAG were minded to recommend prescription in line with the most recent version of the definition.

### **View of TOG**

Without consistent use of diagnostic coding, it will be very challenging to commission based on the current definition. This would probably result in commissioning of these services from all District General Hospitals. An approach which defined specialist service providers may offer some help (reducing the number of providers to around 12) but these would undoubtedly be providing non-specialist care in the same clinics. An alternative would be to identify complex cases in a register and fund the care package- as with Cystic Fibrosis.

### **CAG's review**

CAG accepted that, the bulk of the current definition does not lend itself to separate and direct commissioning. There was felt to be a significant risk if this definition were used for prescription. Commissioners need a clearer description, produced in a way which supports separate contracting, if this service is to be prescribed.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Highly Specialist Dermatology Services

### **Suggested Description**

Highly Specialist Dermatology Services will include services provided by Highly Specialist Dermatology Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## 25 Specialised Pathology (all ages)

This service has been incorporated into other service definitions.

## 26 Specialised Rheumatology services (all ages)

### Services covered

Specialised rheumatology services are those which would normally not be provided in local hospitals. The services cover the needs of a small group of patients with rare conditions and those patients who require specialised investigation and / or management which are not available in local hospital settings.

For both adults and children the multi-disciplinary rheumatology team comprises the following personnel: consultant rheumatologist, specialist nurse, rehabilitation therapists, physiotherapist, occupational therapist, dentist / orthodontist, pharmacist, dietician, ophthalmologist, clinical psychologist / psychiatrist, podiatrist and orthotist (and, in the case of paediatric centres, hospital play specialist / teacher / social worker). (Note: in the case of children the consultant would either be a paediatric rheumatologist OR an adult rheumatologist working within a network linked to a specialist paediatric rheumatology centre.)

The rheumatology team works closely with other specialties (this may involve joint clinics) including:

- orthopaedics (including liaison with the skeletal dysplasia network and metabolic bone disease specialists)
- nephrology (including access to renal biopsy services)
- dermatology
- ophthalmology (for uveitis cases)
- cardiology (including assessment of pulmonary hypertension)
- respiratory medicine (including comprehensive lung function testing)
- psychology / psychiatry.

#### (i) Specialised paediatric rheumatology services

Services are provided in a variety of ways for paediatric rheumatology around the country. All paediatric rheumatologists are trained paediatricians. Paediatric rheumatologists may be based in a specialist paediatric rheumatology centre or in a local hospital general paediatric service. If the service is not provided by a specialist paediatric rheumatology centre the service is likely to be part of a clinical network with the centre acting as the hub of the network.

There are around 12 specialist paediatric rheumatology centres in England; usually with a minimum of 2 paediatric rheumatology posts. The specialist paediatric rheumatology centre takes referrals from local hospitals and also provides advice and support to local hospital paediatricians and adult rheumatologists dealing with children thereby enabling children with less challenging rheumatic disease to be managed in a local hospital.

(ii) Specialised adult rheumatology services

The vast majority of rheumatic conditions in adults are dealt with by adult rheumatologists in local hospitals; these services are not considered specialised rheumatology services.

There are no recognised adult specialist rheumatology centres as such. However, there are a handful of nationally (sometimes internationally) known experts for particular diseases (e.g. systemic lupus, ankylosing spondylitis, hypermobility) based in individual 'centres of excellence'. Adult rheumatologists in local hospitals may refer complex or rare adult rheumatological cases to these acknowledged experts for diagnosis and / or management.

**CAG's initial view**

CAG, informed by the Children's Sub-Group, agreed that there seemed to be a case for certain elements of the rheumatology service to be prescribed. The specialised elements would certainly meet the four factors.

However, there was a concern that the 'centres of excellence' model mentioned in the definition, could miss some highly specialised elements of the care pathway being provided elsewhere. Similarly, an approach which tried to capture all of the activity included in the definition would include most providers.

However, CAG were minded to recommend prescription in line with the most recent version of the definition.

**View of TOG**

The current definition is not sufficiently specific. Current coding does not allow for the identification of the specialised elements envisaged in this definition. As much of the activity is delivered in an out-patient setting, lack of diagnostic coding is again an issue. Regional services for rheumatology have not been commissioned by SCGs for the reasons outlined here.

**CAG's review**

CAG accepted that, the bulk of the current definition does not lend itself to separate and direct commissioning. Commissioners need a clearer description, produced in a way which supports separate contracting.

**CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

**Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of

this service could be secured. A full scope for such a service was presented which informed CAG's suggested description. The paediatric elements of this definition are dealt with elsewhere (Page 168).

### **Suggested text for regulation**

Adult Highly Specialist Rheumatology Services

### **Suggested Description**

Adult Highly Specialist Rheumatology Services will include services provided by Adult Highly Specialist Rheumatology Centres for patients with rare conditions or specified common conditions with complex needs. The service will include out-reach when delivered as part of a provider network.

## 27 Specialised Endocrinology services (adults)

### Services covered

Specialised endocrinology services are not available in every local hospital and are provided in specialist centres which take referrals from a number of local hospitals. In large conurbations, there may be more than one specialist endocrine centre and a developing network approach with individual Trusts taking the lead on particular sub-specialties. The distinction between specialised and non-specialised endocrinology services is not always clear. 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. Local networks will need to determine professional competency levels for the provision of some interventions.

Specialist endocrine centres provide services for the following conditions:

- pituitary disease
- thyroid and parathyroid associated disease
- adrenal disease
- management of neuro-endocrine tumours
- reproductive endocrinology
- metabolic bone disease
- complex hyperlipidaemia
- multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- surveillance of adult survivors of childhood malignancy and endocrine disease.

Almost all patients are assessed and treated on an out-patient basis for diagnosis, medical intervention and in some cases for genetic counselling. Joint clinics may be held, particularly with cancer and obstetric specialties. In-patient treatment comprises investigation for diagnosis of complex cases, surgery and perioperative care.

Surgery is undertaken by a variety of surgical specialties. Endocrine surgeons and ENT surgeons will operate on patients requiring surgery for thyroid and parathyroid condition; endocrine surgeons and urologists may also undertake adrenal operations; neurosurgeons and ENT surgeons undertake pituitary surgery; interventional radiologists undertake highly specialised diagnostic procedures such as petrosal sinus and adrenal vein sampling, and may embolise therapeutically liver metastases.

With the exception of the complex surgical management of these conditions, most are not high cost. However, the maintenance of a robust MDT for rarer and more complex conditions is high cost to providers

### **CAG's initial view**

CAG agreed that there seemed to be a case for certain elements of this definition to be prescribed. The specialised elements would certainly meet the four factors.

However, caveats included in the definition make clear that current coding methods do not allow for the separation of routine and complex care in this pathway. It is not clear what proportion of any of the listed diagnostic areas would require specialist input. It is likely that much of the care pathway would continue to be provided through general endocrine clinics.

However, CAG were minded to recommend prescription in line with the most recent version of the definition.

### **View of TOG**

There is a mismatch between the text of this definition and the associated coding document with some services mentioned in the text not included in the codes and vice versa. The coding is detailed but doesn't reflect the lack of diagnostic coding data for most out-patient activity. This would mean surgery and intervention will be picked up, but most of the care pathway would not.

### **CAG's review**

CAG accepted that the current definition does not lend itself to separate and direct commissioning. Further work is required to make sense of the definition so that it supports separate contracting.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

The service would include: Specialist  
thyroid conditions Specialist  
calcium/bone conditions Specialist  
reproductive conditions Pituitary and  
hypothalamic diseases Adrenal  
disease  
Management of neuro-endocrine tumours of gut and elsewhere  
Familial endocrine disorders

**Suggested text for regulation**

Adult Specialist Endocrinology Services

**Suggested Description**

Adult Specialist Endocrinology Services will include services provided by Adult Specialist Endocrinology Centres for specified conditions. The service will include out-reach when delivered as part of a provider network.

## **28 Hyperbaric Oxygen Treatment Services (adults)**

### **Services covered**

This service was included in v2 of the SSNDS but removed from v3.

Hyperbaric oxygen treatment (HBOT) involves delivery of 100% oxygen inside a treatment chamber at a pressure greater than sea level. There are both monoplace and multiplace chambers available across the UK.

HBOT is widely accepted as standard clinical care for:

- decompression illness
- gas gangrene
- air and gas embolism

There are few alternative treatments for these life-threatening conditions.

HBOT is a recognised treatment for: carbon monoxide poisoning; crush injury; enhancement of healing for wounds such as diabetic foot ulcers; exceptional blood loss (anaemia); intracranial abscess; necrotising soft tissue infections; refractory osteomyelitis; delayed radiation injury (e.g., radiation burns that develop after cancer therapy); skin grafts and flaps that are not healing well; and thermal burns.

However a recent review found limited evidence of clinical and cost effectiveness of HBOT with the exception of the emergency treatment of decompression illness

There were 442 NHS funded admissions for hyperbaric therapy (X52.1) included in HES data for 2009-10. Per treatment costs are relatively low (less than £200) but the cost of the infrastructure means expansion of indications to cover costs is a constant pressure.

### **CAG's initial view**

CAG agreed that this service (as set out in the definition included in v2 of the SSNDS) met the four factors. It was noted that individual cases for this service have increased since it was removed from the definition set. Consistent commissioning of this treatment would be a benefit to the NHS.

CAG were minded to recommend prescription of all services included in the most recent version of the definition.

### **View of TOG**

There are a limited number of providers of HBOT for indications where this is standard clinical care. It should be possible to contract with these with a tight national commissioning policy to make clear the list of indications which will be funded.

**CAG's review**

CAG agreed that the services within this definition would be suitable for prescription.

**CAG recommended to prescribe as per 2<sup>nd</sup> edition of SSNDS****Suggested text for regulation**

Hyperbaric Oxygen Treatment Services

**Suggested Description**

Hyperbaric Oxygen Treatment Services will include provision of this treatment in specified centres for specified conditions. This applies to provision in adults and children.

## 29 Specialised Respiratory Services (adults)

### Services covered

Most of the care and treatment relating to respiratory conditions is given in primary care and local hospitals. Specialised respiratory services encompass a range of services not provided at local hospitals because they require specialist expertise for most, or all, elements of care.

The following conditions and services are provided by specialist respiratory centres:

sleep related problems comprising a neurological component and sleep disordered breathing that fail to respond to simple therapy.

Specialised centres investigate those sleep disorders which may have both a respiratory and neurological component and carry out full polysomnography.

complex home ventilation, often for more than 12 hours, which may include tracheostomy or diaphragm-paced patients

This would be regarded as a specialised service if the patient has more complex needs or greater ventilator dependence, often requiring more than 12 hours home ventilation and/or tracheostomy/diaphragm pacing,. The specialised home ventilation service incorporates in-patient care and a specialist outreach service.

advanced pulmonary function testing

Most pulmonary function testing will take place at local hospitals but the following tests are carried out at specialist respiratory centres:

- respiratory muscle function testing
- specialist cardio-pulmonary exercise testing (CPET)
- oesophageal pH monitoring
- occupational-related bronchial provocation testing.

central airway obstruction

This service is linked to Definition No 1, Cancer Services. Management of central airway obstruction is a specialised service where it is carried out as part of another specialised service, e.g. thoracic surgery and oncology services, and will often involve the insertion of bronchial stents or laser treatment to unblock occluded airways.

specialist respiratory intensive care

The majority of respiratory intensive care takes place in local hospitals' critical care units. However, occasional problems relating to weaning from assisted to spontaneous ventilation, particularly where a neuromuscular disorder or central drive problem is involved, may necessitate patient transfer to a specialist respiratory intensive care unit. The level of service provided is equivalent to a single system failure intensive care unit patient. Conditions would include "Critical Illness Neuromuscular Abnormalities (CINMA)" which are typically associated with severe illness, multiple organ failure, exposure to steroids and prolonged stays in intensive care units. Depressed central drive may be due to encephalitis or neuro-surgical complications.

This section also includes ECMO which is nationally commissioned.

#### occupational lung disease

Although some aspects of occupational lung disease investigation such as serial peak flow readings both during and away from work, may be carried out at secondary care level the main diagnostic service is specialised. Specialised occupational lung disease investigations include bronchial provocation studies (i.e. the patient is exposed to the suspected sensitising agent under controlled conditions and assessed with spirometry) or measurement of specific antibodies. In addition specialised occupational lung disease diagnostic services undertake on-site work environmental assessments and liaise with the appropriate authorities.

#### pulmonary vascular services

Most of this section relates to definition 13(e) and some nationally commissioned services.

#### complex thoracic surgery

Much thoracic surgery is included within Definition No 1, Specialised Cancer Services. Many conditions can be treated with minimally invasive technique.

Complex thoracic surgical procedures for non-cancer indications include:

- lung resections for non-malignant reasons
- recurrent or non resolving pneumothorax
- empyema and related sepsis
- mediastinoscopy/mediastinotomy, treatment of mediastinal lesions
- open lung biopsy
- open pleural biopsy
- bullectomy and lung volume reduction surgery
- diagnostic thoracoscopy, +/- pleurodesis
- rigid bronchoscopy, airway surgery; and chest wall and diaphragmatic surgery, sympathectomy.

#### multi-drug resistant tuberculosis

This service is also included in Definition No 18, Specialised Service for Infectious Diseases. Multi-drug resistant TB is managed predominantly by respiratory physicians with a special interest in TB but it may also be managed by infectious disease physicians in the infectious disease service. The service will have strict isolation facilities, including negative pressure isolation rooms, to avoid any dissemination of airway secretions in this difficult to treat condition. The resources and drugs involved are expensive.

#### immune deficiency syndromes

This service is included in Definition No 16, Specialised Immunology Services. Investigation and treatment of immune deficiency syndromes with respiratory manifestations (e.g. agammaglobulinaemia) requires a joint approach by respiratory physicians and immunologists. Local general hospitals will

frequently manage these patients, often via a shared-care protocol with a specialist centre.

#### severe and difficult-to-control asthma

Specialist centres deal with the more difficult-to-control (Brittle) asthma and perform investigations such as prednisolone assays, food allergy/intolerance assessment (including dietary exclusion and double-blind food challenge), sputum induction, oesophageal pH monitoring, indirect laryngoscopy ENT assessment for vocal cord dysfunction and occupational asthma advice. The difficult-to-control asthma service is multi-disciplinary in nature, linking with ENT, dermatology, clinical allergy and immunology specialties.

#### interstitial lung disease

The diagnosis and management of ILDs is a specialised service. Idiopathic Pulmonary Fibrosis (IPF) one of the more common ILDs; with over 2000 new cases in England and Wales annually, needs a multidisciplinary approach with the integration of clinical, radiological and often histological data to achieve a confident diagnosis. IPF has no effective therapy and a poor prognosis; patients will need best supportive care (access to smoking cessation programmes, pulmonary rehabilitation and palliative care services) and some may also be suitable for a lung transplant.

#### alpha 1-antitrypsin deficiency

A1AD is a genetic disorder which causes emphysema and/or chronic obstructive pulmonary disease in middle age for most patients as well as various liver diseases in a minority of children and adults. It usually produces some degree of disability and reduced life expectancy. It is treated by intravenous infusions of the A1AT protein (i.e. anti-trypsin replacement therapy) and by liver or lung transplantation if appropriate. It is the leading cause of liver transplantation in newborns.

#### primary ciliary dyskinesia

People with PCD are born with a defect in the cilia (hair-like projections on the surface of cells lining the air passages of the respiratory tract that normally clear mucus by beating rapidly) which can result in repeated infections, bronchiectasis and permanent lung damage. Most PCD patients have symptoms from birth but diagnosis in the past has often been late. There are now three nationally designated centres providing a diagnostic service. Treatment for PCD is delivered at local hospitals.

#### chronic pulmonary aspergillosis

This service is nationally commissioned.

There were 9500 admissions for “Full polysomnography” (A84.7) and 3200 tests as out-patients in 2009-10 which the definition uses to identify sleep disorder studies (254 per million). The procedure codes listed in the definition under advanced pulmonary function testing and Occupational Lung Disease account for a total of just over 200 admissions and 2350 tests as out-patients. (51 per million) each year.

Most care is tariff based and procedure and treatment costs are moderate. However, the MDT and facilities required to provide a complex diagnostic service makes this an expensive service for providers.

### **CAG's initial view**

CAG agreed that there seemed to be a case for certain elements of this definition to be prescribed. The specialised elements would certainly meet the four factors.

However, the text of the definition made clear that current coding was unable to identify the specialised activity. There was considerable overlap with other definitions and nationally commissioned services, which meant that CCGs could be left unclear as to which respiratory services would remain locally commissioned.

However, CAG were minded to recommend prescription in line with the most recent version of the definition.

### **View of TOG**

There is a difficulty in that the current coding used for specialised care will also be used for non-specialised care. It may be possible to identify specialised respiratory centres and only commission from these but this would tighten the scope of the service considerably- not least in the elements which are delivered in an out-patient setting.

### **CAG's review**

Following discussion with DH policy leads, CAG accepted that there were significant issues with this definition which would make separate and direct commissioning very challenging and would leave significant risk of CCGs having to commission specialised services. Commissioners need a clearer description, produced in a way which supports separate contracting.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

This service includes:

- Complex home ventilation
- Severe and difficult to control asthma
- Interstitial lung disease
- Management of primary ciliary disease

**Suggested text for regulation**

Adult Highly Specialist Respiratory Services

**Suggested Description**

Adult Highly Specialist Respiratory Services will include services provided by Highly Specialist Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service will include outreach when delivered as part of a provider network.

**Suggested text for regulation**

Adult Thoracic Surgery Services

**Suggested Description**

Adult Thoracic Surgery Services will include services provided by Adult Thoracic Surgery Centres including out-reach when delivered as part of a provider network.

### **30 Specialised Vascular Services (adults)**

#### **Services covered**

This definition was amended between versions 2 and 3 of the SSNDS to remove certain more common procedures on the basis that they were provided in more than 50 centres in England.

The bulk of the elective arterial workload is the treatment of aortic aneurysms, peripheral vascular disease of the lower limbs and carotid intervention. Currently this activity is not regarded as specialised service activity because, although it is delivered by surgeons specialising in vascular surgery as opposed to general surgery, at the moment it occurs in more than 50 hospitals in England.

However over the next few years vascular disease surgery services are likely to be concentrated in fewer hospital sites which may eventually number less than 50. In support of this it should be noted that there is now good evidence that for aortic aneurysm surgery, outcomes improve as volume increases. A treatment threshold of 33 aortic aneurysms per annum- 100 over three years- would equate to around 50 hospitals covering the whole of England; currently there are well over 50 hospitals providing a service. The majority of members of the Vascular Society of Great Britain and Ireland specialise and only treat vascular disease.

CAG considered the broader definition of this service which results from combining both versions 2 and 3.

Services for vascular disease cover the provision of surgical, radiological and medical care to patients with circulatory (arterial and venous) disorders. There is a high volume of out-of hours emergency work.

Interventional radiologists provide services for vascular disease as well as for a wide range of other conditions and work closely with surgeons and physicians including renal physicians and oncologists. This definition is only concerned with interventional radiology services as they relate to vascular disease. The provision of a 24 hour interventional radiology service, for both vascular disease and other diseases, is a significant challenge and the development of appropriate networks and pathways to support safe care is an area of ongoing focus.

NOTE: Vascular specialists also provide care for patients with cancer and renal failure, trauma victims and those patients bleeding from any cause. This definition is only concerned with vascular disease.

Specialised vascular disease service activity may be defined in general terms, as disease-based activity or by the availability of technique-based activity.

The procedures may include:

#### Emergency Procedures

- treatment of ruptured or leaking aneurysms
- treatment of acute ischaemia
- treatment of vascular trauma including life threatening bleeding from any source
- treatment of iatrogenic vascular injury
- management of pulmonary emboli including IVC filter implantation
- surgery for critically ischaemic limbs

#### Elective Procedures

##### Vascular radiology

- angioplasty and thrombolysis
- stenting and stent grafting
- diagnostic angiography, magnetic resonance imaging (MRI), computer tomography (CT) and ultrasound
- embolisation
- transjugular intrahepatic portosystemic shunt (TIPS)

##### Surgical procedures

- repair of abdominal aortic aneurysms including suprarenal aneurysms.
- surgery for intermittent claudication and limb threatening ischaemia
- surgery for peripheral arterial aneurysms
- amputation
- sympathectomy
- carotid artery procedures
- treatment of thoracic outlet syndrome
- vascular reconstruction after cancer resection
- venous surgery (including complex varicose veins)
- medical and surgical care of lymphoedema

There are a number of reasons for considering all varicose vein procedures with vascular services in the commissioning process. These are set out below:

- There is a subgroup of recurrent and complex varicose veins that require specialised assessment and treatment.
- Referring clinicians may not be able to readily identify those requiring specialised assessment.
- Varicose veins are the most common cause of litigation within general and vascular surgery in the UK. Complications and recurrence rate have been shown to be high, often through avoidable causes.
- There is evidence of variability in practice .
- There is evidence that specialist assessment (e.g. the use of hand held Doppler and/or vascular laboratory investigations) improves accuracy of diagnosis.

- There is evidence of considerable variation in the commissioning of services for patients with varicose veins leading to geographical variation and lack of equity.
- Vascular services have a high proportion of urgent and emergency workload, and the inclusion of varicose vein surgery balances this with a volume of elective work.

There are certain services, which, due to the low volume of procedures carried out, need to be planned for and provided in fewer specialised units. They include:

- treatment of thoraco-abdominal aneurysms
- renal artery intervention and surgery
- mesenteric vessel intervention and surgery
- management of lymphatic disease.
- treatment of arterio-venous malformations
- paediatric vascular surgery (included in No. 23, Specialised Services for Children for commissioning purposes)

In 2008 there were 9 centres in England offering a 24 hour diagnostic and interventional radiology service; some of these 24 hour radiology services work on a network basis across several hospitals.

For most of the services listed as specialised vascular surgery there are fewer than 20 providers in England.

Whereas most procedures are moderate cost and within tariff, some stents used in EVAR and FEVAR procedures can be highly expensive. In addition, the provision of a comprehensive service including two parallel on-call rotas (one for surgery and one for VIR) is costly for providers.

### **CAG's initial view**

CAG noted that regional reviews of vascular services had been carried out across England since v3 was published. Concentration of expertise for specialised elements had increased. The distinction between specialised and non-specialised elements in v3 seemed artificial with most elements of this service now meeting the four factors.

However, CAG were minded to recommend prescription in line with the most recent version of the definition but with the reintroduction of procedures included in v2 subject to discussion with the Vascular Society.

### **View of TOG**

Separate commissioning of all elements (v2 plus v3) is considerably easier than the limited list in v3. It should be possible to identify activity at defined specialist centres. Out-reach to other locations, including out-patients clinics could be a challenge- there would be 136 providers in England at present. CCGs would need to commission non-specialised vascular activity which might include treatment of varicose veins.

**CAG's review**

Following discussion with the DH policy team and representation from the Vascular Society, CAG agreed that the comprehensive list of services encompassed in combination of v2 and v3 of this definition would be suitable for prescription. Treatment of varicose veins was considered for inclusion-based on the strong case made in v2- but was not felt to be a suitable addition as it did not meet the four factors.

**CAG recommended to prescribe as per 2<sup>nd</sup> and 3<sup>rd</sup> edition of SSNDS**

This excludes varicose veins but otherwise includes all vascular services.

**Suggested text for regulation**

Adult Specialist Vascular Services

**Suggested Description**

Adult Specialist Vascular Services will include all vascular surgery and vascular interventional radiology services excluding the treatment of varicose veins. The service will include out-reach when delivered as part of a provider network.

## 31 Specialised Pain Management Services (adults)

### Services covered

Specialised pain management services include:

specialised referral centre facility from other pain services advanced pain management techniques in adult palliative care assessment and management of patients with highly complex intractable non cancer pain; this often, although not always, includes:

- neuromodulatory techniques to the spinal cord
- neurodestructive techniques to the spinal cord (largely for cancer patients)
- intrathecal drug delivery systems
- intensive inter-disciplinary in-patient/residential behavioural and cognitive therapies.

In some parts of the country the specialist pain centre has the expertise to deliver only one particular treatment from the range included in specialised pain management services (e.g. cognitive behavioural therapy or spinal cord stimulation). For this reason specialised pain management services tend to be provided as part of a clinical network.

As with other specialised services there are difficulties with the current ICD-10 classification system because it does not identify severity or extent of disability and hence cannot distinguish between complex cases of pain treated by specialist pain management centres services and those treated by local hospitals.

Although the number of particular procedures is limited, they are often undertaken by neurosurgeons and anaesthetists using similar techniques for other interventions. There are not thought to be more than 50 providers for any particular technique.

There were a total of 1621 admissions and a further 440 out-patient procedures relating to neurostimulators in 2009-10 (32 per million). There were 1449 admissions and 43 OPs for spinal stimulators (29 per million). There were 17 admissions for chordotomy and 11 for radiofrequency spinal ablation.

### CAG's initial view

CAG agreed that this service (as set out in the definition) met the four factors. However, it was unclear how these specialised elements could be separately identified. The definition included some highly specialised techniques but also some services which are provided in many hospitals.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

### **View of TOG**

Coding included in this definition is not detailed enough to allow separation of specialised and non-specialised activity in pain management. If the current definition text and codes were used the only option would be to determine specialist providers and include all their activity. However, this would inevitably include substantial activity which is not complex.

### **CAG's review**

CAG agreed that, although there was likely to be a service for this patient group which met the four factors, the current definition failed to identify the specialised elements in such a way as to allow separate commissioning.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Adult Highly Specialist Pain Management Services

### **Suggested Description**

Adult Highly Specialist Pain Management Services will include services provided by Highly Specialist Pain Management Centres. The service will include multidisciplinary assessment including out-reach when delivered as part of a provider network. For specified interventions, the service will include procedure costs (including devices), follow-up and rehabilitation.

## **32 Specialised Ear Services (all ages)**

### **(a) Cochlear Implantation Services**

#### **Services covered**

A cochlear implant is an electronic device designed to provide useful auditory sensations to people who are severely or profoundly deaf and gain little or no benefit from acoustic hearing aids. Cochlear implants bypass dysfunctioning parts of the peripheral auditory system and stimulate the nerve of hearing directly with electrical signals.

Cochlear implantation for adults and children is provided within the ENT and audiology service. The service includes multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). It is a high-cost low-volume speciality.

In England, it is provided at 14 NHS hospitals. There were 864 patients implanted with cochlear implants in 2009-10; 500 of these were aged under 15.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

This service is currently commissioned by SCGs and no issues were identified.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

#### **Suggested text for regulation**

Cochlear Implantation Services

#### **Suggested Description**

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

## **32 Specialised Ear Services (all ages)**

### **(b) Bone Anchored Hearing Aid Services**

#### **Services covered**

The bone anchored hearing aid is a bone conduction hearing aid which utilises osseointegrated fixation into the skull to give both direction and attachment for the aid.

Patients will be primarily referred to a consultant ENT surgeon by GPs or by audiology departments. There are three main components to the treatment.

#### Assessment

Assessment is a multi-disciplinary process requiring sophisticated audiology and otologic opinion.

#### Surgery

Surgery is commonly performed as a single procedure for adults but for children the surgery is usually staged.

#### Hearing aid fitting and rehabilitation

Fitting usually occurs some three months after surgery when the implanted fixtures have become firmly integrated with the bone of the skull. The implanted part will require life long supervision and the aid will require replacement every five years.

It is important to ensure that the transitional care arrangements made for children moving on to an adult service are sensitive to their individual needs.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

BAHAs are provided by a wide range of secondary care ENT services. They have not been picked up by SCGs as they are provided in so many settings.

#### **CAG's review**

After discussion with the DH policy team, CAG agreed that despite this service being provided by many centres, it still met the four factors. As such it should be prescribed- but this could require work by commissioners to separately identify the activity by provider.

#### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

## **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

CAG reviewed the service in relation to the four factors, noting that

868 procedures were performed in the NHS in 2010/11

The 2012/13 tariff price is £1,972 with an additional device cost of around £3,000.

Although around 60 providers perform this procedure, recent evidence suggests 19 perform less than 5 procedures per year

The main risk to CCGs of commissioning this service is in the marked variation in access and provision

It was also noted that there was some sense in this service being commissioned alongside other elements within this definition, notably cochlear implants.

CAG agreed that, the small number of procedures, together with the small number of providers with a moderate critical mass pointed to a recommendation to prescribe this service, but with review in 2 years.

## **Suggested text for regulation**

Bone Anchored Hearing Aid Services

## **Suggested Description**

Bone Anchored Hearing Aid Services will include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children. For early review.

## **32 Specialised Ear Services (all ages)**

### **(c) Auditory Brainstem Implantation Services**

#### **Services covered**

Auditory brainstem implantation (ABI) is designed to provide useful auditory sensation for completely deaf individuals in whom a cochlear implant cannot be utilised due to:

- loss of a functioning auditory nerve
- congenital absent or mal-formed auditory nerves
- congenital absent or severely mal-formed cochleas
- severe acquired abnormalities of the cochlea.

It is estimated that between 10 and 15 patients in England will require ABI each year. Most have neurofibromatosis type 2 (NF2) and are rendered deaf due to the presence of bilateral vestibular schwannomas (acoustic neuromas), which is the hallmark of NF2, or are rendered deaf due to surgery to remove such tumours.

This service is nationally commissioned. Where ABI is funded for a different indication the care will be provided at one of the nationally designated centres.

There are three centres in England providing an ABI service (Manchester Royal Infirmary and Addenbrookes Hospital in Cambridge, and most recently the joint London ABI service between The Royal National Throat, Nose and Ear Hospital, St. Thomas's Hospital and Guy's Hospital). All 3 centres provide a comprehensive NF2 service and cochlear implant service and the ABI expertise is provided against this pre-requisite backdrop. Approximately 20 devices have been inserted in the UK in the last 5 years (to 2008). Because the number of patients treated is always going to be small, expertise will remain confined to a very small number of specialist centres.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

ABI are commissioned almost exclusively by the national services commissioning team, and this is probably the most appropriate commissioning route.

#### **CAG's review**

CAG agreed that the services within this part of the definition would be suitable for prescription.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that the appropriate services were covered by the regulation relating to the existing national service (included here for completeness).

### **Suggested text for regulation**

Neurofibromatosis type 2 service

### **Suggested Description**

Neurofibromatosis type 2 services will include services provided by Highly Specialist Neurofibromatosis Type 2 centres including outreach when provided as part of a managed clinical network. This applies to provision in adults.

## **32 Specialised Ear Services (all ages)**

### **(d) Middle Ear Implantable Hearing Aid Services**

#### **Services covered**

Middle ear implantable devices are provided in a small number of centres in England. Currently 9 ENT/ audiology centres in England offer middle ear implants, all of which are also cochlear implant centres and therefore have the requisite surgical, audiological and rehabilitation experience and skills.

Previously only adults within the niche of failed hearing aid intervention for sensorineural hearing loss had been considered for this treatment. The clinical criteria for middle ear implantation has now expanded to include sensorineural or mixed hearing loss or congenitally malformed external ears (especially for children) and mixed and conductive hearing loss (for adults).

The total number of new cases is currently (2008) estimated to be around 100 cases per annum in England. Although in 2009-10 there were just 19 admissions for implantation - 4 in under 15 year olds.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

#### **View of TOG**

These services are currently commissioned by PCTs and it is not clear how widespread their use has become. If insertion has spread beyond cochlear centres this will need to be considered.

#### **CAG's review**

After discussion with the DH policy team, CAG agreed that despite the possibility that this service was being provided by many centres, it still met the four factors. In view of the comments from TOG it would be wise to review the definition to ensure only specialised elements were being commissioned.

#### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

#### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

**Suggested text for regulation**

Middle Ear Implantable Hearing Aid Services

**Suggested Description**

Middle Ear Implantable Hearing Aid Services will include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children.

## **32 Specialised Ear Services (all ages)**

### **(e) Other Specialised Surgery Services**

#### **Services covered**

##### **Surgery for benign paroxysmal positional vertigo**

There is a small group of patients with benign paroxysmal positional vertigo for whom the usual simple physical treatments and or medication does not help. Numbers are estimated at less than one per four million people per annum. Where the episodes of vertigo are severe surgery may be considered.

The surgery requires skill not routinely employed in other operations. The posterior semicircular canal has to be accurately exposed and opened without causing injury to the other semicircular canals. It is undertaken by advanced otologists who undertake other complex major ear surgery such as cochlear implantation and excision of vestibular schwannoma tumours. No more than three operations are undertaken in England each year.

##### **Surgery for superior semicircular canal dehiscence**

This is a very rare condition in which patients complain of hearing their own body movements in the affected ear. Diagnosis is made radiologically by coronal high definition CT scanning of the petrous temporal bones.

Again the surgery requires skill not routinely employed in other operations. The superior semicircular canal has to be accurately exposed and either resurfaced or plugged without causing injury to the other semicircular canals if a transmastoid approach is employed or the brain if a middle cranial fossa approach is used. This surgery is also usually undertaken by advanced otologists who undertake other complex major ear surgery such as cochlear implantation and excision of vestibular schwannoma tumours. Between one and three operations are undertaken each year.

##### **Surgery for microtia**

Microtia is a congenital malformation of variable severity of the external and middle ear which can be either unilateral or bilateral. It is estimated to affect between one in eight and ten thousand new born children. It has various grades. Those covered by this definition are malformation of the pinna and stenosis /atresia of the ear canal.

The surgical management of the pinna can include:

- reconstruction with the use of a rib cartilage graft
- reconstruction with a silicon auricular prosthesis either stuck on with adhesives or clipped on with titanium screws.

Auditory support cannot be provided by acoustic hearing aids. Two options are available for the affected ears: a bone conduction hearing device or a middle ear implant.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition.

### **View of TOG**

These services are currently commissioned by PCTs and it is not clear how widespread their use has become. Existing coding included in the definition would pick up a lot of non-specialised activity.

### **CAG's review**

After discussion with the DH policy team, CAG agreed that despite the possibility that this service was being provided at an increasing number of centres, it still met the four factors. In view of the comments from TOG it would be wise to review the definition to ensure only specialised elements were being commissioned.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were advised that since the last revision of the definition, Surgery for benign paroxysmal positional vertigo and Surgery for superior semicircular canal dehiscence were no longer considered to be specialised. This relates to the fact that the techniques used are not exclusive to the conditions described. The "ear" aspects of the third listed condition – microtia – was thought to be adequately covered by regulations on bone conduction and middle ear hearing devices. As such, no additional regulation was required. The plastic surgery aspects of microtia are included in the section on Paediatric Plastic Surgery Services (Page 158).

### **33 Specialised Colorectal Services (adults)**

#### **Services covered**

Specialised colorectal services include:

Distal sacrectomy for advanced or recurrent rectal cancer  
These are considered under definition 1 (cancer)

Complex inflammatory bowel disease surgery  
Management of inflammatory bowel diseases, such as Crohn's disease and ulcerative colitis, is carried out in local hospitals. However complications that cannot be managed in the local hospital, e.g. severe intestinal failure or complex wound management (e.g. as a result of laparostomy), may be referred to the specialist centre.

Procedures such as ileoanal pouch operations will be carried out in local hospitals but revisional pouch surgery is a specialised service.

Complex surgical interventions for incontinence  
This refers solely to sacral nerve stimulation and neo sphincter formation (e.g. graciloplasty). These were nationally commissioned until 2006)

Transanal endoscopic micro surgery (TEMS)  
Increasingly being adopted by local hospitals and consequently will cease to be a specialised service in the future (see Definition 1)

Severe intestinal failure  
Commissioned nationally- AGNSS (see Definition12)

Surgery for pseudomyxoma peritonei.  
Commissioned nationally- AGNSS

If TEMS is included, the remainder of the surgical procedures in this definition should take place in around 5 centres in England. Sacral nerve stimulation (SNS) is an emerging technology and costs remain high.

#### **CAG's initial view**

CAG agreed that this service (as set out in the definition) met the four factors. This assumes that the caveat regarding TEMS now applies.

CAG were minded to recommend prescription of all services included in the most recent version of this part of the definition (excluding those considered elsewhere):

Surgical management for complex inflammatory bowel disease  
Complex surgical interventions for incontinence

#### **View of TOG**

If the prescribed services are limited to those listed above, there remains a concern that current coding is insufficient. Repeat procedures will need to be expressly recorded. Since SNS is used for other indications, a bespoke

method of recording the activity in named providers will be needed. However, if prescribed it will be possible to separately commission these services.

**CAG's review**

CAG agreed that the following services within this definition would be suitable for prescription:

- Surgical management for complex inflammatory bowel disease
- Complex surgical interventions for incontinence

For the avoidance of doubt- it was felt that, although most of the surgery involved would be prescribed in children under other proposed regulations- it was appropriate to include children in this regulation.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**

**Suggested text for regulation**

Highly Specialist Colorectal Surgery Services

**Suggested Description**

Highly Specialist Colorectal Surgery Services will include the following services when provided by Highly Specialist Colorectal Surgery Centres:

- Surgical management for complex inflammatory bowel disease
  - Complex surgical interventions for incontinence
- This applies to provision in adults and children.

## **34 Specialised Orthopaedic Services (adults)**

### **(a) Elective**

#### **Services covered**

Specialised orthopaedic services are those services that are not generally provided in local general hospitals. In some cases the service is so specialised it is only provided in a few hospitals and is commissioned on a national basis.

There is significant overlap with the following definitions:

1 Cancer services

6 Spinal Services

7 Rehabilitation Services for Brain Injury and Complex Disability

8 Specialised Neurosciences Services (adult)

Specialised orthopaedic services include:

spine

All surgery included in definition 6 (Complex spinal surgery)

upper limb procedures

See below

lower limb and pelvis procedures tumours

Considered in Definition 1 (Primary malignant bone tumours (PMBT) service is nationally commissioned- AGNSS)

specialised peripheral nerve surgery

See below

soft tissue procedures

See below

other site specific procedures

See below

The specific procedures included in this definition, but not elsewhere, do not always have specific codes to allow for them to be identified separately from more routine procedures. The definition includes a list of procedure codes for specialised procedures but these do not cover all of the procedures mentioned in the text.

#### **CAG's initial view**

CAG agreed that the elective procedures set out in the definition met the four factors. However, it was not clear that these procedures continue to be available only in a few centres.

CAG were minded to recommend prescription of the elective procedures included in the most recent version the definition.

### **View of TOG**

The current definition and accompanying summary of procedure codes leaves significant overlaps in specialised and non-specialised activity. If all codes and procedures are included there are currently 167 providers in England offering an element of this service. Alternatively, these procedures could be commissioned from a restricted number of providers- but these providers would also be performing non-specialised procedures which would be included in these codes. There would be at least 50 such providers.

### **CAG's review**

CAG accepted that there were significant issues with this definition which would make separate and direct commissioning very challenging. Prescription of a procedure should mean restricted provision- it is not clear that there is a good case for restricting provision for all of the listed procedures.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Adult Specialist Orthopaedic Services

### **Suggested Description**

Adult Specialist Orthopaedic Services will include services provided by Adult Specialist Orthopaedic Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex procedures only.

## 34 Specialised Orthopaedic Services (adults)

### (b) Trauma

#### Services covered

Specialised orthopaedic services are those services that are not generally provided in local general hospitals. In some cases the service is so specialised it is only provided in a few hospitals and is commissioned on a national basis.

There is significant overlap with the following definitions:

1 Cancer services

6 Spinal Services

7 Rehabilitation Services for Brain Injury and Complex Disability

8 Specialised Neurosciences Services (adult)

30 Vascular Services

Management of spinal injury

Considered under Definition 6

Emergency treatment of metastatic disease

Considered under Definition 1

Upper limb fractures (complex)

Of upper limb fractures only surgical treatment for complex scapular fractures is a specialised service.

Lower limb fractures (complex)

Of lower limb fractures only surgical treatment for complex fractures is a specialised service.

Acetabular and pelvic fractures (complex)

Of acetabular and pelvic fractures only surgical treatment for complex acetabular and pelvic fractures is a specialised service.

Fractures associated with major vessel injuries

Of fractures associated with vascular injuries only treatment of fractures with major vessel injuries is a specialised service. These fractures require combined orthopaedic, vascular and/or plastic surgery input.

The multiply injured patient

The definition states:

“This is a difficult group to define from ICD codes and OPCS intervention codes as it is a combination of injuries and severity of impact and is often combined with head, chest and abdominal injuries that result in the need for specialist input involving multiple surgical specialities, specialist radiology and intensive care combined in a specialist centre.”

severe open limb fractures requiring plastic reconstruction surgery

limb replant surgery for traumatic amputations of parts of limb / digits  
This surgery usually requires a combined plastic and orthopaedic surgical input and microvascular repair as well as bone reconstruction.

complex and severe injuries of the major nerves of the upper / lower limbs

Since the definition was written, the concept of Major Trauma Networks has developed. Most of the above would be encompassed in the work of a Major Trauma Centre (MTC) . There is a significant overlap between specialised services in this area of medicine- joint working across multiple specialities is essential.

### **CAG's initial view**

CAG agreed that the procedures set out in the definition met the four factors. However, it was felt that the definition needed to be reconsidered in the light of the Major Trauma developments. As such, further advice would be sought from the National Clinical Director.

CAG were minded to recommend prescription of the elements included in the most recent version of the definition.

### **View of TOG**

A new "multiple injury chapter" of PBR was introduced in April 2011. Work is in hand to identify MTCs and the intention is to offer a "Best Value Tariff" for complex trauma care in these centres. At present it is expected that between 20 and 25 networks will be formed, each with at least one MTC. Specific procedures mentioned in the associated codes with this definition are performed in more than 100 providers.

### **CAG's review**

After detailed discussion with the DH policy team, CAG accepted that there were significant issues with this definition which would make separate and direct commissioning very challenging. The definition needs to be reviewed in the light of the Major Trauma Network developments.

### **CAG recommend to prescribe within other services to incorporate major trauma activity within Major Trauma Centres**

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. Emergency orthopaedic procedures may be included in the proposed regulation on Adult Specialist Orthopaedic Services. Although this definition was adults only- the application of MTC approach is applicable to adults and children.

### **Suggested text for regulation**

Major Trauma Services

### **Suggested Description**

Major Trauma Services will include all activity at Major Trauma Centres with an ISS of greater than 8. This applies to provision in adults and children.

## **35 Morbid Obesity Services (all ages)**

### **Services covered**

Most management of obesity and overweight (including morbid obesity) takes place in the community or in primary care, with many people taking responsibility for their own weight management, often supported by commercial slimming organisations. Patients may also have access to dietetic support, exercise referral schemes, psychological support and medical treatment (drug therapy) via their general practitioner. These interventions are appropriate for a high proportion of the obese population, but some patients with more severe obesity require more specialist medical input or surgery.

This definition concerns specialised medical and surgical services for morbid obesity for both children and adults. Only a very small proportion of morbidly obese patients are currently offered surgery. Many patients do not wish to have surgery or are unsuitable for a wide range of reasons; these patients still require specialist management. Surgical provision is provided at specialist morbid obesity surgery centres stocked with specialist equipment and access to anaesthetists with experience of morbid obesity patients.

Not all patients with a BMI greater than 40 require treatment at a specialist morbid obesity centre but surgery is only be undertaken at such centres. Generally patients with a BMI under 40 can be managed in primary care; those with a BMI greater than 40 (or greater than 35 with co-morbidity) are seen in primary care or at their local hospital, depending on local arrangements, leaving the specialist morbid obesity centres to concentrate on managing patients with a BMI over 40 who also have complex needs and/or require detailed assessment prior to surgery. This latter group amounts to approximately 120,000 adults and includes (i) all patients with a BMI over 50 and (ii) patients with a BMI over 40 who have the following (note: this is not an exhaustive list):

- endocrine conditions
- genetic conditions (rare causes of severe obesity)
- organ failure and are being considered for transplantation, e.g. renal, heart
- awaiting major surgery (with the attendant anaesthetic risk)
- women seeking infertility treatment.

For patients with a BMI over 35 and existing co-morbidities, referral for medical management to a specialist morbid obesity centre may be appropriate. For patients with a BMI under 35 there may be rare occasions when special factors (e.g. prior to renal transplant or fertility treatment) necessitate referral to a specialist centre.

There are now around 10,000 operations for morbid obesity each year in England- but not all are funded by the NHS. NICE guidelines suggest a level of provision far greater than that presently in place in most parts of the country. There are 84 surgeons contributing to the National Bariatric Surgery Register, many operating at more than one provider. There are less than 50 NHS funded providers. Individual patient costs for a standard procedure are

less than £10,000. Revision surgery and patients requiring stays in ICU increase costs.

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that the surgical procedures set out in the definition met the four factors. However, there was significant disagreement regarding the appropriateness of separating out the surgery from the rest of the patient pathway. Further, the definition suggested secondary care obesity services were needed for complex care- but community services are developing which have similar clinical skills.

CAG agreed to consider this service again, once more information was available from TOG.

### **View of TOG**

Identification of in-patient surgery is straightforward and not widespread- about 21 major providers. Conversely, the out-patient element of this service is poorly identified in most providers and will need local solutions to ensure only specialised activity is included. There was also concern regarding the initial review of referred patients. The definition envisages an MDT before the patient is seen- there is no satisfactory way to fund such a service.

### **CAG's review**

CAG considered the views of DH policy team on obesity, and set aside a full meeting to consider this service. In summary, a case could be made for returning this service to local (CCG) commissioning, and a case could be made to retain the service in specialised services (to be prescribed and commissioned by NHSCB).

CAG considered again the four factors.

(a) the number of individuals who require the provision of the service or facility  
Current NHS commissioning policy in much of the country is artificially lowering NHS funded activity. NICE estimates would increase the number of procedures but it is not clear by how much. As such, there is a mismatch between those "who require the provision" and those receiving the service.

(b) the cost of providing the service or facility.

The price to commissioners is variable across England with lower prices where more activity is purchased from the same provider (centralised model). However, the care package for these cases is complex and includes a large MDT so the cost to providers of offering this service, especially where standards have been set on the assumption that activity will be 100-200 cases per year, will be very high. This has tended to reduce new entrants to the provision of this service.

(c) the number of persons able to provide the service or facility.

There are just 84 surgeons providing this service in England. This is close to the number for geneticists and immunologists and far less than the number of specialists in renal medicine or cardiac surgery. If we assume NHS provision

requires four consultant to cover a rota, then around 21 centres can be supported by such a workforce- about the same as specialised infectious diseases centres.

(d) the financial implications for clinical commissioning groups if they were required to arrange for the provision of the service of facility.

The greatest concern in relation to this factor is in the backlog of cases that would be eligible according to NICE guidelines, but are not eligible for NHS funding under current commissioning policies. For some CCGs, a move to compliance with this guidance would represent a significant financial risk to viability. The usual risk sharing arrangements would not prevent this as other local CCGs are likely to have similar issues. There is also a concern that the resource allocation to CCGs will not identify high levels of obesity as a financial risk. This means that two similar size CCGs could have a markedly different expenditure on morbid obesity surgery with no difference in allocated funds.

There is a good case for saying that prevention, weight management and surgery should be managed together. But the current proposal is for prevention to sit with Local Authorities within their Public Health allocations, community weight management to be jointly supported, and for surgery to sit solely within the NHS. Any decision on the commissioner for surgery, will need to include a consideration of making appropriate linkages across the pathway.

After much discussion, CAG agreed that, for the first few years of CCG commissioning, these services should be commissioned by the NHSCB, with strong local linkages to provision. This should be reviewed with a view to limiting the scope of NHSCB commissioning to those services which continue to meet the four factors. If a move to consistent commissioning according to NICE guidelines is planned, this should take place while the commissioning is with the NHSCB- to avoid undue risk on CCGs due to the backlog.

It was acknowledged that there would be little direct incentive on CCGs to reduce referrals for morbid obesity surgery and this could reduce the impetus to develop weight management programmes. It was thought to be important that referrals into NHSCB funded services should only be accepted if the appropriate weight management interventions had taken place in the community.

This service should be reviewed in 1-2 years. At this time, CAG expected that at least some elements of the adult service may be suitable for commissioning by CCGs.

**CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS**  
Subject to review in 1-2 years.

### **Suggested text for regulation**

Specialist Morbid Obesity Services

### **Suggested Description**

Specialist Morbid Obesity Services will include service provided by Specialist Morbid Obesity Centres. The service will include 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. For early review.

## **36 Specialised Services for metabolic disorders (all ages)**

### **Services covered**

This was one of three new definitions included in v3 of the SSNDS.

Specialised metabolic disorders services cover a diverse range of primarily genetic conditions which, although varying widely in their presentation and management according to which body systems are affected, are all caused by a disruption in normal biochemical processes. They 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.

Although the individual metabolic disorders are rare, collectively they represent a significant patient population. Approximately 10,000 prevalent cases attend specialist metabolic disorders centres for the management of their condition, but it is estimated that a further 6,000 children and 3,000 adults are lost to follow-up or never attend. There are estimated to be over 600 new cases per year, i.e. 1 in 1,000 live births.

This definition covers the core specialised diagnostic and treatment services for inherited metabolic disorders, and the provision of advice to family members. This activity is provided by specialist centres, supported by metabolic biochemistry laboratory services. Outreach clinics provided by specialised metabolic disorders centres in local hospitals improve accessibility and make best use of scarce expertise. Many patients are treated in local hospitals on a shared care basis with advice from the specialist centre's multi-disciplinary team on the condition itself and its impact on other illnesses.

The definition does not include services for non-specialised conditions such as familial hypercholesterolaemia, diabetes, etc, which are provided by local hospitals.

Patient management is provided by a multi-disciplinary team at the specialist metabolic disorders centre. This will require both clinical and laboratory elements (e.g. for dietary support monitoring).

Most care is provided on an out-patient or shared-care basis with some of this being led by the specialist nurse or dietician member of the specialist metabolic disorders centre team. Rare and expensive drugs are sometimes used in patient care, with infusions commonly taking place in the patient's home.

Fewer than 20 centres provide the highly specialised MDT support needed for advice on routine cases and care for complex cases. Although most costs are included in tariff, it is clear that much of the work of specialist centres is in supporting local care. This service may be better suited to a year of care model. Some disorders have drug treatments with very high costs- most are included in national services

### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

Other than services commissioned once nationally, no SCG commissions any of this definition. The definition identified diagnostic codes but these are equally split between specialised and "may be specialised". This is made more difficult because most of this service is provided on an out-patient basis for which the diagnostic coding is rudimentary. If this definition were restricted to designated providers for specific clinics this would go some way to addressing this point- but would not include all of the service as outlined in the definition.

### **CAG's review**

CAG accepted that there were significant issues with this definition which would make separate and direct commissioning very challenging. There seemed to be a good case for designating a small number of centres to provide specialist support for specific conditions- rather than include all activity related to the condition wherever provided. This was not possible within the terms of the current definition.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Highly Specialist Metabolic Disorder Services

### **Suggested Description**

Highly Specialist Metabolic Disorder Services will include services provided by Highly Specialist Metabolic Disorder Centres for patients with specified conditions. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.

## **37 Specialised Ophthalmology Services (adults)**

### **Services covered**

This was one of three new definitions included in v3 of the SSNDS.

The definition includes a comprehensive list of elements of care:

#### **Orbital disorders**

##### **Lacrimal disorders**

Most surgery for more complex lacrimal problems and for failed primary surgery tends to be regarded as a specialised service.

##### **Oculoplastic surgery**

Specialised services cover advanced ptosis surgery, adnexal and eye tumour management for complex cases and cases with rarer and more malignant pathology; these are managed within a dedicated eyelid tumour clinic by a multidisciplinary team.

##### **Corneal disorders**

Treatment for some corneal conditions including ocular surface reconstructive surgery and severe anterior segment inflammation refractory to topical therapy are considered to be specialised services.

Services for certain types of contact lens fitting, e.g. scleral contact lenses, are only available in a few ophthalmic departments nationally and are regarded as a specialised service.

Excimer lasers are also used in a small number of ophthalmic departments to treat corneal pathology (phototherapeutic keratoplasty-PTK); this is regarded as a specialised service.

##### **Retinal detachment**

Surgery for a subgroup of complex retinal detachments, e.g. giant retinal tears, severe proliferative vitreoretinopathy (PVR), is regarded as a specialised service.

##### **Other vitreoretinal disorders**

Services for a small number of conditions, e.g. severe diabetic traction retinal detachments, and subretinal surgery is regarded as falling under specialised services.

##### **Uveitis**

Posterior uveitis includes a wide range of disorders which can be sight threatening and are often associated with systemic disease. The management of such cases is complex and is regarded as falling under specialised services. There is close liaison with other medical specialties in the investigation and treatment.

### **Glaucoma**

More complex surgical treatment, including tube surgery, is regarded as a specialised service.

### **Strabismus surgery**

Strabismus in adults sometimes involves rare and more complex conditions which may require specialist techniques, e.g. such as injection of botulinum toxin, are considered to fall under specialised services. However the majority of the work on adults is non complex and is not regarded as falling under specialised services.

### **CAG's initial view**

CAG agreed that this service (as set out in the definition) met the four factors. However, it was not clear that the definition lends itself for separate commissioning- especially in view of the way the definition splits out specialised activity.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

For procedures, the codes are available. However, the codes which accompany this definition are frequently used for non-specialised procedures. Here it is complexity which makes the activity specialised- and this is not coded. Out-patient coding will not identify the activity linked to the described conditions as diagnostic coding is limited. If provision of some procedures should be limited to a smaller number of providers- commissioning on that basis could allow an approximation of the list included in the definition.

### **CAG's review**

CAG accepted that there were significant issues with this definition which would make separate and direct commissioning very challenging. Further, it was not clear that specialist services were needed in all instances included in the definition. A comprehensive piece of work is required to identify elements which should be commissioned from a limited number of specialist providers.

### **CAG agreed that the services described meet the factors on the face of the bill.**

However, further advice should be sought to define the service in such a way as to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured.

**Suggested text for regulation**

Adult Specialist Ophthalmology Services

**Suggested Description**

Adult Specialist Ophthalmology Services will include services provided by Adult Specialist Ophthalmology Centres including out-reach when delivered as part of a provider network. The service will include management of rare conditions and complex procedures only.

## **38 Specialised Haemoglobinopathy Services (all ages)**

### **Services covered**

This definition focuses on people with thalassaemia major, sickle cell disease (SCD) and other rare inherited anaemias. There are about 700 patients with thalassaemia and 12,500 with SCD in England. A large number are under 19 years of age. SCD is one of the commonest inherited conditions in England; around 360 babies are born in England each year with SCD compared to 20-30 babies with thalassaemia.

Services for SCD and thalassaemia are provided in specialist haemoglobinopathy centres, in local hospitals and in the community.

SCD predominantly affects black and African-Caribbean people, whilst thalassaemia affects Asian and Mediterranean peoples. The prevalence of rare inherited anaemias varies around the country from high prevalence areas such as London, where two-thirds of SCD patients live, to low prevalence areas where there are relatively few residents who are from high-risk ethnic groups. Local hospitals in high-prevalence areas have large caseloads of patients with SCD and thalassaemia, but local hospitals in low-prevalence areas may only have a handful of patients; these two types of local hospital will have very different levels of knowledge and expertise.

Consequently in high-prevalence areas the local hospital is likely to provide much of the day-to-day care and look to the specialist centre to provide certain outreach services and joint clinics, whereas in low-prevalence areas the local hospital is more likely to refer patients to the specialist centre.

Supervision of blood transfusion management of SCD and thalassaemia and exchange transfusions for SCD

The specialist centre supervises the blood transfusion management of the patient.

Supervision of iron chelation management in SCD and thalassaemia, prescribing iron-chelating drugs, monitoring and adverse event management and optimization of compliance

The overall supervision of the patient resides with the specialist centre and will cover: choice of drug, monitoring for efficacy and side effects, dose adjustments and changes to the chelation regime although shared care arrangements may be applied for ongoing monitoring.

Prevention and management of neurological complications of SCD including transcranial doppler screening in childhood, specialised neuroradiology, neurology and neuropsychology services

All children with HbSS and other severe phenotypes will require annual TCD scanning from the age of 2 under the direct supervision of the specialist centre and subject to a quality assurance system.

#### Management of severe and life-threatening acute complications of SCD and thalassaemia

The most severe episodes with life-threatening acute complications will be treated by the specialist centre.

#### Management of chronic complications of SCD and thalassaemia

Prevention and treatment requires specialist knowledge and experience, close collaboration with other specialties (usually through regular joint clinics) and monitoring protocols agreed between the specialist centre and the local hospitals which can be implemented throughout the network. Within these networks the diagnosis and management of chronic complications is the responsibility of the specialist centre, but the day to day delivery of protocol based treatments can be undertaken at the local hospital in collaboration with the specialist centre.

#### Surgical management of SCD and thalassaemia

Surgery will be carried out in a specialist centre by surgeons and anaesthetists who have experience in treating SCD and thalassaemia patients working closely with the haematology or paediatric haematology specialist.

#### Management of pregnancy in SCD and thalassaemia

Each year in the UK 40-50 women with SCD will become pregnant as will 4-5 women with thalassaemia major. These are high risk pregnancies which ideally are managed in a joint high-risk antenatal clinic by the specialist in SCD and thalassaemia together with an obstetrician who has particular expertise in this area. Decisions about treatment during pregnancy and mode of delivery are made on an individual basis.

#### Stem cell transplantation for SCD and thalassaemia

Both SCD and thalassaemia may be cured during childhood by allogeneic stem cell transplantation, but this requires a histocompatible sibling for stem cell donation. In November 2008 there were two centres in the UK which have built up a large experience in allo-stem cell transplantation for haemoglobinopathies (considered under Definition 2)

#### Out-patient review of SCD and thalassaemia

Annual review - The annual review should be undertaken by a specialist, either in an outreach clinic or in the specialist centre itself.

#### **CAG's initial view**

CAG, also informed by the Children's Sub-Group, agreed that this service (as set out in the definition) met the four factors. There was some concern regarding the continuing need for local services in high prevalence areas.

CAG were minded to recommend prescription of this service as set out in the most recent version of the definition.

### **View of TOG**

In-patient activity will be easily identified- it is not envisaged that this will include surgery- although centres will need to support the care of patients through surgical procedures. It is unlikely that 'local' activity within a specialised centre will be separated- so CCGs close to a centre will not incur costs for any part of the pathway. Conversely, CCGs away from centres will need to commission local and community services linked to a centre within a haemoglobinopathy network. Work undertaken by East Midlands SCG within a DH funded pilot may be helpful.

### **CAG's review**

CAG received further views from the East Midlands project and considered the work to date on defining a service specification for centres. It was agreed that the definition set out the requirements of centres but there would be considerable work needed to allow for consistent commissioning against this definition.

### **CAG recommended to prescribe as per 3<sup>rd</sup> edition of SSNDS.**

However, CAG advised that further work is required to enable separate and direct commissioning of this service.

### **Further Consideration by CAG**

After receiving a detailed response from the NHS providers and commissioners, CAG were assured that separate and direct commissioning of this service could be secured. A full scope for such a service was presented which informed CAG's suggested description.

### **Suggested text for regulation**

Specialist Haemoglobinopathy Services

### **Suggested Description**

Specialist Haemoglobinopathy Services will include all care provided by Specialist Haemoglobinopathy Centres including in-patient care where the cause of admission is related to haemoglobinopathy. The service will include out-reach when delivered as part of a provider network. This applies to provision in adults and children.