Classification: Official

Publication reference: PRN00115

Prescribed Specialised Services Manual

Version 6, 22 March 2023

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

Manual for Prescribed Specialised Services 2023/24

Version number: 6

First published: November 2012

Updated: January 2014 (version 2), May 2016 (version 3), October 2017 (version 4) and September 2018 (version 5), March 2023 (this version)

Prepared by: NHS England

Classification: OFFICIAL

Changes to the previous version of the document are in a table at the end of the document.

Background

The National Health Service Act 2006, as amended by the Health and Care Act 2022, sets out three factors that Ministers take into consideration when they determine which specialised services should be commissioned by NHS England:

- The number of individuals who require the provision of the service or facility;
- The cost of providing the service or facility; and
- The number of persons able to provide the service or facility

Section 65Z5 of the Health and Care Act 2022 provides the power for NHS England to arrange for any functions exercisable by it to be exercised by, or jointly with, one or more ICBs.

Reducing Inequalities

The NHS Act 2006 requires NHS England to:

- Have regard to the need to reduce inequalities between persons in access to health services and between patients with respect to the outcomes achieved (Section 13G of the NHS Act 2006); and
- Exercise its functions with a view to securing that health services are provided in an integrated way, and are integrated with health-related and social care services, where it considers that this would improve quality, reduce inequalities in access to those services or reduce inequalities in the outcomes (Section 13N of the NHS Act 2006).[1]

The NHS Act 2006 requires each ICB to:

- (a) Reduce inequalities between persons with respect to their ability to access health services, and (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services (Section 14Z35 of the NHS Act 2006); and
- Exercise its functions with a view to securing that health services are provided in an integrated way where it considers that this would— (a) improve the quality of those services (including the outcomes that are achieved from their provision), (b) reduce inequalities between persons with respect to their ability to access those services, or (c) reduce inequalities between persons with respect to the outcomes achieved for them by the provision of those services (Section 14Z42 of the NHS Act 2006).

In addition, it is important to make explicit that commissioners of each NHS service must pay ‘due regard’ to their Public Sector Duty under the Equality Act 2010.[2]

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[1] Guidance for NHS commissioners on equality and health inequalities legal duties. NHS England Updated: December 2015

[2] Ibid, p7

The purpose of the Prescribed Specialised Services Manual

The Manual is one of a suite of ‘products’ that have been developed to facilitate the effective commissioning of specialised services and it should be considered alongside these products, for example, service specifications and policies. This edition of the Manual has been combined with the Identification Rule Handbook, the Identification Rules (IRs) being the (technical) means by which specialised activity is captured by providers in data form so that such activities can be identified as being commissioned by NHS England or ICBs. This single document now supersedes previous versions of the Manual and of the IR Handbook and is known as the Manual.

In summary, the text of the Manual describes how NHS England and ICBs ***commission*** specialised services and the IRs describe how NHS England and ICBs identify Specialised Services activity within data flows. Whilst the majority of IRs (*the basis for contracting*) align closely with the text of the Manual (*the basis for commissioning)* there are instances where NHS England and ICBs may commission services but do not contract or pay for them. This may, for example, be due to: national or local coding issues; where payment is part of a pathway payment system; or where funding has been found to be incorrectly aligned to the IR baseline exercise.

The Manual reflects the NHS Act 2006 (as amended) and the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 and not other Regulations.

Definitions of ‘specialist’ and ‘specialised’

In this document, the term ‘specialist’ refers to a level of expertise delivered within a service (with ‘highly’ specialist meaning a very high level of expertise). The terms ‘specialised; and ‘highly specialised’ refer to the commissioning models used by NHS England to commission specialised and highly specialised services respectively.

Commissioning responsibilities of Integrated Care Boards

Section 65Z5 of the NHS Act 2006 permits NHS England to arrange for any functions exercisable by it to be exercised by, or jointly with, one or more ICBs. The ‘Roadmap for integrating specialised services within Integrated Care Systems’[3] set out the approach for taking this forward including setting out the initial list of services that could be delegated to ICBs.

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[3] Roadmap for integrating specialised services within Integrated Care Systems, NHS England, May 2022

The expectation for 2023/24 is that ICBs and NHS England will set up joint working arrangements overseen by a joint committee. This means that, from April 2023 they will have joint responsibility for the specialised services that have been assessed as suitable and ready for greater involvement of ICBs. It is the intention that ICBs will take on statutory delegated commissioning responsibility for these services from April 2024, subject to system readiness.

The Manual has been updated to clarify the expected commissioning responsibility for services, with details under the following headings:

- **What NHS England directly commissions in line with national standards (specifications and policies)** – this sets out those service NHS England will continue to directly commission (including Highly Specialised Services and other services which are either not suitable or not ready for delegation),
- **What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)** – this sets outs those services which NHS England has identified as suitable and ready for delegation**,**
- **What Integrated Care Boards commission (ICBs) in line with local specifications and policies)** – this sets out the services or elements of the pathway that ICBs commission that are not specialised services,
- **Change of service commissioner** – this includes information where a service may be delegated to ICBs in the future.

The Manual will be updated as the appropriateness of services for delegation is reviewed and also as updates to coding are made.

There will be new technologies that will be assessed by NICE and which are for the treatment of patients in services that have been delegated to ICBs but, because of clinical or commercial complexity are more efficiently commissioned on a national basis, at least in the first instance. The list of treatments affected will be agreed with ICBs.

Detailed information about the Identification Rules

What are the Identification Rules?

The Identification Rules (IRs) are a mechanism by which healthcare activities can be identified as prescribed specialised services. The data flows used to support the commissioning process consist of both standard and non-standard flows of various quality and content. It is therefore not yet possible to have one single identification method for prescribed activity. Instead there are four different methods of identification:

1. Application of the IR rules software tool against standard inpatient and outpatient data flows.

2. Application of a defined national identification rule not otherwise contained within the IR rules software tool against standard inpatient and outpatient data flows (including cross reference to patient registry data where applicable).
3. Comparison of service provision against a list (i.e. list of high cost drugs and devices)
4. If none of the three previous methods of identification are possible creation of local (to provider) data capture processes to illustrate patients who meet the criteria of being specialised

Therefore, the Identification Rules are a combination of all four elements. For some services, one identification method is sufficient to locate the specialised activity but, for some services, a combination of rules is required (sometimes as a cross-reference). The IRs utilise where possible the naming convention and data formats as detailed in the NHS Data Dictionary.

The IRs must be read in conjunction with the guidance documents issued by NHS Digital for the IR software tool available here.

Note: When healthcare providers implement Commissioning Data Set (CDS) v6.3 data flows to the Secondary Uses Service (SUS), the expectation is that all providers will insert the appropriate Service Code into the SERVICE CODE field of the CDS record where activity is identified as specialised by either IR tool application, other national rule derivation, or agreed local rule where no national IR exists. This technical rule set is updated on an annual basis to accommodate changes to Information Standard Notices and (clinical) Service Specifications.

IMPORTANT NOTICE

The Identification Rules are based on the premise that all organisations are using the most up to date coding conventions (ICD and OPCS) and have implemented all reporting requirements as detailed in the NHS Data Dictionary and Information Standard Notices (ISNs) or Data Set Change Notices (DSCNs). Where provider data is not consistent with the requirements of the Data Dictionary the IR software tool generates a data quality error and does not attribute the healthcare activity to a service line. Providers should regularly check the output from the IR software tool as there is a risk that appropriate healthcare activities are not identified as specialised activities and therefore by default fall to ICB commissioning responsibility.

Locating related source materials

IR tool for use with standard inpatient and outpatient data flows

NHS Digital has been commissioned to produce a bespoke software tool (as zipped executable software) that replicates the Inpatient and Outpatient IRs. The software requires local data flows to be passed through the software which firstly performs a series of data quality checks and, where data passes those checks, perform a series of logical tests to establish whether the activity meets the criteria for a specific service. The tool also ensures that each healthcare activity is attributed to a single service code using an inbuilt service hierarchy. The software solution is also supported by a User manual, Installation guide, sample input and output files and a user-friendly User Guide (xls. document that demonstrates how each service identification rule is compiled). These products are available on the Downloads page of The National Casemix Office section of the NHS Digital website.

Specialised Services commissioned drugs

Providers are required to regularly review the list of drugs excluded from National Tariff, located on the NHS England drugs list, to identify the drugs appropriate to specialised commissioning. This document is regularly updated to reflect changes arising from the regulation of new drugs e.g., to the Cancer Drugs Fund. Providers should note the indication for which the drug is funded, the stop and start criteria and the Technology Appraisal (TA) or Policy that the drug use relates to, thereby ensuring that the drug is attributed to specialised commissioning when the drug is used as described in the excluded from national tariff list. All NHS England commissioned providers are required to submit a patient level drug dataset as part of the monthly commissioning data flow. See Contract Monitoring - NHS Digital.

For Specialised Commissioning tariff-excluded high cost drugs, regions will contract with providers on the following basis in 2022/23:

- Drugs categorised as ‘block’ is part of the fixed element of the contract
- Drugs categorised as ‘cost and volume’ has a notional baseline (based on 2021/22 spend) in the fixed element of the contract with under or over performance subject to variable payment.

Specialised Services commissioned devices

The responsible commissioner for high cost tariff excluded devices (HCTED) is identified in the National Tariff Payment System Guidance Annex A workbook, tab 14a HC devices (penultimate column). The final column of the table also identifies the devices which are within scope of the central procurement for excluded devices managed by the National Specialised Services Device Programme (SSDP) in partnership with NHS Supply Chain (known as the Visible Cost Model or VCM).

Whilst the entire device category is either the commissioning responsibility of NHS England Specialised Commissioning or ICBs (but never both), the responsible commissioner for the associated spell is dependent on a combination of the IRs and the delegation status of the relevant service line (if specified activity). Therefore, it is possible for a device to be charged to NHS England and the associated spell charged to ICBs and vice versa.

The budget for devices identified in the 14a Table as NHS England Specialised Commissioning is held centrally, with providers reimbursed directly by the national NHS England finance team in line with national guidance and standard processes.

All devices procured via the VCM or legacy Zero Cost Model (ZCM) are reimbursed based on a monthly report received directly from NHS Supply Chain and reconciled using the Financial Reconciliation Process (FRP). The FRP is a semi pre-populated spreadsheet distributed to providers for completion on a monthly basis. For some very high cost device categories, providers also need to submit a patient level devices dataset as part of the monthly commissioning data flow in accordance with the dataset template provided on the NHS England website. The financial value for VCM (or legacy ZCM) procured devices is recorded as £0 on the dataset template.

Where a specialised device category or individual device is not available for procurement via the VCM, providers are required to report the device details, including the cost, in the patient level devices dataset. Reimbursement is still managed via the national budget but is based on the dataset template rather than the NHS Supply Chain report. Devices which are available via the VCM but procured locally, will only be reimbursed if there is an agreed exception in place.

NHS Providers may request a copy of the SSDP finance guidance from: england.speccomm-hctedfinance@nhs.net

Clinical databases used in support of specialised service delivery

For a large proportion of specialised services standard data collection processes are insufficiently detailed to describe the service. As a consequence, clinical databases/registries are used to compliment and extend common data collections. The clinical databases/registries used to support provision of services are captured in Appendix A.

1. Adult ataxia telangiectasia services

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

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

Other relevant service(s):

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

About the condition/service

Ataxia telangiectasia (AT) is a rare, neurodegenerative and progressive condition that starts in early childhood causing severe disability and premature death. It affects many parts of the body and a wheelchair is often needed by the age of 10. The average life expectancy is 25 years. During the adult stage of the condition, there is increased susceptibility to leukaemias, lymphoma, pneumonia, chronic lung disease and neurological decline. Fewer than 100 adults in England have AT.
This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions adult ataxia telangiectasia services from Highly Specialist Adult Ataxia Telangiectasia Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Highly Specialist Adult Ataxia Telangiectasia Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23G

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS

How the activity for this service is identified

Activity is identified via the application of IR and reported via local and SUS data flows, which apply to established designated centres only.

How to use the Identification Rules

1. Inpatient activity can be identified by selecting activity meeting the diagnosis code and provider as documented in the IR software tool.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to the NCBPS23G service code for specialised commissioning.
3. Outpatient activity can be identified by selecting outpatient activity meeting the detail in the IR software tool.

This is a highly specialised service. This activity must be included in SUS data flows as well as the specific Highly Specialised Service data flow and annotated with the NCBPS23G service code.

2. Adult congenital heart disease services

[Programme of Care – Women & Children, CRG – Congenital Heart Services]

Service summary

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

Other relevant service(s):

- 7. Adult specialist cardiac services
- 83. Paediatric cardiac services

About the condition/service

Adult congenital heart disease (ACHD) affects people aged 16 and over living with a heart defect acquired during fetal development. Largely as a consequence of successful cardiac surgery in childhood, there are increasing numbers of adults with congenital heart disease with a prevalence of more than 4 per 1,000 adults. The number of ACHD patients with complex disease is increasing with 10% of the ACHD population now falling within the complex group.

Congenital heart disease is diagnosed antenatally, during childhood or may remain undetected until adult life. Most patients with ACHD require access to expert care and advice throughout their lives. The patient's condition requires regular monitoring, supported by diagnostic investigations. Adults with ACHD may require a variety of interventions including transcatheter intervention, cardiac surgery, interventional electrophysiology and pacing procedures, advanced heart failure management, palliative care and transplantation. The majority of ACHD patients require ongoing follow-up and treatment throughout adult life in a centre with expertise in ACHD.

How the service is organised

Services are delivered in a three-tier system. Level 1 (Specialist ACHD Surgical Centres) deliver all ACHD care including cardiac surgery, catheter intervention, interventional electrophysiology and pacing. Level 2 (Specialist ACHD Centres) deliver all non-invasive specialist ACHD care and certain units may also provide a limited catheter intervention service to close atrial septal defects and patent foramen ovale. Level 3 (Local ACHD Centres) provide outpatient ACHD services under network arrangements with a Level 1 or 2 unit. Services in Level 3 units are led by a consultant cardiologist with special expertise in ACHD.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in in 2023/24 in line with national standards (specifications and policies)

ICBs commission all adult congenital heart disease services delivered by Level 1 and 2 units. This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services provided by Local ACHD Centres (Level 3 units).

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 13X
- 13Y

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Adult critical care activity via SUS
- Aggregate and patient level Contract Monitoring via Data Landing Portal
- Providers are also routinely required to submit data to the following clinical registries/databases as appropriate:
    - National congenital heart disease audit (part of the national cardiac audit programme)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data, which requires the use of Treatment Function Code 331 (Congenital heart disease) as the basis for identification.

2A. Adult oesophageal gastric services in the form of gastro-electrical stimulation for patients with intractable gastroparesis

[Programme of Care – Internal Medicine, CRG – Specialised Colorectal Services]

Service summary

Adult oesophageal gastric services include activity provided by Adult Specialist Oesophageal Centres.

Other relevant service(s):

- 110. Specialist gastroenterology, hepatology and nutritional support services for children

About the condition/service

Gastroparesis describes a condition where there is delayed emptying of gastric content without mechanical obstruction. Symptoms include nausea, vomiting, abdominal pain, distension and bloating. In severe cases these symptoms can result in failure to maintain body weight and hydration significant enough to require hospital admission. Severe metabolic disturbance can occur. It is associated with a reduction in quality of life. The mainstay of treatment for gastroparesis is based on dietary modification and prokinetic medications. Invasive procedures are possible in more severe and intractable cases. Gastro-electrical stimulation has been suggested as a potential treatment option for individuals with intractable gastroparesis. The treatment involves the insertion of electrodes, which are fixed to the muscle of the lower stomach. The connector end of each lead is then attached to the neurostimulator. When the neurostimulator is turned on, electrical impulses are delivered via the electrodes. The aim of gastro-electrical stimulation is reduced symptoms and enhanced gastric emptying.

How the service is organised

Services are delivered by Adult Oesophageal Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all gastro-electrical stimulation services for adults with intractable gastroparesis.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other services for patients with gastroparesis.

Change of service commissioner

There are no plans to review commissioning arrangements for this service

Identification Rules information

NCBPS service code(s)

- 39A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care (CDS) via SUS
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.

3. Adult specialist pain management services

[Programme of Care – Trauma, CRG – Neurosurgery and Spinal Surgery]

Service summary

Adult specialist pain management services are delivered by multi-disciplinary teams working in tertiary settings to manage patients where locally commissioned pain services have not achieved adequate symptom control. They include the tertiary level management of condition-specific presentations as well as complex cases of a more generic nature. Adult specialist interventions may include: pain-specific psychological interventions; inpatient care; complex medicines optimisation; follow up; and rehabilitation. Patients may be treated either within the tertiary setting or via a networked approach with more local providers.

Other relevant service(s):

- 63. Specialist pain management services for children

About the condition/service

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

Adult specialist pain management services treat patients with complex problems, including:

- Multiple system involvement
- Inpatient pain medication optimisation for highly complex patients requiring constant supervision in an inpatient setting. This includes drug dependency associated with prescribed medications for managing pain
- Pain related psychological and psychosocial problems that significantly complicate pain symptoms and rehabilitation
- Cancer patients refractory to specialist medical management provided by palliative care or local specialist pain services, including as a consequence of radiotherapy and chemotherapy

Inpatients with specific complex pain and pain-associated disability who remain on wards for significant periods of time, or frequent attenders who require input from an inpatient multidisciplinary pain team

How the service is organised

Adult Specialist Pain Management Centres are providers that meet the following criteria:

- Have a combined catchment area of over one million
- Have multispecialty and multi-disciplinary clinics and pain assessment
- Have medical input from more than one specialty
- Deliver interdisciplinary and multidisciplinary pain assessment, management and rehabilitation by appropriately trained pain specialists for specified areas of pain medicine
- See patients with complex pain and pain-associated disability
- Provide complex pain interventions
- Provide training for pain management specialists working in secondary and community care settings
- Operate in a dedicated pain management environment
- Collect pain management specific outcome data to inform future developments

Referrals are from secondary or tertiary care sources.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist pain management services from Adult Specialist Pain Management Centres, including services delivered on an outreach basis as part of a provider network. The service includes interdisciplinary and multispecialty assessment and, for specified interventions (including spinal cord stimulation and other neuromodulation), the service includes procedure costs, devices, specialist pain-specific psychological interventions, inpatient care, follow up and rehabilitation.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the majority of community and local specialist secondary care pain management services, including those secondary care services where the provider is also an Adult Specialist Pain Management Centre. ICBs commission spinal cord stimulation and other neuromodulation where this does not take place in Adult Specialist Pain Management Centres as part of a specialised episode.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 31Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS to SUS (where service provided) Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Outpatient activity should be identified by application of the IR software tool.
2. There is no identification rule for inpatient activity and therefore providers are required to employ local identification processes to identify any associated activity meeting the service specification. Where inpatient activity is identified, it must be annotated with the NCBPS31Z service code within all relevant datasets.

4. Adult specialist respiratory services

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

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

Other relevant service(s):

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

A. Complex home ventilation

About the condition/service

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

How the service is organised

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

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions complex home ventilation services from Specialist Respiratory Centres.

B. SEVERE ASTHMA

About the condition/service

Over five million people suffer from asthma in the UK and it remains responsible for more than 1,200 deaths each year. The vast majority of patients with asthma have mild to moderate disease and have the potential to be well-controlled with existing therapies, assuming that well-established national guidelines are followed. A small proportion of patients, estimated at less than 5% of all asthmatics, have severe asthma. These patients have ongoing daily symptoms despite maximal medical therapy, may suffer from side effects due to cumulative oral steroid exposure and are more likely to be admitted to hospital and to access out-of-hours emergency healthcare than asthmatics with mild to moderate disease. Biologic therapies are approved by NICE for the treatment of severe uncontrolled asthma. They reduce exacerbations, hospital admissions and oral steroid dependence, preventing steroid related side effects.

How the service is organised

Each severe asthma centre receives referrals from nearby secondary care sites and from their local area. Patients referred to a severe asthma centre are systematically evaluated by a dedicated multi-disciplinary team (MDT).

Centres in England contribute to the UK Severe Asthma Registry to ensure a national governance process and allow benchmarking via the NHS Quality Dashboard.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission severe asthma services from Specialist Respiratory Centres.

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

- An episode of acute severe asthma, which is life threatening, and requiring invasive ventilation
- Requirement for maintenance oral steroids for at least three months at a dose equal to or above 5 mg prednisolone per day or a daily dose equivalent of this averaged over 12 months

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[4] https://www.brit-thoracic.org.uk/standards-of-care/guidelines/btssign-british-guideline-on-the-management-of-asthma/

- Three or more exacerbations treated with prednisolone within the last 12 months in patients despite prescribed medications and adherent to high dose inhaled steroids
- Referred as an adolescent transition patient from a paediatric severe asthma service.
- Any patient that the referrer deems as needing input from the specialist severe asthma MDT

The decision to start biologic therapy is determined by the severe asthma MDT. Once initiated on a biologic, patients require ongoing monitoring to assess treatment response and to stop and potentially switch the targeted therapy if treatment is ineffective.

C. INTERSTITIAL LUNG DISEASE

About the condition/service

Interstitial lung diseases comprise a broad spectrum of conditions, all of which are characterised by inflammation or fibrosis of the alveolar wall with impairment of gas exchange. The commonest of these conditions are idiopathic pulmonary fibrosis (IPF), sarcoidosis and hypersensitivity pneumonia (HP), formerly known as extrinsic allergic alveolitis (EAA). It has been estimated that over 5000 new cases of IPF are diagnosed each year in the UK, and over 30,000 are living with the condition. Sarcoidosis has an incidence of around 7 per 100,000 per year in the UK. ILD is also common in patients with connective tissue diseases (also known as collagen vascular diseases) such as rheumatoid arthritis and scleroderma and in some cases up to 80% of these patients develop ILD. There are many other less common causes of ILDs (e.g. non-specific interstitial pneumonitis, desquamative interstitial pneumonitis, respiratory bronchiolitis interstitial lung disease, acute interstitial pneumonia, lymphocytic interstitial pneumonitis, pulmonary alveolar proteinosis, histiocytosis X and lymphangioleiomyomatosis (LAM)) each with an estimated incidence of between 0.1-5 per 100,000 individuals per year

Drug associated ILD is increasing in incidence. The introduction of novel therapeutic medication in the treatment of many cancers, such as checkpoint inhibitors, have the potential to cause severe, potentially fatal pneumonitis, and is a source of increasing referrals to ILD specialists. Finally, ILD specialists now see patients with (in some cases severe) pulmonary fibrosis as a complication of acute Covid pneumonitis, as well as patients who have interstitial lung abnormalities (ILAs) detected on CT screening for lung cancer.

How the service is organised

Over 4,000 new patients are diagnosed with ILD in England each year with the majority having either sarcoidosis or IPF. Disease-specific management plans are drawn up following MDT assessment at regional specialist units. Networks of care need developing so that the majority of subsequent follow up is provided in local secondary care units. Centres in England contribute to the British Thoracic Society (BTS) ILD Registry.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission interstitial lung disease services from Specialist Respiratory Centres.

D. All adult specialist respiratory services

What NHS England directly commissions in line with national standards (service specifications and policies)

- Management of central airway obstruction: this may include tumours or foreign bodies and requires specialist expertise under bronchoscopy for management or removal).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other respiratory services, including:

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

Change of service commissioner

There are plans to review whether complex home ventilation and management of central airway obstruction should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- Management of central airway obstruction: 29E

- Alpha 1 antitrypsin service: 29H
- Lung volume reduction 29L
- Interstitial lung disease: 29M
- Severe asthma: 29S

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS (in relation to interstitial lung disease and severe asthma)
- Adult critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Severe asthma – uploading of information into the British Thoracic Society asthma database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient attendances used to support the clinical management of interstitial lung disease patients can be identified by applying the list of diagnosis codes to outpatient data or using locally held registries of patient who meet the service definition as described in the Manual. If the provider is able to identify severe asthma patients locally, then these should be flagged as specialised and activity submitted to SUS including the NCBPS29S service code.

NCBPS service code(s)

- Complex home ventilation: 29V

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Local data flow

How the activity for this service is identified

Activity can be identified through locally agreed identification rules. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. The text above provides a description of the prescribed service. Specialised providers and commissioners are required to agree a commissioning process to secure provision of a service, supported by locally agreed identification and recording of relevant activity. Such identified activity should be included within contract monitoring dataflows to enable commissioners to quantify activity volumes.

5. Adult specialist rheumatology services

[Programme of Care – Internal Medicine, CRG – Specialised Rheumatology]

Service summary

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

Other relevant service(s):

- 27. Behçet's syndrome service (adults and adolescents)
- 38. Complex Ehlers Danlos syndrome service (adults and children)
- 129. Specialist rheumatology services for children

About the condition/service

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

How the service is organised

Specialist Rheumatology Centres are each an Adult Specialist Rheumatology Centre for the treatment of one or more rare conditions or specified common conditions with complex needs. Most of these work in informal networks, sharing care with the referring unit.

What Joint Committees (NHS England and Integrated Care Boards (ICBs) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist rheumatology services from Adult Specialist Rheumatology Centres for patients with rare conditions or patients who have specified common conditions with complex needs. This includes services delivered on an outreach basis as part of a provider network.

ICBs commission:

A. Paediatric and transitional care rheumatology (as part of Specialist rheumatology services for children)

B. Inherited disorders of connective tissue and complex metabolic bone disorders:
    - Ehlers Danlos syndrome

    - Marfan syndrome
    - Skeletal and other dysplasias
    - Osteogenesis imperfecta
    - Dysostoses
    - Fibrous dysplasia
    - Osteopetroses
    - Osteosclerosis

C. Severe manifestations of autoimmune rheumatic disorders:
    - Systemic lupus erythematosus
    - Antiphospholipid syndrome
    - Systemic sclerosis/scleroderma (including severe secondary Raynaud’s, scleroderma-like diseases such as severe morphea, fasciitis and eosinophilic fasciitis)
    - Primary Sjogren’s syndrome
    - Relapsing polychondritis
    - Myositis/inflammatory muscle disease
    - Overlap autoimmune connective diseases with features of myositis, systemic lupus erythematosus and/or systemic sclerosis

D. Severe manifestations of vasculitides, including:
    - Giant cell arteritis (and polymyalgia rheumatica)
    - Rheumatoid vasculitis
    - Granulomatosis with polyangiitis (formerly known as Wegener’s granulomatosis)
    - Polyarteritis nodosa and microscopic polyangiitis
    - Eosinophilic granulomatosis with polyangiitis (formerly known as Churg Strauss syndrome)
    - Behçet’s disease
    - Takayasu’s arteritis
    - IgA vasculitis (formerly known as Henoch Schonlein purpura)
    - Cryoglobulinaemia

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other rheumatological services, including:

- All new patients presenting with undiagnosed musculoskeletal symptoms for evaluation and initial management;
- Patients transferring from paediatric to adult rheumatology services with well-controlled disease;
- Rheumatoid arthritis, spondyloarthritis, reactive arthritis, septic arthritis, crystal arthritis, mild polymyalgia;

- The majority of bone conditions (for example, osteoporosis, Paget's disease, regional bone disorders, osteomalacia, other metabolic bone diseases); and
- All patients with autoimmune rheumatic diseases or rare arthropathies, where the diagnosis is already established, and the manifestations are well-controlled by conventional management and the patient and the rheumatologist are satisfied with treatment response and progress of the disease.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 26Z

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Local management of a patient list/registry/database of patients that meet the prescribed service definition

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Providers are advised to use a facility like a specialist Rheumatology MDT to identify patients who meet the criteria of specialist Rheumatology. The MDT is advised to log details about those patients on a local registry when specialist diagnosis is confirmed and then remove them from the local registry once specialist management is no longer required. This can be used as a reference point for commissioning data flows.
2. The IR software tool does not include an identification rule for inpatient activity. If specialist rheumatology providers have the capability to identify specialist inpatient rheumatology activities (expected to be limited to day case activity) based on the patient registry above, then those activities should be flagged locally using the NCBPS26Z service code.
3. The IR software tool does include an identification rule for outpatient activities based on two Treatment Function Codes and provider organisation code. This is a simplistic approach to identification and is expected to be replaced with a more comprehensive identification rule in the future.

6. Adult secure mental health services

Whilst this section makes reference to ‘women’, it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Mental Health, LD and Autism, CRG – Adult Secure Services]

Service summary

Adult secure mental health services include high, medium and low secure inpatient care and associated non-admitted care including Access Assessment Services and Forensic Outreach and Liaison Services when delivered by a specialist service.

Other relevant service(s):

- 98. Specialist secure forensic mental health services for young people
- 116 Specialist mental health services for Deaf adults

About the condition/service

Secure adult mental health services are provided to adults who:

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

All patients admitted to a secure inpatient setting will have undergone an Access Assessment to determine the appropriate level of security required to safely deliver services.

Patients in secure inpatient settings are detained under the Mental Health Act as their risk of harm to others and risk of escape from hospital cannot be managed safely within other mental health settings. Patients typically have complex chronic mental disorders that are linked to offending or seriously harmful behaviour. Some are involved with the criminal justice system (CJS), courts and prison and may have Ministry of Justice (MoJ) restrictions imposed.

A number of sub-specialist secure inpatient services are commissioned to meet the specific needs of patients who are Deaf, have personality disorders, neurodevelopmental disorders including learning disabilities and/or autism or acquired brain injuries.

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

How the service is organised

Secure inpatient services for adults are provided at three levels:

- High secure services provide care and treatment to those adults who present a grave and immediate risk to the public and who must not be able to escape from hospital
- Medium secure services provide care and treatment to those adults who present a serious risk of harm to others and whose escape from hospital must be prevented
- Low secure services provide care and treatment who present a significant risk of harm to others and whose escape from hospital must be impeded

All secure services provide:

- Assessment, management and treatment of mentally disordered offenders
- A comprehensive range of physical, procedural and relational security measures
- Advice, liaison and collaborative working across multiple other agencies including the criminal justice system
- The provision of reports for court and legal purposes

Access to secure inpatient services is managed through the Access Assessment Service delivered by medium and low secure services. The Access Assessment is a crucial part of the secure care pathway, its purpose is to:

- Determine if admission to secure care is necessary and to consider alternatives to admission
- Provide specialist clinical assessment and formulation of the mental health and risk management needs of an individual. This assessment is used to inform decisions about the most appropriate inpatient placement for the person in terms of their care and treatment needs and the level of security required.
- Inform clinical decisions regarding the readiness or need for patients to move within the secure care pathway between levels of security, for example, stepping down from high to medium or from medium to low secure services.

Forensic Outreach and Liaison Services (FOLS) are a vital component in supporting and facilitating delivery of safe and effective transitions of high-risk patients from medium and low secure inpatient care back into the community. Making the transition from secure inpatient services to the community is recognised as a particularly difficult time for patients. FOLS provide ongoing mental health assessment, formulation and treatment to promote recovery and manage risk during and after transition between services.

This involves:

- Facilitation of the transition to the appropriate Community Mental Health Team; or
- Outreach care (including care coordination) from the Specialist Centre particularly in respect of the management of risk; or
- Sustained and non-time limited outreach for those patients requiring the specialist risk management and support from the Specialist Centre, as part of a sustained, frequently multi-agency risk management approach.

Local area protocols need to take into account the needs of those discharged from secure inpatient care in a particular geographical region, including the nature of disorders (for example, neurodevelopmental disorder and learning disability) and demand issues such as numbers and complexity of high risk individuals with recognised mental disorders.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Offender Personality Disorder services, High Secure services, Medium and Low Secure Acquired Brain Injury (ABI), Medium and Low Secure Deaf adults, Women's Enhanced Medium Secure Service (WEMSS), medium and low secure services and associated non-admitted care including Access Assessment Services and FOLS for those detained under the Mental Health Act.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

Integrated Care Boards (ICBs) commission services for patients on the secure pathway who do not or no longer require high, medium or low secure care or FOLS.

Change of service commissioner

There are plans to review whether further services could be delegated to ICBs including WEMSS, Medium and low secure ABI and medium and low secure Deaf services.

Identification Rules information

NCBPS service code(s)

- 22S

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set submitted via NHS Digital Strategic Data Collection Service
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and MHSDS data.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Service. Activity is identified via attribution of Specialised Mental Health Service Category Codes by providers, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

7. Adult specialist cardiac services

[Programme of Care – Internal Medicine, CRG – Cardiac Services]

Service summary

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

- All cardiac surgery activity
- Adult complex cardiac rhythm management
- Inherited cardiac condition services including genetic testing (but not services for) patients with heterozygous familial hypercholesterolaemia
- Complex interventional cardiology services
- Primary percutaneous coronary intervention (PPCI) services for ST-elevation myocardial infarction
- Provision of cardiac magnetic resonance imaging (cardiac MRI)

Other relevant service(s):

- 2 Adult congenital heart disease services
- 57. Heart and lung transplantation service (including mechanical circulatory support) (adults and children)
- 72. Major trauma services (adults and children)
- 83. Paediatric cardiac services
- 93. Pulmonary thromboendarterectomy service (adults and adolescents)

A. CARDIAC SURGERY

About the condition/service

Cardiac surgery is a surgical sub-specialty within the specialism of cardiothoracic surgery and includes provision of surgical interventions for coronary artery disease requiring surgical revascularisation, valve disease requiring surgical valve repair or replacement, surgery of the aorta in the thorax, both emergency and elective, surgery to deal with trauma involving the heart and a group of miscellaneous conditions such as primary surgery for cardiac arrhythmias and resections of muscular obstruction within the heart.

How the service is organised

The service is provided by cardiac surgery centres.

B. ADULT COMPLEX CARDIAC RHYTHM MANAGEMENT SERVICES

Cardiac electrophysiology and ablation

About the condition/service

Cardiac electrophysiology studies and ablations are usually performed for symptomatic fast heart rhythms. The electrophysiology study allows the specialist to diagnose the precise problem and judge where to perform ablation. Ablation involves heating (or sometimes freezing) small areas of the heart muscle in order to prevent the heart racing.

How the service is organised

Specialist centres provide electrophysiology services.

Complex device therapy

About the condition/service

Implantable cardioverter defibrillators (ICDs) are small, battery-powered electrical impulse generators that are implanted in patients at risk of sudden death.
In 2019/20, 5,304 patients had an ICD implanted (94 per million of the population).

Cardiac resynchronisation therapy (CRT) resynchronises the contractions of the heart ventricles by sending tiny electrical impulses to the heart muscle. In 2019/20, 3,678 patients had a CRT-D (defibrillator) device implanted (66 per million of the population). CRT-Ds also incorporate the additional function of an ICD to quickly terminate an abnormally fast, life-threatening heart rhythm. (BHRS, NICOR 2021). Depending on the device and the number of activations, ICDs/CRT-Ds need replacing after a number of years as the battery life declines. Specialised cardiac centres undertake revisions based on their caseload volume and complex case mix.

How the service is organised

Specialist centres implant ICDs and CRT-Ds.

C. INHERITED CARDIAC CONDITION SERVICES – see also 83. Paediatric cardiac services

About the condition/service

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

Hypercholesterolaemia is defined as a raised level of cholesterol in the blood, typically including elevated low-density lipoprotein cholesterol (LDL-C). In some people, hypercholesterolaemia is caused by an inherited genetic condition known as familial hypercholesterolaemia (FH). FH may be heterozygous (inherited from one parent) or, rarely, homozygous (inherited from both parents). Homozygous FH is rare, with an incidence of approximately 1 case in a million.

How the service is organised

Specialist centres treat patients with inherited cardiac conditions, although others provide elements of care through formal and informal links with these centres.

D. COMPLEX INTERVENTIONAL CARDIOLOGY SERVICES

About the condition/service

There are a number of therapeutic interventional cardiology procedures which are carried out in relatively small numbers nationally when compared with the more common procedures used for treating coronary artery disease. These procedures include TAVI (Transcatheter Aortic Valve Implantation), BAV (Balloon Aortic Valvuloplasty), BMV (Balloon Mitral Valvuloplasty) and Alcohol Septal Ablation for selected patients with Hypertrophic Cardiomyopathy, mitral valve leaflet repairs and others. These procedures are not carried out as ’open’ operations but generally require insertion of instruments through the skin and into the body to treat a problem Complex interventional cardiology procedures utilise new and/or evolving techniques and/or devices, require a high level of expertise and familiarity with the techniques and are performed in relatively small numbers; for all these reasons, centralisation of resources in a limited number of centres is required to ensure consistently good clinical outcomes. Some of these procedures are specifically separately identified to those undertaken as part of the adult congenital heart service.

How the service is organised

Specialist centres undertake complex interventional cardiology procedures.

E. PRIMARY PERCUTANEOUS CORONARY INTERVENTION (PPCI) SERVICES FOR ST-ELEVATION MYOCARDIAL INFARCTION

About the condition/service

Percutaneous coronary intervention (PCI), or coronary angioplasty, is a procedure carried out under local anaesthetic in which narrowings (stenoses) of the coronary arteries are dilated with a balloon catheter and are then treated with a stent (a tubular metal alloy device), which is implanted in the artery. The stent provides a permanent internal scaffold to maintain patency of the artery; ICBs commission most of these procedures. However, in patients with a specific form of heart attack known as ST segment elevation myocardial infarction (or STEMI), the artery supplying the relevant area of heart muscle is usually completely blocked by a combination of atheroma and blood clot. Primary angioplasty (PPCI) is the use of the PCI technique to relieve the blockage as the main or first treatment for patients suffering a heart attack; PPCI requires emergency access to the treatment to maximise benefit. NHS England commissions this aspect of angioplasty. In 2020/21 there were 21,489 PPCI procedures completed in England (BCIS 2020/21 data).

How the service is organised

Specialist centres provide PPCI, which should be on a 24/7 basis.

F. CARDIAC MAGNETIC RESONANCE IMAGING

About the condition/service

Cardiac MRI is a specialist radiation-free technique that allows assessment of the anatomy, function and viability of the heart. In addition, cardiac MRI can also detect ischaemia (reduction in blood supply) infarction (heart tissue death caused by reduced blood supply); it can be used to assess congenital heart disease, the cause of heart failure, heart valve dysfunction and the presence of inherited diseases.

How the service is organised

Cardiac MRI services are provided by specialist centres, many of which have scanners used exclusively for cardiac MRI.

ALL SPECIALIST ADULT CARDIAC SERVICES

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist cardiac services from Adult Specialist Cardiac Centres, including services delivered on an outreach basis as part of a provider network. Adult specialist cardiac services include:

- all cardiac surgery activity
- adult complex cardiac rhythm management
- inherited cardiac condition services (all ages), including genetic testing (but not services for) patients with heterozygous familial hypercholesterolaemia and services for patients with homozygous familial hypercholesterolaemia
- complex interventional cardiology services
- PPCI for ST-elevation myocardial infarction
- provision of cardiac magnetic resonance imaging (cardiac MRI)

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other cardiological services, including CRT-pacemaker (CRT-P) devices), PCI (angioplasty) for patients with stable angina and patients with non-ST elevation MI (NSTEMI), most heart failure and rehabilitation services, and services for patients with heterozygous familial hypercholesterolaemia.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Cardiac surgery (inpatient): 13E
- Cardiac surgery (outpatient): 13Z
- Complex device therapy: 13A
- Cardiac electrophysiology and ablation: 13B
- Inherited cardiac conditions: 13C
- PPCI for ST-elevation myocardial infarction: 13F
- Percutaneous Transcatheter Aortic Valve Implantation: 13T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Devices Patient Level Contract Monitoring via Data Landing Portal
- Where relevant, the uploading of patient information to the National TAVI clinical database and the Central Cardiac Audit Database (CCAD)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Inpatient activity for Cardiac surgery inpatients, TAVI, Cardiac electrophysiology inpatients, inherited heart conditions should be identified by application of the IR software tool to CDS data.
2. PPCI and structural heart disease inpatients: Inpatient activity should be identified by application of the IR software tool. It is recognised that this identification rule is not a perfect match for PPCI activity and simply provides a proxy solution based on standard data flows.
3. Cardiac surgery outpatient activity should be identified by application of the IR software tool to CDS data.

4. Cardiac electrophysiology outpatient attendances used to support the clinical management of patients with cardiac arrhythmias or abnormal rhythms should be identified as specialised. There is no operational identification rule to support this element of service and therefore providers should utilise local means of identification, attributing the NCBPS13B service code to data where possible
5. Inherited heart conditions outpatient attendances used to support the clinical management of patients with inherited heart conditions should be identified as specialised. There is no operational identification rule to support this element of service and providers are encouraged to create a local method of identification, attributing the NCBPS13C service code to data where possible to do so.
6. Any critical care activity associated with spells identified using the above rules require local identification and attribution to specialised commissioning.

NCBPS service code(s)

- Cardiac magnetic resonance imaging: 13H

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

The IR software tool does not include an identification rule for this service; instead providers are required to identify unbundled activity with the HRG codes of RD08Z, RD09Z and RD10Z and attribute to the NCBPS13H service code within all relevant dataflows (as described above).

8. Adult specialist eating disorder services

[Programme of Care – Mental Health, LD and Autism, CRG – Eating Disorder Services]

Service summary

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

Other relevant service(s):

- 32. Children and young people's mental health service

About the condition/service

Eating disorders refer to a group of conditions defined by abnormal eating habits that may involve insufficient food intake, excessive exercise, binge eating or purging behaviour that result in high physical, psychological and social morbidity.

Patients with severe and complex eating disorders are defined as those with: complex psychiatric or medical comorbidity; high medical, psychiatric or social risk; and poor outcomes from standard community treatment. They generally fall into one of three categories:

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

About 900 individuals each year need access to this service.

How the service is organised

Services are delivered in Adult Specialist Eating Disorder Centres.

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

- Assessment
- Inpatient stays
- Naso-gastro tube feeding

- Intensive medical monitoring once a patient’s medical condition has been stabilised
- Provision of evidenced-based psychological therapies
- Psychosocial interventions
- Bespoke packages of intensive day treatment for individuals who would otherwise be admitted as an inpatient or as part of a discharge pathway
- Liaison with referring community eating disorder/mental health services.

Specialist outreach treatment may take the form of:

- Provision of specialist treatments for complex cases that are not available in the community service (for example, family therapy, psychodynamic psychotherapy, cognitive analytic therapy, dietetics)
- Continuation of specialist psychological treatment/MDT intervention provided in the inpatient unit (which may itself have been a continuation of treatment initiated in the community before admission)
- Specialist medical and psychiatric management (for example, of medically complicated cases)
- Specialist occupational therapy and nursing interventions
- Close monitoring and the facility for rapid re-admission of high-risk patients

What NHS England commissions in line with national standards (specifications and policies)

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

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

Change of service commissioner

There are plans to review whether adult specialised eating disorder services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22E

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set submitted to NHS Digital Strategic Data Collection Service
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and MHSDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

9. Adult specialist endocrinology services

Whilst this section makes reference to ‘men’, from an anatomical point of view it may also relate to trans women and individuals who identify as non-binary and who retain natal male reproductive organs.

[Programme of Care – Internal Medicine, CRG – Specialised Endocrinology]

Service summary

Adult specialist endocrinology services include services provided by Adult Specialist Endocrinology Centres for specified conditions.

Other relevant service(s):

- 5. Adult specialist rheumatology services
- 11. Adult specialist neuroscience services
- 12. Adult specialist ophthalmology services
- 105. Specialist cancer services (adults)
- 109. Specialist endocrinology services for children
- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

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

How the service is organised

Adult Specialist Endocrinology Centres provide services to patients; some deliver these services in more local hospitals through networking arrangements.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission:

A. Specialist thyroid conditions
  - All thyroid malignancies (differentiated thyroid cancer, medullary thyroid cancer and thyroid lymphoma, anaplastic carcinoma)
  - Thyroid ophthalmopathy
  - Complex thyroid conditions in pregnancy

B. Specialist calcium/bone conditions
  - Complex hyperparathyroidism (recurrent/with bone complications/localisation issues/familial)

- Complex problems of calcium/phosphate handling (including familial calcium/phosphate disorders)
- Male or juvenile osteoporosis
- Osteogenesis imperfecta (and other syndromes of high fracture risk)
- Paget's disease of bone
- Hypoparathyroidism
- Refractory hypocalcaemia

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

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

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

F. Neuroendocrine tumours of gut and elsewhere

- Carcinoid syndrome
- GI pancreatic neuroendocrine tumours
- Insulinoma
- Gastrinoma
- Glucagonoma
- Paraganglioma
- Vipomas
- Non-functioning pancreatic neuroendocrine tumours
- Neuro-endocrine tumours outside the gut
- Familial syndromes involving neuroendocrine tumours

G. Familial endocrine disorders, for example:
  - Multiple endocrine neoplasia syndromes
  - Von Hippel Lindau disease
  - Neurofibromatosis
  - Familial paraganglioma syndromes
  - Familial medullary carcinoma
  - Familial hyperparathyroidism

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

I. Rare lipid disorders
  - Familial chylomicronaemia syndrome

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission assessment and treatment services for all other endocrinology conditions, including:

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

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

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

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

E. Specific male disorders:
    - Male hypogonadism and androgen replacement therapy
    - Gynaecomastia
    - Erectile dysfunction
    - Assessment of male infertility

F. Endocrine disorders of pregnancy:
    - Thyroid disorders

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

H. Miscellaneous:
    - Initial assessment and management of hypoglycaemia
    - Obesity
    - Endocrinology of critical illness

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 27Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only

How to use the Identification Rules

1. The IR software tool does not contain an identification rule for inpatient activity. Should a provider have a local means to identify specialised endocrinology inpatient activity (perhaps via a patient registry) then, the inpatient activity should be attributed to the NCBPS27Z service code within all relevant dataflows (as above).
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

11. Adult specialist neurosciences services

[Programme of Care – Trauma, CRGs – Neurology and Neurosurgery & Spinal Surgery]

Service summary

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

- All neurosurgery activity
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care)
- Neurology outpatients where the outpatient has been referred by a consultant
- Neuro-interventional radiology services for acute ischaemic and haemorrhagic stroke

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

Other relevant service(s):

- 78. Neuropsychiatry services (adults and children)
- 48. Diagnostic service for rare neuromuscular disorders (adults and children)
- 77. Neuromyelitis optica service (adults and adolescents)
- 119. Specialist neuroscience services for children

About the condition/service

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

How the service is organised

Adult specialist neurosciences services are provided by Adult Neurosciences Centres and Adult Neurology Centres. Some services are delivered as outreach.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist services for patients with Creutzfeldt-Jakob disease.

This service is in the highly specialised portfolio.

NHS England commissions an inherited white matter disorders diagnostic and management service for adults (and children).

This service is in the highly specialised portfolio.

NHS England commissions Transcranial magnetic resonance guided focused ultrasound (TcMRgFUS)

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist neurosciences services provided by Adult Neurosciences or Neurology Centres, including services delivered on an outreach basis as part of a provider network.

ICBs commission:

- Neurosurgery activity, including specialist interventions (such as thrombectomy) for patients who have had a stroke
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care)
- Neurology outpatients, where the outpatient has been referred by a consultant
- Low Volume Neurosurgery activity (national, regional and those delivered at neuroscience centres).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission neurology outpatients at Adult Neurosciences or Neurology Centres that have not been referred by a consultant. ICBs also commission neurology inpatients and neurology outpatients where these are provided at local hospitals that are not Adult Neurosciences or Neurology Centres. ICBs commission services for patients who have had a stroke except where those patients need specialist interventions such as thrombectomy.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

NEURO-INTERVENTIONAL RADIOLOGY SERVICES FOR ACUTE ISCHAEMIC AND HAEMORRHAGIC STROKE

About the condition/service

There are approximately 80,000 stroke admissions in England per year. A proportion of the patients who suffer a stroke require assessment and intervention from an interventional neuroradiologist.

Interventional neuroradiology is a subspecialty of radiology that involves the investigation and treatment of patients with neurological diseases.

A combined interventional neuroradiology service must provide 6-7-day endovascular aneurysm treatment as well as a stroke thrombectomy service.

How the service is organised

The service is delivered by specialist interventional neuroradiology services within an Adult Neurosciences Centre.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission interventional neuroradiology services from Adult Neurosciences Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other areas of the stroke pathway including Hyper Acute Stroke Units (HASU), Acute Stroke Units (ASU), ambulance services for critical patient transfers, acute stroke services and stroke rehabilitation services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information – all services

NCBPS service code(s)

- Neurology: 08O
- Neurophysiology: 08P
- Neuroradiology: 08R
- Neurosurgery: 08S
- Neurosurgery Low volume procedures (national): 08E – effective from April 2023
- Neurosurgery Low volume procedures (Neuroscience centres): 08G – effective from April 2023
- Neurosurgery Low volume procedures (regional): 08F – effective from April 2023
- ICB commissioned stroke care: 08S-Exc

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Neurology inpatients: activity should be identified using the IR software tool applied to CDS data. All stroke services where a specialised procedure is not performed are eliminated from the identification rule for Neurology as these are the responsibility of ICB commissioners.
2. Neurophysiology inpatients: activity should be identified using the IR software tool.
3. Neuroradiology inpatients: activity should be identified using the IR software tool.
4. Neurosurgery inpatients: activity should be identified using the IR software tool. Routine stroke activity is identified by the NCBPS08_Exc rule and requires attribution to ICB commissioning.
5. Any critical care activity associated with the inpatient activity at 1 – 4 above (excluding stroke) requires local identification and attribution to specialised commissioning. Any critical care associated with stroke rule (NCBPS08S_Exc) should be attributed to ICB commissioning.
6. Neurology outpatients: activity can be identified using the IR software tool where the attendance is recorded to neurology service (main speciality codes 400 and 421) at an organisation listed in the provider list and where referred by a consultant.
7. All stroke services are eliminated from the identification rule for Neurology as these are the responsibility of ICB commissioners.
8. Neurophysiology outpatients: activity should be identified using the IR software tool applied to CDS data.
9. Neurosurgery outpatients: activity should be identified using the IR software tool applied to CDS data.

Changes will occur to the content of the IR for 2023/24 that will result in the IR for Neurosurgery being split into 3 separate service codes.

12. Adult specialist ophthalmology services

[Programme of Care – Trauma, CRG – Specialised Ophthalmology Services]

Service summary

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

Adult specialist ophthalmology services also include the provision of artificial eyes.

Other relevant service(s):

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

About the condition/service

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

The National Artificial Eye Service provides a manufacturing and fitting service for the supply of ocular prostheses to all eligible patients (adults and children) throughout England. The service sees about 1,000 new patients each year.

How the service is organised

Adult specialist ophthalmology services are provided within operational delivery networks. The networks comprise a group of providers working together within the patient pathway.

The National Artificial Eye Service is administrated centrally but has clinics and outreach services. There are also other artificial eye services.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Retinal Gene Therapies and Limbal Cell Treatment (Holoclar)

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist ophthalmology services from Adult Specialist Ophthalmology Networks, including services delivered on an outreach basis when delivered as part of a provider network.

ICBs commission the following specialist services, including emergency care:

- Orbital disorders (all major orbital pathology, lid tumours spreading to the orbit, exenteration, severe thyroid eye disease, provision of ocular prosthesis)
- Lacrimal disorders (complex lacrimal disorders or when there is co-morbidity)
- Oculoplastic surgery (complex surgery)
- Corneal disorders (severe anterior segment inflammation including systemic/local immunosuppression, high risk keratoplasty, endothelial keratoplasty, deep anterior lamellar keratoplasty, ocular surface reconstruction, keratoprosthesis, collagen cross linking, excimer laser to treat corneal pathology) and sclera contact lens fitting
- Eye banking and plasma/serum production
- Vitreoretinal surgery
- Medical retina services (to provide second opinions and management of uncommon conditions)
- Uveitis and scleritis (where it requires systemic or complex treatment)
- Complex surgical treatment of glaucoma
- Neuro-ophthalmology (the evaluation and multidisciplinary care of patients with a range of serious neurological conditions that may all first present with visual problems)
- Eye movement recording facilities
- Ocular genetic disorders
- Retinal prostheses

What Integrated Care Boards (ICBs) commission (in line with local specifications and policies)

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

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 37E
- 37Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified using the IR software tool and is based on a list of procedure codes.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning within contract monitoring data There is no outpatient rule present in the PSS IR software tool for this service. Health care providers are required to utilise local methods of identification to locate any specialised outpatient activity and annotate with the NCBPS37Z service code.

13. Adult specialist orthopaedic services

[Programme of Care – Trauma, CRG – Specialised Orthopaedics]

Service summary

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

Other relevant service(s):

- 65. Specialist services for adults with infectious diseases (bone and joint infections)
- 89. Primary malignant bone tumours service (adults and adolescents)
- 121. Specialist orthopaedic services for children

About the condition/service

The majority of orthopaedic services are delivered in secondary care providers. Adult specialist orthopaedic services are defined by any one or more of the following criteria:

- The rarity of the condition
- The complexity of the condition and the multi-disciplinary team required to treat it
- The expertise required to treat the condition.

How the service is organised

Services are delivered in Adult Specialist Orthopaedic Centres, some of which provide outreach clinics as part of a provider network.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist orthopaedic services from Adult Specialist Orthopaedic Centres including services delivered on an outreach basis as part of a provider network. ICBs commission the following specialist services:

- **Hip** – secondary or tertiary referred revisions; primary revision (all stages); infected revision; replacement requiring modular prosthesis; massive acetabular defects requiring bone grafting or metal augmentation; complex femoral reconstructive segmental reconstruction
- **Knee** – partial knee replacement; infected joint replacement; all revision joint replacements; autologous transplant of the knee; failed ligament reconstruction of the knee; failed osteotomy/complications of osteotomy; complex patella/femoral dysfunction

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

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

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Specialist orthopaedic surgery: 34A
- 34J
- Orthopaedic revisions: 34R

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified using the IR software tool and is based on a list of procedure codes listed in the identification rules.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning within contract monitoring data.

14. Adult specialist pulmonary hypertension services

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

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

Other relevant service(s):

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

About the condition/service

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

- Shortness of breath
- Fatigue
- Feeling faint or dizzy

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

Pulmonary hypertension has many causes and may affect up to 1% of the population. The majority of patients have pulmonary hypertension associated with left heart disease or lung disease where treatment is aimed primarily at the underlying cause. In contrast, forms of pulmonary hypertension, for which specific treatments are available aimed at the pulmonary circulation, are uncommon. Pulmonary arterial hypertension (due to narrowings in the blood vessels in the lungs) can be treated by drugs or lung transplantation. The cause may be unknown (idiopathic), but it may also be associated with other conditions including connective tissue disease, congenital heart disease, liver disease, HIV or rarely may be heritable. Chronic thromboembolic pulmonary hypertension (due to narrowings and blockages in the lungs) can be treated by surgery, angioplasty techniques and drugs or combinations of these approaches.

It is estimated that approximately 20 new patients per million of population per year with treatable forms of pulmonary hypertension such as pulmonary arterial hypertension or chronic thromboembolic pulmonary hypertension require either drug therapy of surgical intervention.

Due to the heterogenous nature of pulmonary hypertension, a significant proportion of patients with suspected severe pulmonary hypertension who are evaluated in specialist centres do not require specific therapy and on-going follow-up and are discharged for local treatment.

The severity of disease is based on the estimated one-year mortality rate based on a traffic light system of green (low risk, <5%), amber (intermediate risk 5-10%) and red (high risk >10%) of one-year mortality. This incorporates a multi-parameter risk approach including assessment of symptoms such as WHO Functional Class, exercise capacity (6-minute walk distance or incremental shuttle walk test difference) and an assessment of right ventricular function (including blood tests such as NTproBNP, right heart catheter measures or cardiac MRI measures).

The specialist service focuses primarily on patients treated with pulmonary arterial hypertension targeted therapies or mechanical intervention with the majority of patients in WHO Functional Classes III and IV.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all adult specialist pulmonary hypertension services from Adult Specialist Pulmonary Hypertension Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all services for patients with pulmonary hypertension not under the care of a Specialist Pulmonary Hypertension Centre.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 13G

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- All designated centres are required to submit data to the National Pulmonary Hypertension Audit

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified Adult Highly Specialist Pulmonary Hypertension centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning
3. Outpatient activity should be identified by application of the IR tool to CDS data.

15. Adult specialist renal services

[Programme of Care – Internal Medicine, CRG – Renal Services]

Service summary

Adult specialist renal services include:

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

Other relevant service(s):

- 49. Encapsulating peritoneal sclerosis treatment service (adults)
- 85. Pancreas transplantation services (some kidney transplants are undertaken simultaneously with the pancreas)
- 127. Specialist renal services for children
- 21A. Atypical haemolytic uraemic syndrome services (adults and children)

About the condition/service

Each year, in England, about 7,000 people start treatment for kidney failure and there are currently about 58,000 people receiving treatment for end stage kidney failure. Not treating or withdrawal of treatment leads to death in the majority of patients with kidney failure within three weeks. Of those receiving Renal Replacement Therapy:

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

'fresh' dialysis fluid lasts roughly 35 minutes and is either repeated about four times each day or performed overnight. Most often the patients are trained to carry out these treatments themselves, but some patients have this treatment with the supervision of healthcare professionals.

There were 2,903 adult kidney only transplants undertaken in the UK in 2021/22 along with 244 paediatric transplants, 884 of which involved organs from living donors. Some deceased donor transplants were undertaken in conjunction with transplantation of other organs and this included 120 kidney with pancreas transplants.

How the service is organised

Services are provided in Adult Renal Transplant Centres and Adult Specialist Renal Centres, all of which operate satellite haemodialysis units to reduce the distance patients have to travel to receive treatment.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions:

- All transplant-related care provided by Adult Specialist Renal Centres and Adult Renal Transplant Centres. Transplant-related care includes the work-up of potential living donors, recipients and post procedure care.
- All surgical transplantation activity provided by Adult Renal Transplant Centres. This includes living donor nephrectomy for living donor transplantation

NHS England commissions a management service for cystinosis (adults and children), which is a rare, autosomal recessive genetic disease, diagnosed early in childhood, usually before the age of two. It leads to an increase in many parts of the body of the amino acid cystine. This build up causes cystine crystals to form in many organs. These crystals form firstly in the kidneys and the eyes, and later in the muscles, pancreas, thyroid gland and white blood cells.

This service is in the highly specialised portfolio.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission adult specialist renal services from Adult Specialist Renal Centres and Adult Renal Transplant Centres, including services delivered on an outreach basis as part of a provider network. ICBs commission:

- All chronic dialysis services
- Intermittent haemodialysis and plasma exchange for patients with acute kidney injury of such severity that without treatment they would die excluding continuous treatments as below.

- Specific disease-modifying management for patients with intrinsic renal conditions that have a high probability to progress to end stage kidney failure without intervention. Examples include membranous glomerulonephritis or focal and segmental glomerulosclerosis.
- Outpatient assessment and preparation for renal replacement at Adult Specialist Renal Centres; this includes Low Clearance Clinics (also known as Advanced Kidney Care clinics) and procedures relating to establishing renal access prior to dialysis, for example, creating and maintaining arteriovenous fistulae or inserting peritoneal dialysis catheters
- Management and maintenance of fistulas by vascular radiology

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- Inpatient and outpatient renal services (including services for acute kidney injury for patients not requiring dialysis or plasma exchange). The majority of general nephrology patients have chronic kidney disease, which is not so severe as to warrant treatment with either dialysis or transplantation.
- The general management of intrinsic renal conditions that have a low potential to progress towards end stage kidney disease. Examples include chronic tubulointerstitial nephritis or obstructive uropathy.
- Transport for haemodialysis patients
- Continuous haemodialysis/filtrations treatments when used as a component of intensive and high dependency care

Change of service commissioner

There are plans to review whether renal transplantation services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 'Preparation for renal replacement therapy : 11C
- Renal transplantation: 11T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Providers of renal transplantation services are required to contribute data to the Kidney transplant dataset

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Access for renal dialysis inpatients: should be identified by application of the IR software tool to CDS data.
2. Renal transplantation inpatients: should be identified by application of the IR software tool to CDS data
3. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning. commissioning.
4. Access for renal dialysis outpatients: should be identified by application of the IR software tool to CDS data. Renal transplantation outpatients: should be identified by application of the IR software tool to CDS data.

NCBPS service code(s)

- Renal dialysis: 11B

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Renal Dataset
- Providers of renal services are also required to contribute data to the UK Renal Registry

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. The PSS IR software tool does not include a rule for this service. Dialysis session activity (for HD, PD delivered via hospital or homecare) can be identified from the renal registry submission made by the provider (or the clinical area) and attributed to NCBPS11B within all relevant commissioning dataflows.
2. Renal dialysis activity can also be identified using the unbundled HRGs LD01-LD13 for chronic disease and should be attributed to NCBPS11B within all relevant commissioning dataflows.

16. Adult specialist services for people living with HIV

[Programme of Care – Blood & Infection, CRG – HIV]

Service summary

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

Other relevant service(s):

- 130. Specialist services for children with infectious diseases

About the condition/service

Human immunodeficiency virus (HIV) is a virus that causes acquired immunodeficiency syndrome (AIDS), a condition in which progressive failure of the immune system allows life-threatening opportunistic infections and cancers to thrive. About 97,740 people were living with HIV in England at the end of 2020, of whom 95% were diagnosed.

How the service is organised

Whilst affected individuals tend to be concentrated in urban areas – particularly London – those in areas of low HIV prevalence require access to services that can be facilitated through local networks.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist services for the treatment of adults diagnosed with HIV from Adult Specialist HIV Treatment Centres. This includes the inpatient care provided by the Specialist Centres and outpatient care, which may be delivered as part of a provider network.

ICBs commission antiretroviral drugs (ARVs) for the treatment of HIV. This applies to individuals diagnosed with HIV. NHS England is responsible for the payment of ARVs used for post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).

PEP is used when someone has had a sexual exposure or a needle stick injury involving someone else who is known or thought to be HIV positive. Another example is where the baby of an HIV positive woman is given ARVs to prevent the baby from developing HIV. PrEP is used by individuals who do not have HIV but who are at high risk of HIV infection.

PEP drugs are delivered across a variety of settings including; Accident & Emergency (A&E) departments, maternity services, Sexual Assault and Referral Centres (SARCs) and Local Authority commissioned services such as Sexual Health and genitourinary medicine (GUM) services.

PrEP drugs are delivered through Local Authority commissioned services such as Sexual Health and GUM services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the promotion of opportunistic testing in line with NICE guidance, and treatment of conditions secondary to HIV infection, for example, neurological rehabilitation services.

What local authorities commission

Local authorities commission testing of sexually transmitted infections, including HIV. Local authorities also commission sexual health and GUM services, which provide sexual health advice, HIV prevention services including the delivery of PEP and PrEP drugs, sexual health promotion and services for the treatment of sexually transmitted infections.

How the activity for this service is identified

This service includes specified activity at specified centres, linked to the treatment of HIV in adult and children and young people living with the condition.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 14Z (service code in use 2022/23)
- 14A service code to be introduced for 2023/24 commissioning
- 14C service code to be introduced for 2023/24 commissioning

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Adults – Providers are required to upload data to the HIV and AIDS reporting System (HARS)
- Paediatrics – Providers are required to upload data to the Integrated Screening Outcomes Surveillance Service (ISOSS) – Children’s HIV and AIDS Reporting System (CHARS)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via specified dataflows. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. The PSS IR software tool can be used to identify Inpatient activity based on activity meeting the appropriate diagnosis codes.
2. Outpatient activity should be identified using a locally agreed rule, which may be based on the presence of an appropriate diagnosis code.

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17. Adult specialist vascular services

[Programme of Care – Internal Medicine, CRG – Vascular Disease]

Service summary

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

About the condition/service

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

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

How the service is organised

All providers of specialist vascular services must work together in agreed network configurations that support: centralisation of arterial surgery in arterial centres only to maintain expertise; and clear patient care pathways to enable defined elements of the pathway to be provided in local settings.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions adult specialist vascular services, including all vascular surgery and vascular interventional radiology services, with the exception of the treatment of varicose veins. This includes services delivered in non-arterial centres and on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for the treatment of varicose veins and diabetic foot services

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 30Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Providers are also routinely required to submit data to the following clinical registries/databases as appropriate:
  - The British Society of Interventional Radiology Iliac Angioplasty and Stenting Database (BIAS)
  - The Carotid Endarterectomy Audit (CEA)
  - The National Vascular Registry

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the PSS IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the PSS IR software tool to CDS data.

18. Adult thoracic surgery services

[Programme of Care – Cancer, CRG –Cancer Clinical Advisory Group]

Service summary

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

Other relevant service(s):

- 105. Specialist cancer services (adults)
- 4. Adult Specialised Respiratory Services

About the condition/service

Adult thoracic surgery involves the surgical assessment and operative treatment of all thoracic diseases. Although dominated by the management of lung cancer, about 50% of patients managed by thoracic surgeons are affected by other conditions. Data on thoracic surgical activity in England collected on behalf of the Society for Cardiothoracic Surgery (SCTS) showed that for the year 2010/11 a total of 22,548 patients required thoracic surgery of which 15,302 were major operations.

How the service is organised

Operative thoracic surgery has historically been carried out in tertiary thoracic or cardiothoracic units, with some surgeons undertaking cardiac and thoracic activity. Thoracic surgery is becoming more specialised and it is anticipated that, in the long term, mixed-practice surgeons will be replaced by consultants who only undertake thoracic surgery.

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

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs all adult thoracic surgery services from Adult Thoracic Surgery Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Complex thoracic surgery: 29B
  Outpatients: 29Z
  Lung Volume Reduction Procedures 29L

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Adult critical care activity via SUS
- Outpatient CDS via SUS
- Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

19. Alkaptonuria service (adults)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

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

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

Alkaptonuria (AKU) is a rare inherited disorder that causes considerable morbidity in the peak of adulthood due to severe premature destruction of the joints and spine. Disability, often severe, is the norm for those over 30 years of age. There are about 125 people in England with AKU.

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions alkaptonuria services for adult patients from Highly Specialist Alkaptonuria Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by the Highly Specialist Alkaptonuria Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 20A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Drug Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms,, and is undertaken by Highly Specialist Alkaptonuria Centres only.

How to use the Identification Rules

There is no nationally defined identification rules within the PSS IR tool for this service. Providers and commissioners should, where possible, locally agree suitable mechanisms for identifying activity. Where activity is identified against this service, the service code NCBPS20A should be attributed within all commissioning dataflows.

19A. Alpha 1 antitrypsin services (adults)

This service was added to the list of prescribed specialised services in 2018 on the basis that a disease-modifying therapy would be made available and that a specialised service would be required to deliver it. The therapy was originally referred to NICE but has been paused since May 2021. In the event that NICE recommends a disease-modifying therapy, NHS England will consider whether it should directly commission the service (and whether any aspects of the service should be commissioned by ICBs in line with local specifications) or whether the commissioning responsibility for the service should be delegated to ICBs.

20. Alström syndrome service (adults and children)

[Programme of Care, Women & Children - CRG – Specialised Paediatric Endocrinology]

Service summary

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

Other relevant service(s):

- 109. Specialist endocrinology services for children

About the condition/service

Alström is a rare genetic syndrome that usually presents with blindness in childhood. Patients go on to develop insulin-resistant diabetes, fibrosing cardiomyopathy (where abnormal tissue grows in the heart and stops it working effectively) and renal failure. They may also become deaf. There are fewer than 100 people affected by Alström syndrome in England.

How the service is organised

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

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Alström syndrome services for adults and children from Highly Specialist Alström Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by the Highly Specialist Alström Syndrome Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- H23

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Alström Syndrome Centres only.

How to use the Identification Rules

The PSS IR software tool does not contain rules for identification of this service. Where outpatient data is identifiable locally and the activity must be attributed to the NCBPSH23 service code within all relevant commissioning dataflows.

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21. Ataxia telangiectasia service for children

[Programme of Care – Women & Children, CRG – Paediatric Neurosciences]

Service summary

Ataxia telangiectasia services for children include services provided by Highly Specialist Children's Ataxia Telangiectasia Centres.

Other relevant service(s):

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

About the condition/service

Ataxia telangiectasia (AT) is a rare, neurodegenerative and progressive condition that starts in early childhood causing severe disability and premature death. It affects many parts of the body and a wheelchair is often needed by the age of 10. The average life expectancy is 25 years. Fewer than 150 children in England have AT.

How the service is organised

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

This service is in the highly specialised portfolio.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions ataxia telangiectasia services for children from Highly Specialist Children's Ataxia Telangiectasia Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Highly Specialist Children's Ataxia Telangiectasia Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- J23

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Outpatient CDS via SUS
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Children's Ataxia Telangiectasia Centres only.

How to use the Identification Rules

The PSS IR software tool identification rules does not include a methodology for identification of this service. Where outpatient data is identifiable locally the activity must be attributed to the NCBPSJ23 service code within all relevant commissioning dataflows.

21A. Atypical haemolytic uraemic syndrome services (adults and children)

[Programme of Care – Internal Medicine, CRG – Renal Services]

Service summary

Atypical haemolytic uraemic syndrome services include services provided by Highly Specialist Atypical Haemolytic Uraemic Syndrome Centres, including services delivered on an outreach basis as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 15. Adult specialist renal services
- 127. Specialist renal services for children

About the condition/service

Atypical haemolytic uraemic syndrome (aHUS) can occur at any age. Onset in childhood appears slightly more common than in adulthood (around 60% and 40% of all cases respectively). Most children (70%) who develop aHUS experience the disease for the first time before the age of two years. The service manages a caseload of around 130 individuals but the true incidence and prevalence of aHUS in England is uncertain because some patients remain undiagnosed. Worldwide, the prevalence of aHUS ranges from 2.7–5.5 per million population, with an incidence of about 0.40 per million population.

This service is in the highly specialised portfolio.

How the service is organised

The aim of the service is to provide national diagnostic and management advice for patients with aHUS. The service offers comprehensive diagnostic clinical and pathological investigations and expert opinion, facilitating optimal patient management on a shared-care basis with referring clinicians and other specialist services.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions atypical haemolytic uraemic syndrome service for adults and children from Highly Specialist Atypical Haemolytic Uraemic Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 11A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Atypical Haemolytic Uraemic Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not contain a mechanism for identifying activity for this service. Providers and commissioners should, where possible, locally agree suitable mechanisms for identifying activity. Where activity is identified against this service, the service code NCBPS11A should be attributed within all commissioning dataflows

22. Autoimmune paediatric gut syndromes service

[Programme of Care – Women & Children, CRG – Specialised Paediatric Allergy Immunology and Infectious Disease Services]

Service summary

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

Other relevant service(s):

- 29. Haematopoietic stem cell transplantation services (adults and children)
- 100. Severe combined immunodeficiency and related disorders service (children)
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

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

The service includes:

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

The service stabilises about 10 children each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions autoimmune paediatric gut syndrome services from Highly Specialist Autoimmune Paediatric Gut Syndromes Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 16A

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via the Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Autoimmune Paediatric Gut Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Where outpatient data is identifiable locally, the activity must be attributed to the NCBPS16A service code within all relevant commissioning dataflows.

23. Autologous intestinal reconstruction service for adults

[Programme of Care – Internal Medicine, CRG – Specialised Colorectal Services]

Service summary

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

Other relevant service(s):

- 101. Severe intestinal failure service (adults)

About the condition/service

Adult patients in the UK with chronic intestinal failure usually receive home parenteral nutrition (HPN). Autologous intestinal reconstruction in adults (AuGIR) is a surgical procedure that can be undertaken in adult patients with short bowel syndromes who are on parenteral nutrition. Patients have insufficient bowel to take in enough food by mouth to provide adequate nutrition. The aim of the service is to employ surgical techniques for autologous intestinal reconstruction (from the patient's own intestine) and lengthening. If successful, this treatment allows the patient to gain nutritional autonomy and thus cease to require, or have a reduced requirement for, HPN. This is an established procedure in children.

How the service is organised

The service covers outpatient and inpatient assessment, surgery and lifelong follow up. The service undertakes one or two procedures per annum.

This service is in the highly specialised portfolio.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions autologous intestinal reconstruction services for adults from Highly Specialist Autologous Intestinal Reconstruction in Adults Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 12A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Uploading of information to National Intestinal Failure Registry

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Autologous Intestinal Reconstruction in Adults Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS12A service code within all relevant commissioning dataflows.

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

[Programme of Care – Women & Children, CRG – Specialised Paediatric Endocrinology]

Service summary

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

Other relevant service(s):

- 109. Specialist endocrinology services for children

About the condition/service

Bardet-Biedl syndrome is a highly debilitating autosomal-recessive genetic disorder that causes early-onset blindness, renal failure, obesity, diabetes, Hirschsprung disease, urological problems and neurological deficits. About 1 in 100,000 babies are born each year with Bardet-Biedl syndrome, i.e. five or six each year in England. There service treats a caseload of around 80 individuals.

How the service is organised

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

Following this review, a management plan for local care providers is agreed and communicated to allow the local health care professionals to implement the recommendations and monitor their progress. Bardet Biedl Syndrome UK co-ordinates the clinics at the Centres and provides advocacy and support to patients attending the clinics.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Bardet-Biedl syndrome services for adults and children from Highly Specialist Bardet-Biedl Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by the Highly Specialist Bardet-Biedl Syndrome Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 20B

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Bardet-Biedl Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS20B service code within all relevant commissioning dataflows.

25. Barth syndrome service (adults and children)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

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

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

Barth syndrome is an x-linked disorder of lipid metabolism presenting as cardiac/skeletal myopathy, neutropenia (reduced white blood cell count leading to susceptibility to infection) and growth retardation with a high infant mortality rate. Patients present with frequent cardiac problems and, in two-thirds, neutropenia (reduced white blood cell count leading to susceptibility to infection). When undiagnosed or treated by non-specialists, patients typically experience frequent hospital admissions for a range of diagnostic tests and treatment of severe infections. Infections are significantly reduced through protocol-driven prescription of granulocyte colony stimulating factor (G-CSF). About 30 people in England have Barth syndrome

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Barth syndrome services for mainly male adults and children from Highly Specialist Barth Syndrome Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Highly Specialist Barth Syndrome Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 36A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Drug Patient Level Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via locally agreed mechanisms, and is undertaken by Highly Specialist Barth Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS36A service code within all relevant commissioning dataflows.

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

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

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

Other relevant service(s):

- 43. Craniofacial service (adults and children)

About the condition/service

Beckwith-Wiedemann syndrome is a disorder present at birth, characterised by an increased risk of childhood cancer and certain congenital features. One of the congenital features is macroglossia (significant enlargement of the tongue), which causes: drooling; feeding, speech, orthodontic and dental problems; and significant psychosocial consequences. About 1 in 15,000 babies are born each year with Beckwith-Wiedemann syndrome but only about half have macroglossia, i.e. about 15-20 babies each year. The service has a caseload of around 240 individuals.

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Beckwith-Wiedemann syndrome with macroglossia services from Highly Specialist Beckwith-Wiedemann Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 36B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Lading Portal
- Patient Level Contract Monitoring via Data Landing portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Beckwith-Wiedemann Syndrome Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. There is no nationally defined outpatient rule for this service. The health care provider and commissioner should agree local methods of identification to locate any specialised outpatient activity and annotate with the NCBPS36B service code within all relevant commissioning flows.

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

[Programme of Care – Internal Medicine, CRG – Specialised Rheumatology]

Service summary

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

Other relevant service(s):

- 5. Adult specialist rheumatology services
- 61. Specialist dermatology services (adults and children)

About the condition/service

Behçet’s syndrome is a chronic, inflammatory, multisystemic vasculitic disorder with a wide spectrum of clinical presentations that may include blindness, severe ulceration and cardiovascular problems. The aim of the service is to ensure that patients of all ages suffering from Behçet’s syndrome can access timely definitive diagnosis, or exclusion, of Behçet’s syndrome and receive optimal treatment equitably across the country, usually in local centres. The service has a caseload of around 2,000 individuals.

This service is in the highly specialised portfolio.

How the service is organised

The service provides multi-disciplinary, expert care for this group of patients.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and adolescents with Behçet’s syndrome from Highly Specialist Behçet’s Syndrome Centres. Behçet’s Patients’ Centres provides a co-ordinating role in the service.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 16B

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Behçet's Syndrome Centres only.

How to use the Identification Rules

The IR tool does not contain a mechanism to identify outpatient activity for this service. The health care provider and commissioner should agree local methods of identification to locate any specialised outpatient activity and annotate with the NCBPS16B service code within all relevant commissioning dataflows.

28. Bladder exstrophy service (children)

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

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

Other relevant service(s):

- 136. Specialist paediatric urology services

About the condition/service

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

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

Between 1 in 30,000 and 1 in 50,000 babies are born each year with bladder exstrophy, i.e. around 20 babies each year in England.

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for children with bladder exstrophy, primary epispadias, cloacal exstrophy (and all variants) from Highly Specialist Bladder Exstrophy Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- D23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Bladder Exstrophy Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPSD23 service code in all relevant commissioning dataflows.

29. Haematopoietic stem cell transplantation services (adults and children)

[Programme of Care – Blood & Infection, CRG – Blood and Marrow Transplantation]

Service summary

Haematopoietic stem cell transplantation (HSCT), also known as blood and marrow transplantation (BMT) services includes all care provided by Specialist Blood and Marrow Transplantation Centres including preparatory care, donation, transplant, aftercare and subsequent treatment. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 22. Autoimmune paediatric gut syndromes service
- 86. Paroxysmal nocturnal haemoglobinuria service (adults and adolescents)
- 100. Severe combined immunodeficiency and related disorders service (children)
- 105. Specialist cancer services (adults)
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)

About the condition/service

Haematopoietic stem cell transplantation (HSCT), is used to treat a wide spectrum of haematological and, increasingly, non-haematological, disorders. The most common clinical indications for HSCT are the leukaemias, lymphomas and myeloma. HSCTs are broadly divided into two main types: allogeneic and autologous transplantation.

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

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

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

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

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

How the service is organised

All centres have JACIE accreditation and be compliant with JACIE standards. Some centres have shared-care arrangements with their local referring hospitals for post-transplant care and follow up.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all blood and marrow transplantation services provided by Specialist HSCT Centres, including preparatory care (including for patients who do not go on to have transplants), donation, transplant, aftercare and subsequent treatment. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children

NHS England commissions treatments 30 days prior to transplant and up to 100 days post-HSCT. NHS England commissions all extra corporeal photopheresis in relation to HSCT services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission care for patients who are over 100 days post-transplant; this includes: long-term follow up and support; the monitoring and treatment of late effects; support for rehabilitation; and access to psychological support services.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 02Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- All patients (except those that refuse) should be registered on the British Society of Blood and Marrow transplantation and Cellular Therapy (BSBMTCT) registry
- Inpatient waiting list/prior approval request
- Donor searches
- The Transplantation Centres are also expected to contribute to the International Bone Marrow Transplant Registry (IBMTR) or the European Group for Bone Marrow Transplantation (EBMT)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data. The service specification details the point at which the NHS England picks up the commissioning of this service and the point at which commissioning is handed back to ICBs. At that point, providers are expected to record all activity under the 308 BMT Treatment Function Code.
2. The inpatient rule identifies each HSCT physically performed using appropriate procedure codes or a combination. Providers need to note the date of transplant and identify all Inpatient and outpatient activities undertaken within 100 days of the physical transplant and record the relevant NHS England commissioning hub as the responsible commissioner.
3. Outpatient activity should be identified by application of the IR software tool to CDS data
4. Particular care should be taken with the reporting and identification of donor patients (particularly where the donor work-up occurs at a different provider site form that performing the physical HSCT).
5. Commissioners of specialised services would expect to fund patients who have been identified as requiring a HSCT, who have been worked up but subsequently do not go forward with the HSCT (perhaps because an alternative treatment has been identified or is no longer required). In these circumstances provider information/finance departments should liaise with their HSCT clinical area to gather details about incomplete pathways. Generally, it is only the clinical areas involved who know the details of the patient cohort with incomplete pathways.

6. All commissioned HSCT activities should be cross referenced by the provider with the information input to the British Society of Blood and Marrow transplantation and Cellular Therapy (BSBMTCT) registry.

30. Bone conduction hearing implant services (adults and children)

This service combines the previous service 30' Bone anchored hearing aid services' with service 75 'Middle ear implantable hearing aid services'

[Programme of Care – Trauma, CRG – Specialised Ear Services]

Service summary

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

Other relevant service(s):

- 36. Cochlear implantation services (adults and children)
- 108. Specialist ear, nose and throat services for children

About the condition/service

Bone conduction hearing implants (BCHIs) are hearing aids that require surgical implantation to rehabilitate hearing loss when surgical options or conventional hearing aids are considered to be of less benefit.

Centres implant about 1,400 bone anchored hearing devices each year. Some centres implant very few devices. About 65 patients have a middle ear implant each year.

How the service is organised

Patients would normally be referred from an Audiology service when conventional hearing aids have not been appropriate or from an ENT surgeon when ear disease and hearing loss that preclude the use of conventional hearing aids is encountered.

The assessment for BCHIs is a multidisciplinary process involving audiologists, audiological scientists, hearing therapists and specialised ear surgeons. If a BCHI is considered to be an option, there is an additional requirement for the patient to trial the device and the most appropriate device used.

If middle ear implantation is considered to be an option, there may be a requirement for additional CT and/or MRI scans. Those considered for middle ear implantation also have a Direct Drive Simulator test (an active trial of middle ear stimulation).

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission BCHIs and associated implant services. This includes the multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all hearing assessments of adults and children and the associated provision of hearing aids when required. Some of these patients may then go on to have specialist assessment for BCHIs.

Change in service commissioner

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

Identification Rules information

NCBPS service code(s)

- Bone anchored hearing aid services: 32B
- Middle ear implantable hearing aid services: 32D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data
2. Outpatient appointment associated with the initial specialist assessment and inpatient surgery should be identified locally and attributed to the relevant service code within all relevant commissioning dataflows.
3. All patients currently with bone anchored hearing aids requiring annual maintenance should be identified as a separate list and their annual maintenance charge identified and recorded within the Aggregate Contract Monitoring and Patient Level Contract monitoring using the NCBPS32B.

31. Pain-related complex cancer late effects rehabilitation service (adults)

[Programme of Care – Cancer, CRG – Radiotherapy]

Service summary

Pain-related complex cancer late effects rehabilitation services include services provided by Pain-related Complex Cancer Late Effects Rehabilitation Centres, including services delivered on an outreach basis as part of a provider network.

About the condition/service

This service is for individuals who have severe and persistent pain due to the consequences of cancer treatment at any tumour site.

How the service is organised

The service provides a specialist, multidisciplinary rehabilitation service which can include residential packages.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for patients with severe and persistent pain due to the consequences of cancer treatment from Pain-related Complex Cancer Late Effects Rehabilitation Centres, supported by three oncology centres as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local therapy recommended in the management plan developed by the Pain-related Complex Cancer Late Effects Rehabilitation Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Pain-related complex cancer late effects rehabilitation Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Where a provider is able to identify inpatient care locally then the NCBPS01A service code should be applied within all relevant commissioning dataflows.

32. Children and young people's inpatient mental health service

[Programme of Care – Mental Health, LD & Autism, CRG – Child & Young People’s Mental Health Services]

Service summary

Children and young people's mental health (CYPMH) service include inpatient care, bespoke packages of care for intensive day care (as an alternative to admission) and associated out of hospital care when provided by Specialist Children and Young People’s Inpatient Mental Health Centres.

Other relevant service(s):

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

About the condition/service

Children and young people's inpatient mental health service (Tier 4 CYPMH) are specialist services for the assessment and treatment of severe and complex mental disorders in children and young people. Services are part of a specialist pathway for children and young people with a level of complexity that cannot be met by comprehensive secondary or community services. Specialised CYPMH inpatient services are provided over larger planning footprints for children and young people whose needs can’t be met clinically or cost effectively over a smaller footprint such as a single ICB. The complexity and severity rather than the nature of the disorder determines the need for specialist inpatient care.

Approximately 4,200 children and young people access CYPMH inpatient services each year.

How the service is organised

CYPMH services are delivered by Specialist Children and Young People’s Mental Health Centres and comprise a range of services including:

- General Adolescent inpatient services (which may include specialised eating disorder services)
- General Children’s Services
- Specialised Eating Disorder inpatient services
- Specialist Learning Disability inpatient services
- Psychiatric Intensive Care Units (PICU)
- Low Secure inpatient services

- Medium Secure inpatient services
- Community Forensic CYPMH services

CYPMH provision includes inpatient services, day-patient care (as an alternative to admission) and out of hospital care including specialised assessment, intervention and treatment, and advice and liaison.

The majority of referrals to inpatient services are made by community CYPMH and are for inpatient admission or day-patient care. Referrals may also be made between different types of CYPMH services, for example general adolescent services may refer patients to PICU where a brief period of more intensive inpatient treatment is required.

CYPMH inpatient services include specialist services for children and young people with complex eating disorders and some specialist Autistic Spectrum Conditions services. There are a very small number of specialised services for families who may be involved in or at risk of care proceedings and where parenting/family assessment and treatment is required.

Admission to CYPMH inpatient or day-patient settings is usually for one or more of the following reasons:
- The child or young person's level of risk associated with their mental disorder and their treatment needs means they cannot be safely cared for in a community setting or by community CYPMH specialist services
- There is a need for specialist inpatient assessment, such as assessing a response to inpatient treatment than can be provided in an outpatient/community setting
- The young person meets the criteria for compulsory treatment under the Mental Health Act

Services in the wider CYPMH pathway are multi-agency; NHS England and ICBs should liaise with Local Authority Children's Services (Social Care and Education) when planning integrated CYPMH pathways, facilitating discharge and delivering effective aftercare arrangements.

CYPMH out of hospital care should be delivered as part of an integrated pathway of care and provider network. A single team may deliver all the functions of an out of hospital care service to provide continuity of care and greater efficiencies. The range of CYPMH service functions include:
- Assessment and intensive management services for young people presenting in crisis and with high level of risk
- Access assessment to facilitate admission to inpatient care where this is clinically appropriate
- supported discharge services (step down services) to facilitate timely discharge from an inpatient setting
- planned intensive home or community-based treatment services for young people equivalent to that provided in an inpatient setting

- specialist treatment services for example for young people with eating disorders or severe self-harm (e.g. dialectical behaviour therapy) when their needs exceed the capacity or skill mix of a community CYPMH service
- specialist services for young people with complex neurodevelopmental or neuropsychiatric difficulties and other rare disorders requiring expertise not available in ICB size localities (community specialist services) and where inpatient services are environmentally unsuitable.

In the case of some CYPMH Inpatient Children's Units (excluding those delivering specialist learning disability services) out of hospital care is delivered:

- as part of pre-admission or access assessment
- during admission to ensure liaison with services in the home base area
- post-discharge as part of transition/step-down care to services in the home base area.

Out of hospital care may take the form of visits by the Inpatient CYPMH before and during admission to inpatient or day-patient care. In the post-discharge period, contact may be extended by agreement with local community CYPMH services and NHS England Area Teams to allow a period of shared care to embed interventions used in the inpatient setting in the home environment; this may require joint working with and supervision/consultation to the home-base team.

Community Forensic CYPMH are tertiary advice and consultation services for health and multi-agency professionals involved with the most complex and high-risk children and young people. More information about these services is set out in chapter 98.

CYPMH general adolescent, Learning Disability Services, PICU, low secure, medium secure and Community Forensic CYPMH cover a larger planning footprint than a single ICB.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions Child and Young People's Mental Health Services Children's services (under 13s) and Children and Young People's Mental Health Medium Secure Unit (MSU) service, including general adolescent (including eating disorders), low secure, Psychiatric intensive Care Unit (PICU), Learning Disabilities (LD) and Autism Spectrum Disorder (ASD).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission mental health services for children and young people requiring care in a range of community services which may include crisis and home treatment and outreach to reduce the risk of admission to inpatient CYPMH services.

Change of service commissioner

There are plans to review whether Children and young people's inpatient mental health services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22C

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set (MHSDS) submitted via Strategic Data Collection Service (SDCS)
- Aggregate Contract Monitoring via Data Landing Portal Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

This service includes specified activity at specified centres.

How to use the Identification Rules

1. The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document ‘Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)’. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider’s contract, or the Provider Collaborative ODS Code, as per the document ‘Determining the NHS-led Provider Collaborative’.

33. Choriocarcinoma service (adults and adolescents)

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care– Cancer, CRG – Cancer Clinical Advisory Group]

Service summary

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

Other relevant service(s):

- 105. Specialist cancer services (adults)

About the condition/service

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

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

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and adolescents with suspected and confirmed choriocarcinoma from Highly Specialist Choriocarcinoma Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01I

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Choriocarcinoma Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient appointment associated with the inpatient care should be identified locally attributed to the NCBPS01I service code within all relevant commissioning dataflows

It should be noted that:

- The identification rule attributes activities to over 19's to this service line. All activity associated with individuals under 19 years old is captured within the cancer service for teenage and young people when performed at a principal treatment centre.

34. Chronic pulmonary aspergillosis service (adults)

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

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

Other relevant service(s):

- 4. Adult highly specialist respiratory services

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The service is an assessment and long-term clinical management service of CPA. It diagnoses patients referred by appropriate hospital consultants with probable chronic aspergillosis infection and classifies the specific nature of any detected aspergillus infection. Those patients confirmed to have CPA within the parameters of this specification are offered clinically appropriate treatment options. The service has a caseload of around 400 individuals.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults with chronic pulmonary aspergillosis from Highly Specialist Chronic Pulmonary Aspergillosis Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 29Q

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Drug Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Chronic Pulmonary Aspergillosis Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Where a provider is able to identify inpatient care locally then the NCBPS29Q service code should be applied within all relevant commissioning dataflows.

35. Cleft lip and palate services (adults and children)

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

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

About the condition/service

Clefts of the lip and/or palate (CLP) are congenital anomalies resulting from failure of fusion of embryological parts forming the lip, nose and palate. They are the most common craniofacial anomaly, occurring in between 1 in 600 and 1 in 700 live births. There are approximately 1,000 new cleft births in England each year.

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

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

How the service is organised

Services are organised in Networks in England. Some elements of the specialist service are delivered in the Centres by the specialist team, some are delivered via outreach arrangements and others are provided locally but prescribed by the Centres.

The service in its entirety includes:

- Pre-natal and post-natal diagnosis
- Hospital paediatric care
- Pre- and peri-natal specialist cleft nursing, including support of new-born feeding and ongoing assessment and management
- Genetic assessment and chromosomal studies
- Multi-disciplinary pre-surgery assessment
- Initial lip and/or palate surgery and post-operative assessment
- Specialist paediatric dentistry, including dental health education
- Alveolar cleft bone grafting and associated orthodontics
- Cleft-related dento-alveolar surgery

- Velopharyngeal dysfunction (VPD) investigations, therapy, surgery and/or prosthetics with follow up, including investigation and treatment of non-cleft velopharyngeal dysfunction
- Specialist speech and language assessment and therapy
- Audiology and otology assessment and treatment of hearing problems
- Orthodontics
- Restorative dentistry including implants and prosthetics
- Orthognathic surgery/distraction osteogenesis techniques to correct cleft-related jaw deformities, including associated orthodontics
- Rhinoplasty
- Cleft lip and/or palate revisions and fistula repair
- Specialist psychological care for children, adults and families
- Revision treatment, including surgery where necessary, in adulthood
- Locally provided services (for example, health visitors, children's community services and community paediatric care, education, speech and language therapy, hearing services (audiology and ENT), sometimes local psychology support, orthodontics and primary dental care) usually prescribed by and always supported by the specialist team
- Data submission to the national register (CRANE) database

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission all specialist cleft lip and palate services provided by Cleft Lip and Palate Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies)

ICBs commission some services that support the specialist clinical pathway by providing care prescribed by the Centres. Such services facilitate care closer to home to ensure optimum outcomes for families. These services include: local speech and language therapy; local ENT and audiology; and community and local paediatric care. These locally delivered services work collaboratively with the Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 15Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Uploading of patient information to CRANE database
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. All patients diagnosed with cleft lip and palate should be documented on the CRANE database. This patient register should be cross referenced to reported provider activities.
2. Inpatient activity should be identified by application of the IR software tool to CDS data.
3. Any outpatient activity associated with this clinical care should be identified locally and attributed to the NCBPS15Z service code within all relevant commissioning dataflows.

36. Cochlear implantation services (adults and children)

[Programme of Care – Trauma, CRG – Specialised Ear Services]

Service summary

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

Other relevant service(s):

- 30. Bone conduction hearing implant services (adults and children)
- 76. NF2-schwannomatosis service (adults and children)
- 108. Specialist ear, nose and throat services for children

About the condition/service

Cochlear implants are devices used for profound hearing loss that is not appropriately helped by conventional hearing aids.

Centres implant about 1,300 devices each year.

How the service is organised

Patients may be referred to a cochlear implant service from other hearing services or ENT services and occasionally direct from GPs

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

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission cochlear implantation services. This includes the multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission general hearing assessment for children and adults some of whom may go on to have specialist assessment for cochlear implants.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 32A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data.

How to use the Identification Rules

1. The IR software tool identifies inpatient activity based on appropriate procedure codes.
2. Outpatient appointments associated with the initial specialist assessment and inpatient surgery should be identified locally and attributed to the NCBPS32A service code within all relevant commissioning dataflows.
3. All patients currently with implants and requiring annual maintenance should be identified as a separate list and their annual maintenance charge identified for attribution to the NCBPS32A service code.

37. Complex childhood osteogenesis imperfecta service

[Programme of Care – Women & Children, CRG – Specialised Paediatric Endocrinology]

Service summary

Complex childhood osteogenesis imperfecta services include services provided by Highly Specialist Complex Osteogenesis Imperfecta Centres including outreach when delivered as part of a provider network.

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

Osteogenesis imperfecta (OI) is a genetic condition characterised by bones that break easily, often from little or no apparent cause. The condition can vary quite drastically from one person to another: a person can have just a few or as many as several hundred fractures in a lifetime. About 300 children in England have severe or complex OI.

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for children with severe, atypical or complex OI from Highly Specialist Complex Osteogenesis Imperfecta Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- K23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Drug Patient Level Contract Monitoring

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Complex Osteogenesis Imperfecta Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPSK23 service code within all relevant commissioning dataflows.

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

[Programme of Care – Internal Medicine, CRG – Specialised Rheumatology]

Service summary

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

Other relevant service(s):

- 5. Adult specialist rheumatology services
- 61. Specialised dermatology services
- 101. Severe intestinal failure services
- 129. Specialist rheumatology services for children

About the condition/service

Ehlers-Danlos syndrome (EDS) is a group of heritable disorders of connective tissue. The major clinical features are hyperextensible skin, hypermobile joints and tissue fragility. In severe cases, patients can have life-threatening complications such as aortic dissection, where the layers of the wall of the aorta separate. Each of the types of EDS has its own specific management.

This service is in the highly specialised portfolio.

How the service is organised

The fully comprehensive service (under the auspices of the clinical genetics service) gives patients a precise clinical diagnosis and manages the subset in whom clinical diagnosis is not straight forward or diagnosis through laboratory testing needs to be confirmed with further clinical evaluation.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions diagnostic services for adults and children with complex EDS from Highly Specialist Ehlers Danlos Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission diagnostic services for adults and children whose EDS does not meet the definition of ‘complex’. ICBs also commission treatment services for ALL patients with EDS, including patients with complex EDS.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- M23

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Ehlers Danlos Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPSM23 service code within all relevant commissioning dataflows.

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39. Complex neurofibromatosis type 1 service (adults and children)

[CRG –Genomic Medicine]

Service summary

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

About the condition/service

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

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

This service is in the highly specialised portfolio.

How the service is organised

The service includes:

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and children with complex NF1 from Highly Specialist Complex Neurofibromatosis Type 1 Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 08A

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Genetic testing and PET-CT scan activity via Patient Level Contract Monitoring

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Complex Neurofibromatosis Type 1 Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify this activity locally and attribute the NCBPS08A service line within all relevant commissioning dataflows.

40. Complex spinal surgery services (adults and children)

[Programme of Care - Trauma, CRG – Neurosurgery & Spinal Surgery]

Service summary

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

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

About the condition/service

This service encompasses elements of care provided by spinal surgeons from both orthopaedic and neurosurgery disciplines.

How the service is organised

Services are delivered by Specialist Spinal Surgery Centres and Specialist Paediatric Spinal Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs complex spinal surgery services for adults from Specialist Spinal Surgery Centres including services delivered on an outreach basis as part of a provider network. ICBs commissions complex spinal surgery services for children from Specialist Paediatric Spinal Surgery Centres.

Integrated Care Boards commissions:

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

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

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 06Z
- 08Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.

41. Complex tracheal disease service (children)

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

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

Other relevant service(s):

- 83. Paediatric cardiac services

About the condition/service

The Complex Tracheal Disease Service assesses and treats children with severe and rare conditions affecting the trachea (long segment tracheal stenosis). Patient selection is particularly complex. The service operates on around 40 children per annum

This service is in the highly specialised portfolio.

How the service is organised

A range of surgical procedures are offered, including slide tracheoplasty.

About 60 babies and children are referred to the service each year for assessment.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions complex tracheal disease services for children from Highly Specialist Complex Tracheal Disease Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- B23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Complex Tracheal Disease Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPSB23 service code within all relevant commissioning dataflows.

42. Congenital hyperinsulinism service (children)

[Programme of Care – Women & Children, CRG – Specialised Paediatric Endocrinology]

Service summary

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

Other relevant service(s):

- 109. Specialist endocrinology services for children

About the condition/service

Congenital hyperinsulinism (CHI) is a condition characterised by excess insulin production from the pancreas, resulting in hypoglycaemia. The clinical presentation and progress of CHI lies on a spectrum, varying between those with transient hypoglycaemia to those unresponsive to medical treatment and requiring pancreatectomy. In the absence of expert management, children may show development delay because of brain injury in infancy from prolonged or recurrent hyperinsulinaemic hypoglycaemia.

How the service is organised

The service diagnoses patients (usually in the new-born period) and refers them to one of the national centres. If immediate transfer cannot be arranged, then the national centre supports the referring unit to provide appropriate care for the patient. The national centre may also require the referring hospital to carry out investigations to confirm the diagnosis of CHI. The service liaises and works with a surgical team to manage those children whose condition and response to medical management indicates that surgery is a viable option.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions congenital hyperinsulinism services for children from Highly Specialist Congenital Hyperinsulinism Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission ongoing prescription of drugs suitable for shared care.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- N23

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- PET scan activity included within the Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Congenital Hyperinsulinism Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify this activity locally and attribute the NCBPSN23 service code within all relevant commissioning dataflows .

43. Craniofacial service (adults and children)

[Programme of Care, Women & Children - CRG – Specialised Surgery in Children]

Service summary

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

Other relevant service(s):

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

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

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

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

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions craniofacial services for adults and children from Highly Specialist Craniofacial Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 15A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Craniofacial Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPS15A service code within all relevant commissioning dataflows.

44. Cryopyrin associated periodic syndrome service (adults and children)

[Programme of Care – Blood & Infection, CRG – Specialised Immunology and Allergy]

Service summary

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

Other relevant service(s):

46. Diagnostic service for amyloidosis (adults and children)

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The service assesses patients and makes or confirms a diagnosis; drug treatment may be appropriate.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and children with cryopyrin associated periodic disorder from Highly Specialist Cryopyrin Associated Periodic Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 02A

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Drug Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Cryopyrin Associated Periodic Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPS02A service code within all relevant commissioning dataflows. .

45. Cystic fibrosis services (adults and children)

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

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

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

About the condition/service

Cystic fibrosis (CF) is one of the UK's most common life-threatening inherited diseases. CF affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. About 10,800 people in the UK are living with cystic fibrosis.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all cystic fibrosis services provided by Adult Cystic Fibrosis Centres and Paediatric Cystic Fibrosis Centres. This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies)

ICBs are responsible for meeting the costs of long-term nutritional supplementation via gastrostomy or nasogastric tube feeding and all other chronic specific medication, for example long-term oral antibiotics, pancreatic enzyme replacement therapy and vitamin supplements. In addition, some ICBs are responsible for meeting the continuing costs associated with prescribing named specialist drugs initiated by the Cystic Fibrosis Centre as their GPs have a shared care arrangement with the Centre in place.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 10Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing portal
- All patients who approve their data being shared are required to be recorded on the UK Cystic Fibrosis register

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

46. Diagnostic service for amyloidosis (adults and children)

[Programme of Care, Blood & Infection, CRG – Specialised Immunology and Allergy]

Service summary

Diagnostic services for amyloidosis include diagnostic services (including specialist laboratory services) provided by Highly Specialist Amyloidosis Centres. This applies to provision in adults and children.

About the condition/service

Amyloidosis is a condition in which abnormal protein deposits accumulate in many different organs.

How the service is organised

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

The service provides a diagnostic service to about 1,400 new patients each year.

This service is in the highly specialised portfolio.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions a diagnostic service for patients with amyloidosis from Highly Specialist Amyloidosis Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the majority of treatment services for patients with amyloidosis with the exception of blood and marrow transplants, which are also commissioned by NHS England.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 02B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Cardiac MRI activity recorded in Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Amyloidosis Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS02B service code within all relevant commissioning dataflows.

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

[Programme of Care – Internal Medicine, CRG – Specialist Respiratory]

Service summary

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

Other relevant service(s):

- 4. Adult specialist respiratory services
- 88. Primary ciliary dyskinesia management service (adults and children)
- 128. Specialist respiratory services for children

About the condition/service

Primary ciliary dyskinesia is a genetic disorder of the air tubes of the lungs (the bronchi), which become infected and filled with pus due to abnormalities of the hair-like structure (cilia) of the cells lining the respiratory tract. This can lead to repeated infections and damage the lung, especially if the diagnosis is delayed. About 150 children are diagnosed with PCD each year in England.

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (service specifications and policies)

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBS do not commission any elements of the pathway.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 29D

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Primary Ciliary Dyskinesia Diagnostic Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS29D service code within all relevant commissioning dataflows .

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

[Programme of Care – Trauma, CRG – Neurology]

Service summary

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

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

Other relevant service(s):

- 11. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children

About the condition/service

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

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

This service is in the highly specialised portfolio.

How the service is organised

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

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions diagnostic services for adults and children with rare neuromuscular disorders from Highly Specialist Rare Neuromuscular Disorders Centres as well as treatment services for non-dystrophic myotonia.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended on the management plans developed by the Highly Specialist Rare Neuromuscular Disorders Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 08B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported Highly Specialist Rare Neuromuscular Disorder Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS08B service code within all relevant commissioning dataflow.

49. Encapsulating peritoneal sclerosis treatment service (adults)

[Programme of Care, Internal Medicine, CRG – Renal Services]

Service summary

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

Other relevant service(s):

- 15. Adult specialist renal services

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

EPS is a condition associated with significant morbidity and mortality and with poor outcomes if not recognised early and treated. With centralising treatment in specified national centres, experience has been consolidated leading to better patient outcomes, mirroring the best international experience.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults with encapsulating peritoneal sclerosis from Highly Specialist Encapsulating Sclerosing Peritonitis Surgical Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 11D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Any critical care stays associated with inpatient admissions via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Encapsulating Peritoneal Sclerosis Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS11D service code within all relevant commissioning dataflows.

50. Epidermolysis bullosa service (adults and children)

[Programme of Care Internal Medicine, CRG – Specialised Dermatology]

Service summary

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

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

Other relevant service(s):

- 61. Specialist dermatology services (adults and children)

About the condition/service

Epidermolysis bullosa (EB) is the name given to a group of rare inherited disorders that cause lifelong blistering and ulceration of the skin and often the mucous membranes. Blistering is almost always apparent at or soon after birth, but the severity of the condition varies greatly, depending on the type of Epidermolysis bullosa present.

This service is in the highly specialised portfolio.

How the service is organised

The national EB service aims to provide diagnosis and assessment of infants, children, adolescents and adults with suspected or known EB, supporting symptom relief and prevention of complications including long-term support.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults with EB from Highly Specialist Adult Epidermolysis Bullosa Centres.

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

Both services include:

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission dressings that are required once patients have been returned to the care of local providers. This includes where the Highly Specialist Paediatric Epidermolysis Bullosa Centre is also the patient’s local provider.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 24A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Epidermolysis Bullosa Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

51. Extra corporeal membrane oxygenation service for adults with respiratory failure

[Programme of Care – Trauma, CRG – Adult Critical Care]

Service summary

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

Other relevant service(s):

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

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The specialist centres function as a national network, working closely with their local critical care networks. All centres provide a retrieval service that includes the capability to undertake 'mobile' ECMO when this is deemed clinically necessary. The service assesses about 1,000 patients for treatment each year and about 300 of these are treated with ECMO.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions ECMO services for adults with severe potentially reversible acute respiratory failure from Highly Specialist Adult Respiratory ECMO Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission local non-specialist care once the patient has been discharged from intensive care.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 29F

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Adult Respiratory ECMO Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS29F service code within all relevant commissioning dataflows.

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

[Programme of Care – Women & Children, CRG – Paediatric Critical Care]

Service summary

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

Other relevant service(s):

- 51. Extra corporeal membrane oxygenation for adults with respiratory failure
- 57. Heart and lung transplantation service (including mechanical circulatory support (adults and children)
- 83. Paediatric cardiac services
- 122. Paediatric critical care services

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The centres work closely with local neonatal networks and paediatric intensive care units. Some patients receive mobile ECMO. The service provides treatment for about 100 patients each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions ECMO services for neonates, infants and children with respiratory failure from Highly Specialist ECMO Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission local non-specialist care once the child has been discharged from paediatric intensive care or neonatal intensive care.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- R23

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist ECMO Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPSR23 service code within all relevant commissioning dataflows.

53. Ex-vivo partial nephrectomy service (adults)

[Programme of Care – Cancer, CRG – Cancer Clinical Advisory Group]

Service summary

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

Other relevant service(s):

- 105. Specialist cancer services (adults)

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The overall aim of the service is to provide patients with complex renal tumours in solitary kidneys or bilateral disease not suitable for conventional treatments, the possibility of cancer cure and avoidance of dialysis. The service provides; initial assessment and evaluation, surgery and postoperative recovery; and long-term follow-up.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions ex-vivo partial nephrectomy services for adult patients from Highly Specialist Ex-vivo Partial Nephrectomy Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Ex-vivo Partial Nephrectomy Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS01D service code within all relevant commissioning dataflows.

54. Fetal medicine services (adults and adolescents)

Whilst this section refers specifically to ‘women’, from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Women & Children, CRG – Specialised Women’s Services]

Service summary

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

About the condition/service

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

How the service is organised

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

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission fetal medicine services provided by Fetal Medicine Centres. These include services delivered on an outreach basis by a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission those services for common fetal conditions that are provided by local hospitals.

Change of service commissioner

There are no plans to review commissioning arrangements for this service. There is a proposal to unbundle fetal medicine services from the national maternity tariff so that these elements can be separately commissioned.

Identification Rules information

NCBPS service code(s)

- 04C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Foetal Test information is required to be captured in Patient Level Contract Monitoring via Data Landing Portal
- Foetal medicine providers are required to upload information to either Viewpoint (GE Healthcare) or Astraia clinical databases
- Providers of foetal medicine services are also required to ensure that the maternity services secondary usage dataset is populated and submitted to SUS to include details of any foetal medicine tests performed

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. All foetal medicine activities are required to be uploaded to Viewpoint [GE Healthcare] or Astraia clinical databases
2. The IR software tool does not include a rule for this service. Providers are required to identify this activity locally and attribute the NCBPS04C service code within all relevant commissioning dataflows.

It should be noted that the cost of foetal medicine is covered by the maternity tariff and therefore should not be billed for separately.

55. Gender dysphoria services (children and adolescents)

[CRG – Gender Dysphoria (Children)]

Service summary

Gender dysphoria services include services provided by Gender Dysphoria Centres including outreach when delivered as part of a provider network.

Other relevant service(s):

- 32. Children and young people's inpatient mental health service
- 56. Gender dysphoria services (adults)
- 109. Specialist endocrinology services for children

About the condition/service

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

This service is in the highly specialised portfolio.

How the service is organised

The service provides outreach support to patients and families across the country. This network model of management for children struggling with the development of their gender identity involves close collaboration between the national service and local child and adolescent mental health services.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions gender dysphoria services for children and adolescents from Gender Dysphoria Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Gender Dysphoria Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS22A service code within all relevant commissioning dataflows.

56. Gender dysphoria services (adults)

[CRG – Gender Dysphoria (Adults)]

Service summary

Gender dysphoria services includes specialist assessment, non-surgical care packages, certain surgical interventions and immediate associated after care provided by Gender Dysphoria Clinics.

Other relevant service(s):

- 55. Gender dysphoria services (children and adolescents)

About the condition/service

The service accepts referrals of people who have gender dysphoria that is a consequence of their gender identity being incongruent with their physical sex characteristics and/or the social role typically associated with those characteristics (gender incongruence).

Sometimes, gender dysphoria is sufficiently intense that people elect to *transition* from one point on a notional gender continuum to another – most commonly from Male-to-Female (MtF) or Female-to-Male (FtM) but there are also other changes in gender identity expression, such as to a non-binary or non-gender expression. Transition typically involves changes to social role and presentation, as well as physical and medical intervention, and may necessitate treatment from a range of options, including psychological therapies, voice and communication therapy, cross-sex hormones and/or having gender related surgery.

How the service is organised

The gender dysphoria services pathway is complex and necessitates careful co-ordination between primary care services, secondary care services and specialised services. The delivery of specialist services for gender dysphoria (adults) falls into two main categories:

A. Gender Dysphoria Clinics provide specialist assessment, pathway co-ordination and treatment of gender dysphoria. Available treatments may include: psychological therapies, specialist voice and communication therapy; recommendations for endocrine treatments; and referral for surgical procedures and aftercare. Services accept referrals from GPs and other health professionals of people from 17 years of age believed to have gender dysphoria.

Patients referred to Gender Dysphoria Clinics are not required to have started living in their desired social gender role or to have had a psychiatric assessment or have engaged in psychotherapy prior to referral.

B. Surgical services

Surgical services offer procedures to people with gender dysphoria from 17 years of age. These procedures may include specialist genital reconstructive and other specified specialist surgeries necessary for the patient to achieve their gender expression goal.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions the following services from Gender Dysphoria Clinics:

- Assessment and diagnosis, including recommendations for endocrine treatments
- Psychological interventions
- Specialist voice and communication therapies (at specialist clinics)
- Referrals for facial depilation and donor site (surgical) epilation
- Masculinising chest reconstruction
- Feminising genital reconstructive surgery
- Masculinising genital reconstructive surgery
- Immediate surgical aftercare

Conversion therapy

Gender Dysphoria Clinics do not deliver, promote or refer individuals to any form of conversion therapy. The practice of conversion therapy is unethical and potentially harmful. For the purposes of this document 'conversion therapy' is an umbrella term for a therapeutic approach, or any model or individual viewpoint that demonstrates an assumption that any gender identity is inherently preferable to any other, and which attempts to bring about a change of gender identity, or seeks to supress an individual's expression of gender identity on that basis.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

The patient's GP is responsible for organising blood and other diagnostic tests, and for prescribing pharmacological treatments as recommended by the Specialist Gender Identity Centres.

ICBs are responsible for funding procedures that may be required by people on the transgender pathway but which are not specialised interventions for the alleviation of gender dysphoria related to gender incongruence, such as: hysterectomy and bilateral salpingo-oophorectomy as standalone procedures; non-specialist speech and language therapy; corrective surgical procedures after the patient has been discharged from the specialist surgical unit (with the exception of subsequent functional impairment experienced by a man after phalloplasty).

Discussions regarding fertility form part of the assessment by Gender Dysphoria Clinics and should take place before any treatment that potentially compromises fertility is recommended and initiated. Hormone therapy has the potential to cause infertility and its long-term use is a pre-requisite to genital surgery. Genital surgery causes irreversible loss of fertility. Patients with gender dysphoria who are to have hormone therapy or surgery and, therefore, are likely to develop infertility as an unwanted consequence of treatment, are given information about their reproductive options by the Gender Dysphoria Clinics. Those who wish to pursue sperm or egg harvesting and storage may have this funded in accordance with ICB policy, just as might any patient who is likely to become infertile as an unwanted consequence of other NHS treatments. ICBs are the responsible commissioner for the retrieval and storage of gametes, or any subsequent assisted conception treatment.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 42A Gender Dysphoria: Genital Surgery (Trans Feminine)
- 42B Gender Dysphoria: Genital Surgery (Trans Masculine)
- 42C Gender Dysphoria: Chest Surgery (Trans Masculine)
- 42D Gender Dysphoria: Non-Surgical Services (Adults)
- 42E Gender Dysphoria: Other Surgical Services

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. The IR software tool does not contain a mechanism to identify outpatient activity which is prescribed as specialised. Any outpatient activity associated with this clinical care should also be identified locally and attributed to NCBPS42D service code within all relevant commissioning dataflows.

56ZA. Ovarian and testicular cryopreservation for patients receiving gonadotoxic treatment who are at high risk of infertility and cannot store mature eggs or sperm

[Programme of Care – Women & Children, CRG – Paediatric Medicine]

Service summary

Ovarian and testicular cryopreservation for patients receiving gonadotoxic treatment who are at high risk of infertility and cannot store mature eggs or sperm include services provided by Gonadal Tissue Cryopreservation Service Centres.

About the condition/service

The service provides fertility advice, treatment, tissue cryopreservation and fertility restoration to patients who are at high risk of reproductive failure linked to treatment interventions and who cannot store mature eggs or cannot store sperm.

How the service is organised

There are three components to the service:

- Ovarian tissue cryopreservation (OTC) for patients who are at high risk of infertility, and cannot store mature eggs
- Testicular tissue cryopreservation (TTC) service for patients who are at high risk of infertility, and cannot store sperm
- Fertility and endocrine restoration using cryopreserved ovarian tissue

What NHS England directly commissions in line with national standards and policies (specifications and policies)

NHS England commissions ovarian and testicular cryopreservation for patients receiving gonadotoxic treatment who are at high risk of infertility and cannot store mature eggs or sperm include services from Gonadal Tissue Cryopreservation Service Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies)

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

To be determined

Data flows

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool does not include a rule for these services. Providers are required to identify activity locally and attribute the relevant NCBPS service code within all relevant commissioning dataflows.

56A. Hand and upper limb transplantation service (adults)

[Programme of Care – Trauma, CRG – Rehabilitation and Disability and Spinal Cord Injury]

Service summary

Hand and upper limb transplantation services include services provided by Highly Specialist Hand and Upper Limb Transplantation Centres. This applies to provision in adults.

About the condition/service

Hand and upper limb transplantation is possible following cadaveric donation. The surgery involved is extremely complex and recipients have, as with other cadaveric transplants, to take immunosuppressive drugs for life to prevent the transplanted organ being rejected.

This service provides assessment, transplantation and follow-up.

This service is in the highly specialised portfolio.

How the service is organised

The service provides assessment, transplantation and follow-up.

What NHS England directly commissions in line with national standards and policies (specifications and policies)

NHS England commissions hand and upper limb reconstruction using vascularised composite allotransplantation services for adults from Highly Specialist Hand and Upper Limb Transplantation Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies)

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 40A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Hand and Upper Limb Transplantation Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS40A service code within all relevant commissioning dataflows.

57. Heart and lung transplantation service (including mechanical circulatory support) (adults and children)

[Programme of Care – Internal Medicine, CRG – Cardiac Services] [Adults] Specialised Respiratory Services]
[Programme of Care – Women & Children, CRG – Congenital Heart Services] [Children]

Service summary

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

Other relevant service(s):

- 45. Cystic fibrosis services (adults and children)
- 52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- 70. Lymphangioleiomyomatosis service (adults)
- 83. Paediatric cardiac services

About the condition/service

(a) Heart and lung transplant service

The heart and lung transplant service provides: assessment of patients who are eligible for a heart transplant; the transplant operation; and lifelong follow up.

(b) Bridge to heart transplant using mechanical circulatory support (adults)

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

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

The implantation of a VAD may be considered in patients with advanced heart failure who are listed for a transplant and who are deemed to be deteriorating so rapidly that they would not survive long enough to receive a heart via the urgent allocation scheme. A short-term VAD can be used as a bridge to decision in extremely sick or ‘moribund’ patients who have contraindications to the implantation of a long-term VAD or urgent transplantation at the time of presentation. Contraindications must be considered acute and potentially reversible.

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

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

In 2020/21, there were 150 heart and 107 lung transplants in adults. There were 29 cardiothoracic transplants in children.

This service is in the highly specialised portfolio.

How the service is organised

In England there is one centre which provides heart and lung transplant in children; one centre which provides heart and lung transplant in children and adults; and four centres that provide heart and lung transplant in adults. In addition, one centre provides a follow up service for patients only.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions heart and lung transplant services and bridge to transplant services for adults and children from Highly Specialist Heart and Lung Transplant Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission care for patients who are on ambulatory mechanical circulatory support (older children and adults) whilst waiting for a heart transplant unless the patient requires care from a specialised service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 13N

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

- Highly Specialised data template via Data Landing Portal
- Organs transplanted data from NHS Blood and Transplant

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Heart and Lung Transplant Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
   .
3. Any follow-up outpatient activity associated with the transplant should be identified locally and attributed to NCPS13N service code within all relevant commissioning dataflows.

58. Specialist adult gynaecological surgery and urinary surgery services for females

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care - Women & Children, CRG – Specialised Women's Services]

Service summary

Specialist adult gynaecological surgery and urinary surgery services for women include complex procedures provided by Specialist Adult Gynaecological and Urinary Surgery Centres.

Other relevant service(s):

- 106A. Specialist colorectal surgery services (adults)

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

B. MANAGEMENT OF RECURRENT PELVIC ORGAN PROLAPSE/FAILED PRIMARY SURGICAL TREATMENT AND

C. MANAGEMENT OF COMPLICATIONS OF PROLAPSE OR INCONTINENCE SURGERY

About the condition/service

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

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

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

How the service is organised

Services are delivered by Specialist Adult Gynaecological and Urinary Surgery Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for patients where mesh was used to manage stress urinary incontinence and vaginal prolapse from Specialist Adult Gynaecological and Urinary Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission the following services from Specialist Adult Gynaecological and Urinary Surgery Centre:

- The investigation and management of women whose primary surgery for urinary incontinence has failed
- The investigation and management of women whose primary surgery for stress urinary incontinence has failed or who have recurrence of the condition
- The investigation and management of women whose primary surgery for pelvic organ prolapse has failed or who have recurrence of the condition

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission primary surgical treatment for urinary incontinence, primary surgery for stress urinary incontinence and primary surgery for pelvic organ prolapse.

D. MANAGEMENT OF LOWER URINARY TRACT/URETHRAL FISTULAE

About the condition/service

Lower urinary tract fistulae are most commonly caused by pelvic surgery. There are about 120 cases each year in England and Wales.

How the service is organised

Services are delivered in Specialist Adult Gynaecological and Urinary Surgery Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for the management of low urinary tract fistulae from Specialist Adult Gynaecological and Urinary Surgery Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

E. INDIVIDUALS WITH COMPLEX URINARY AND FAECAL INCONTINENCE AND WOMEN WITH GENITAL AND ANORECTAL PROLAPSE

About the condition/service

Although primary surgery for urinary or faecal incontinence and for genital or anorectal prolapse are carried out by gynaecologists, uro-gynaecologists and colorectal surgeons, women who have a combination of both urinary incontinence and anorectal incontinence or whose primary surgery has failed need specialist interventions.

How the service is organised

Services are delivered by Specialist Adult Gynaecological and Urinary Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission the following services from Specialist Adult Gynaecological and Urinary Surgery Centres:

- assessment and treatment of combined urinary and faecal incontinence
- assessment and surgical treatment of combined genital and anorectal prolapse
- incontinence combined with major prolapse, for example, grade 2 or 3 uterine descent with grade 2 or 3 cystocele
- incontinence associated with voiding difficulties
- incontinence due to a combination of significant detrusor over-activity, with sphincter incompetence
- assessment and treatment of surgical complications of treatments for urinary and faecal incontinence and genital prolapse, for example, first repeat surgery
- assessment and surgical treatment of rectovaginal fistula
- incontinence associated with neurological conditions such as paraplegia or multiple sclerosis, and/or has more than one cause simultaneously
- intractable incontinence requiring urinary or faecal diversion procedures or sacral nerve neuromodulation

- assessment and treatment of surgical complications of treatments for urinary and faecal incontinence and genital prolapse, for example, second or more repeat surgery, significant mesh complications
- repeat surgery for urinary and faecal incontinence and genital prolapse requires more expertise because the procedures are generally more complex than the initial procedure and the potential for damaging complications is considerably increased by the consequences of previous surgery

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission primary surgical treatment for urinary and faecal incontinence and for genital and anorectal prolapse. ICBs commission sacral nerve modulation for conditions other than urinary and faecal incontinence.

F. MANAGEMENT OF SEVERE ENDOMETRIOSIS

About the condition/service

Medical and surgical treatment of non-severe endometriosis is undertaken by gynaecologists with a special interest. Severe endometriosis requires additional laparoscopic expertise and often multi-disciplinary surgery with urologists and colorectal surgeons involved.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission services for patients with severe endometriosis, for example, that requiring multi-disciplinary surgery with urologists and colorectal surgeons, from Specialist Adult Gynaecological and Urinary Surgery Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission medical and primary surgical treatment of non-severe endometriosis.

G. MANAGEMENT OF CONGENITAL GYNAECOLOGICAL ANOMALIES

About the condition/service

Patients with congenital gynaecological anomalies, who fall into two groups:

- those diagnosed in childhood, who are transferring from paediatric care to adult care services; the diagnosis may have been made at birth with genital ambiguity or during childhood and adolescence with early or delayed puberty and growth, or virilisation; in addition, the diagnosis may have arisen from genetic testing because of an affected family member; and

- those who present for the first time in adolescence or adulthood; presentation may be with delayed puberty, virilisation, primary amenorrhoea or obstructed menstruation.

Conditions include:
- Disorders of sex development and Mullerian anomalies.
- Congenital absence of the vagina and/or associated gynaecological structures
- Gynaecological outflow tract obstruction with primary amenorrhoea with cyclical abdominal pain and pelvis mass
- Occluded hemi-vagina
- Virilisation
- Abnormal anatomy requiring surgical reconstruction

How the service is organised

Services are delivered by Specialist Adult Gynaecological and Urinary Surgery Centres.

This service helps young women by providing assessment, inpatient care (including dilation therapy or surgical reconstruction), expert psychology input, outpatient support and follow up care after reconstructive surgery of female genital tract.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions management services for patients with congenital gynaecological anomalies from Specialist Adult Gynaecological and Urinary Surgery Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

H. ALL HIGHLY SPECIALIST ADULT GYNAECOLOGICAL SURGERY AND URINARY SURGERY SERVICES FOR WOMEN

Change of service commissioner

There are plans to review whether services for patients where the mesh was used to manage stress urinary incontinence and vaginal prolapse should be delegated to ICBs in the future.

There are plans to review whether reconstructive surgery and congenital anomalies of the female genital tract should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 04A: Severe endometriosis

- 04D: Complex urinary incontinence and genital prolapse
- 04J: Urinary fistula
- 04K: Specialised services for women with complications of mesh inserted for urinary incontinence and genital prolapse
- 04L: Reconstructive surgery and congenital anomalies of the female genital tract

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- All providers of vaginal mesh services are required to contribute data to NHS Digital Surgical Devices and Implants Information System

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

The IR software tool should be used to identify all activity relating to these services

58A. Specialist adult urological surgery services for men

Whilst this section refers specifically to ‘men’, from an anatomical point of view it may also relate to trans women and individuals who identify as non-binary and who retain natal male reproductive organs.

[Programme of Care – Cancer, CRG – Cancer Clinical Advisory Group]

Service summary

Specialist adult urological surgery services for men include the following services when provided by Specialist Urological Surgery Centres:

- sacral nerve stimulation for urinary incontinence
- urethral reconstruction surgery
- penile prosthesis surgery
- surgical sperm retrieval

Other relevant service(s):

- 105. Specialist cancer services (adults)

About the condition/service

Specialist adult urological services for men require a critical mass of expertise in these surgical areas that is possible only in units large enough to allow specialisation in these disciplines and it is only in units receiving referrals from a wide geographical area that sufficient experience is gained.

How the service is organised

Services are delivered by Specialist Adult Urological Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission the following specialist adult urological surgery services from Specialist Adult Urological Surgery Centres:

- sacral nerve stimulation for urinary incontinence
- urethral reconstruction surgery
- penile prosthesis surgery
- surgical sperm retrieval

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission primary surgical treatment for urinary incontinence. ICBs commission sacral nerve modulation for conditions other than urinary and faecal incontinence. ICBs commission initial diagnostics for male infertility and erectile dysfunction.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Penile implants: 41P
- Surgical sperm retrieval: 41S
- Urethral reconstruction: 41U

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

Inpatient activity should be identified by application of the IR software tool to CDS data.

59. Specialist allergy services (adults and children)

[Programme of Care – Blood & Infection, CRG – Specialised Immunology and Allergy] [Adults]
[Programme of Care – Women & Children, CRG – Specialised Paediatric Allergy Immunology and Infectious Disease Service] [Children]

Service summary

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

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

Other relevant service(s):

- 61. Specialist dermatology services (adults and children)
- 115. Specialist immunology services for adults with deficient immune systems
- 115A. Specialist immunology services for children with deficient immune systems

About the condition/service

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

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

How the service is organised

Most allergy-related hospital activity takes place in an outpatient or day-case setting. Specialist services are currently delivered exclusively by adult or paediatric physicians trained in allergy or immunology or who have had long experience in the practice of allergy, or other clinicians who are directly supported within a network of such.

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

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

Integrated Care Boards (ICBs) commission Specialist Allergy Services from Specialist Allergy Centres for patients with severe allergic conditions or who have common allergic conditions for which conventional management has failed and for whom specified specialist treatments are required. This includes services delivered on an outreach basis as part of a provider network.

Integrated Care Boards commission services (including procedures and treatments) for patients with:

- **Complex drug allergy** – investigation including drug challenges, and desensitisation (antibiotics, analgesics (NSAID/aspirin/opiates), anaesthetics, contrast media, biologics) where there is a severe presentation, excluding ACE inhibitor-induced angioedema
- **Bee and wasp venom allergy requiring specific immunotherapy**
- **Vaccine allergy**
- **Anaphylaxis** that is recurrent, idiopathic or if there are multiple triggers, including all grade II and above, potentially recurrent
- **Systemic mast cell disorders (predominantly adults)**
- **Severe rhinitis/sinusitis** – allergic rhinoconjunctivitis requiring allergen specific immunotherapy; rhinosinusitis with recurrent nasal polyps or NERD (NSAID-exacerbated respiratory disease); disease unresponsive[5] to conventional therapy requiring immunotherapy; or rhinosinusitis/nasal polyps in patients with multiple previous surgical procedures.[5]
- **Hereditary angioedema**
- **Severe atopic dermatitis** – when referred from another specialist because of inability to control the disease or requirement for complex dietary manipulation
- **Severe allergic asthma** – disease requiring treatment with biologics; and Disease unresponsive to conventional therapy[5], including aspirin sensitive and severe fungal allergy
- **Hypereosinophilic disorders** – managed predominantly in a subset of the specialist centres

Specialist Allergy Centres should have expertise in delivering the following specialist treatments:

- **Specialist allergy testing techniques** – using drugs, foods or venom (skin prick/intradermal not available elsewhere)
- **High risk allergen challenge/provocation testing** – both high risk individuals and provocation to rare allergens when other procedures have failed to diagnose allergy using foods/venom/latex/aeroallergen and drug

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[5] As per British Society for Allergy and Clinical Immunology guidelines

challenges including aspirin, NSAIDs, penicillins and other antibiotics (oral, injected, subcutaneous, inhaled, nasal)

- **Immunotherapy** – the most severe patients requiring hospital-based injected allergen and home-based treatment via oral sublingual immunotherapy[5]
  Multi-disciplinary team management of the complex patient – including ENT, respiratory medicine, immunology and dermatology with specialist allergy nurses, allergy dietician, social care and laboratory diagnostic support providing comprehensive management
- **Drug allergy investigation and de-sensitisation (oral or injected)** – high risk desensitisation procedures for antibiotics and biologics
- **Biological therapies for severe allergic asthma**

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other allergy services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 17Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contact Monitoring via Data landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

61. Specialist dermatology services (adults and children)

[Programme of Care – Internal Medicine, CRG – Specialised Dermatology]

Service summary

Specialist dermatology services include services provided by Specialist Dermatology Centres for patients with rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 50. Epidermolysis bullosa service (adults and children)
- 105. Specialist cancer services (adults)
- 143. DNA nucleotide excision repair disorders service (adults and children)

About the condition/service

It is estimated that about 10% of patients requiring dermatology services (about 10,000 each year) need care from Specialist Dermatology Centres.

Adult dermatology services are provided in local hospitals and deal with a wide range of conditions. Specialist adult dermatology services include the diagnosis, investigation and treatment of rare diseases and the management of severe diseases not suitable for, or not responding to, conventional treatment available in local dermatology departments. These cases usually require multidisciplinary input (for example, surgery, radiology, haematology, immunology, oncology, ophthalmology, nephrology, respiratory, cardiology and genetics), which may be delivered in a multidisciplinary clinic.

Similarly, paediatric dermatology services are available in most local hospitals and include a wide range of conditions. Paediatric dermatology services are usually provided by dermatologists in local hospitals often with support from paediatricians. Specialist paediatric dermatology services incorporate any skin condition affecting a child, which a general dermatologist or paediatrician has been unable to diagnose or manage because it is atypical, severe, or complicated by other paediatric, medical or social factors.

How the service is organised

Services are provided in Specialist Dermatology Centres, each of which is a Specialist Dermatology Centre for the treatment of one or more rare conditions or specified common conditions with complex needs. There are specific Specialist Dermatology Centres for children.

There is a service specification for patients with Stevens-Johnson syndrome (SJS) and toxic Epidermal Necrolysis (TEN), which is commissioned in specific centres, to provide specialist care for children and adults in age-appropriate critical care settings, co-located with burns services, for the population of England.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England is in the process of commissioning a service for Stevens-Johnson syndrome and toxic epidermal necrolysis (SJS-TEN).

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist dermatology services from Specialist Dermatology centres. For adults, this is the diagnosis, investigation and treatment of rare diseases and the management of severe diseases not suitable for, or not responding to, conventional treatment available in local dermatology departments. For children, it is those services for children with conditions that general dermatologists or paediatricians have been unable to diagnose or manage because they are atypical, severe or complicated.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plans developed by Specialist Dermatology Centres as well as all other dermatology services. ICBs commission services for dermatological conditions that arise as a complication or sequelae of conditions that fall within their commissioning responsibility.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 24Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Providers of specialised dermatology are also required to input information into the British Association of Dermatologists database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

62. Specialist metabolic disorder services (adults and children)

[Programme of Care Women & Children, CRG – Metabolic Disorders]

Service summary

Specialist metabolic disorder services include services provided by Specialist Metabolic Disorder Centres for patients with specified conditions. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 19. Alkaptonuria service (adults)
- 25. Barth syndrome service (adults and children)
- 37. Complex childhood osteogenesis imperfecta service
- 71. Lysosomal storage disorder service (adults and children)
- 73. McArdle's disease service (adults)
- 95. Rare mitochondrial disorders service (adults and children)
- 99. Severe acute porphyria service (adults and children)

About the condition/service

Specialist inherited metabolic disorders (IMDs) cover a diverse range of over 600 conditions, some of which are extremely rare.

Although varying widely in their presentation and management according to which body systems are affected, IMDs are caused by a disruption in normal biochemical processes. Conditions are lifelong and most are due to single enzyme deficiencies that lead to severe disturbance of metabolic processes in the body, resulting in either a deficiency of products essential for health or an accumulation of unwanted or toxic products. This can cause disease or damage in many organ systems, leading to severe learning or physical disability and death at an early age. Some disorders do not manifest symptoms for many years, and mature patients are referred frequently for investigation in other specialties, for example, nephrology and cardiology. This can lead to misdiagnosis, delayed diagnosis or multiple investigations.

About 10-12,000 people attend Specialist Metabolic Disorder Centres.

How the service is organised

NHS England commissions services from paediatric and adult Specialist Metabolic Disorder Centres. These are units that have the following attributes:

- Provision of 24/7 clinical and laboratory cover
- Expertise in individual IMD syndromes
- Managed links to pharmaceutical industry including research, orphan drugs.
- Care delivered by multi-disciplinary teams

- Co-location with other specialist services to treat multi-systemic conditions
- Provision of complex and expensive therapies in line with agreed drug lists

IMD patients may present initially to primary or secondary care services with varied and often nonspecific signs and symptoms. The specialist centre provides accurate clinical and laboratory diagnosis with confirmatory tests; identifies newborns through population screening programmes (PKU, MCADD, MSUD, GA1, IVA and homocystinuria); and identifies other at-risk family members. Centres provide inpatient facilities for patient observation and stabilisation and input from other specialties, for example, neurology, cardiology may be required.

Inpatient care includes planned admissions for investigations, initiation of and monitoring ongoing treatment, and routine assessments as well as emergency admissions for patients with acute metabolic decompensation. In addition to core MDT members, close liaison with healthcare professionals from other specialist services may be needed to provide comprehensive patient care, respite and appropriate end-of-life care.

Outpatient or shared-care services, led by an IMD consultant or specialist nurse/dietician, allow patients to be treated at home or in local facilities.

The Centres provide a number of outreach clinics and shared care with local hospitals is encouraged to enable patients to receive care as close to their homes as possible. All Centres work co-operatively to share expertise in individual syndromes.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for patients with CLN2 disease.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions specialist metabolic disorder services for patients with IMDs from Specialist Metabolic Disorder Centres, including services delivered on an outreach basis as part of a provider network.

ICBs commission a number of specialist dietary products for the treatment of IMD patient with certain disorders only when initiated by the Centre and only for a 1-2-week period.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs, via GPs, are responsible for ongoing prescription of all specialist dietary products for patients with IMD, once initiated by the Centre. ICBs, via GPs, are responsible for ongoing prescription of all medications except those that are already accepted as commissioned directly by NHS England. ICBs commission services for general metabolic conditions such as diabetes or common IMD conditions such as heterozygous familial hypercholesterolaemia in adults.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 36Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. There is no nationally defined identification rule for adult metabolic services for admitted patient care activities. Providers should use the detail of the service specification and local methods of identification, and to attribute such records to service line NCBPS36Z in all relevant commissioning dataflows.
2. Similarly, outpatient activity relating to adult patients may prove problematic to identify and therefore providers are advised to manage specialist outpatient activity via a locally held patient list. Providers should attribute any identified activity to service line NCBPS36Z in all relevant commissioning dataflows.
3. The IR software tool should be used to identify paediatric metabolic disorder outpatient activity.

Additional note:
The World Health Organisation have been asked to consider some revisions to the International Classification Disease code set, which will enable a greater level of granularity of coding for the metabolic service.

63. Specialist pain management services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist pain management is a specialised service for children provided by Specialist Paediatric Pain Management Centres. The service includes:

- Multi-disciplinary assessment of childhood complex chronic pain (disease- and non-disease related) and pain-associated disability
- Specified inter-disciplinary interventions including intensive inpatient, residential and outpatient management programmes

This includes outreach when delivered as part of a provider network.

Other relevant service(s):

- 3. Adult specialist pain management services

About the condition/service

Chronic pain in children is recurrent or persistent pain that persists beyond the usual course of an acute disease or which is associated with an underlying chronic condition. Traditionally, chronic pain in children is pain that has been present after a period of three months. However, there are specific chronic pain conditions, such as complex regional pain syndrome and some cancer pains, which manifest before this period has elapsed. A small, significant cohort of children has such overwhelming pain (disease- and non-disease related) and pain-associated disability that they are unable to re-integrate into developmentally appropriate activities (including school, family life, independent social activity, physical activities). Family life can disintegrate, and healthcare usage markedly increases. These children, and their families, require specialist, interdisciplinary input to manage their pain and support their physical and psychosocial rehabilitation.

The prevalence of chronic pain in children, as currently defined, is reported as between 6-25%. As stated previously, the majority of these CAYP are managed and rehabilitated effectively by non-specialist services in primary, secondary and tertiary centres. Based on current service activity figures, it is estimated that there are approximately 2,000 patients nationally who would benefit from referral to Specialist Paediatric Pain Management Services.

How the service is organised

Services are delivered by Specialist Paediatric Pain Management Centres in England. Some of these centres provide intensive inpatient or residential pain management programmes for the most severely disabled patients.

The service is delivered via a networked approach similar to that provided by other specialist paediatric services and is closely linked with existing major centres for adult chronic pain to allow easy transition to these services. Management of complex chronic pain in children is provided by a multidisciplinary team involving pain specialists, specialist paediatric anaesthetists, clinical psychologists, nurses, occupational therapists and physiotherapists. Specialist paediatric pain management services need to link in with other specialist paediatric services: rheumatology, gastroenterology, anaesthesia, neurology, orthopaedic surgery, paediatric surgery, paediatric urology, dentistry, neurosurgery, plastic surgery, ENT surgery, oncology, psychology, mental health services and interventional radiology.

The Specialist Centres link to social services, primary care (GPs and community nursing), educational services and other secondary and tertiary providers of children's services. Links to adult chronic care services are essential to ensure robust transitional arrangements are in place. Very occasionally, a child or young person requires interventional management that is provided only in Adult Specialist Pain Management Centres. Chronic pain management is generally given to children and their families, rather than neonates or infants, and may be delivered in outpatient, day case, residential or inpatient settings.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

Integrated Care Boards (ICBs) commission the following specialist pain management services for children from Specialist Paediatric Pain Management Centres:

- Multi-disciplinary team review for chronic pain
- Administration of pain-relieving blocks under anaesthesia
- Specialist pain management services for children referred from other pain management or paediatric services.

This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the majority of pain management services for children, including services from secondary and tertiary care providers.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23Y

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

64. Specialist palliative care services for children and young adults

[Programme of Care – Women & Children, CRG –Specialised Paediatric Palliative Care]

Service summary

Specialist palliative care services for children and young adults include services provided by Specialist Paediatric Palliative Care Centres including outreach when delivered as part of a provider network.

This provision relates to children and young adults up to the age of 24.

About the condition/service

Palliative care for children and young adults with life threatening and life shortening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's or young adult's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child or young adult and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

How the service is organised

Specialist palliative care services for children and young adults can be provided in the following ways:

- Direct support through an individual or joint consultation (involving other professionals) with the child/young adult and family in any care setting
- Direct support through provision of Specialist Inpatient Paediatric Palliative Care in a children's hospice
- Direct support through facilitation and leadership of a multidisciplinary team, including multi-disciplinary team meetings
- Indirect advice provided to other professionals, including other providers of paediatric palliative care and other providers of health, social care or education by telephone, in writing or by participation in a multidisciplinary team meeting
- Support for other professionals through palliative care education and training. This may be generic education and training or specific teaching to facilitate support of an individual child and family (for example, training of a community nursing team to use a syringe driver for continuous infusion of medication to facilitate symptom management and end of life care at home).
- Education and training of patient or family (for example, relaxation techniques to control breathlessness or teaching how to administer medication for pain and symptom management) [This is also an aspect of other palliative care services for children and young adults.]

- Ongoing direct and indirect support through a formal or informal shared care arrangement

Although all paediatric palliative care services are able to deliver many interventions, generally speaking, the more complex the child's or young adult's problems, particularly where multiple problems are interacting with each other and the greater the number of interventions required, the greater the requirement for support from Specialist Paediatric Palliative Care Services.

Interventions that may be provided by Specialist Paediatric Palliative Care Services include:

- Complex interventions that exceed those that can be provided by the child's usual (condition specific) specialist service, core palliative care services or universal services, for example, end-stage osteosarcoma and complex pain and psychological symptoms, requiring interventions for pain management including an epidural and/or the use of specialist palliative care drug management techniques.

The Specialist Paediatric Palliative Care Centres link with the eight Children's Palliative Care Networks across England.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist palliative care services for children and young adults from Specialist Paediatric Palliative Care Centres. These services have the following features:

- Delivered by a consultant-led multi-professional specialist palliative care team
- Providing a clinical leadership role in planning delivery and evaluation of children's palliative care services across a managed clinical network
- Led by a medical consultant working at Paediatric Palliative Care Competency Level 4
- Providing the full range of specialist paediatric palliative care interventions including use of alternative opioids
- Able to treat all children and young adults, regardless of their age

This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line local specifications and policies

ICBs commission:

- Children's community nursing teams
- Specialist short break services/respite
- Routine care delivered by a children's hospice service that is not a Highly Specialist Paediatric Palliative Care Centre

- Carers and care packages
- Local, community-based palliative care services

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- E23

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

The IR software tool does not contain a methodology for identification of this service. Providers are required to identify this activity locally and attribute the NCBPSE23 service code within all relevant commissioning datasets.

65. Specialist services for adults with infectious diseases

[Programme of Care – Blood & Infection, CRG – Infectious Diseases]

Service summary

Specialist services for adults with infectious diseases includes:

- Patients affected by specified organisms provided by Specialist Adult Infectious Disease Centres
- High Consequence Infectious Disease Units (adult and paediatric)
- Tropical Disease Centres
- Specialist Bone and Joint Infection Centres
- Human T-cell Lymphotropic Virus Centres

Other relevant service(s):

- 13. Adult specialist orthopaedic services
- 130. Specialist services for children with infectious diseases
- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

Infectious diseases are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; the diseases can be spread, directly or indirectly, from one person to another. Zoonotic diseases are infectious diseases of animals that can cause disease when transmitted to humans. Infectious diseases can cause a range of symptoms, which in some cases can be life threatening.

How the service is organised

Although most hospitals treat patients with infectious diseases, specialist centres provide services to patients affected by rare organisms. Such centres have specialist infectious disease facilities such as isolation units with negative pressure facilities.

There are also some highly specialist centres that provide care to patients (including children) with very rare conditions:

- High Consequence Infectious Disease Units
- Tropical Disease Centres
- Bone and Joint Infections (Adults)
- Human T-cell Lymphotropic Virus Centres

The multi-disciplinary specialist infectious disease team co-ordinates a rapid and effective evaluation of the infection and its risk of transmission and provides appropriate diagnostic and medical management on a 24-hour basis. Some conditions require special isolation facilities with appropriate air handling and air filtration systems. Such facilities are serviced by teams of doctors with specialist training in infectious disease and microbiology, with support from their colleagues in nursing, radiology and pharmacology.

The specialist infectious disease team also provides telephone advice on patients being treated in local hospitals.

About 25,000 patients each year require access to specialist services for adults with infectious diseases.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions the following infectious disease services:

- Adult high consequence infectious airborne disease services
- Adult high consequence infectious contact disease services
- Human T- Cell Lymphotropic Virus Type 1 and 2 (all ages)
- Tropical Disease (all ages)
- Operational Delivery Networks for Hepatitis C care in adults

What Joint Committees (NHS England and Integrated Care Boards (ICBs) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions the following infectious disease services:

- Bone and joint infections (adults)
- Specialist infectious disease services (adults)

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the non-complex elements of this service along with any services for infectious diseases provided outside of the specialist centres.

Change of service commissioner

There are plans to review whether Tropical Disease services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- Infectious diseases: 18A (adults)
- Infectious diseases: 18C (children)
- 18D
- 18EInfectious disease isolation units: 18U

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS

- Adult critical care activity via SUS Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

This service includes ALL activity at: High Consequence Infectious Disease Units, Tropical Disease Centres, Specialist Bone and Joint Infection Centres and Human T-cell Lymphotropic Virus Centres.

For all other specialist services for adults with infectious diseases, this service includes specified activity at specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. There are a very small number of specialist isolation units in which all activity undertaken within those units is considered specialised. These centres should report all activity associated with such units as specialised

66. Hyperbaric oxygen treatment services (adults and children)

[Programme of Care– Trauma, CRG - Hyperbaric Oxygen Therapy]

Service summary

Hyperbaric oxygen treatment services include hyperbaric oxygen treatment services provided by Specialist Hyperbaric Oxygen Treatment Centres for specified conditions. This applies to provision in adults and children.

About the condition/service

Hyperbaric oxygen treatment (HBOT) involves breathing oxygen at a partial pressure greater than 100 kPa. It is typically administered at a partial pressure substantially higher than 100 kPa and seldom less than 200 kPa. The high partial pressures are achieved by supplying gases to patients inside pressurised treatment chambers. In certain circumstances, divers require prolonged exposure to ambient pressure in excess of 100 kPa but the partial pressure of oxygen is reduced to 50 kPa or less in order to avoid pulmonary toxicity. Whilst this is technically not HBOT, it is included in the scope of service as a necessary adjunct to HBOT.

Hyperbaric centres are classified depending on the availability of additional medical facilities, suitability for different types of patients and whether they use mono- or multi-place chambers and are categorised from levels 1 to 4. Mono-place chambers are inappropriate for some patients such as those receiving initial treatment for decompression injury. Multi-place chambers are usually fixed facilities, allow an attendant or nurse to care for the patient or to deal with emergencies in the chamber and often have room for more than one patient. Patients in a multi-place chamber typically inhale oxygen or a therapeutic mixture of gases via a hood or a mask. Standard treatment for decompression illness takes five hours but many diving casualties require longer treatment depending on severity of injury and response to treatment. These treatments take place in Category 1 and 2 facilities:

- Category 1: facilities receive patients in any diagnostic category who may require Advanced Life Support either immediately or during HBOT.
- Category 2: facilities receive patients in any diagnostic category who are judged by the referring medical practitioner not to be likely to require Advanced Life Support during HBOT.

How the service is organised

The service is delivered by Specialist Hyperbaric Oxygen Treatment Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions facilities delivering hyperbaric oxygen treatment services from Specialist Hyperbaric Oxygen Treatment Centres (registered as Hyperbaric

Chamber Services with the Care Quality Commission) for specified conditions in category 1 and category 2 facilities.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 28Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Uploading of patient activities to the British Hyperbaric Association database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. No outpatient rule exists within the IR software tool, but should the service be provided as an outpatient treatment then the inpatient procedure and diagnosis code restriction described within the IR software tool workbook should be applied manually by providers.

67. Insulin-resistant diabetes service (adults and children)

[Programme of Care - Internal Medicine, CRG – Specialised Endocrinology]

Service summary

Insulin-resistant diabetes services include services provided by Highly Specialist Insulin-resistant Diabetes Centres. This provision applies to adults and children.

Other relevant service(s):

- 109. Specialist endocrinology services for children

About the condition/service

Insulin-resistant diabetes occurs because of either a genetic condition or because the individual has developed antibodies to insulin. In addition to the usual complications of diabetes (renal failure, stroke, etc) the condition can also affect the liver and can result in pancreatitis.

This service is in the highly specialised portfolio.

How the service is organised

The aim of the service is to provide diagnostic, therapeutic and educational support for both patients and their local healthcare professionals, and to establish and disseminate evidence-based recommendations for the therapy of this severe group of conditions.

What NHS England directly commissions in line with national standards and policies

NHS England commissions insulin-resistant diabetes services for adults and children from Highly Specialist Insulin-resistant Diabetes Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 27A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal

- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Insulin-resistant Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify this activity locally and annotate the NCBPS27A service code.

68. Islet transplantation service (adults)

[Programme of Care – Internal Medicine, CRG – Specialised Endocrinology]

Service summary

Islet transplantation services include services provided by Highly Specialist Islet Transplantation and Laboratory Centres. This provision applies to adults.

Other relevant service(s):

- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

Islet transplantation is of proven benefit for a very small group of eligible patients with Type 1 diabetes who suffer from recurrent episodes of severe hypoglycaemia. Successful transplantation can abolish episodes of hypoglycaemia unawareness and improve the quality of life of recipients, whilst also improving overall metabolic control. Patients who are already immunosuppressed for a kidney transplant may also benefit from islet transplantation through the improved metabolic control afforded by an islet after kidney transplant.

This service is in the highly specialised portfolio.

How the service is organised

Two centres isolate and transplant patients and a further three centres undertake transplantation only. There were 22 islet cell transplants in 2021/22.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions islet transplantation services for adults from Highly Specialist Islet Transplantation and Laboratory Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 27B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Organs transplanted data from NHS Blood and Transplant
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Islet Transplant and Laboratory Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. No outpatient rule exists within the IR software tool. Providers should utilise local means to identify the initial specialist assessment and outpatient appointments associated with the surgery and attribute them to the NCBPS27B service code within all relevant commissioning dataflows.

69. Liver transplantation service (adults and children)

[Programme of Care – Internal Medicine, CRG – Hepatobiliary and Pancreas] [Adults]
[Programme of Care – Women & Children, CRG – Specialised Paediatric Gastroenterology Services] [Children]

Service summary

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

Other relevant service(s):

- 123. Specialist paediatric liver disease service
- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

This service provides assessment, transplantation and lifelong follow up for patients requiring liver transplant surgery, including from living donors.

The three main indications for liver transplantations are primary and secondary biliary cirrhosis, chronic hepatitis and fulminant hepatic failure.

The main conditions for paediatric liver transplantation are: biliary atresia, congenital metabolic conditions,; other cirrhosis, mostly non-recurring; tumours; and acute liver failure.

There were 848 liver transplants in 2021/22, 91 of which were undertaken in children.

This service is in the highly specialised portfolio.

How the service is organised

In England there is one centre which provides paediatric liver transplant; two centres that provide paediatric and adult liver transplant and four centres that provide adult liver transplant.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions liver transplantation services for adults and children from Highly Specialist Liver Transplant Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 19T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Organs transplanted data from NHS Blood and Transplant

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Liver Transplant Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. No outpatient rule is included within the IR software tool. Providers should utilise local means to identify the initial outpatient specialist assessment and outpatient appointments associated with the inpatient surgery and attribute them to NCBPS19T service code within all relevant commissioning dataflows.

70. Lymphangioleiomyomatosis service (adults)

Whilst this section refers specifically to 'females', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

Lymphangioleiomyomatosis services include services provided by Highly Specialist Lymphangioleiomyomatosis Centres. This provision applies to adults.

Other relevant service(s):

- 4. Adult specialist respiratory services
- 57. Heart and lung transplantation service (including mechanical circulatory support (adults and children)

About the condition/service

Lymphangioleiomyomatosis (LAM) is a rare, progressive disease characterised by lung cysts, kidney tumours and lymphatic abnormalities. LAM occurs in a sporadic form, which affects only females, usually of childbearing age; LAM also occurs in patients who have tuberous sclerosis complex (TSC), a genetic condition that causes non-malignant tumours to grow in the brain and on other vital organs.

This service is in the highly specialised portfolio.

How the service is organised

The service is delivered through outpatient assessment and management and lung transplant referral.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions LAM services from Highly Specialist Lymphangioleiomyomatosis Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 29C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Genetic testing activity via local data flows
- Drug Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribe as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Lymphangioleiomyomatosis Centres only.

How to use the Identification Rules

The identification IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS29C service code within all relevant commissioning dataflows.

71. Lysosomal storage disorder service (adults and children)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

Lysosomal storage disorder services include services provided by Highly Specialist Lysosomal Storage Disorder Centres including outreach when delivered as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

Lysosomal storage disorders (LSDs) are a group of rare genetic storage disorders, characterised by specific lysosomal enzyme deficiencies. Some LSDs can be treated using enzyme replacement therapies (ERTs), substrate reduction therapy (SRT) or other disease modifying drugs.

There are licensed disease-modifying treatments for nine LSDs:

- Gaucher's disease
- Anderson-Fabry's disease
- Mucopolysaccharidosis type I (MPSI, which occurs as Hurler's syndrome, Hurler-Scheie syndrome and Scheie syndrome)
- Mucopolysaccharidosis Type IVa (Morquio syndrome)
- Mucopolysaccharidosis type VI (MPSVI or Maroteaux Lamy syndrome)
- Pompe's disease
- Mucopolysaccharidosis type II (MPSII)
- Niemann Pick type C
- Batten's Disease, Ceroid Lipofuscinosis Neuronal 2 (CLN2)

This service is in the highly specialised portfolio.

How the service is organised

The service has a caseload of about 2,100 patients.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and children with lysosomal storage disorders from Highly Specialist Lysosomal Storage Disorder Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 36C

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- In addition to the above activity flows, providers are required to submit within 10 working days notification of change of circumstance for new patients, changes of dosage, deaths and discharges, and transfers in accordance with the protocol for Enzyme Replacement Therapy.

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Lysosomal Disorder Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify this activity locally and attribute the NCBPS36C service code within all relevant commissioning dataflows.

72. Major trauma services (adults and children)

[Programme of Care – Trauma, CRG – Major Trauma and Burns]

Service summary

Major trauma services include all activity (except A&E) at Major Trauma Centres for patients with an Injury Severity Score of greater than eight. This applies to provision in adults and children.

Other relevant service(s):

- 7. Adult specialist cardiac services
- 11. Adult specialist neurosciences services
- 17. Adult specialist vascular services
- 18. Adult specialist thoracic services
- 126. Specialist rehabilitation services for patients with highly complex needs (adults and children)

About the condition/service

Major trauma means serious injuries that could result in death or a life-changing disability. These might include serious head injuries, severe gunshot wounds or road traffic accidents. These sorts of severe and complex injuries are quite rare: major trauma represents only 0.1% of total Accident & Emergency (A&E) activity, with the average Major Trauma Centre (MTC) seeing on average three cases per day. In 2016, the Trauma Audit and Research Network (TARN) identified 25,000 cases of major trauma in England that were treated in Major Trauma Centres (MTC) and a further 17,000 that were treated in a Trauma Unit (TU).

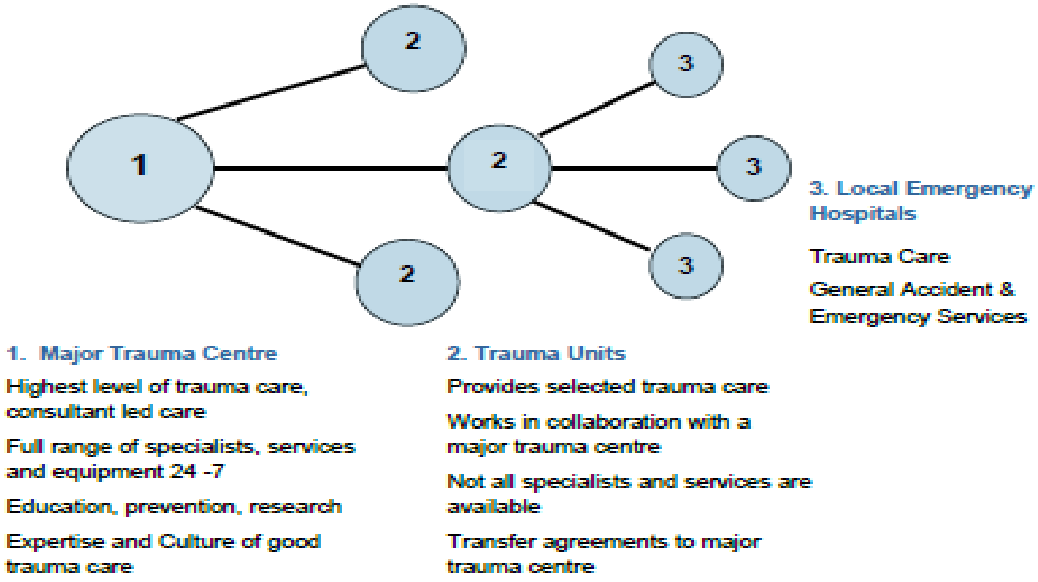
As major trauma is uncommon, it is not possible for all hospitals to have the equipment, onsite specialties and specialist doctors needed to treat it effectively. For this reason, patients with multiple, serious injuries should be taken directly to or transferred into an MTC. This is a hospital designed for the definitive care of seriously injured patients. On arrival they are immediately assessed by a specialist Trauma Team led by a consultant 24/7. There is rapid access to diagnostic testing and surgery can be carried out immediately by a full range of trauma specialists.

How the service is organised

A Regional Trauma Network (RTN) is the name given to the collaboration between all providers of Trauma Care, from pre-hospital care through to rehabilitation. RTNs deliver trauma care services in a geographical area: at its heart is the ‘Major Trauma Centre’, linked through the network into other care providers such as ambulance services and local Trauma Units.

MTCs may be adult only, standalone children’s or combined and operate through Major Trauma Networks. Only these centres have the necessary onsite range of specialities, clinical expertise and major trauma services needed to deliver the care required to treat these complex major trauma patients.

Figure 1 Trauma Network



What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions major trauma services from Major Trauma Centres for patients taken to those centres with an Injury Severity Score (ISS) of greater than eight.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services from Major Trauma Centres for patients with an ISS of eight or less and trauma services and activity for all injured patients treated at local emergency hospitals and Trauma Units. ICBs also commission all A&E services regardless of whether this relates to patients with an ISS of more than eight.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 34T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Upload of information to the TARN database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by major trauma centres only.

How to use the Identification Rules

1. There is no identification rule for this service documented within the identification rules software tool because the identification of relevant patients is first identified via provider data submission to TARN. All clinical activities relating to major trauma patients with an ISS of > 8 (as determined by TARN) should be identified with the NCBPS34T service code within commissioning dataflows.
2. All critical care stays associated with the inpatient admission above should be identified locally and attributed to specialised commissioning.

73. McArdle's disease service (adults)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

McArdle’s services include services provided by Highly Specialist McArdle’s Disease Centres. This provision applies to adults.

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

McArdle's disease is a condition caused by an inborn deficiency of muscle phosphorylase resulting in an abnormal accumulation of glycogen in muscle tissue, characterised by exercise intolerance, muscular pain, fatigability and muscle cramping. Rhabdomyolysis (the breakdown and death of muscle fibres and release of their contents into the bloodstream following a direct or indirect muscle injury) leading to renal failure is a particularly severe complication of McArdle's disease.

This service is in the highly specialised portfolio.

How the service is organised

The service provides an accurate diagnosis and outpatient management of the condition.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults with McArdle’s disease and related rare glycogenolytic disorders from Highly Specialist McArdle’s Disease Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Highly Specialist Adult McArdle’s Disease Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 26A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist McArdle's Disease Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify the activity locally and attribute the NCBPS26A service code within all relevant commissioning dataflows.

74. Mental health service for Deaf children and adolescents

[Programme of Care – Mental Health, LD & Autism, CRG –Mental Health Services for Deaf People]

Service summary

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

Other relevant service(s):

- 32. Children and young people's mental health service
- 116. Specialist mental health services for Deaf adults

About the condition/service

The specialist inpatient centre offers short-term admissions for young Deaf people with acute mental health problems, together with targeted assessment and intervention admissions for emotional and mixed or complex disorders associated with, or complicated by, deafness or language acquisition.

Community-based outreach services provide specialist advice, assessment and treatment in a comprehensive network model with multiple satellite clinics across the country.

Specialist community outreach services provide alternative care to hospital admission that is culturally and linguistically accessible and facilitates admission and discharge from hospital helping to ensure smooth functioning of care pathways. The specialist Deaf community outreach services have formal links (captured in Memoranda of Understanding with areas covered including: clinical pathways; education and training; supervision, communication policies; quality development and review) with one of the Specialist Centres and operate a network model.

Services delivered by specialist community outreach services may include:

- Psychiatric assessment and treatment
- Psychopharmacological interventions
- Advice on medication management
- Psychological assessment treatment, consultation and advice
- Specialist neurodevelopmental assessments
- Complex psychosocial care planning
- Specialist language and communication assessments and interventions
- Community care assessments, development of packages of support as well as advice on appropriate placements
- Multidisciplinary, multiagency care planning
- Parenting assessments and support where appropriate
- Family support and therapy

- Development of a positive Deaf identity and integration in the Deaf community
- Assessment and development of Activities for Daily Living
- Support in access to Deaf services, information, and advocacy
- Employment and education support
- Planning and support for transition to adult services
- Advice, support and signposting to primary care, child mental health, child health, social services and education services

How the service is organised

There are about 350 referrals to the service each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions mental health services for Deaf children and adolescents from Highly Specialist Deaf Child and Adolescent Mental Health Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission Tiers 1 to 3 mental health services for Deaf children and adolescents.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 22B

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set submitted via Strategic Data Collection Service
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity is identified via local data flows, which apply to Highly Specialist Deaf Child and Adolescent Mental Health Centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document ‘Mental Health Price Activity Matrix (MH PAM)

Template (Schedule 2B)’. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider’s contract, or the Provider Collaborative ODS Code, as per the document ‘Determining the NHS-led Provider Collaborative.

75. Mitochondrial donation service

This service number was previously used for 'Middle ear implantable hearing aid services' but has now been combined with service 30 to form a single service entitled 'Bone conduction hearing implants'.

[CRG –Genomic Medicine]

Service summary

Mitochondrial donation includes services provided by Highly Specialist Mitochondrial Donation Centres. This provision applies to adults.

Other relevant service(s):

- 95. Rare mitochondrial disorders service (adults and children)

About the condition/service

Mitochondrial donation is a technique that involves replacing the unhealthy mitochondria in a woman who carries a mitochondrial disease, with the healthy mitochondria from a donor woman, during the process of in vitro fertilisation. The resulting baby would have all the genetic traits of the mother and father but would also have healthy mitochondria and so would be free from disease.

Serious mitochondrial diseases cause very significant morbidity and often early mortality. The impact of disease can include: blindness, blocked heart, muscle wastage and weakness, learning disabilities, Deafness and diabetes.

This service is in the highly specialised portfolio.

How the service is organised

The Human Fertilisation and Embryology Authority authorises individual expert centres to undertake mitochondrial donation and also undertakes a case-by-case assessment of those seeking mitochondrial donation.

What NHS England directly commission in line with national standards (specifications and policies)

NHS England commissions mitochondrial donation from Highly Specialist Mitochondrial Donation Centres.

This service is part of an evaluative commissioning approach. NHS England commissions the mitochondrial donation pathway, which includes specialised MDTs, tests and the in vitro fertilisation procedures required to carry out the mitochondrial donation.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the normal antenatal, postnatal care and normal child paediatric surveillance elements of this service. ICBs commission all general in vitro fertilisation services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 20D

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Mitochondrial Donation Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute the NCBPS20D service code to all relevant records within commissioning dataflows.

76. NF2-schwannomatosis service (adults and children)

[CRG –Genomic Medicine]

Service summary

NF2-schwannomatosis service include services provided by Highly Specialist NF2-schwannomatosis Centres including outreach when provided as part of a provider network. This applies to provision in adults and children.

Other relevant service(s):

- 36. Cochlear implantation services (adults and children)
- 105. Specialist cancer services
- 106. Specialist cancer services for children and young adults

About the condition/service

NF2-schwannomatosis is a genetic disorder characterised by the growth of non-cancerous tumours in the central nervous system. NF2 patients develop bilateral vestibular schwannomas (abnormal tissue growth originating in the cells of the sheath around the nerve), meningiomas (a type of benign brain tumour) and spinal tumours; usually causing deafness, balance problems, compression of the brain stem and premature death.

This service is in the highly specialised portfolio.

How the service is organised

The service includes:

- outpatients: MDT outpatients and satellite outpatients
- mutation testing for NF2-schwannomatosis
- auditory brainstem implants and auditory implants
- vestibular schwannomas surgery
- stereotactic radiosurgery
- Hearing Link’s NF2 course (intensive rehabilitation programmes for adults with significant hearing impairment)
- drug treatment in line with agreed protocols

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and children with NF2-schwannomatosis from Highly Specialist NF2-schwannomatosis Centres, including services delivered on an outreach basis as part of a provider network. A small number of patients need an auditory brainstem implant.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 08C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly NF2-schwannomatosis Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS08C service code within all relevant commissioning dataflows.

77. Neuromyelitis optica service (adults and adolescents)

[Programme of Care – Trauma, CRG – Neurology]

Service summary

Neuromyelitis optica services include services provided by Highly Specialist Neuromyelitis Optica Centres. This provision applies to adults and adolescents.

Other relevant service(s):

- 11. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children

About the condition/service

Neuromyelitis optica (NMO) (also known as Devic's disease) is a rare inflammatory demyelinating disorder of the central nervous system that typically presents as severe optic neuritis (inflammation of the optic nerve) and longitudinally extensive myelitis (inflammation of the spinal cord) often followed by further severe attacks, which usually result in permanent disability (visual loss, limb weakness, respiratory muscle weakness). There are high mortality and morbidity rates associated with the condition. About 1,000 people in England have NMO.

This service is in the highly specialised portfolio.

How the service is organised

The service provides an accurate diagnosis, inpatient or outpatient assessment and review.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions services for adults and adolescents with NMO from Highly Specialist Neuromyelitis Optica Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Highly Specialist Neuromyelitis Optica Centres and care for acute relapses.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 08D

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Drug Patient Level Contract Monitoring

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Neuromyelitis Optica Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS08D service code within all relevant commissioning dataflows.

78. Neuropsychiatry services (adults and children)

[Programme of Care – Trauma, CRG – Neurology]

Service summary

Neuropsychiatry services include services provided by Specialist Neuropsychiatry Centres or teams within a neuroscience centre. This includes assessment and treatment for patients with:

- Neurological diseases and associated severe psychiatric symptoms; or
- Severe and disabling neurological symptoms without identified neurological cause.

This applies to provision in adults and children.

Other relevant service(s):

- 11. Adult specialist neurosciences services
- 119. Specialist neuroscience services for children

About the condition/service

Neuropsychiatry services work closely with other neuroscience and mental health services and have expertise provided by neither service alone. Neuropsychiatry services see patients with conditions such as young onset dementia including Huntington’s disease, movement disorders, neuro-developmental disorders, epilepsy, sleep disorders, and acquired brain injury for example from head injury, cerebral tumours or a cerebrovascular accident. These patients are usually seen because of cognitive, behavioural or psychiatric symptoms.

Other patients are seen because of neurologically unexplained symptoms or altered states of conscious level or mental symptoms of uncertain aetiology.

How the service is organised

Neuropsychiatry Services are delivered by Specialist Neuropsychiatry Centres, which may be Neurosciences Centres, Neurology Centres or Mental Health Centres. It is estimated that there are only about 20 neuropsychiatrists in the country. There is a National Centre for Neuropsychiatry with a 10-bedded inpatient unit.

Specialist neuropsychiatric activity includes:

- inpatient and outpatient assessment for complex conditions presenting with psychiatric symptoms
- access to clinical and nursing expertise, including neuropsychological assessment and brain scanning facilities and assessment of physical function
- intensive nursing care in specialist units and within community teams
- links with neuropathological centres
- access to detailed genetic investigations and counselling.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specification and policies)

ICBs commission neuropsychiatry services from Specialist Neuropsychiatry Centres, which may be Neurosciences Centres, Neurology Centres or Mental Health Centres. This includes assessment and treatment for patients with:

- Neurological diseases and associated psychiatric symptoms; or
- Severe and disabling neurological symptoms without identified neurological cause.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission dementia services included within elderly care.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 08Y

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool does not include a rule for this service. Providers are required to identify activity locally and attribute NCBPS08Y service code within all relevant commissioning dataflows.

79. Ocular oncology service (adults)

[Programme of Care – Trauma, CRG – Specialised Ophthalmology Services]

Service summary

Ocular oncology services include services provided by Highly Specialist Ocular Oncology Centres. This applies to provision in adults.

Other relevant service(s):

- 12. Adult specialist ophthalmology services
- 80. Ophthalmic pathology service (adults and children)
- 90. Proton beam therapy service (adults and children)
- 105. Specialist cancer services (adults)

About the condition/service

The ocular oncology service provides diagnosis and treatment of adults with suspected malignant tumours of the eye. Of the patients referred to the service one third (about 700 each year) are confirmed as having eye cancer.

This service is in the highly specialised portfolio.

How the service is organised

There are a number of different treatment modalities:

- surgery
- radiotherapy
- phototherapy
- cryotherapy
- chemotherapy

These aim, whenever possible, to preserve vision in the affected eye and can be used individually or in combination. At present it is unclear if any of these treatments have better outcomes than the others. Follow-up care is provided for patients whose tumours recur or who have complications requiring treatment.

What NHS England directly commission in line with national standards (specifications and policies)

NHS England commissions services for patients with suspected and confirmed ocular oncology from Highly Specialist Ocular Oncology Centres.

What Integrated Care Boards (ICBs) commission in line with local specification and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01H

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Ocular Oncology Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS01H service code within all relevant commissioning dataflows.

80. Ophthalmic pathology service (adults and children)

[Programme of Care – Trauma, CRG – Specialised Ophthalmology Services]

Service summary

Ophthalmic pathology services include diagnostic services Including specialist laboratory services) provided by Highly Specialist Ophthalmic Pathology Centres. This applies to provision in adults and children.

Other relevant service(s):

- 12. Adult specialist ophthalmology services
- 79. Ocular oncology service (adults)
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young adults

About the condition/service

The National Specialist Ophthalmic Pathology Service (NSOPS) is the core national reference service for the specialist reporting of ophthalmic histopathology and cytology specimens.

This service is in the highly specialised portfolio

How the service is organised

This service includes diagnosis and advice relevant to the clinical management of eye conditions. The service provides a comprehensive diagnostic service for malignant and non-malignant conditions for the following specimen types: eyelid, conjunctiva, cornea, aqueous and vitreous humour, iris, ciliary body, retina, choroid, sclera and orbit (including lacrimal gland and optic nerve).

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions diagnostic ophthalmic pathology services from Highly Specialist Ophthalmic Pathology Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 37A

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Ophthalmic Pathology Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS37A service code within all relevant commissioning.

81. Osteo-odonto-keratoprosthesis service for corneal blindness (adults)

[Programme of Care – Trauma, CRG – Specialised Ophthalmology Services]

Service summary

Osteo-odonto-keratoprosthesis services for corneal blindness include services provided by Highly Specialist Osteo-odonto-keratoprosthesis Centres. This applies to provision in adults.

Other relevant service(s):

- 12. Adult specialist ophthalmology services

About the condition/service

Osteo-odonto-keratoprosthesis (OOKP) surgery is a specialist surgical intervention that can restore meaningful vision to patients suffering from end stage corneal blindness, and for whom conventional corneal surgery is not possible for reasons such as severe ‘dry eyes’ that causes heavy scarring of the cornea. OOKP is only contemplated in patients where no other treatments would restore sight.

This service is in the highly specialised portfolio.

How the service is organised

During OOKP, patients are initially assessed by ophthalmic and maxillofacial consultants, involving examination of the eyes, teeth and mouth. OOKP is then a two-stage procedure that firstly involves the extraction of the patient’s own tooth and bone, which are then fashioned into a ‘bolt’ and placed within the eye for supporting a synthetic optical cylinder.

The second stage of the procedure is performed about four months after the first stage. Each surgical procedure lasts about six hours and patients require lifelong follow up.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Osteo-odonto-keratoprosthesis services for adults from Highly Specialist Osteo-odonto-keratoprosthesis Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 37B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Osteo-odonto-kerato-prosthesis Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS37B service code within all relevant commissioning dataflows.

82. Paediatric and perinatal post mortem services

[Programme of Care – Women & Children, CRG – Specialised Women's Services]

Service summary

Paediatric and perinatal post mortem services include all post mortems performed by Highly Specialist Paediatric Post Mortem Centres including examination of fetuses, babies, neonates and children.

About the condition/service

Although most cases of infant death are under the direction of the coroner, paediatricians commonly have an active involvement during attempted resuscitation and subsequent follow up with families. These cases are usually subject to a multidisciplinary review meeting between paediatrician, primary care, social care and the police, as part of the child death review process. Post mortem following neonatal death is more frequently performed for clinical reasons with parental consent. This is also the case in termination for fetal abnormality or intra-uterine death, where consent for post mortem is frequently sought.

How the service is organised

The service is delivered by Highly Specialist Paediatric Post Mortem Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions paediatric and perinatal post mortem services from Highly Specialist Paediatric Post Mortem Centres, including examination of fetuses, babies, neonates and children.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- F23

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is undertaken and should be identified/reported by specified centres as agreed with commissioners.

How to use the Identification Rules

There is no nationally defined Identification Rule for this service. Providers of this service are required to agree a mechanism for recording activity related to this service.

83. Paediatric cardiac services

[Programme of Care – Women & Children, CRG – Congenital Heart Services]

Service summary

Paediatric cardiac services include all activity provided by Specialist Children’s Surgical Centres and Specialist Children’s Cardiology Centres, including outreach when delivered as part of a provider network.

Other relevant service(s):

- 2. Adult congenital cardiac services
- 7. Adult Specialist cardiac services
- 41. Complex tracheal disease service (children)
- 52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- 54. Fetal medicine services (adults and adolescents)
- 57. Heart and lung transplantation service (including mechanical circulatory support (adults and children)
- 92. Pulmonary hypertension service for children

About the condition/service

Paediatric cardiac services include the diagnosis and treatment of all heart conditions in children (including the fetus), including inherited cardiac conditions (see also 7. Adult specialist cardiac services), congenital heart disease and acquired heart disease. About 4,000 cardiac surgical procedures and 4,000 interventional catheter procedures are undertaken on children each year in England.

How the service is organised

Services are delivered through Congenital Cardiac Heart Networks across England through a three-tier system. Level 1 units (Specialist Children’s Surgical Centres) deliver all aspects of children's cardiac services including surgery, catheter intervention, invasive electrophysiology and pacing procedures. They provide active leadership within the cardiac networks. Level 2 units (Specialist Children’s Cardiology Centres) deliver all non-invasive aspects of children’s cardiac services. Level 3 units (Local Children’s Cardiology Centres) provide outpatient children’s cardiac services through a network arrangement with a Level 1 or 2 unit. Level 1 and 2 units also provide outreach services to Level 3 units to support the local consultant paediatrician with special expertise in cardiology.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions all children's cardiac services delivered by Level 1 and 2 units. This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services provided by Local Children's Cardiac Centres (Level 3 units).

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contact Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Providers are also routinely required to submit data to the following clinical registries/databases as appropriate:
    - National congenital heart disease audit (part of the national cardiac audit programme)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

84. Paediatric intestinal pseudo-obstructive disorders service

[Programme of Care – Women & Children, CRG – Specialised Paediatric Gastroenterology Services]

Service summary

Paediatric intestinal pseudo-obstructive disorder services include services provided by Highly Specialist Paediatric Intestinal Pseudo-obstructive Disorders Centres.

Other relevant service(s):

- 110. Specialist gastroenterology, hepatology and nutritional support services for children

About the condition/service

Chronic intestinal pseudo-obstruction is an intestinal motility disorder. Impaired intestinal motor activity causes recurrent symptoms of intestinal obstruction in the absence of mechanical occlusion. The service provides expert, multi-disciplinary diagnostic services for infants and children under five with congenital and acquired variations of the condition.

How the service is organised

This service provides a prompt and accurate diagnosis leading to rapid access to definitive treatment. There is evidence of unnecessary investigation without a definitive diagnosis. The service treats children under the age of five.

The service treats about 20 children each year.

This service is in the highly specialised portfolio.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions intestinal pseudo-obstructive disorder services for children from Highly Specialist Paediatric Intestinal Pseudo-obstructive Disorders Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 12B

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Paediatric Intestinal Pseudo-obstructive Disorders Centres.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS12B service code within all relevant commissioning dataflows.

85. Pancreas transplantation service (adults)

[Programme of Care – Internal Medicine, CRG – Specialised Endocrinology]

Service summary

Pancreas transplantation services include services provided by Highly Specialist Pancreas Transplant Centres. This applies to provision in adults.

Other relevant service(s):

- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

This service provides assessment, transplantation and lifelong follow up for diabetic patients requiring pancreas transplant surgery. In 2021/22, there were 131 pancreas transplants.

How the service is organised

There are six centres in England that provide pancreas transplantation.

This service is in the highly specialised portfolio.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions pancreas transplantation services for adults from Highly Specialist Pancreas Transplant Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

How the activity for this service is identified

Activity is identified via local data flows, which apply to Highly Specialist Pancreas Transplant Centres only.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 27C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Organs transplanted data from NHS Blood and Transplant

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Pancreas Transplant Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS27C service code within all relevant commissioning dataflows.

86. Paroxysmal nocturnal haemoglobinuria service (adults and adolescents)

[Programme of Care – Blood & Infection, CRG – Blood and Marrow Transplantation]

Service summary

Paroxysmal nocturnal haemoglobinuria services include services provided by Highly Specialist Paroxysmal Nocturnal Haemoglobinuria Centres including outreach when provided as part of a provider network. This provision applies to adults and adolescents.

Other relevant service(s):

- 29. Haematopoietic stem cell transplantation services (adults and children)

About the condition/service

Paroxysmal nocturnal haemoglobinuria (PNH) is a rare disease in which red blood cells break down earlier than normal. Symptoms include abdominal pain, back pain, blood clots, dark urine, easy bruising or bleeding, headache and shortness of breath.

This service is in the highly specialised portfolio.

How the service is organised

This service provides diagnosis, clinical review and ongoing management for patients with the haemolytic form of paroxysmal nocturnal haemoglobinuria who are eligible for treatment with anti-complement targeted therapy.

Outreach clinics are held in locations outside of the centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and adolescents with paroxysmal nocturnal haemoglobinuria from Highly Specialist Paroxysmal Nocturnal Haemoglobinuria Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 03A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient activity CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

In addition to the above activity flows, providers are required to submit within 10 working days notification of change of circumstance for new patients, changes of dosage, deaths and discharges, and transfers in accordance with the protocol for paroxysmal nocturnal haemoglobinuria.

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Paroxysmal Nocturnal Haemoglobinuria Centres only.

How to use the Identification Rules

The identification rules do not include a methodology for identification of this service. Providers are required to identify activity locally and attribute to NCBPS03A service code within all relevant commissioning dataflows.

87. Positron emission tomography-computed tomography services (adults and children)

[Programme of Care – Cancer, CRG –Cancer Clinical Advisory Group]

Service summary

Positron emission tomography-computed tomography (PET-CT) services include all use of this diagnostic modality. This applies to provision in adults and children.

Other relevant service(s):

- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young adults

About the condition/service

A PET-CT scan combines a CT scan (anatomical) and a PET (metabolic) scan into one scan. A CT (computerised [axial] tomography) scan takes a series of x-rays and uses a computer to put them together. The CT machine takes pictures of your body from different angles and gives a series of cross sections or 'slices' through the part of the body being scanned. PET (positron emission tomography) uses a very small amount of an injected radioactive material (for example, glucose) to show where cells are active in the body.

A PET-CT scan can give important information about cancer and other diseases. It can help to:

- Diagnose a cancer
- Stage a cancer
- Show whether a lump is cancer or not
- Show whether a cancer has spread to other parts of the body
- Help doctors decide on the best treatment for the cancer
- Show how well treatment is working
- Show the difference between scar tissue and active cancer tissue
- Alter the management strategy in selected patients in disease areas other than cancer, at the discretion of the lead clinician

How the service is organised

PET-CT scanning services are usually delivered in Specialist Cancer Centres but may also be delivered independently. Services may be delivered on both mobile and static bases.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions ALL activity at specified centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of the services.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 01P

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- PET-CT reporting via Data Landing Portal
- Inputting of information into Diagnostic Imaging Dataset

How the activity for this service is identified

This service includes specified activity described below.

How to use the Identification Rules

The IR software tool does not identify this activity. Instead providers are required to identify locally all unbundled HRGs (RN01A, RN01B, RN01C, RN02A, RN02B, RN03A, RN03B, RN07A, RN07B, RN07C) and attribute these to NCBPS01P service code within all relevant commissioning dataflows.

88. Primary ciliary dyskinesia management service (adults and children)

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory] [Adults]
[Programme of Care – Women & Children, CRG – Specialised Paediatric Respiratory] [Children]

Service summary

Primary ciliary dyskinesia management services include services provided by Highly Specialist Primary Ciliary Dyskinesia Management Centres including outreach when delivered as part of a provider network. This provision applies to adults and children.

Other relevant service(s):

- 47. Diagnostic service for primary ciliary dyskinesia (adults and children)
- 128. Specialist respiratory services for children

About the condition/service

Primary ciliary dyskinesia (PCD) is a genetic condition in which the microscopic cells in the respiratory system called cilia do not function normally. Ciliary dysfunction prevents the clearance of mucous from the lungs, paranasal sinuses and ears. Recurring respiratory infections can lead to an irreversible scarring and obstruction in the bronchi (bronchiectasis) and severe lung damage. Cilia are also present in the ventricles of the brain and in the reproductive system so ciliary dysfunction can also affect other parts of the body.

This service is in the highly specialised portfolio.

How the service is organised

Primary ciliary dyskinesia management services include services provided by Highly Specialist Primary Ciliary Dyskinesia Management centres including outreach when delivered as part of a provider network. This provision applies to adults. Patients will transition into the service from the paediatric PCD service.

The adult service has been recently established, with service set up in the same centres that provide the paediatric service. The service started in 2019/20 but mobilisation was impacted by the pandemic response.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions management services for adults and children with PCD from Highly Specialist Primary Ciliary Dyskinesia Management Centres, including services delivered on an outreach basis delivered as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission episodes of care for adults and children with PCD from local providers. Although this service is prescribed in the Regulations in both adults and children, the contractual responsibility for this service in adults has not yet transferred to NHS England and the budget and commissioning responsibility remain with ICBs.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 29P

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Primary Ciliary Dyskinesia Management Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS29P service code within all relevant commissioning dataflows.

89. Primary malignant bone tumours service (adults and adolescents)

[Programme of Care – Cancer, CRG –Cancer Clinical Advisory Group]

Service summary

Primary malignant bone tumours services include services provided by Highly Specialist Primary Malignant Bone Tumours Centres including outreach when provided as part of a provider network. This provision applies to adults and adolescents.

Other relevant service(s):

- 13. Adult specialist orthopaedic services
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young adults
- 121. Specialist orthopaedic services for children

About the condition/service

This service provides diagnosis and surgery for primary malignant bone cancers. Examples of conditions include osteosarcoma, chondrosarcoma and Ewing’s sarcoma. The key aim is to avoid amputation if possible while ensuring complete removal of the cancer.

How the service is organised

The service receives about 1,000 referrals of suspected primary malignant bone tumours (PMBT) each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and adolescents with suspected and confirmed primary malignant bone tumours from Highly Specialist Primary Malignant Bone Tumours Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 01E

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Primary Malignant Bone Tumours Centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. Providers are required to identify activity locally and attribute NCBPS01E service code within all relevant commissioning dataflows.

90. Proton beam therapy service (adults and children)

[Programme of Care Cancer - CRG – Radiotherapy]

Service summary

Proton beam therapy services include services provided by Highly Specialist Proton Beam Therapy Centres. This provision applies to adults and children.

Other relevant service(s):

- 79. Ocular oncology service (adults)
- 94. Radiotherapy services (adults and children)
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young adults

About the condition/service

Proton Beam Therapy (PBT) is a type of radiotherapy that uses a beam of high energy protons (rather than energy x-rays) to treat specific types of cancer. The physical properties of protons, results in almost no radiation dose being deposited in the normal tissue beyond the tumour.

This service is in the highly specialised portfolio.

How the service is organised

PBT is a highly complex technology and the services are part of major cancer centres, including highly specialist surgery and cancer services. The PBT service improves cancer outcomes, reduce morbidity arising from treatment, and support the patient and family throughout their cancer journey and beyond.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions proton beam therapy services for adults and children from Highly Specialist Proton Beam Therapy Centres. The clinical indications for which NHS England commissions PBT are:

- paediatric cancer treatment
- teenage and young adult cancer treatment
- skull base tumour treatment (adults)

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01B

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Proton Beam Therapy Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS01B service code within all relevant commissioning dataflows.

91. Pseudomyxoma peritonei service (adults)

[Programme of Care – Internal Medicine, CRG – Specialised Colorectal Services]

Service summary

Pseudomyxoma peritonei services include services provided by Highly Specialist Pseudomyxoma Peritonei Centres. This provision applies to adults.

Other relevant service(s):

- 105. Specialist cancer services (adults)

About the condition/service

Pseudomyxoma peritonei (PMP) is a rare, mucus-producing tumour, which spreads to compress the abdominal organs. PMP usually arises from a ruptured tumour of the appendix. The condition is of borderline malignancy in that it does not metastasise by the blood stream or through lymphatic spread in the early stages. The tumour spreads locally within the peritoneal cavity and eventually compresses the abdominal organs. The disease is slow growing and is considered a relatively benign condition. However, without specialist cancer treatment, the majority of patients die either from complications of repeated surgery or from compression of the small bowel with resulting malnutrition.

The symptoms of PMP are varied with most patients complaining of gradual abdominal swelling over a period of time affecting their ability to eat normally.

This service is in the highly specialised portfolio.

How the service is organised

Treatment options include:

- cytoreduction with HIPEC (hyperthermic intraperitoneal chemotherapy)
- debulking of the tumour is also an option.
- draining of the abdomen as part of supportive care.

About 200 new patients present each year in England with PMP.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults with PMP from Highly Specialist Pseudomyxoma Peritonei Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01F

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Pseudomyxoma Peritonei Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS 01F service code within all relevant commissioning.

91A. Psychological medicine inpatient services for severe and complex presentations of medically unexplained physical symptoms (adults)

This service was added to the list of prescribed specialised services in 2018. Subsequent discussions within NHS England indicated that it is not feasible to commission this service. It proved difficult to accurately identify the cohort of patients for this service because they can present across a range of NHS provision, including in acute and mental health facilities and in the community. There was an in depth discussion about a proposed service by both the Specialised Mental Health Clinical Reference Group and the Mental Health Programme of Care Board. In addition, two reports were commissioned by colleagues in Public Health England to better understand the evidence base for inpatient treatment in this group of patients. Taking all this into account, the clinical advice is that the most appropriate model is to build on existing psychiatric liaison models and to develop a service for those patients with only the most intractable disease (other patients continuing to be the local responsibility of Integrated Care Boards). However, and in line with NHS England’s Long Term Plan (LTP), the aim of such a service would be for this to be based as locally as possible so as to promote recovery from a disabling, long-term condition and it would be unlikely, again in line with the LTP, that it would be delivered through inpatient beds.

92. Pulmonary hypertension service for children

[Programme of Care – Women & Children, CRG – Congenital Heart Services]

Service summary

Pulmonary hypertension services for children include services provided by Highly Specialist Pulmonary Hypertension Centres including outreach when delivered as part of a provider network.

Other relevant service(s):

- 14. Adult specialist pulmonary hypertension services
- 83. Paediatric cardiac services
- 93. Pulmonary thromboendarterectomy service (adults and adolescents)
- 128. Specialist respiratory services for children

About the condition/service

Paediatric pulmonary hypertension (PH) is a high pressure in the circulation of blood through the lungs, leading to progressive heart failure. The prognosis has improved with recently developed drugs. Some patients also need a lung (or heart and lung) transplant.

This service is in the highly specialised portfolio.

How the service is organised

All patients are investigated, diagnosed, have their treatment for PH determined and their care package organised at the Highly Specialist Pulmonary Hypertension Centre by a multi-disciplinary team.

The service provides care for patients with pulmonary hypertension including cardiac catheterisation, invasive radiology, echocardiography, non-invasive imaging (CT scanning, magnetic resonance imaging), exercise physiology and lung function testing. Patients may also need frequent access to microbiology, dental services, psychology, dietetics and other paediatric expertise.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions pulmonary hypertension services and treatments (including drugs) for children from Highly Specialist Hypertension Centres, including service delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 13J

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- UK National Pulmonary Hypertension Audit

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Pulmonary Hypertension Centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.

93. Pulmonary thromboendarterectomy service (adults and adolescents)

[Programme of Care – Internal Medicine, CRG – Specialised Respiratory]

Service summary

Pulmonary thromboendarterectomy services include services provided by Highly Specialist Pulmonary Thromboendarterectomy Centres. This provision applies to adults and adolescents.

Other relevant service(s):

- 7. Adult specialist cardiac services
- 14. Adult specialist pulmonary hypertension service
- 92. Pulmonary hypertension service for children

About the condition/service

Pulmonary thromboendarterectomy (PTE) is complex surgery to remove blood clots and related material from the pulmonary artery of people with chronic pulmonary thrombo-embolic disease (repeated episodes of blood clots travelling to the lung) that may cause life-threatening pulmonary hypertension (raised pressure in the artery that carries blood to the lung).

This service is in the highly specialised portfolio.

How the service is organised

Through the network of adult pulmonary hypertension units, all patients with a diagnosis of CTEPH are referred for consideration of surgery.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions PTE services for adults and adolescents from Highly Specialist Pulmonary Thromboendarterectomy Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 13M

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- UK National Pulmonary Hypertension Audit

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Pulmonary Thromboendarterectomy Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS13M service code within all relevant commissioning dataflows.

94. Radiotherapy services (adults and children)

[Programme of Care – Cancer, CRG – Radiotherapy]

Service summary

Radiotherapy services include all use of this treatment modality including brachytherapy and any associated outpatient activity. In addition, the service includes all provision of intracranial stereotactic radiosurgery/radiotherapy and extracranial stereotactic radiotherapy. This applies to provision in adults and children.

Other relevant service(s):

- 90. Proton beam therapy service (adults and children)
- 105. Specialist cancer services (adults)
- 106. Specialist cancer services for children and young adults

About the condition/service

Radiotherapy, also known as radiation treatment, is the controlled use of high energy x-rays to treat many different types of cancer. About 40% of people with cancer have radiotherapy. In a few cases, radiotherapy can also be used to treat benign (non-cancerous) tumours. Radiotherapy may be used:

- to cure an illness – for example, by destroying a tumour (abnormal tissue)
- to control symptoms – for example, to relieve pain
- before surgery – to shrink a tumour to make it easier to remove
- after surgery – to destroy small amounts of tumour that may be left

How the service is organised

Radiotherapy can be given in two ways: it can be given from outside the body (external beam radiotherapy) or within the body (internal radiotherapy, also known as **brachytherapy**, which uses sealed sources) and molecular radiotherapy (unsealed sources/radiopharmaceuticals).

Radiotherapy is usually given as a course of treatment that lasts for a number of days or weeks. Radiation treatment is divided into a number of small doses called fractions, which are usually given over a number of weeks (up to seven). Fractions are used to reduce the side effects of a full dose of radiation. The number of fractions required depends on the type of cancer being treated.

Stereotactic radiosurgery/radiotherapy delivers a very precise dose of radiation to a tumour site. Stereotactic means locating a point using three-dimensional coordinates. This ensures that the maximum amount of radiation is aimed at the tumour and surrounding tissue is not exposed. It may be given as a single dose in the treatment of intracranial lesions (stereotactic radiosurgery) or delivered over several sessions (stereotactic radiotherapy). The number of fractions is determined by a number of factors including the type and extent of the cancer.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission all radiotherapy services, including brachytherapy and stereotactic radiosurgery, in accordance with national commissioning policy.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Stereotactic radiosurgery/radiotherapy: 01S
- 51R

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Admitted Patient Care CDS via SUS
- Contribute data to the Radiotherapy Data Set

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool should be used to identify stereotactic radiosurgery activity.

Identification Rules information

NCBPS service code(s)

- Radiotherapy: 01R

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Radiotherapy information also to be submitted via the Radiotherapy Data Set to the National Cancer Action Team

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool does not identify this activity. Instead providers are required to identify locally all unbundled HRGs (all ‘SC’ HRGs) and attribute them to NCBPS01R service code within all commissioning dataflows.

95. Rare mitochondrial disorders service (adults and children)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

Rare mitochondrial disorders services include diagnostic services provided by Highly Specialist Rare Mitochondrial Disorders Centres. This provision applies to adults and children.

Other relevant service(s):

- 75. Mitochondrial donation service

About the condition/service

Mitochondria are small organelles – present in every cell in the body – whose function is to process the cell's energy. They contain their own genetic complement, the mitochondrial genome, and their principal task is to provide the energy necessary for normal cell functioning and maintenance. Disruption of this energy supply can have devastating effects for the cell, organ and individual. One important consequence of mitochondrial involvement in all cell types is that mitochondrial disease can affect virtually any organ and present with a plethora of symptoms and signs to a variety of specialties. These genuinely multi-system diseases are associated with significant morbidity and mortality.

This service is in the highly specialised portfolio.

How the service is organised

The service provides diagnostic services for those patients with suspected rare mitochondrial disorders, which cannot be diagnosed by standard genetic tests available at Clinical Molecular Genetics Society-affiliated diagnostic laboratories.

The Highly Specialist Mitochondrial Disorders Centres provide:

- Specialist histochemical, biochemical and molecular genetics
- Multi-disciplinary outpatient assessment, including access to cardiology, ophthalmology, diabetology, neurology, genetics, physiotherapy, speech therapy

The service diagnoses about 280 new patients each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions diagnostic services for adults and children with rare mitochondrial disorders from Highly Specialist Rare Mitochondrial Disorders Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in management plans developed by the Highly Specialist Rare Mitochondrial Disorders Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 36D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Rare Mitochondrial Disorders Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS36D service code within all relevant commissioning dataflows.

97. Retinoblastoma service (children)

[Programme of Care – Cancer, CRG – Children and Young People]

Service summary

Retinoblastoma services include services provided by Highly Specialist Retinoblastoma Centres. This provision applies to children.

Other relevant service(s):

- 106. Specialist cancer services for children and young adults

About the condition/service

Retinoblastoma is a malignant tumour of the retina and usually presents in children under the age of two. It is an aggressive eye cancer which can result in the loss of vision and in extreme cases, death.

This service is in the highly specialised portfolio.

How the service is organised

The treatment modalities are as follows:

- laser treatment – heat treatment to destroy the tumour
- cryotherapy – freezing treatment to destroy the tumour
- radiotherapy – external beam plaque brachytherapy to damage the tumour and control its growth
- chemotherapy – to shrink the tumour (often combined with laser treatment)
- enucleation – surgical removal of the eye in advanced cases

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for children with suspected and confirmed retinoblastoma from Highly Specialist Retinoblastoma Centres.

What Integrated Care Boards (ICBs) commissions in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 01G

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Admitted Patient Care CDS via SUS
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Retinoblastoma Centres only.

How to use the Identification Rules

1. The IR software tool identifies inpatient activity using diagnosis code and provider organisation codes.
2. The IR software tool identifies outpatient activity using diagnosis code and provider organisation codes.

98. Specialist secure forensic mental health services for young people

[Programme of Care – Mental Health, LD and Autism, CRG – Child & Young People's Mental Health Services]

Service summary

Specialist secure forensic mental health services for young people are part of the range of services provided by Specialist Children and Young People's Mental Health (CYPMH) services and include services provided by Specialist Secure Forensic Mental Health Service Centres for young people and Community Forensic CAMHS (fCAMHS).

Other relevant service(s):

- 6. Adult secure mental health services
- 32. Children and young people's inpatient mental health service

About the condition/service

Specialised secure forensic mental health services for young people (secure inpatient and community) provide:

- highly specialist inpatient care in a medium secure environment for young people with severe mental disorders who are a risk to themselves and/or others and who may have committed criminal offences; and
- a specialist community forensic tertiary advice and consultation service for health and multi-agency care professionals involved with the most complex and high-risk children and young people.

How the service is organised

The medium secure CYPMH inpatient service treats about 140 young people each year. The Community Forensic CAMHS is involved with around 2,500 cases per year.

The medium secure CYPMH inpatient services and Community Forensic CAMHS cover a larger planning footprint than a single ICB. The Community Forensic CAMHS delivers a highly specialist advice and liaison service. Functions include:

- Assessment and advice on the management of high-risk young people (principally those presenting high risk of harm to others) into and out of secure settings for young people
- Expert community liaison and knowledge of the range of disposals (including the Mental Health Act, Children Act, youth justice orders) for young people and the ability to identify appropriate cases for specialist CYPMH inpatient care as well as alternatives to inpatient care
- Development of relationships with a wide range of services working with children and young people across a defined planning footprint, including close links and knowledge of secure settings, team working with them and input into

tripartite funding panels and custodial planning arrangements; such relationships are necessarily wide-ranging and include local, regional and national provision

What NHS England commissions in line with national standards (specifications and policies)

NHS England commissions medium secure CYPMH inpatient services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for patients on the secure pathway who are stepping down from secure care, but who are assessed as not high risk, and Community Forensic CAMHS for young people from Highly Specialist Secure Forensic Mental Health Services Centres for young people.

ICBs also commission access assessment for secure mental health service for young people.

Change of service commissioner

There are plans to review whether medium secure CYPMH inpatient service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22C

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set via Strategic Data Collection Service
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity is identified via local data flows, which apply to Specialist Secure Forensic Mental Health Services Centres for young people only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

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99. Severe acute porphyria service (adults and children)

[Programme of Care – Women & Children, CRG – Metabolic Disorders]

Service summary

Severe acute porphyria services include services provided by Highly Specialist Severe Acute Porphyria Centres. This provision applies to adults and children.

Other relevant service(s):

- 62. Specialist metabolic disorder services (adults and children)

About the condition/service

Acute porphyrias are a rare, inherited disorder, typically presenting in young adults. Acute attacks can be life-threatening. The condition can result in permanent disability and even death due to progressive motor neuropathy.

How the service is organised

The service comprises two elements:

- An acute support service to hospitals around the country. Advice is given on the treatment of the patient and the three centres also arrange for a stock of the drug, haem arginate, to be sent where appropriate
- A structured multi-disciplinary follow up service for patients after acute attacks and severely affected patients with recurrent attacks, often complicated by paralysis, and increased risk of kidney disease and hypertension

The service treats about 150 people with acute porphyria who meet the definition of ‘severe’ disease.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions severe acute porphyria services for adults and children from Highly Specialist Severe Acute Porphyria Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- All treatment of acute porphyria outside of the Highly Specialist Severe Acute Porphyria Centres (regardless of whether advice is given by the Specialist Centre or haem arginate prescribed by the Specialist Centre
- All treatment of acute porphyria that takes place at the Specialist Centres that does not meet the definition of ‘severe’

Change of service commissioner

There are no plans to review whether commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 27D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Acute Porphyria Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS27D service code within all relevant commissioning dataflows.

100. Severe combined immunodeficiency and related disorders service (children)

[Programme of Care – Blood & Infection, CRG – Blood and Marrow Transplantation]

Service summary

Severe combined immunodeficiency and related disorders services include services provided by Highly Specialist Severe Combined Immunodeficiency and Related Disorders Centres. This provision applies to children.

Other related services:

- 22. Autoimmune paediatric gut syndromes service
- 29. Haematopoietic stem cell transplantation services (adults and children)
- 138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)

About the condition/service

Severe combined immunodeficiency disorders (SCID) is the term used to cover the most serious types of primary immunodeficiency where various components of the body’s defence system are defective, leaving the child prone to unusual and/or frequent infections. In all forms of SCID, both T and B lymphocyte functions, the body’s defence mechanisms, are defective from birth.

This service is in the highly specialised portfolio.

How the service is organised

Treatment is usually through a bone marrow or stem cell transplant to boost the immune system. In some cases, gene therapy or thymus transplantation is appropriate.

There are about 60 referrals to the service each year and about the same number of transplants.

The service comprises:

- **Outpatient clinics**
- **Interventions:** screening for viruses, liver and kidney function, graft vs. host disease. Appropriate interventions are made if necessary, including antibiotics, pre-transplant work-up and donor searches where applicable
- **Inpatient activity:** patients are admitted one to two weeks prior to their transplant for preparation and conditioning. Patients are re-admitted if there are complications following their discharge.
- **Follow up:** the follow up process runs for the period of time agreed with the referring clinician. A clinical review is required within three months post-

transplant between referring and Specialist Centre clinicians to enhance communication, plan further treatment and agree on transfer arrangements.
- **Transplant:** bone marrow transplants, stem cell transplants, gene therapy, thymus transplants

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for children with severe combined immunodeficiency and related disorders from Highly Specialist Severe Combined Immunodeficiency and Related Disorders Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 16C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Severe Combined Immunodeficiency and Related Disorders Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS16C service code within all relevant commissioning dataflows.

101. Severe intestinal failure service (adults)

This service has merged with service 10 ‘Adult specialist intestinal failure services’.

[Programme of Care – Internal Medicine, CRG – Specialised Colorectal Services]

Service summary

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

Other relevant service(s):

- 23. Autologous intestinal reconstruction service for adults
- 103. Small bowel transplantation service (adults and children)
- 106A. Specialist colorectal surgery services (adults)
- 110. Specialist gastroenterology, hepatology and nutritional support services for children

About the condition/service

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

Patients with Type II Intestinal Failure are metabolically unstable patients characterised as unable to meet their nutritional needs via absorption of nutrients and fluids through the intestines and requiring intravenous nutrition for prolonged periods. The incidence of cases is about 10 per million of the population each year.

Patients with Type III intestinal failure are metabolically stable patients requiring prolonged artificial nutritional support via intravenous feeding (parenteral nutrition) delivered to them in community settings by specialist suppliers of intravenous nutrition. This includes the supply of home parenteral nutrition (HPN) products and associated specialist nursing support for those unable to self-administer intravenous feeds. The prevalence of patients on HPN is about 40 per million.

The severe intestinal failure service treats patients with the most severe cases of intestinal failure. These patients are referred from general hospitals and teaching hospitals and have intestinal conditions that cannot be managed in a lower-intensity setting at local or regional intestinal failure units.

The major conditions covered by the service include:

- Severe and/or fistulating Crohn's disease

- Short bowel syndrome after massive intestinal resection for mesenteric vascular catastrophe
- Patients suffering from complications of severe pancreatitis
- The after-effects of therapy for malignancy
- Other conditions in which the intestine has ceased to function (for example, pseudo-obstruction)

How the service is organised

The service sees about 425 patients each year.

What NHS England directly commissions in line with national standards (specifications and policies)

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

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for patients who require management for short term intestinal failure (usually peri-operatively) for fewer than 28 days and prescribing of parenteral nutrition of under 14 days[6] duration due to circumstances where the **primary medical issue is not one of sub-optimal bowel function**, i.e. patients who do not have Intestinal Failure Type II and III. Examples include coma patients being managed in intensive care, patients with significant burns affecting the upper GI tract, inpatient palliative care for end-stage oncology patients).

How the activity for this service is identified

This service includes specified activity at specified centres. In a small number of cases, activity is identified via local data flows.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 12Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal

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[6] Parenteral nutrition for the first 14 days is in tariff

- Patient Level Contract Monitoring via Data Landing Portal
- Uploading of information to National Intestinal Failure Registry

How the activity for this service is identified

This service includes specified activity at specified centres. It should be noted that, at the time of compiling this guidance document, a national review of Intestinal Failure providers is underway with the intention of designating a list of national providers. This will change the way in which the Identification Rules should be used.

How to use the Identification Rules

1. The IR software tool does not include a rule for this service. Providers are required to identify activity locally and attribute NCPS12Z service code within all relevant commissioning dataflows.
2. All patients who meet the criteria of an intestinal failure patient are documented within National Intestinal Failure Registry. The patients within that database should be cross-referenced to inpatient and outpatient activities and to identify relevant activities for submission in CDS dataflows to SUS (attributing to service code NCBPS12Z).
3. In addition, Inpatients requiring more than 14 days consecutive use of intravenous nutrition (PN) are a good indicator of type II Intestinal Failure.

102. Severe obsessive compulsive disorder and body dysmorphic disorder service (adults and adolescents)

[Programme of Care – Mental Health, LD & Autism, CRG – Severe OCD and BDD Services]

Service summary

Severe obsessive compulsive disorder and body dysmorphic services include services provided by Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder Centres. This applies to provision in adults and adolescents.

Other relevant service(s):

- 32. Children and young people's inpatient mental health services

About the condition/service

This service offers inpatient and outpatient care for patients assessed as being at Level 6 (patients who are diagnosed as severe on a scale of 1-6) on the NICE guidelines for obsessive compulsive and body dysmorphic disorders.

How the service is organised

There are about 130 referrals to the service each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and adolescents with severe obsessive compulsive disorder and body dysmorphic disorder from Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for patients who are not diagnosed as severe, i.e. are on a scale of 1-5 as set out in the NICE guidelines.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22F

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Mental Health Services Data Set via Strategic Data Collection Service

How the activity for this service is identified

Activity is identified via local data flows, which apply to Highly Specialist Severe Obsessive Compulsive Disorder and Body Dysmorphic Disorder Centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

103. Small bowel transplantation service (adults and children)

[Programme of Care – Internal Medicine, CRG – Hepatobiliary and Pancreas] [Adults]
[Programme of Care – Women & Children, CRG – Specialised Paediatric Gastroenterology Services] [Children]

Service summary

Small bowel transplantation services include services provided by Highly Specialist Small Bowel Transplant Centres. This applies to provision in adults and children.

Other relevant service(s):

- 84. Paediatric intestinal pseudo-obstructive disorders service
- 101. Severe intestinal failure service (adults)
- 110. Specialist gastroenterology, hepatology and nutritional support services for children

About the condition/service

This service provides assessment, transplantation and lifelong follow up of adult and paediatric patients requiring small bowel transplantation.

This service is in the highly specialised portfolio.

How the service is organised

There were 27 transplants in 2021/22.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions small bowel transplantation services for adults and children from Highly Specialist Bowel Transplant Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 12D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal
- Organs transplanted data from NHS Blood and Transplant

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Small Bowel Transplant Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS12D service code within all relevant commissioning dataflows.

103A. Specialist adult haematology services

[Programme of Care – Blood & Infection, CRG – Specialised Blood Disorders]

Service summary

Specialist adult haematology services include services provided by Specialist Adult Haematology Centres.

This applies to provision in adults.

Other relevant service(s):

- 113. Specialist haematology services for children

About the condition/service

Idiopathic multicentric Castleman disease (iMCD) is a rare disorder of uncontrolled growth of cells in lymph nodes. It causes lymph node enlargement, enlargement of liver and spleen, constitutional symptoms, fluid retention and biochemical and haematological disturbances. Severe disease can lead to multiorgan failure, a requirement for critical care support and death.

Thrombotic thrombocytopenic purpura (TTP) is a very serious rare blood disease, which is caused by the formation of tiny blood clots in the blood vessels all over the body and a depletion of platelets. The resulting low platelet count is one of the main features of TTP and is called thrombocytopenia. The low platelet count can also cause bruising, known as purpura. TTP can affect the heart and brain; it can also cause a high temperature and affect the kidneys.

This service is in the highly specialised portfolio.

How the service is organised

iMCD is treated in Specialist Adult Haematology Centres.

TTP is treated in a network of Specialist Adult Haematology Centres that between them form networks with catchment areas that between them cover the whole country.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist adult haematology services from Specialist Adult Haematology Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by Specialist Adult Haematology Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission any local care recommended in the management plan developed by Specialist Adult Haematology Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for these services.

Identification Rules information

NCBPS service code(s)

Castleman disease: 03C
Thrombotic thrombocytopenic purpura (TTP): 03T

Data flows

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool does not include a rule for these services. Providers are required to identify activity locally and attribute the relevant NCBPS service code within all relevant commissioning dataflows.

104. Specialist burn care services (adults and children)

[Programme of care – Trauma, CRG – Major Trauma and Burns]

Service summary

Specialist burn care services include all burn care delivered by Burn Centres, Burn Units and Burn Facilities delivered as part of an Operational Delivery Network. This covers the whole pathway including:

- Specialist assessment
- Admission to a Centre, Unit or Facility and
- Rehabilitation and surgical reconstruction
- Outreach

This applies to provision in adults and children.

About the condition/service

Burn injuries range from the most minor, dealt with in the community, to the most severe and devastating, and affect adults and children and social groups. The definition of severity is based on the size and anatomical site of the injury, the depth of skin injury, the age of the patient and the presence of co-existing conditions.

Specialist burn care service activity is low volume and high cost, is driven by emergency admissions (although there is a very small number of elective cases) and requires multi-professional input and care delivered over a long period of time, involving acute, rehabilitation and outreach services.

Demand for burn care varies significantly across the country, especially for the more severe injuries.

How the service is organised

In England and Wales, specialist burn care services are organised using a tiered model of care (centre, unit and facility) whereby the most severely injured are cared for in services recognised as centres, those requiring less intensive clinical support are cared for in services recognised as units, and those with non-complex burn injuries are cared for in services recognised as facilities. A burn care service at a given level also provides a ‘lower’ level service to its local population (for example an adult burn centre also provides an adult unit and facility level service). The National Burn Care Referral Guidance (2012) describes the injury severity thresholds for each level of service.

Burn Facilities provide acute care for people with non-complex burns. These services form part of a plastic surgery service. Burn Facilities refer patients to Burn Units and Centres for the treatment of more complex injuries (in line with national and local threshold guidance). Burn Facilities are an integral part of the patient pathway in the provision of a rehabilitation service for patients from their local area who have more complex injuries. Some services currently work at Facility level only About 10,000 individuals require access to a Burn Facility each year.

Burn Units provide care for patients with a burn of moderate size and/or moderate complexity. These services treat patients across a wider area than Facilities and provide treatment for patients requiring critical care (such as care in a high dependency unit). Unit level services may be adult only, child only or both). These services deliver burn care at both Facility and Unit level. About 1,200 individuals require access to a Burn Unit each year.

Burn Centres provide care for patients with the most complex injuries and for those requiring the highest level of critical care. Centres may be adult only, child only or both). These services provide burn care at Centre, Unit and Facility level. About 100 adults and fewer than 50 children require access to a Burn Centre each year.

The burn care pathway includes:

- Inpatient management of the acute burn by an extensive multi-disciplinary team focusing on intensive surgical care (including critical care and specialist anaesthesia), specialist nutritional care and therapy services, including physiotherapy, occupational therapy, psychology, speech and language therapy
- Discharge (from the acute service)
- Ongoing care, including outreach, reconstruction and rehabilitation

There are four Operational Delivery Networks of Specialist Burn Care Services across England and Wales.

There is a service specification for patients with Stevens-Johnson syndrome (SJS) and toxic Epidermal Necrolysis (TEN), which is commissioned in specific centres, to provide specialist care for children and adults in age-appropriate critical care settings, co-located with burns services, for the population of England.

This service is in the highly specialised portfolio

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all specialist burn care services provided by Burn Centres, Burn Units and Burn Facilities, delivered as part of a provider network. NHS England also commissions services for patients with toxic epidermal necrolysis, severe staphylococcal scalded skin syndrome, necrotising fasciitis and other skin loss conditions when they are treated in a Specialist Burn Care Centre.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission burn care services from any providers that are not identified as Burns Centres, Burns Units or Burns Facilities. ICBs commission care for patients at Specialist Burn Care Centres once the burn care episode is complete.

NHS England is in the process of commissioning a service for Stevens-Johnson syndrome and toxic epidermal necrolysis (SJS-TEN).

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 09A
- 09C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- All patients (except those that refuse) should be logged on the International Burns Injury Database (IBID) clinical database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

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105. Specialist cancer services (adults)

[Programme of Care – Cancer, CRG – Cancer Clinical Advisory Group]

Service summary

Specialist cancer services include:

- All care provided by Specialist Cancer Centres for rare cancers[7]
- Complex surgery for specified common cancers provided by Specialist Cancer Centres (including assessment if performed at the Specialist Centre)
- Certain specified interventions provided by specified Specialist Cancer Centres (including assessment if performed at the Specialist Centre)
- Chemotherapy[8]: the procurement and delivery of chemotherapy including drug costs

Other relevant service(s):

- 13. Adult specialist orthopaedic services
- 18. Adult thoracic surgery services
- 29. Haematopoietic stem cell transplantation services (adults and children)
- 33. Choriocarcinoma service (adults and adolescents)
- 53. Ex-vivo partial nephrectomy service (adults)
- 76. NF2-schwannomatosis service (adults and children)
- 79. Ocular oncology service (adults)
- 80. Ophthalmic pathology service (adults and children)
- 87. Positron emission tomography-computed tomography services (adults and children)
- 89. Primary malignant bone tumours service (adults and adolescents)
- 90. Proton beam therapy service (adults and children)
- 91. Pseudomyxoma peritonei service (adults)
- 94. Radiotherapy services (adults and children)
- 106. Specialist cancer services for children and young adults
- 106A. Specialist colorectal surgery services (adults)
- 131. Specialist services for complex liver, biliary and pancreatic diseases in adults

About the condition/service

Over 300,000 people are diagnosed with cancer each year and more than 1 in 3 people will develop cancer during their lifetime. There are over 200 types of cancer,

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[7] 'All care' includes cancer-related activity from referral to specialist centre to discharge including diagnostics, chemotherapy, surgery and any long term follow up. This includes outreach when delivered as part of a provider network. In addition, the service includes specialist palliative care and survivorship, when provided by a Specialist Cancer Centre.

[8] 'Chemotherapy' refers to any systemic anti-cancer therapy. This includes monoclonal antibodies, targeted therapies, intravenous, subcutaneous, intrathecal and oral chemotherapy as well as topical treatments.

of which about 50% are classified as ‘rare’. All cancer patients’ treatments are discussed and agreed by an appropriate site-specific multi-disciplinary team at the time of diagnosis.

How the service is organised

Specialist Cancer Centres treat specified rare cancers and/or provide specialist interventions for patients with more common cancers. Some services are delivered on an outreach basis. In addition, a much larger number of providers deliver chemotherapy for patients with common cancers.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist cancer services for adults, including:

- Penile cancer
- Soft tissue sarcoma

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

Integrated Care Boards (ICBs) commission specialist cancer services for adults, including services delivered on an outreach basis as part of a provider network. Specialist cancer services include:

A. All care provided by Specialist Cancer Centres for rare cancers, for example:
    - Anal cancers
    - Brain/central nervous system cancers for all low- and high-grade tumours (linking with Specialist Neurosciences Centres)
    - Endocrine cancers
    - Germ cell cancers (except initial diagnosis and treatment)
    - Gynaecological cancers (except early stage cervical and endometrial cancers and initial assessment of all gynaecological cancers)
    - Head and neck cancers
    - Mesothelioma
    - Pituitary cancers (linking with Specialist Neurosciences Centres)
    - Skin cancers (patients with invasive skin cancer with a greater risk or rarity and patients with cutaneous skin lymphomas)
    - Upper gastrointestinal cancers
    - Urological cancers (testicular)

B. All care provided to Teenagers and Young Adults by defined Specialist Teenage and Young Adult Cancer Centres

C. Certain complex surgery for specified common cancers provided by specified Specialist Cancer Centres (including assessment if performed at the Specialist Centre) for example:
    - Germ cell cancers (for example, gynaecological and testicular except initial diagnosis and non-complex surgery)

- Gynaecological cancers (except early stage cervical and endometrial cancers and initial assessment of all gynaecological cancers)
- Urological cancers (specialist surgery only for bladder, kidney and prostate cancers, including exenterations)

D. Certain specified interventions provided by defined Specialist Cancer Centres (including assessment if performed at the Specialist Centre) for more common cancers, for example:
   - **Gastrointestinal cancer interventions:**
     - laparoscopic liver resection
     - thoracoscopically assisted oesophagectomy
     - preoperative high dose rate brachytherapy for rectal cancer
     - microwave ablation for hepatocellular carcinoma
     - laparoscopic gastrectomy for cancer

   - **Gynaecological cancer interventions:**
     - exenterative surgery for gynaecological cancer
     - high dose rate brachytherapy for carcinoma of the cervix

   - **Lung cancer interventions:**
     - continuous hyperfractionated accelerated radiotherapy (CHART) for non-small cell lung cancer
     - thoracic surgery for lung cancer
     - cryotherapy for malignant endobronchial obstruction

   - **Skin cancer interventions:**
     - Mohs surgery for defined skin cancers
     - total skin electron beam radiotherapy (TSEB)
     - photopheresis for cutaneous (skin) T-cell lymphoma
     - immunocompromised patients at increased risk of developing skin cancers, for example, transplant patients

E. Chemotherapy: the procurement and delivery of chemotherapy including drug costs and molecular diagnostic testing for targeted medicine (noting all molecular diagnostic testing is considered to be in tariff unless otherwise specified).

F. Blood and bone marrow transplantation for haematological cancers and lymphomas

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for patients with the following specified common cancers with the exception of radiotherapy, chemotherapy and the specialist interventions listed above:

- Adjuvant drug treatments, for example, hormone therapies not excluded from tariff, drugs affecting bone metabolism
- Bladder and kidney cancer (except specialist surgery)

- Breast cancer
- Germ cell cancer (initial diagnosis and treatment)
- Gynaecological cancers (Initial assessment of all cancers; treatment of early stage cervical and endometrial cancers)
- Haematological cancers and associated haemato-oncological pathology
- Lower gastrointestinal cancer
- Lung cancer
- Prostate cancer (except specialist surgery)
- Sarcoma (soft tissue where local surgery is appropriate)
- Skin cancer (except for patients with invasive skin cancer and those with cutaneous skin lymphomas)
- Specified interventions that are commissioned by NHS England for the treatment of cancers where the indication is not cancer-related, for example, Moh's surgery for the treatment of non-cancerous indications

Change of service commissioner

There are plans to review whether penile cancer should be delegated to ICBs in the future.

There are plans to review whether soft tissue sarcoma should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- Anal cancer: 01J
- Biliary tract cancer: 01V
- Bone sarcoma: 01O
- Head and neck cancer: 01M
- Gynaecological cancer: 04F
- Kidney, bladder and prostate cancer: 01N
- Liver cancer: 01W
- Malignant mesothelioma: 01K
- Oesophageal and gastric cancer: 01U
- Pancreatic cancer: 19V
- Penile cancer: 01X
- Rare brain and CNS cancer: 01Q
- Rare cancer: 01Y
- Skin cancer: 24Y
- Soft cell cancer: 01L
- Testicular cancer: 01Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS

- Adult critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

For rare cancers, the service includes all activity, and activity is identified via the identification rules described below. Activity is undertaken and should be identified/reported by specified centres only.

For surgery and interventions, the service includes specified activity, and activity is identified via the identification rules described below. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

NCBPS service code(s)

- Chemotherapy: 01C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Inputting of information into Systemic Anti-Cancer Therapy (SACT) dataset managed by the Cancer Intelligence Unit

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All unbundled chemotherapy activity in the HRG range SB01Z to SB15Z, SB16Z and SB17Z should be identified and attributed to NCBPS01C service code within all relevant commissioning dataflows.

106. Specialist cancer services for children and young adults

[Programme of Care – Cancer, CRG – Children and Young People]

Service summary

Specialist cancer services for children and young adults include:

- All specialist care for children within children’s Principal Treatment Centres (PTCs)
- All specialist care for teenagers and young adults within Teenage and Young Adult PTCs including transitional care
- All shared care overseen by PTCs
- All cancer chemotherapy and radiotherapy
- All specialist cancer palliative care services
- Planning after care (as part of the survivorship initiative)

This provision relates to children and young people up to the age of 24.

Other relevant service(s):

- 76. NF2-schwannomatosis service (adults and children)
- 80. Ophthalmic pathology service (adults and children)
- 87. Positron emission tomography-computed tomography services (adults and children)
- 89. Primary malignant bone tumours service (adults and adolescents)
- 90. Proton beam therapy service (adults and children)
- 94. Radiotherapy services (adults and children)
- 97. Retinoblastoma service (children)
- 105. Specialist cancer services (adults)

CHILDREN’S CANCER SERVICES

About the condition/service

Each year, about 1,200 children aged 0 to 14 years are newly diagnosed with cancer. Paediatric cancer is rare with about one in 600 children being diagnosed with a cancer by the age of 15.

How the service is organised

Children are treated primarily in Children’s Principal Treatment Centres (PTCs) and teenagers at either the Children’s PTCs or Teenage and Young Adult PTCs. In addition, there are Paediatric Oncology Shared Care Units (POSCUs).

So as to provide care as close to the child or young person’s home as possible, the PTCs decide and direct which elements of specialist cancer care can be delivered in hospitals designated for cancer shared care. The PTCs are staffed by doctors and nurses with specialist qualifications and training in cancers in this age group, who work using a multi-disciplinary approach. POSCUs have a designated lead consultant paediatrician and a named POSCU nurse, supported by a nursing skill mix that ensures sufficient numbers of staff have relevant paediatric cancer-related training. The PTCs link with associated children's services such as education.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions specialist cancer services for children and young adults from Children's PTCs and Teenage and Young Adult PTCs. ICBs also commissions services delivered at shared care centres through the PTCs. Specialist cancer services for children and young adults include:

- All cancer chemotherapy (including delivery) and radiotherapy
- Specialist palliative care services
- Survivorship
- Long-term follow up
- Specialist therapies and rehabilitation

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

TEENAGE AND YOUNG ADULT CANCER SERVICES

About the condition/service

Each year, about 500 teenagers aged 15 to 18 years and 1,300 young adults aged 19 to 24 are diagnosed with cancer.

How the service is organised

TYA patients aged 16 years (13 years in some networks) to 18 years are treated primarily at TYA Principal Treatment Centres (PTCs). Patients aged 19-24 are offered the choice of treatment in the PTC or at a TYA Designated Hospital (DH) located closer to home.

In order to minimise disruption to patients, some elements of care may be delivered closer to home at 'shared' care centres, in partnership with and directed by the PTCs. These 'shared care' centres may be TYA DHs or Paediatric Oncology Shared Care Units.

The TYA PTCs are staffed by a comprehensive multidisciplinary team with specialist qualifications and training in cancers in this age group, and expertise in age appropriate care. The DHs are staffed by tumour site specific experts, with specialist qualifications and training and a special interest in TYA cancer care. The shared care sites for children are staffed by paediatric multidisciplinary teams with a special interest in cancer.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist cancer services for teenagers and young people from Teenage and Young Adult PTCs. NHS England also commissions services delivered at Children's PTC for younger teenagers and at TYA designated hospitals. Specialist cancer services for children and young adults include:

- All cancer chemotherapy (including delivery) and radiotherapy
- Specialist palliative care services
- Survivorship
- Long-term follow up
- Specialist therapies and rehabilitation

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Children's cancer: 23A
- Teenage and young adult cancer: 01T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.

2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

It should be noted that all proton beam therapy provided to children or teenage and young adult cancer patients is covered in the proton beam therapy identification rule.

106A. Specialist colorectal surgery services (adults)

This service was previously called ‘Highly specialist colorectal surgery services (adults)

[Programme of Care – Internal Medicine, CRG – Specialised Colorectal Services]

Service summary

Specialist colorectal surgery services include the following services when provided by Specialist Colorectal Surgery Centres:

- Surgical management for complex inflammatory bowel disease
- Complex surgical interventions for faecal incontinence

This applies to provision in adults.

Other relevant service(s):

- 58. Specialist adult gynaecological surgery services
- 91. Pseudomyxoma peritonei service (adults)
- 101. Severe intestinal failure services (adults)
- 103. Small bowel transplantation service (adults and children)
- 105. Specialist cancer services (adults)

About the condition/service

Specialist colorectal services require a critical mass of expertise in surgery, medicine, radiology, pathology and nursing. This is possible only in units large enough to allow specialisation in all of these disciplines and it is only in units receiving referrals from a wide geographical area that sufficient experience is gained in dealing with the more difficult and complex cases.

How the service is organised

Services are currently provided at Specialist Colorectal Surgery Centres only with networks under development.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions cytoreductive surgery and heated intra peritoneal chemotherapy (HIPEC) for peritoneal carcinoma from colorectal origin.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission the following specialist colorectal surgery services from Specialist Colorectal Surgery centres:

- distal sacrectomy for advanced or recurrent cancer (a procedure in which bowel tumours that involve the sacrum (the bone at the base of the spine) are removed
- surgery for complex inflammatory bowel disease: ileoanal pouch formation (pouches that have been constructed for people who have had their large intestine surgically removed due to disease or injury), excision of ileoanal pouch, revisional pouch surgery
- complex surgical interventions for faecal incontinence: sacral nerve stimulation (a procedure that involves the implantation of a programmable stimulator to control faecal incontinence); graciloplasty (the creation of a new anal sphincter), implantable sphincters, anal bulking (the injection of materials to improve faecal incontinence), sphincter repair surgery, endoscopic radiofrequency therapy
- transanal endoscopic microsurgery (TEMS) (a minimally invasive technique for the treatment of rectal neoplasia) and other trans anal techniques for the treatment of early rectal cancer

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other colorectal surgery services, except where these are specified elsewhere in this document. ICBs commission sacral nerve stimulation for conditions other than faecal incontinence.

Change of service commissioner

Ileoanal pouch formation has been moved and this will require a transfer of funds from ICBs to NHS England and then to ICBs when the service is delegated.

Identification Rules information

NCBPS service code(s)

- Complex inflammatory bowel disease: 33B
- Complex surgery for faecal incontinence: 33A
- Transanal endoscopic microsurgery: 33C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

Inpatient activity should be identified by application of the IR tool to CDS data.

NCBPS service code(s)

- Cytoreductive surgery and hyperthermic intraperitoneal chemotherapy for colorectal cancer: 33E
- Distal sacrectomy for advanced and recurrent rectal cancer: 33D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

This service includes specified activity at specified centres.

How to use the Identification Rules

The IR software tool does not include a rule for these services. Providers are required to identify activity locally and attribute the relevant NCBPS service code within all relevant commissioning dataflows.

107. Specialist dentistry services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist dentistry services for children include services provided by Specialist Paediatric Dental Surgery Centres including outreach when delivered as part of a provider network. The service includes:

- Dental management of rare or complex conditions in children
- Provision of specified dental procedures in children
- Dentistry management of more common dental conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

Other relevant service(s):

- 43. Craniofacial service (adults and children)

About the condition/service

Most children who require dentistry procedures can be cared for by their local non-specialist children's dentistry service.

Specialist paediatric dental care is required for patients under the age of 18 when: the procedure is complex; the condition being managed is rare and/or when the child has complex co-morbidities.

How the service is organised

Services are delivered by Specialist Paediatric Dental Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist dentistry services for children from Specialist Paediatric Dental Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- Dental management of rare or complex conditions in children
- Provision of specified dental procedures in children
- Dentistry management of more common dental conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

ICBs also commission all other dental services through their dental contracts (to be delegated by NHS England from April 2023).

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service as these services are commissioned directly by NHS England.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23P

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Any critical care activities associated with the inpatient activity identified at 1 require local identification and attribution to specialised commissioning.
3. Outpatient activity should be identified by application of the IR software tool to CDS data.

108. Specialist ear, nose and throat services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist ear, nose and throat (ENT) services for children include services provided by Specialist Paediatric Ear, Nose and Throat Surgery Centres including outreach when delivered as part of a provider network. This service includes:

- Surgical management of rare ear, nose and throat (ENT) conditions in children
- Provision of specified specialist ENT procedures in children
- Surgical management of more common ENT conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

In addition, this service includes Specialist Audiology Services.

Other relevant service(s):

- 30. Bone conduction hearing implant services (adults and children)
- 36. Cochlear implantation services (adults and children)
- 43. Craniofacial service (adults and children)

A. SPECIALIST EAR, NOSE AND THROAT SURGERY

About the condition/service

Most children who require routine ENT management or procedures can be cared for by their local children’s ENT service.

Specialist ENT surgical care is required for patients under the age of 18 when the: surgical condition being managed is rare (for example, Choanal atresia); the surgery is complex (for example, Laryngotracheal reconstruction) and/or when the baby or child has complex co-morbidity (for example, adenotonsillectomy is normally a routine non-specialist procedure but requires specialist peri-operative care when the child has complex co-morbidities). In these circumstances, specialist paediatric anaesthesia and/or pain relief are usually required. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

Specialist services are delivered by Specialist Paediatric Ear, Nose and Throat Surgery Centres.

What NHS England directly commissions in line with national standards (specifications and policies)

There is a specific auditory brainstem implant (ABI) service, which is commissioned to provide services for children under the age of five. The ABI service is for children with profound deafness who have no functional hearing as a result of congenital abnormalities affecting the auditory nerve or the cochlea, thus rendering them unable to gain adequate benefit from conventional well-fitted hearing aids or cochlear implants. The service includes multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant).

This service is in the highly specialised portfolio.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

NHS England commissions specialised ear, nose and throat services for children from Specialist Paediatric Ear, Nose and Throat Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes specialist audiology services where these are part of specialist ear, nose and throat services for children.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine ENT surgical management when the child or the procedure is not high risk, including:

- Tonsillectomy
- Adenoidectomy
- Insertion of grommets

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above is required to be identified locally and attributed to the relevant NCBPSNIC or NCBPSPIC service code. .
3. The IR software tool should be used to identify outpatient activity using CDS data.

B. SPECIALIST AUDIOLOGY SERVICES

About the condition/service

About 700 children are identified with bilateral hearing loss each year, 50-100 due to acquired hearing loss. About 12,000 children require access to Specialist Audiology Services.

How the service is organised

To be determined

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission Specialist Audiology Services. Specialist Audiology Services are those audiological services that are part of a paediatric hearing aid service and include:

- Differential audiological diagnosis
- Etiological investigations (including radiology and genetics) and medical assessment (including vestibular assessment) for newly diagnosed hearing loss (both uni- and bilateral) without any obvious cause such as otitis media with effusion (glue ear)
- Hearing aid provision
- Frequency modulated hearing aid provision where this is related to a health (and not education) need
- Transitional arrangements to adult services
- Outreach support to education

It also includes specialist audiology for rare conditions such as:

- Vestibular assessment and management
- Auditory Processing disorder (APD)
- Hearing assessment and hearing aid provision in children with complex comorbidity, for example, children with programmable ventriculo-peritoneal (VP) shunts

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other children’s audiology services, including: services for children with unilateral hearing loss, glue ear and auditory neuropathy spectrum disorder; and assessment of children referred for professional concern or following a school screen.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23D

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

It should be noted that the IR software tool does not include a separate identification rule for this Audiology service. Providers are asked to identify activity locally and attribute NCBPS23D service code within all relevant commissioning dataflows where activity can be identified locally.

109. Specialist endocrinology services for children

[Programme of Care – Women & Children, CRG – Specialised Paediatric Endocrinology]

Service summary

Specialist endocrinology services for children include:

- care for complex endocrine conditions provided by Paediatric Endocrine Centres (PECs)

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant service(s):

- 9. Adult specialist endocrinology services
- 20. Alström syndrome service (adults and children)
- 24. Bardet-Biedl syndrome service (adults and children)
- 42. Congenital hyperinsulinism service (children)
- 55. Gender dysphoria services (children and adolescents)
- 67. Insulin-resistant diabetes service (adults and children)
- 139A. Specialist morbid obesity services for children
- 142. Wolfram syndrome service (adults and children)

About the condition/service

Common paediatric endocrinology conditions are managed in local hospitals or primary care settings, but complex and rare endocrine conditions are managed in conjunction with Paediatric Endocrine Centres.

The incidence of these conditions varies from 1 in 1,000 where specialist endocrine input is required for some with the condition at a certain point in their lives (for example, puberty), through to 1 in 5,000-10,000 where the condition requires a higher level of endocrine input (in some cases lifelong), through to rare (<1 in 10,000) endocrine conditions that require intensive input at various stages during childhood and adolescence, including lifelong endocrine input.

How the service is organised

Specialist endocrinology services for children are provided in conjunction with other specialist paediatric services (including neonatal/paediatric Intensive and high dependency care, oncology, neurosurgery, endocrine surgery, biochemistry, genetics, imaging, histopathology, pharmacy, dietetics, physio/occupational therapy) and provide on-call cover for their region. The majority of children are assessed and treated on an outpatient or day case basis by the specialist multi-disciplinary team; these teams may focus on one set of conditions, for example, bone disorders. Treatment and follow up are lifelong and planned transition to adult services takes place via joint and/or hand-over clinics.

Outreach clinics led by the specialist endocrine teams from the centres may take place in more local settings. These may include assessment of new patients referred from local paediatricians and review of existing patients through shared care arrangements.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist endocrinology and diabetes services for children from Paediatric Endocrine Centres, including services delivered on an outreach basis as part of a provider network. ICBs commission services for the following conditions:

(a) Endocrinology:

- complex growth problems including Turner syndrome and growth hormone deficiency; puberty disorders including precocious, delayed or absent puberty
- pituitary disease including hypopituitarism, pituitary and peri-pituitary tumours
- complex fluid balance problems (for example, in neurosurgery)
- thyroid and parathyroid associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease, for example, care of endocrine problems in cancer survivors, cystic fibrosis related diabetes, growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
- severe or repeated hypoglycaemia
- disorders of bone and calcium metabolism
- multiple endocrine neoplasia (MEN) syndromes and other familial endocrine disorders
- DSD (differences in sex development)
- morbid obesity
- children with some forms of diabetes, including those with diabetes complications in childhood, would be managed by local diabetes services but may receive input and advice from specialist paediatric endocrinology and other services, as required.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission children’s insulin pumps including associated pump consumables and associated continuous glucose monitoring devices.

ICBs commission all other paediatric endocrine and diabetes activity.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23E

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activity using CDS data.

110. Specialist gastroenterology, hepatology and nutritional support services for children

[Programme of Care – Women & Children, CRG – Specialist Paediatric Gastroenterology Services]

Service summary

Specialist gastroenterology, hepatology and nutritional support (GHNS) Services for children include:

- care for complex conditions provided by Paediatric Specialist GHNS Centres
- care for more common conditions requiring support from Paediatric Specialist GHNS Centres

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant service(s):

- 84. Paediatric intestinal pseudo-obstructive disorders service
- 103. Small bowel transplantation service (adults and children)
- 123. Specialist paediatric liver disease service

About the condition/service

Specialist Gastroenterology, Hepatology and Nutritional Support (GHNS) Services for children focus on the investigation and management of rare disorders and on complex or atypical cases of more common disorders. In some cases the role of the specialist gastroenterology, hepatology and nutrition centre may be to provide advice to a local clinical service and in many cases the centre shares clinical management with the local hospital but some patients require the intensive involvement of the specialist centre, particularly during periods of illness or for diagnostic evaluation including endoscopy, gastrointestinal imaging, manometry or liver biopsy.

How the service is organised

Specialist GHNS Services for children perform colonoscopy and have a service for gastrointestinal bleeding and are co-located with paediatric surgery. A smaller number of centres in England provide comprehensive out of hours cover for Gastroenterology 365 days per year. GHNS Services for children are delivered as part of a clinical network in order to provide the best patient care, facilitate optimal use of resources and maximise local access for patients.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission specialist GHNS services for children from Paediatric Specialist GHNS centres, including services delivered on an outreach basis as part of a provider network. ICBs commission services for the following conditions:

- Inflammatory bowel disease
- Intestinal failure
- Chronic diarrhoea/malabsorption
- Gastrointestinal polyps and polyposis syndromes
- Eosinophilic disorders
- Gastrointestinal motility disorders, including gastric pacing procedures
- Exocrine pancreatic insufficiency and pancreatic disorders including pancreatitis
- Acute and chronic liver disorders
- Gastrointestinal bleeding
- Specialist nutritional support

ICBs commission the following specialist investigations:

- upper gastrointestinal endoscopy (diagnostic and therapeutic)
- ileo-colonoscopy (diagnostic and therapeutic)
- video-capsule endoscopy
- endoscopic ultrasonography (EUS)
- endoscopic retrograde cholangiopancreatography (ERCP) (diagnostic and therapeutic)
- oesophageal pH and impedance monitoring
- diagnostic breath tests including hydrogen breath tests
- pancreatic function intestinal intubation tests
- gastrointestinal motility investigations (including oesophageal and gastrointestinal manometry, electrogastrography)
- enteroscopy

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for patients with these conditions once they have been discharged to local follow up following input from the specialist centre at presentation. These conditions can be managed by a local hospital initially as secondary care and then be referred for specialist care:

- Coeliac disease
- Peptic ulcer disease including *H. Pylori* gastritis
- Fabricated and induced illness presenting with gut symptoms
- Multiple food intolerances (actual and perceived) as part of a network including allergist and local paediatrician.

ICBs commission services for patients with these common conditions only when referral to the specialist centre is required

- Gastro oesophageal reflux disease
- Constipation
- Gastrointestinal functional disorders

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23F

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activity using CDS activity.

111. Clinical genomic services (adults and children)

[CRG –Genomic Medicine]

Service summary

Clinical genomic services comprise both a clinical service, delivering care to patients with, or at risk of, genomic conditions and genomic laboratories providing a genomic testing service.

This applies to provision in adults and children. This service includes the provision of pre-implantation genetic diagnosis and associated in-vitro fertilisation services.

About the condition/service

Most individual genetic diseases are rare, but diseases with a genetic component are estimated to affect at least 6%-8% of the population.

How the service is organised

The clinical element of the service is provided by Regional Clinical Genomic Services and NHS Genomic Laboratory Hubs deliver genetic testing services.

Clinical genomic services are delivered in Regional Clinical Genomic Centres and in outreach services in District General Hospitals (DGHs) and in Fetal Medicine Centres, delivered as part of a managed clinical network of care.

The clinical genomic service is a medical speciality and provides a consultant led service. Clinical staff comprises of specialist genetic medical consultants, genetic counsellors and clinical nurse specialists. Familial cancer genetic services provided by clinical genomic services are led by a consultant specialising in cancer genetics. Clinical genomic services deliver a comprehensive clinical genomic and counselling service for the diagnosis and management of patients of all ages and their families, who have or are at risk of having a rare genetic disease or inherited cancer by utilising clinical assessment, new technologies, clinical interpretation and sequencing results.

Genomic Laboratory Hubs provide genomic testing for inherited disorders and somatic genomic testing in cancer. Genomic Laboratory Hubs provide tests for a wide range of referrers, from primary care, to secondary and tertiary specialists as well as clinical geneticists and genetic counsellors.

What NHS England directly commission in line with national standards (specifications and policies)

NHS England commissions clinical genomic services and genomic testing services

NHS England also commissions the provision of pre-implantation genetic diagnosis and associated in-vitro fertilisation services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all in-vitro fertilisation services, except those associated with pre-implantation genetic diagnosis and those for members of the armed forces and some veterans.

Change of service commissioner

There are plans to review whether clinical genomic service and genomic testing services should be delegated to ICBs in the future.

There are plans to review whether pre-implantation genetic diagnosis and associated in-vitro fertilisation services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 20H
- 20Z

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Tests via a local data flow

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify outpatient activity using CDS data.
2. All genetic tests in the NHS England Test Directory: https://www.england.nhs.uk/publication/national-genomic-test-directories/
3. Activities associated with pre-implantation genetic diagnosis service should be identified for specialised commissioning.

112. Specialist gynaecology services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist gynaecology services for children include all activity provided by Specialist Paediatric Gynaecology Centres including outreach when delivered as part of a provider network. The service includes:

- Management of rare gynaecological conditions in children
- Provision of specified specialist gynaecological procedures during childhood
- Surgical management or procedures for more common gynaecological conditions when a child requires specialist pre-operative, anaesthetic or post-operative care

Other relevant service(s):

- 135. Specialist paediatric surgery services
- 136. Specialist paediatric urology services

About the condition/service

Most children who require routine surgical procedures can be cared for by their local surgical or gynaecological services.

Specialist paediatric gynaecological care is required for patients under the age of 18 when: the surgery is complex; the surgical condition being managed is rare; and/or when a baby of child has complex co-morbidities. The same group of patients may also require the input of specialist paediatric radiology services.

Congenital abnormalities of the genital tract are rare and include differences in sex development (DSD) and Mullerian anomalies. Children with congenital abnormalities of the genital tract fall into two groups. The first group consists of those who are diagnosed at birth or during childhood before puberty. The diagnosis may have been made at birth with genital ambiguity or during childhood with precocious puberty, virilisation or with an inguinal hernia found to contain a testis. Genetic testing can lead to diagnosis because of an affected family member. These children usually have a DSD. The second group consists of those who present for the first time in adolescence. Presentation may be with delayed puberty, virilisation, primary amenorrhoea or obstructed menstruation. This may be due to a DSD or Mullerian anomaly.

How the service is organised

Services are delivered by Specialist Paediatric Gynaecology Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist gynaecology services for children from Specialist Paediatric Gynaecology Centres, including services delivered on an outreach basis as part of a provider network.

ICBs commission specialist gynaecology services for children from Specialist Gynaecology Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- Management of rare gynaecological conditions in children
- Provision of specified specialist gynaecological procedures during childhood Surgical management or procedures for more common gynaecological conditions when a child requires specialist pre-operative, anaesthetic or post-operative care

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine surgery for children who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Examination under anaesthetic/swab taking in the event of suspected child abuse

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Within 23X

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

It should be noted that the IR software tool does not generate a separate service code for this activity. The activity is currently subsumed within the identification rule for specialist paediatric surgery services (23X) which is contained within the IR software tool.

113. Specialist haematology services for children

[Programme of Care – Women & Children, CRG – Paediatric Haematology Services]

Service summary

Specialist haematology services for children include services provided by Specialist Paediatric Haematology Centres including outreach when delivered as part of a provider network.

About the condition/service

The majority of care for children with haematological disorders can be provided by their local hospital. Some of the most common acute complications involve treatment of infections and many conditions require the regular transfusion of blood products; both of these services are better delivered locally. With the exception of children who have self-limited conditions or who are at low risk of complications, the diagnosis should be confirmed, and a management plan formulated and regularly reviewed by a Specialist Paediatric Haematology Centre.

How the service is organised

Specialist Paediatric Haematology Specialist Centres provide:

- 24/7 access to care by a consultant paediatric haematologist
- Access to a paediatric haematology clinical nurse specialist, paediatric clinical psychologist and haematology laboratory scientist

Many of the specialist centres deliver outreach clinics, which have an important role in (a) the diagnosis of conditions with limited complexity and (b) follow up of patients.

Outreach services are delivered as part of a provider network and involve:

- A paediatric haematologist from the specialist centre
- A paediatric haematology clinical nurse specialist
- A local general paediatrician
- A local clinical nurse specialist (in some cases)
- A local haematologist (in some cases)

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist haematology services for children from Specialist Paediatric Haematology Centres, including services delivered on an outreach basis as part of a provider network.

ICBs commission services for the following conditions:

- Vitamin B_{12}, iron and folate deficiency anaemia (see also below)
- Anaemia due to enzyme disorders (see also below)

- Hereditary haemolytic anaemia (see also below)
- Acquired haemolytic anaemia
- Acquired pure red cell aplasia
- Aplastic anaemia
- Sideroblastic anaemia
- Congenital dyserythropoietic anaemia
- Methahaemoglobinaemia
- Neutropenia
- Functional disorders of neutrophils
- Other disorders of white cells
- Myeloproliferative disorders
- Myelodysplasia
- Haemophagocytic lymphohistiocytosis
- Asplenia
- Hereditary or acquired coagulation deficiencies
- Purpura and other haemorrhagic conditions
- Thrombosis

ICBs commission the following investigations from Specialist Paediatric Haematology Centres:

- Blood films
- Bone marrow aspirate and trephine
- Special haematology investigations
- Interpretation of special transfusion investigations
- Factor assays and special coagulation investigations
- Insertion of central venous catheters
- Plasmapheresis
- MR techniques for iron load assessment
- Liver biopsies
- Genetic testing

ICBs commission the following interventions from Specialist Paediatric Haematology Centres:

- Initiation and monitoring of anticoagulation
- Initiation and monitoring of immunomodulatory therapy
- Monoclonal antibodies
- Initiation of anabolic steroids
- Initiation of chelation treatment
- Growth factors
- Initiation of hydroxycarbamide treatment
- Transfusions
- Treatment of all infections including invasive fungal infections and viral reactivations

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the following services:

- Vitamin B_{12}, iron and folate deficiency anaemia
  - Nutritional anaemia not presenting with pancytopenia
  - Monitoring of stable disease
- Anaemia due to enzyme disorders
  - Uncomplicated G6PD
- Hereditary haemolytic anaemia
  - Mild hereditary spherocytosis
  - Monitoring of anaemia

ICBs commission the following investigations:

- Blood films
- Factor assays and special coagulation investigations
  - Clotting screen
- Iron, B12, folate and coagulation tests

ICBs commission the following interventions:

- Monitoring of anticoagulation
- Monitoring of single immunomodulatory therapy
- Monitoring of chelation treatment
- Monitoring of hydroxycarbamide treatment
- Transfusions
- Treatment of infections

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23H

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activity using CDS data.

114. Specialist haemoglobinopathy services (adults and children)

[Programme of Care – Blood & Infection, CRG – Haemoglobinopathies]

Service summary

Specialist haemoglobinopathy services include all care provided by specialist haemoglobinopathy centres including inpatient care where the cause of admission is related to haemoglobinopathy. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

About the condition/service

There are about 1,000 patients with thalassaemia and 15,000 with Sickle Cell Disease (SCD) living in England at present, a large number of whom are under 19 years of age. The disorders occur predominantly but not exclusively in ethnic minority communities. SCD is the most common inherited condition in England; about 350 babies are born in England each year with SCD compared with 20-30 babies with thalassaemia. 60% of patients with SCD live in Greater London with the majority of the others within other inner-city areas.

How the service is organised

The specialist haemoglobinopathy services aim is to reduce the levels of morbidity and mortality and improve patient outcomes. Services are provided to support network working to deliver high quality equitable care across agreed geographical areas.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions care provided by the Specialist Haemoglobinopathy Teams across England. The teams provide clinical services including specialist interventions to enable equitable access to high standard care.
Haemoglobinopathy coordinating centres (HCC) provide leadership and learning with responsibility for promoting a system wide networked approach. The National Haemoglobinopathy Panel (NHP) supports the HCCs to provide expert advice on options for individuals with complex needs living with SCD, thalassemia or rare inherited anaemias. The NHP also supports the decision making on novel treatments, improving access to interventions.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission Local Haemoglobinopathy Teams (LHTs), which sit outside of the Specialist Haemoglobinopathy services but link into the SHTs and are part of the network model.

Change of service commissioner

There are plans to review whether the commissioning of Specialist Haemoglobinopathy Teams, sickle cell anaemia direct patient care, thalassemia direct patient care and Haemoglobinopathy Coordinating Centres should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- Sickle cell anaemia: 38S
- Thalassaemia: 38T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Inputting of patient clinical information into the National Haemoglobinopathy Register (NHR)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data. Providers should cross reference this information to the information stored in the National Haemoglobinopathy Register (NHR).
2. It is probable that providers manage the provision of outpatient service via dedicated clinics and, where local identification via these means are already in place, then all activity related to those dedicated clinics should be identified for attribution to the relevant NCBPS service code. Providers should cross reference this information to the information stored in the National Haemoglobinopathy Register (NHR).

115. Specialist immunology services for adults with deficient immune systems

This service was previously a combined adult and children's service. The children's service is now service 115A.

[Programme of Care – Blood & Infection, CRG – Specialised Immunology and Allergy]

Service summary

Specialist immunology services include services provided by Highly Specialist Immunology Centres, including outreach when delivered as part of a provider network, for the following:

- All primary immunodeficiencies
- Autoimmune and autoinflammatory disease where there is associated immunodeficiency
- Complex autoimmune and vasculitic conditions as shared care
- Autoinflammatory syndromes

Services include provision of cytokines and other immunomodulatory therapies for the above conditions.

Other relevant service(s):

- 59. Specialist allergy services (adults and children)
- 115A. Specialist immunology services for children with deficient immune systems

About the condition/service

Primary immunodeficiencies are disorders in which part of the body's immune system is missing or does not function properly. Patients with primary immunodeficiencies have an increased susceptibility to recurrent, severe and/or unusual infections, which may be in any body system. Patients die from infections if not treated or can have recurrent health problems and may develop serious and debilitating illness. Primary immunodeficiencies may present not only with infections, but also with severe and often early onset autoimmune and autoinflammatory conditions, or infection-associated cancers such as lymphoma. Most primary immunodeficiencies are genetic disorders; the majority are diagnosed in young children, although milder forms may not be recognised until later childhood or adulthood. There are an estimated 6,000 people in England (adults and children) living with a primary immunodeficiency. This number includes patients with the condition hereditary angioedema (C1 inhibitor enzyme deficiency), which causes life-threatening swellings.

Following worldwide shortages of immunoglobulin in 2007, the Department of Health published a Demand Management Programme (DMP) on Immunoglobulin Use to ensure that immunoglobulin was available and funded for all essential infusions to patients and to ensure that the most appropriate cases received supply in times of shortage. There is a national database onto which all immunoglobulin usage is recorded, regardless of the indication. Sub Regional Immunoglobulin Advisory Panel (SRIAPS) play a key role in supporting clinical teams in the delivery and management of immunoglobulin.

How the service is organised

Specialist Immunology Centres in England provide expert care to adults with primary immunodeficiencies. They incorporate the investigation, clinical assessment, treatment and holistic management of patients with suspected and established primary immunodeficiencies. The management of patients with primary immunodeficiencies requires either lifelong therapy with a limited and expensive blood product called immunoglobulin or with other biological agents such as interferons, C1 inhibitor concentrate, bradykinin receptor antagonists or colony stimulating factors.

All centres work through a multi-disciplinary team due to the complex nature of the conditions and heterogeneity of patient presentations; members include Specialist Nurses, dieticians, physiotherapists, genetic counsellors and social workers. Often, patients have shared care with other organ-based medical specialties.

Services are often delivered through network arrangements, including shared care and education for peripheral hospitals.

Immunology nurse specialists are essential to operate home therapy provision safely for patients, which is common for the administration of immunoglobulins. Access to a specialist diagnostic immunology laboratory is an integral component of the service.

A small number of centres provide specialist immunological management of complex autoimmune, autoinflammatory conditions and vasculitic conditions, including diagnosis and treatment. This is often undertaken in collaboration with rheumatology, respiratory and neurology services.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist immunology services for adults and children with deficient immune systems from Specialist Immunology Centres, including services delivered on an outreach/shared care basis as part of a provider network. NHS England commissions services for the following conditions:

- All suspected and confirmed primary immunodeficiencies including functional disorders of polymorphonuclear neutrophils, hyposplenism, immunodeficiency with predominantly antibody defects, combined immunodeficiencies, immunodeficiency associated with other major defects, common variable immunodeficiency, other immunodeficiencies, for example, infection-induced cancers, ataxia telangiectasia

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs may commission local immunology diagnostic laboratory support or clinical services.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 16X

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Drug Patient Level Contract Monitoring via Data Landing Portal
- Uploading of information to the national IVIG database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. The IR software tool should be used to identify outpatient activity using CDS data.

115A. Specialist immunology services for children with deficient immune systems

This service was previously included in a combined service with services for adults but has been separated.

[Programme of Care – Women & Children, CRG – Specialised Paediatric Allergy, Immunology and Infectious Disease Services]

Service summary

Specialist immunology services include:
(a) Services provided by Specialist Immunology Centres, including outreach when delivered as part of a provider network, for the following:

- All primary immunodeficiencies
- Autoimmune and autoinflammatory disease where there is associated immunodeficiency
- Complex autoimmune and vasculitic conditions as shared care
- Autoinflammatory syndromes

Services include provision of immunomodulatory therapies for the above conditions.

Other relevant service(s):

- 59. Specialist allergy services (adults and children)
- 115. Specialist immunology services for adults with deficient immune systems

About the condition/service

Primary immunodeficiencies are disorders in which part of the body's immune system is missing or does not function properly. Patients with primary immunodeficiencies have an increased susceptibility to recurrent, severe and/or unusual infections, which may be in any body system. Patients die from infections if not treated or can have recurrent health problems and may develop serious and debilitating illness. Primary immunodeficiencies may present not only with infections, but also with severe and often early onset autoimmune and autoinflammatory conditions, or infection-associated cancers such as lymphoma. Most primary immunodeficiencies are genetic disorders; the majority are diagnosed in young children, although milder forms may not be recognised until later childhood or adulthood. There are an estimated 6,000 people in England (adults and children) living with a primary immunodeficiency. This number includes patients with the condition hereditary angioedema (C1 inhibitor enzyme deficiency), which causes life-threatening swellings.

Following worldwide shortages of immunoglobulin in 2007, the Department of Health published a Demand Management Programme (DMP) on Immunoglobulin Use to ensure that immunoglobulin was available and funded for all essential infusions to patients and to ensure that the most appropriate cases received supply in times of shortage.

There is a national database onto which all immunoglobulin usage is recorded, regardless of the indication. Sub Regional Immunoglobulin Advisory Panel (SRIAPS) play a key role in supporting clinical teams in the delivery and management of Immunoglobulin.

How the service is organised

Specialist Immunology Centres provide expert care to children with primary immunodeficiencies. These centres co-ordinate provider networks over large geographical areas.

Adult and paediatric services are usually separate but work closely together and are often co-located. Transition arrangements for seamless transfer between paediatric and adult services is essential to ensure that young people take responsibility for their condition, its treatment and what they can do to minimise the risks to their health.

Specialist Immunology Centres incorporate the investigation, clinical assessment, treatment and holistic management of patients with suspected and established primary immunodeficiencies. The management of patients with primary immunodeficiencies requires either lifelong therapy with a limited and expensive blood product called immunoglobulin or with other biological agents such as interferons or colony stimulating factors. A small number of children requiring stem cell transplantation are referred to supra-regional national centres.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist immunology services for adults and children with deficient immune systems from Specialist Immunology Centres, including services delivered on an outreach/shared care basis as part of a provider network. NHS England commissions services for the following conditions:

- All suspected and confirmed primary immunodeficiencies including functional disorders of polymorphonuclear neutrophils, hyposplenism, immunodeficiency with predominantly antibody defects, combined immunodeficiencies, immunodeficiency associated with other major defects, common variable immunodeficiency, other immunodeficiencies, for example, infection-induced cancers, ataxia telangiectasia
- Recurrent infections (investigation and management of)
- Inflammatory conditions affecting children including Kawasaki’s disease, periodic fever syndromes and autoimmune diseases associated with primary immunodeficiency

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs may commission local immunology diagnostic laboratory support or clinical services.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 16Y (children)

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing portal
- Uploading of information to the national IVIG database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. The IR software tool should be used to identify outpatient activity using CDS data.

115B. Specialist maternity care for adults diagnosed with abnormally invasive placenta

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Women & Children, CRG – Specialised Women's Services]

Service summary

Specialist maternity care for adults diagnosed with abnormally invasive placenta includes services provided by Specialist Maternal Care Centres including outreach when delivered as part of a provider network.

About the condition/service

Abnormally invasive placenta (AIP) is a condition in which the placenta becomes abnormally adherent to the uterine wall and may invade adjoining organs, potentially leading to massive haemorrhage. It is the most common cause of peripartum hysterectomy. Incidence is increasing as a result of increasing rate of caesarean section, older childbearing and IVF. It is estimated that there are about 950 cases of AIP per annum in the UK.

How the service is organised

To be determined

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist maternity care for adults diagnosed with abnormally invasive placenta services from Specialist Maternal Care Centres. This includes the treatment of AIP, including prenatal diagnosis and imaging by ultrasound and MRI, specialist assessment and surgery.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs also commission all other maternal care services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 04G

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. The IR software tool does not contain a mechanism to identify outpatient activity. Providers are required to identify activity locally and attribute to NCBPS04G service code within all relevant commissioning dataflows.

116. Specialist mental health services for Deaf adults

[Programme of Care – Mental Health, LD & Autism, CRG –Mental Health Services for Deaf People]

Service summary

Specialist mental health services for Deaf adults includes inpatient and non-admitted care including assessment and treatment services for Deaf people provided by Specialist Centres. In addition, the service includes advice to general mental health services on the management and treatment of the Deaf person's mental illness.

Other relevant service(s):

- 74. Mental health service for Deaf children and adolescents

About the condition/service

Specialist Mental Health Services for Deaf Adults are services for those patients who cannot be effectively managed and treated in an acute mental health service ward. This is usually because of communication difficulties, which can impact significantly on the person's mental health and wellbeing and the lack in availability of staff who are proficient in British Sign Language and other communication skills, have knowledge of Deaf culture **as well as** having experience in the care and treatment of Deaf people with mental illness. Specialist mental health and Deaf services have environments specifically adapted to the needs of the patient group and are staffed by mental health professionals who are expert in assessing and addressing the needs of people who are Deaf and experience mental ill health.

About seven per 10,000 people in the general population have severe or profound Deafness where onset was before language was established. About 50% of these individuals experience mental health difficulties at some time in their lives, ranging between mild depression and psychosis.

How the service is organised

The service includes inpatient, outpatient and community outreach services including assessment and treatment services for Deaf people and advice to general mental health services on the management and treatment of Deaf people with mental illness.

Services are delivered in Specialist Centres and linked specialist community outreach services.

Specialist community outreach services provide alternative care to hospital admission that is culturally accessible and facilitates admission and discharge from hospital helping to ensure smooth functioning of care pathways. The specialist Deaf community outreach services have formal links (captured in Memoranda of

Understanding with areas covered including: clinical pathways; education and training; supervision, quality development and review) with one of the Specialist Centres and operate a network model.

Services delivered by specialist community outreach services may include:

- Psychiatric assessment and treatment
- Psychopharmacological interventions
- Advice on medication management
- Psychological assessment, treatment, consultation and advice.
- Assessment and treatment by speech and language therapists, occupational therapists
- Community care assessments, development of packages of support as well as advice on appropriate placements
- Carers assessments where appropriate
- Family support and therapy
- Development of a positive Deaf identity and integration in the Deaf community
- Social and recreational groups
- Assessment and development of Activities for Daily Living
- Support in access to Deaf services, information, and advocacy
- Employment and education support
- Advice, support and signposting to primary care, mental health and social services

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist mental health services for Deaf adults from Specialist Centres. This includes inpatient and non-admitted care including assessment and treatment services. In addition, the service includes advice to general mental health services on the management and treatment of the Deaf person's mental illness.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission inpatient, outpatient and community mental health and learning disability teams, which work closely with the specialist inpatient and specialist community Deaf services to ensure Deaf patients have access to local services, including crisis teams and home treatment teams. Unless specifically agreed otherwise – and where a patient has a very high level of complexity – community mental health and learning disability teams hold the care co-ordination responsibility for patients.

ICBs ensure that multidisciplinary adult mental health services have access to appropriate interpreting services and technology to ensure that they are able to implement their Equality Duty (Equality Act 2010) with due regard to people who are Deaf.

ICBs commission primary care based psychological services such as IAPT (Improving Access to Psychological Therapies), which are accessible by Deaf patients either via providing appropriate interpreting services and technology (to implement their Equality Duty (Equality Act 2010)) or via commissioning services specifically designed for Deaf patients.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22D

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Mental Health Services Data Set via Strategic Data Collection Service

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and MHSDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document ‘Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)’. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider’s contract, or the Provider Collaborative ODS Code, as per the document ‘Determining the NHS-led Provider Collaborative.

118. Neonatal critical care services

[Programme of Care – Women & Children, CRG – Neonatal Critical Care]

Service summary

neonatal critical care services include all activity undertaken by Neonatal Critical Care Units, Local Neonatal Units and Special Care Units including associated retrieval services. This includes transitional care and any associated outpatient and outreach services.

Other relevant service(s):

- 122. Paediatric critical care services

About the condition/service

Much of the care of newborn babies, either healthy or with lesser problems, is carried out at the hospital at which they were born. Complex and intensive care, particularly of the extremely preterm, is carried out in tertiary centres, called NICUs (see below), for the most part. Tertiary centres provide care for both complex cases on a regional basis as well as services for sick newborn babies from the local population that may not be complex.

How the service is organised

- In order to facilitate the newborn access to appropriate care as near to home as possible and to reduce the need for long transfers for intensive care, groups of hospitals providing various levels of expertise locally are organised into neonatal operational delivery networks in England. There are three types of hospital neonatal service:
    - Special Care Units (SCUs; usually look after all local births at 32 weeks of gestation or greater)
    - Local Neonatal Units (LNUs; look after all local births at 27 weeks of gestation and greater and babies over 27 weeks transferred from SCUs)
    - Neonatal Intensive Care Units (NICUs; look after all local births and network babies <27 weeks, alongside babies with other complex intensive care needs)

Networked neonatal critical care services include:

- Neonatal transport team
- Respiratory support including high frequency oscillation and nitric oxide therapy
- Therapeutic hypothermia for hypoxic-ischaemic encephalopathy
- Total parenteral nutrition (including expert pharmacy support)
- Access to neonatal surgery service (this is covered under the individual paediatric surgery sections)

- Availability of peritoneal dialysis service
- Neonatal physiotherapy
- Access to clinical imaging services (cardiac, general and cranial ultrasound scanning and magnetic resonance imaging and computerised tomography)
- Access to specialist paediatric services and advice, for example, neurology, metabolic/endocrine, cardiology, microbiology (infection control), clinical genetics

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission neonatal critical care services through 10 Neonatal Operational Delivery Networks, with services delivered in Intensive Care Units, Local Neonatal Units and Special Care Units. This includes associated retrieval services, transitional care (i.e., where the baby needs some medical care but is well enough to receive this at their mother's bedside) and associated outpatient services.

ICBs commission an immunisation service for neonates at risk of contracting respiratory syncytial virus, in particular those very young infants born prematurely who have predisposing conditions such as chronic lung disease, congenital heart disease or who are immunodeficient.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any element of neonatal critical care services except normal care, as part of the maternity contract.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- NIC

Data flows

The data flows that are used to support this service are:

- Neonatal critical care data extensions in the Admitted Patient Care CDS record in SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Providers are required to upload information to BadgerNet.

How the activity for this service is identified

This service includes ALL activity described in the IR rules below at specified centres.

How to use the Identification Rules

There is no identification rule within the IR software tool for this service. All unbundled XA HRGs (with the exception of XA05Z (normal care) are to be used locally to identify NICU activity.

It should be noted that all XA chapter HRGS should be mapped to NHS England.

119. Specialist neuroscience services for children

Whilst this section makes reference to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Women & Children, CRG – Paediatric Neurosciences]

Service summary

Specialist neuroscience services for children include all services provided by Specialist Paediatric Neurosciences Centres including:

- Neurosurgery (including paediatric neuro critical care)
- Neurology
- Neurophysiology
- Neuroradiology
- Specialist services for children with neuromuscular conditions
- Neuropsychology and neuropsychiatry
- Specialist services for children with neurodisability and specialist neurorehabilitation
- Neuroanaesthesia

The service includes inpatient, day case and outpatient services including outreach when delivered as part of a provider network.

Other relevant service(s):

- 11. Adult specialist neurosciences services
- 21. Ataxia telangiectasia services for children
- 43. Craniofacial service (adults and children)
- 48. Diagnostic service for rare neuromuscular disorders (adults and children)
- 78. Neuropsychiatry services (adults and children)
- 77. Neuromyelitis optica service (adults and adolescents)
- 126. Specialist rehabilitation services for patients with highly complex needs (adults and children)
- 140. Vein of Galen malformation service (adults and children)

About the condition/service

Children with neurological disease require a sustained and integrated network of care involving a variety of organisations, professionals and equipment, often over a prolonged period of time. Services operate within managed networks to provide care that revolves around the individual child's needs.

About 4,500 children each year have neurosurgical interventions.

How the service is organised

Specialist Paediatric Neurosciences Centres in England provide specialist paediatric neurosciences services through a multi-disciplinary approach to the diagnosis and management of a range of neurological disorders. Services are both centrally-based (inpatient and outpatient) and outreach to local hospitals where the Centre staff work in partnership with local paediatricians and therapy teams to facilitate care as close to a child’s home as possible.

Specialist services work in collaboration with community services, particularly in the long-term management of neurological conditions, neurodisability and neuromuscular conditions.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commission the following services:

- Spinal muscular atrophy – gene therapy

NHS England commissions a gene therapy service for children with spinal muscular atrophy.

This service is in the highly specialised portfolio.

- Inherited white matter disorders diagnostic and management service for children and adults

NHS England commissions an inherited white matter disorders diagnostic and management service for children (and adults).

This service is in the highly specialised portfolio.

- Multiple sclerosis management service for children

The Multiple Sclerosis (MS) Management Service for Children, is commissioned to provide a service for children with: MS; suspected MS; equally rare ‘MS-like’ recurrent acquired demyelinating syndromes; or who have had a first demyelination episode.

This service is in the highly specialised portfolio.

- Open fetal surgery to treat fetuses with open spina bifida

Spina bifida is an in-utero condition where the spinal column and cord are not fully formed. Babies born with this condition are often unable to walk, incontinent of urine and faeces, may develop hydrocephalus due to incomplete closure of the spinal canal and often require postnatal neurosurgical interventions. For a carefully selected group of women and their babies open fetal surgery (operating on the baby while it is still in the womb) can be used to successfully close the spinal defect and achieve good clinical outcomes for the baby.

The service provides assessment, open fetal surgery and supporting medical services. The service is delivered by an expert MDT in a shared care pathway with existing local maternity units / Regional Fetal Medicine Units (RFMUs) and regional neurosurgery centres.

This service is in the highly specialised portfolio.

- Children's Epilepsy Surgery Service (CESS),

There is a specific Children's Epilepsy Surgery Service (CESS), which is commissioned to provide specialist epilepsy pre-surgical evaluation and surgery to children in specialised CESS centres, for the population of England.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission the following specialist neuroscience services for children from Specialist Paediatric Neurosciences centres, including services provided on an outreach basis when delivered as part of a provider network:

- All paediatric neurosurgery, neurology, neuropsychology, neuropsychiatry, neurodisability and complex/specialist neurorehabilitation
- Diagnosis and specialist support for the long-term management of neuromuscular conditions
- Complex paediatric neuroradiology (for example, detailed MRI for subtle antenatal or postnatal malformations, evaluation of non-accidental injury or whether a tumour has remained stable, angiography, interventional procedures, MRI spectroscopy, SPECT/PET scans)
- Complex paediatric neurophysiology (for example, video-EEG, brainstem and visual evoked potentials, nerve and muscle studies) and neuro-ophthalmology
- Selective dorsal rhizotomy services

In addition, there are a very small number of specialist centres that provide brain injury and Neurorehabilitation services outside the tertiary care setting.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission long-term rehabilitation carried out by community disability teams.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23M

- 07Y
- 08J

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Paediatric critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. Inpatient activity should be identified by application of the IR software tool to CDS data.
2. Outpatient activity should be identified by application of the IR software tool to CDS data.
3. All critical care provided to paediatric neurosciences patients is covered in the neonatal critical care services and paediatric critical care identification rules and should be attributed to NCBPSNIC or NCBPSPIC.

120. Specialist ophthalmology services for children

[Programme of Care – Trauma, CRG – Specialised Ophthalmology Services]

Service summary

Specialist ophthalmology services for children include services provided by Specialist Paediatric Ophthalmology Networks including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex or high-risk procedures only.

Specialist ophthalmology services for children also include the provision of artificial eyes.

Other relevant service(s):

- 12. Adult specialist ophthalmology services
- 80. Ophthalmic pathology service (adults and children)
- 97. Retinoblastoma service (children)
- 139. Stickler syndrome services (adults and children)

About the condition/service

Specialist ophthalmology services for children encompass the investigation and management of visual, ocular and ocular adnexal disorders in children

How the service is organised

Specialist ophthalmology services for children are routinely delivered by both paediatric ophthalmologists and adult ophthalmologists (the latter in environments that meet national guidelines for the care of children). The service is provided within operational delivery networks, the networks comprising of a group of providers working together within the patient pathway.

The National Artificial Eye Service is administrated centrally but has clinics and outreach services. There are also other artificial eye services.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions Retinal Gene Therapies.

This service is in the highly specialised portfolio.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commissions the following specialist ophthalmology services for children from Specialist Paediatric Ophthalmology Networks in England, including emergency care:

- Orbital disorders (including the provision of ocular prostheses and with the exception of minor surgery and orbital cellulitis)
- Oculoplastic and lacrimal surgery (with the exception of routine syringe and probing and minor lid surgery)
- Cataract and lens disorders for younger children (< 2 years of age, but the age limit remains under review)
- Glaucoma
- Corneal disorders (except emergency corneal repair)
- Eye banking
- Vitreoretinal surgery – in neonates and infants (under two years of age) and children over the age of two (with specific rare and uncommon diagnosis), where it is a tertiary referral and where surgery is required
- Treatment of retinopathy of prematurity
- Medical retina services (to provide second opinions and management of uncommon conditions.
- Uveitis (where it requires systemic or complex treatment)
- Ocular genetic disorders
- Neuro-ophthalmology (including multidisciplinary developmental paediatric clinics for sight impaired children and/or a clinic with a specialist interest in cerebral visual impairment led by a paediatric neuro-ophthalmologist or paediatric ophthalmologist)
- Eye movement recording facilities.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other paediatric ophthalmology services including strabismus and amblyopia.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23N

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by established designated centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activities using CDS data.

121. Specialist orthopaedic services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist orthopaedic services for children include services provided by Specialist Paediatric Orthopaedic Centres including outreach when delivered as part of a provider network. The service includes:

- Surgical management of rare orthopaedic conditions in children
- Provision of specified specialist orthopaedic procedures in children
- Surgical management or procedures for more common orthopaedic conditions when a child requires specialist pre-operative, anaesthetic or post-operative care

Other relevant service(s):

- 13. Adult specialist orthopaedic services
- 40. Complex spinal surgery services (adults and children)
- 72. Major trauma services (adults and children)
- 89. Primary malignant bone tumours service (adults and adolescents)

About the condition/service

Most children who require routine orthopaedic management or procedures can be cared for by their local orthopaedic service.

Specialist orthopaedic surgical care is required for patients under the age of 18 when: the surgical condition being managed is rare (for example, congenital short tibia); the surgery is complex (for example, surgical correction of developmental dysplasia of the hip); and/or when a baby or child has complex co-morbidities (for example, removal of metalwork after trauma care is normally a routine procedure but requires specialist peri-operative care when the child has complex co-morbidities. In these circumstances, specialist paediatric anaesthesia and/or pain relief are usually required. The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

Services are delivered by Specialist Paediatric Orthopaedic Centres in England.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist orthopaedic services for children from Specialist Paediatric Orthopaedic Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- Surgical management of rare orthopaedic conditions in children
- Provision of specified specialist orthopaedic procedures in children
- Surgical management or procedures for more common orthopaedic conditions when a child requires specialist pre-operative, anaesthetic or post-operative care

ICBs commission specialist orthotics where these are part of specialist orthopaedic surgery services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine surgery for children who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Removal of metalwork from wrist after trauma care

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23Q

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

This service includes specified activity at specified centres.

How to use the Identification Rules

1. The IR software tool identifies inpatient using Treatment Function Codes and provider organisation codes.
2. Any critical care activity associated with 1 above should be captured within the Neonatal or Paediatric Intensive Care rule.
3. The IR software tool identifies outpatient activity using Treatment Function Codes and provider organisation list .

122. Paediatric critical care services

[Programme of Care – Women & Children, CRG – Paediatric Critical Care]

Service summary

Paediatric critical care services include all activity undertaken by Level 2 and Level 3 Paediatric Critical Care Units and associated Paediatric Critical Care Transport Services.

Other relevant service(s):

- 52. Extra corporeal membrane oxygenation services for neonates, infants and children with respiratory failure
- 118. Neonatal critical care services

About the condition/service

Paediatric critical care (PCC) services provide a care pathway for the sick child from recognition and stabilisation, through retrieval (if necessary), to delivery of care in an appropriate paediatric critical care facility be that in a PCC Level 3 Unit (PICU) or in a PCC Level 2 Unit (High Dependency/HDU. The service is provided to ensure, as far as possible, that the same standard of care is delivered to all critically ill children, regardless of their location. PCC is also an intimate part of some other specialist paediatric services (for example, paediatric cardiac, general surgery, neurosciences and oncology) and has a number of significant interdependencies (for example, paediatric anaesthesia, ENT and a variety of medical specialties).

PCC Level 2 (HDU) is provided in tertiary centres, both to their local populations and to specialist tertiary services. It is also provided in some larger local hospitals. PCC Level 1 (HDU), for example, the management of diabetic ketoacidosis or acute exacerbations of asthma, is part of the critical care pathway but, as it is provided in all units where there are paediatric inpatient beds, it does not meet the criteria for specialised commissioning and is therefore the service is commissioned by ICBs.

How the service is organised

Paediatric critical care (PCC) is configured with lead centres serving a network of referring hospitals, in a network model, supported by retrieval services. The referring hospitals have responsibility for the initial management and stabilisation of critically ill children.

The level of complexity of patients varies as described in the table below:

PCC level	Provided in:	Description	Nurse: patient ratio
1	Level 1,2 & 3 PCCU	Children requiring monitoring or interventions defined by PCC HRG 07Z (PCC Basic Critical Care)	0.5:1

2	Level 2 &3 PCCU	Children requiring monitoring or interventions defined by PCC HRG 06Z (PCC Intermediate Critical Care)	(1:1 if in a cubicle)
3	Level 3 PCCU	Children requiring ventilatory support or support of two or more organs systems. Children at level 3 are usually intubated to assist breathing. PCC HRG 05Z/04Z (PCC Advanced Critical Care 1 and 2)	1: 1
		Children undergoing complex monitoring and/or therapeutic procedures, including advanced respiratory support. PCC HRG 03Z/02Z (PCC Advanced Critical Care 3 and 34)	1.5 : 1
	Level 3 PCCU, which supports cardiac surgery	Children receiving treatment by extra corporeal membrane oxygenation (ECMO) PCC HRG 01Z (PCC Advanced Critical Care 5)	2 : 1

The transfer of children in referring hospitals into a PCC Level 3 Unit is performed by a dedicated PCC Transport Service, which also performs a bed location function and provides clinical advice. Some PCC Transport Services transfer children into PCC Level 2 Units and to repatriate children from PCC Level 2 and Level 3 Units. There is overlap with neonatal transfer services.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission paediatric critical care (PCC) services from PCC Level 2 and Level 3 Units, including associated transport services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- Inpatient services:
    - PCC Level 1
    - Children with a PCC Level 2 or 3 Unit stay of less than four hours
    - Children who are medically stable on long term ventilation after 90 days

- Transport services:
    - General ambulance transfer to or from any Level of PCC unless undertaken by a dedicated PCC Transport Service

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Paediatric intensive care services: PIC

- Paediatric long-term ventilation: no rule yet exists

Data flows

The data flows that are used to support this service are:

- Paediatric critical care data extensions in the admitted patient care record in SUS
- Providers are required to upload information to PICANET

How the activity for this service is identified

This service includes specified activity at specified centres.

How to use the Identification Rules

1. All bed day care of paediatric patients on Level 2 and 3 Paediatric Intensive Care Units should be attributed to NCBPSPIC service code. These activities are reported in National Tariff as unbundled activities using HRG codes beginning XB.
2. All paediatric retrieval services (i.e. HRG XB08Z) should be identified via the SUS data flow and attributed to NCBPSPOC service code.

123. Specialist paediatric liver disease service

[Programme of Care – Women & Children, CRG – Paediatric Medicine]

Service summary

Specialist paediatric liver disease services include services provided by Highly Specialist Paediatric Liver Disease Centres including outreach when provided as part of a provider network.

Other relevant service(s):

- 110. Specialist gastroenterology, hepatology and nutritional support services for children
- 69. Liver transplantation service (adults and children)

About the condition/service

This service provides a diagnostic, assessment and treatment service for paediatric liver disease. The major conditions covered by the service are:

- acute liver failure
- biliary atresia
- chronic liver disease
- hepatitis A, B and C
- metabolic liver disease
- neonatal hepatitis

This service is in the highly specialised portfolio.

How the service is organised

The service cares for about 1,100 children at three providers.

What NHS England directly commissions in line with national standards (service specifications)

NHS England commissions specialist paediatric liver disease services from Highly Specialist Paediatric Liver Disease Centres, including services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- C23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Paediatric Liver Disease Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute to NCBPSC23 service code within all relevant commissioning dataflows.

124. Specialist perinatal mental health services (adults and adolescents)

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Mental Health, LD and Autism, CRG – Perinatal Mental Health]

Service summary

Specialist perinatal mental health services are provided by Specialist Mother and Baby Units. Services include inpatients and associated non-admitted care including outreach provided by these units when delivered as part of a provider network. These specialist perinatal mental health services are provided to women who are aged 16 and over, who are either pregnant women or have a child under the age of 12 months.

About the service

Specialist perinatal mental health services provide a safe and secure environment for the care of women who experience severe mental illness and their infants. These psychiatric units which are separate from other acute mental health facilities provide care for women with severe mental illness and disorders and those with complex needs. They provide expert psychiatric and psychological care for the mother whilst at the same time ensuring the physical and emotional care of the infant and avoiding unnecessary separation of mother and baby.

Based on the known epidemiology of postpartum psychosis and other severe and complex disorders, at least 2,750 women need access to Specialist Mother and Baby Units and associated outreach services each year.

How the service is organised

Services are delivered by Specialist Mother and Baby Units, most of which have integrated community teams.

Specialist Mother and Baby Units provide assessment of maternal mental health needs and mother-infant care, attachment and interaction. In addition to providing acute care to the mother, they provide supervision, support, assistance and guidance in the care of the infant whilst the mother is ill, ensuring that the emotional needs of mother and infant are met. They offer timely and equitable access so that mothers are not admitted to general adult psychiatric wards without their babies. Specialist Perinatal Psychiatric Outreach Teams assess and manage women with serious mental illness or complex needs in the community who would otherwise be admitted to the unit or who are in the transition phase from being an inpatient, facilitating discharge and preventing avoidable relapse.

Specialist Perinatal Psychiatric Outreach Teams can also offer preconception counselling to women with pre-existing serious mental health disorders and those who are well but at high risk of a postpartum condition. They can also provide an advisory role for maternity, obstetric and adult psychiatric services on the detection, proactive management and prevention of illness in women at high risk of postpartum illness.

Mother and Baby Units provide care for women and their infants from 32 weeks pregnancy to 1 year postpartum, and community teams look after women from conception to 1 year.

What NHS England commissions directly in line with national standards (specifications and policies)

NHS England commissions specialist perinatal mental health services from Specialist Mother and Baby Units. Services include inpatients and associated non-admitted care including outreach provided by these units when delivered as part of a provider network.

NHS England also commissions Specialist Perinatal Psychiatric Outreach Teams where these are provided by or through a Specialist Mother and Baby Unit.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission activity from those perinatal community teams that are not provided by or through Specialist Mother and Baby Units. ICBs commission all community perinatal mental health services for women, co-working with the Specialised Mother and Baby Unit and the Specialist Perinatal Psychiatric Outreach Teams, as well as working with mothers and their infants if the mothers have moderate to severe mental illness.

What Local Authorities Commission

Local authorities commission parenting assessments undertaken by a small number of Specialist Mother and Baby Units.

- can be high, placing a potential financial risk on individual ICBs.

Change of service commissioner

There are plans to review whether Specialist perinatal mental health services should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22P

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set via Strategic Data Collection Service
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres only.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

125. Specialist plastic surgery services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist plastic surgery services for children include services provided by Specialist Paediatric Plastic Surgery Centres including outreach when delivered as part of a provider network.

- Management of rare plastic surgery conditions in children
- Provision of specified specialist plastic surgery procedures during childhood
- Surgical management or procedures for more common plastic surgical conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

Other relevant service(s):

- 35. Cleft lip and palate services (adults and children)
- 72. Major trauma services (adults and children)
- 104. Specialist burn care services (adults and children)

About the condition/service

Most children who require routine plastic surgical procedures can be cared for by local children' surgical services.

Specialist plastic surgical care is required for patients under the age of 18 when: the surgery is complex; the surgical condition being managed is rare and/or when the baby or child has complex co-morbidities (for example, a routine non-specialist procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidities).The same group of patients may also require the input of specialist paediatric radiology services.

How the service is organised

Services are delivered by Specialist Plastic Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission specialist plastic surgery services for children from Specialist Paediatric Plastic Surgery Centres, including services delivered on an outreach basis as part of a provider network. The service includes:

- Management of rare plastic surgery conditions in children
- Provision of specified specialist plastic surgery procedures during childhood
- Surgical management or procedures for more common plastic surgical conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine surgery for children who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Excision of a benign skin lesion

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23R

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. The IR software tool should be used to identify outpatient activity using CDS data.

126. Specialist rehabilitation services for patients with highly complex needs (adults and children)

[Programme of Care – Trauma, CRGs – Rehabilitation and disability &Spinal Cord Injury, Paediatric Neurosciences]

Service summary

Specialist rehabilitation services for patients with highly complex needs includes tertiary specialist rehabilitation for patients whose rehabilitation needs fall into Category A following brain injury or with other disabling conditions. These may be provided in designated Level 1 or 2a facilities. This applies to provision in adults and children.

Other relevant service(s):

119. Specialist neuroscience services for children

About the condition/service

Rehabilitation is a process of assessment, treatment and management by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition.

Following illness or injury, the majority of patients have category C or D needs and progress satisfactorily down the care pathway with the help of their local non-specialist (Level 3) rehabilitation services. Some patients with more complex needs (Category B) may require referral to local specialist rehabilitation services (Level 2b). A small number of patients with highly complex needs (Category A) require tertiary specialist rehabilitation in centres that have the requisite staff expertise and facilities to manage their needs.

Tertiary specialist rehabilitation is the total active care of patients with any disabling condition who have highly complex (Category A) needs for rehabilitation that are beyond the scope of their local general and specialist services.

The rehabilitation is provided:

- Under the care of a consultant trained and accredited in rehabilitation medicine, neuropsychiatry or paediatric neurodisability, depending on the nature of the programme;
- By a multi-professional team who have undergone recognised specialist training in rehabilitation; and
- In designated tertiary (Level 1) services or in Level 2a services in parts of the country where there is insufficient coverage/capacity with the Level 1 services and have the requisite staff expertise and facilities to manage a highly complex caseload.

Programmes fall broadly into four categories:

- Programmes for people with profound and complex physical disability
- Cognitive/behavioural rehabilitation programmes for people who are independently mobile but have severe cognitive/behavioural/neuropsychiatric needs
- Specialist community integration/transitional living/vocational rehabilitation programmes
- Programmes for children, adolescents and young adults (16-25 years) who require tertiary specialist rehabilitation in the context of schooling or on-going education. These integrate into school and preparation for Statement of Special Educational Needs and incorporate both the physical as well as cognitive requirements.

Tertiary specialist rehabilitation commissioned under this definition may be provided along three main pathways:

- *Restoring function* (for example, following a ‘sudden onset’ or ‘intermittent’ condition)
- *Managing disability* (for those with stable or progressive conditions)
- *‘Neuro-palliative rehabilitation’* at the interface between rehabilitation and palliative care
- It is delivered in time-limited, goal-orientated programmes – usually up to six months (with extension where appropriate subject to negotiation). Activity under this definition does not include long term care or slow stream rehabilitation programmes with an expected time-course of >12 months.
- It is largely milieu-based (i.e., residential/inpatient/day-rehab and associated outreach/community activity). There are benefits to patients and their families if patients are managed within a peer group of people facing a similar level of challenge. It does not include rehabilitation delivered solely in the community, as it is rarely practical to provide such support from a distance compatible with the extended catchment (>1m population) of tertiary specialist services.

It is estimated that about 2,500 individuals each year need access to tertiary specialist rehabilitation services.

How the service is organised

Services for Category A patients (adults and children) are delivered by Level 1 and 2a units.

Confirmation of eligibility for Level 1/2a status requires that tertiary specialist rehabilitation services have the expertise and facilities to meet the demands of a highly complex caseload:

- All services must be registered with the UK Rehabilitation Outcomes Collaborative (UKROC) database and must submit the full UKROC dataset for each case episode;

- UKROC is a national clinical database set up with Department of Health funding to collate the NHS Information Centre's inpatient rehabilitation dataset; and
- It provides the commissioning dataset for specialist rehabilitation services and national benchmarking on needs for rehabilitation, inputs and outcomes.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications)

ICBs commission tertiary specialist rehabilitation services for patients with Category A needs in specified centres that meet the criteria for Level 1/2a services.[9]

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission rehabilitation services for patients with Category B needs and non-specialist rehabilitation for patients with C and D needs. They also commission long term care and slow stream rehabilitation programmes with an expected time-course of >12 months; and rehabilitation delivered solely in the community.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 07Z

Data flows

The data flows that are used to support this service are:

- Critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Inputting of patient registration and activities into the UK Rehabilitation Outcomes Collaborative (UKROC)
- Admitted Patient Care CDS via SUS

How the activity for this service is identified

This service includes specified activity at specified centres.

When patients are transferred to a tertiary specialist rehabilitation service, the sole purpose of admission is for rehabilitation. This activity is therefore quite separate from rehabilitation in the context of acute care services:

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[9] **https://www.bsrm.org.uk/downloads/specialised-neurorehabilitation-service-standards--7-30-4-2015-pcatv2-forweb-4-5-16.pdf**

- Activity is identified through the UKROC database, which is also the commissioning vehicle through which the multi-level weighted bed-day tariff for these services is operated
- Category A patients are identified using a Patient Categorization tool and complexity of needs are identified using the Rehabilitation Complexity Scale

How to use the Identification Rules

1. There is no identification rule documented within the IR software tool since the method of patient identification is driven by the data submission to UKROC. All providers delivering specialist rehabilitations are required to record patient information in UK Rehabilitation Outcomes Collaborative (UKROC) database as population of the database determines the category of the patient.
2. Commissioners of prescribed specialised services commission category A patients from Level 1 and 2a specialist rehabilitation service providers. All inpatient, critical care and outpatient (including outreach activity) associated with the category A patient (as determined by UKROC) requires identification in provider systems and activity attributed to specialised commissioning.

127. Specialist renal services for children

[Programme of Care – Women & Children, CRG – Specialised Paediatric Renal]

Service summary

Specialist renal services for children include services provided by Specialist Paediatric Renal Centres including outreach when delivered as part of a provider network.

Other relevant service(s):

- 15. Adult specialist renal services
- 21A. Atypical haemolytic uraemic syndrome services (adults and children)

About the condition/service

Specialist Renal Services for children provide care for a wide variety of conditions. Many children with uncomplicated general nephrological conditions, for example, simple urinary tract infection or steroid responsive nephrotic syndrome, may be managed by general paediatricians in local hospitals without reference to a specialist paediatric nephrologist at the specialist renal centre. Some children develop complications of common conditions or have rare conditions benefiting from specialist expertise whilst others require specialist diagnostic and therapeutic procedures including dialysis and transplantation that can only be provided by a Specialist Paediatric Renal Centre. About 900 children in the UK have established renal failure.

How the service is organised

Children requiring more complex paediatric nephrology services are treated at about 10 Specialist Paediatric Renal Centres, all of which provide chronic dialysis and most of which also provide paediatric renal transplantation.

Children with renal disease often have multi-system problems and require co-location with other specialties. The aim is to care for children as close to home as possible with the local hospital providing as much of the care as possible. This is achieved by creating clinical networks. Each local hospital within the clinical network has at least one general paediatrician with a special interest in nephrology; the specialist renal centre provides support to the local hospital clinician where appropriate.

Specialist renal services may be delivered in the following ways:

- care within a specialist paediatric renal unit (both inpatient and outpatient)
- expert advice from a paediatric nephrologist to other paediatric specialists within a referral centre, for example, paediatric intensive care, oncology, endocrinology, cardiology
- outreach clinics with the specialist and the general paediatrician in the local hospital

- expert advice from a paediatric nephrologist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP
- expert advice from non-medical multidisciplinary renal team members to other healthcare providers, for example, specialist paediatric renal nurses, dieticians, psychologists, pharmacists, etc
- visits from members of the multi-disciplinary team to the patient's home and school to provide training and support to the child, family and other carers.
- specialist antenatal counselling
- managed transition to adult services

What NHS England directly commissions in line with national standards (service specifications)

- NHS England commissions a management service for cystinosis (adults and children), which is a rare, autosomal recessive genetic disease, diagnosed early in childhood, usually before the age of two. It leads to an increase in many parts of the body of the amino acid cystine. This build up causes cystine crystals to form in many organs. These crystals form firstly in the kidneys and the eyes, and later in the muscles, pancreas, thyroid gland and white blood cells.

This service is in the highly specialised portfolio.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

Integrated Care Boards commission specialist renal services for children from Specialist Paediatric Renal Centres, including services delivered on an outreach basis as part of a provider network. Integrated Care Boards commission services for the following conditions:

- acute kidney injury including those requiring haemodialysis (HD) or peritoneal dialysis (PD)
- moderate and severe chronic kidney disease (i.e., chronic kidney disease KDOQI categories 3-5)
- complicated nephrotic syndrome
- severe or chronic glomerular disease
- vasculitis (except mild Henoch-Schönlein purpura)
- tubulointerstitial disorders including renal tubular transport disorders that are primary or secondary to acquired or metabolic disease
- complex/severe hypertension
- nephrolithiasis
- complex neuropathic bladder particularly those requiring other specialist services

Integrated Care Boards commission the following specialist interventions:

- hospital dialysis (i.e., HD and peritoneal dialysis) for acute kidney injury and chronic kidney disease

- training for home peritoneal dialysis (and more rarely for home HD) for chronic kidney disease
- access surgery for dialysis
- paediatric urology
- plasmapheresis
- renal transplantation (including tissue typing)
- renal biopsy
- urodynamics
- specialist and interventional radiology
- visits from members of the multidisciplinary team to the patient's home to provide training and support to the child and the family/carers

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

For the following common conditions, ICBs commission services for patients when specialist input is NOT required, and the NHS England commissions the services when specialist input IS required:

- uncomplicated urinary tract infection
- nocturnal enuresis
- daytime enuresis
- antenatal hydronephrosis
- chronic kidney disease (mild-moderate CKD 1-2) not requiring dialysis
- acute kidney injury not requiring dialysis (if mild and uncomplicated)
- uncomplicated nephrotic/nephritic syndrome
- haematuria
- proteinuria
- mild/moderate renal hypertension

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23S

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above should be captured in the neonatal or paediatric critical care rules.
3. The IR software tool should be used to identify outpatient activity using CDS data.

128. Specialist respiratory services for children

[Programme of care – Women & Children CRG – Specialised Paediatric Respiratory]

Service summary

Specialist respiratory services for children include services provided by Specialist Paediatric Respiratory Centres for patients with rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network.

Other relevant service(s):

- 4. Adult specialist respiratory services
- 47. Diagnostic service for primary ciliary dyskinesia (adults and children)
- 88. Primary ciliary dyskinesia management service (adults and children)
- 92. Pulmonary hypertension service for children

About the condition/service

Common paediatric respiratory conditions are managed in local hospitals or primary care settings, but complex and rare conditions are managed in conjunction with a Specialist Paediatric Respiratory Centre. About 11,000 children require access to Specialist Paediatric Respiratory Centres each year.

How the service is organised

Services are delivered by Specialist Paediatric Respiratory Centres.

Children are assessed/treated on an outpatient, inpatient and day case basis by the specialist multidisciplinary team. Treatment and follow up of many of these conditions are lifelong and planned transition to adult services takes place via joint and/or hand-over clinics. The Specialist Respiratory Service works as part of a clinical pathway with colleagues in local hospitals to provide care for children with difficult or complex respiratory disorders as near to their home as is possible. Much of the work is done on an ambulatory basis with an outpatient and diagnostic service for patients whose care is shared with secondary providers and inpatient services often working closely with other tertiary paediatric specialists. Support via outreach services is often needed for children with complex respiratory disorders, typically those requiring respiratory support from a portable ventilator and those with artificial airways (either tracheostomy or nasopharyngeal tubes).

Outreach work by members of the specialist team extends to

- shared care outpatient clinics in local hospitals
- support for ward staff in local hospitals and community staff as appropriate
- support to patients and staff in palliative care facilities
- support to patients and carers and families in the home
- education and support to secondary care multidisciplinary teams

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist respiratory services for children, including services delivered on an outreach basis as part of a provider network. ICBs commission services for the following conditions:

- difficult to control asthma
- congenital lung and airway disease
- rare lung disease
- empyema, parapneumonic effusion and pneumothorax
- bronchiectasis and obliterative bronchiolitis
- chronic cough
- chronic neonatal lung disease with co-morbidity
- lung disease associated with primary and secondary immunodeficiency
- complicated pulmonary tuberculosis
- restrictive and chronic lung disease associated with thoracic dystrophy, severe scoliosis and neuromuscular disease
- sleep disordered breathing
- acute and chronic airway problems
- home respiratory support

ICBs commission the following interventions and investigations from Specialist Paediatric Respiratory Centres as part of a specialist respiratory service for children:

- flexible bronchoscopy and bronchography
- complex pulmonary function testing
- sleep studies
- nasal ciliary brushings
- exhaled and nasal nitric oxide
- sweat testing
- high resolution CT and other complex respiratory imaging.
- investigation of pulmonary hypertension
- lung biopsy
- chest drain insertion and management
- access to rigid bronchoscopy and airway intervention
- training in the use of assistive technologies such as use of cough assist machines, invasive and non-invasive ventilators, etc

ICBs commission the following devices, whose use should be initiated and monitored for continuing suitability by the specialist respiratory team:

- ventilators for use at home via tracheostomy
- ventilators for use at home via mask (non-invasive ventilation) (including bi-level Positive Airway Pressure (BiPAP) devices.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- Non-specialist work undertaken in local hospitals
- Non-specialist work undertaken in specialist centres
- Cough-assist devices for use at home
- The maintenance of ventilators for use at home

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23T

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above should be captured in the neonatal or paediatric critical care rule.
3. The IR software tool should be used to identify outpatient activity using CDS data.

129. Specialist rheumatology services for children

[Programme of Care – Women & Children, CRG – Specialised Paediatric Rheumatology]

Service summary

Specialist rheumatology services for children include care provided by Specialist Paediatric Rheumatology Centres for complex conditions. The service includes outreach when delivered as part of a provider network.

Other relevant service(s):

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

About the condition/service

Paediatric rheumatology spans adults and children from neonates into late adolescence, encompassing a broad spectrum of conditions, many of which are rare/complex and often chronic. Many conditions require specialist care, co-dependency with paediatric sub-specialities and often complex/expensive interventions and treatments. Rapid access to a variety of specialist diagnostic services to underpin the clinical services, laboratory and radiological investigations and often requiring expert interpretation, is crucial in excluding alternative diagnoses, monitoring response to treatment and emphasises the co-dependencies of the service with other paediatric sub-specialties.

How the service is organised

Services are delivered by Specialist Paediatric Rheumatology Centres.

Most specialist rheumatology services are delivered in an ambulatory setting. The multi-disciplinary teams at the Specialist Paediatric Rheumatology Centres work within networks delivering outreach and shared care with local hospitals.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission specialist rheumatology services for children from Specialist Paediatric Rheumatology Centres, including services delivered on an outreach basis as part of a provider network. ICBs commission services for the following conditions:

- Inflammatory and non-inflammatory rheumatic conditions
- Pain syndromes
- Unexplained fevers
- Complex multisystem disease
- Uveitis
- Connective tissue diseases
- Genetic syndromes associated with stiff joints or severe hypermobility

- Inflammatory conditions affecting children including Kawasaki's disease, periodic fever syndromes and autoimmune diseases associated with primary immunodeficiency

ICBs commission specialist investigations and interventions, including all drugs initiated, prescribed, delivered and monitored in specialist care.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service. ICBs may prescribe some non-specialist drugs initiated by the Specialist Paediatric Rheumatology Centre.

Change of the service commissioner

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

Identification Rules information

NCBPS service code(s)

- 23W

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above should be captured in the paediatric critical care rule.
3. The IR software tool should be used to identify outpatient activity using CDS data.

130. Specialist services for children with infectious diseases

[Programme of Care – Blood & Infection, CRG – HIV] [Adults and children]
[Programme of Care – Women & Children, CRG – Specialised Paediatric Allergy, Immunology and Infectious Disease Services] [Children]

Service summary

Specialist services for children with infectious diseases include services provided by Specialist Infectious Diseases Paediatric Centres. This includes management of:

- Overwhelming bacterial septicaemia/sepsis
- Severe and life-threatening viral infections
- Severe, complicated and drug-resistant tuberculosis
- Unusual or severe fungal infections
- HIV infection
- Tropical infections and infections in returning travellers
- Common infections in the immunocompromised host
- Specialist advice on infections in children treated by other (paediatric and adult) sub-specialties including those requiring intensive care for medical and surgical management and trauma and those receiving immunomodulatory medications
- Bloodstream healthcare associated infections in children
- Congenital infections (babies infected *in utero* with viruses, bacteria or parasites)

These include inpatient, day case and outpatient services including outreach (including telephone advice) when delivered as part of a provider network.

Other relevant service(s):

- 16. Adult specialist services for people living with HIV
- 65. Specialist services for adults with infectious diseases

About the condition/service

Infectious diseases are caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi; the diseases can be spread, directly or indirectly, from one person to another. Zoonotic diseases are infectious diseases of animals that can cause disease when transmitted to humans. Infectious diseases can cause of range of symptoms, which in some cases can be life threatening. There are approximately 1,500 cases each year of healthcare associated bloodstream infections in children. The increasing use of immunosuppressive and immunomodulatory treatments has increased the numbers of children developing complex infectious problems.

How the service is organised

Most infections in children are treated in primary care or by paediatricians in secondary care settings. However, children who have complex needs that require management in specialist centres are often more prone to severe or unusually complicated infections. Even though their day-to-day management is co-ordinated by their specialist team, advice is required from a Paediatric Immunology and Infectious Disease (PIID) Team for optimal management of their infection.

The multi-disciplinary specialist paediatric infectious disease team co-ordinates a rapid and effective evaluation of the infection and its risk of transmission and provides appropriate diagnostic and medical management on a 24-hour basis.

PIID Teams provide high quality guidelines, advice and consultation services to more common infections in children looked after by other teams. The specialist team also provides telephone advice on patients being treated in local hospitals.

PIID Teams provide specialist paediatric antimicrobial stewardship advice and infection prevention support to all tertiary children's services (along with clinical microbiologists).

As in the case of adult infections, some conditions require special isolation facilities with appropriate air handling and air filtration systems available at a limited number of centres. Children are treated in these units by PIID Teams and a paediatric multi-disciplinary team.

Specialist Infectious Diseases Paediatric Centres co-ordinate clinical networks across wide geographic areas.

Services for children with HIV are organised in regional networks, with each of the networks linked to a specialist centre, all of which are based in London.

Very rarely, children are treated in highly specialist infectious disease centres, which provide care to patients with very rare conditions:

- High secure infectious disease units
- Bone and Joint Infection Centres
- Human T-cell Lymphotropic virus centres

Details of these centres are included in service 65.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions:

- HIV (all care related to HIV infection for children and young people living with HIV) High consequence infectious airborne disease services for children
- High consequence infectious airborne disease services for children
- High consequence infectious contact disease services for children

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

Integrated Care Boards (ICBs) commission specialist services for children with infectious disease from Specialist Infectious Diseases Paediatric Centres, including services delivered on an outreach basis as part of a provider network. ICBs commission services for patients with suspected and confirmed:

- ‘common’ (severe) infections in the immunocompromised host
- recurrent infections (investigation and management of)
- opportunistic infections secondary to: immunodeficiency of unknown aetiology, immunodeficiency due to malignancy, chemotherapeutic drugs, viruses
- severe paediatric infections including those requiring intensive care
    - meningococcal disease
    - staphylococcal/streptococcal sepsis and toxic shock syndromes
    - bacterial meningitis
    - encephalitis
    - brain abscess
    - sinusitis
    - mastoiditis
    - ophthalmic infections and inflammatory conditions
    - empyema
    - endocarditis
    - abdominal sepsis and gastrointestinal infections
    - viral hepatitis
    - complicated urinary tract infections
    - complex musculo-skeletal infection
    - complex skin infections
- severe healthcare associated infections
- inflammatory conditions affecting children including Kawasaki’s disease, periodic fever syndromes and autoimmune diseases associated with primary immunodeficiency
- fever of unknown origin (greater than two weeks duration)
- nosocomial infections/healthcare associated infection (central line infections, ventilator-associated pneumonia, methicillin resistant *Staphylococcus aureus*, complicated *C difficile* infection and multi-antibiotic resistant bacterial infection)
- serious post-operative infections and post traumatic infections
- Tuberculosis (TB) (congenital, central nervous system, extra-pulmonary disease, complicated pulmonary disease, drug-resistant TB)
- complex and unusual manifestations of neonatal infections (for example, candida, multi-resistant organisms, pertussis)
- congenital infections (for example, HIV, Hepatitis, toxoplasmosis, cytomegalovirus, syphilis, rubella, herpes simplex virus, varicella, chlamydia)
- prevention of perinatal infection (for example, HIV, hepatitis, toxoplasmosis)

- persistent cervical lymphadenopathy and atypical/non-tuberculous mycobacterial infection
- sexually transmitted infections in children
- infections with unusual patterns of antimicrobial resistance (bacterial, fungal and viral)
- complex vaccine advice for passive and active immunisation (non-response, failures, immunocompromised)
- rare, imported and emerging paediatric infections, (for example, Lyme disease, brucellosis, leptospirosis), slow infections of the CNS (SSPE, spongiform encephalopathies), worldwide emerging new infections (dengue, SARS, influenza, chikungunya), imported infections (severe and complicated malaria, typhoid fever, visceral and cutaneous leishmaniasis).
- zoonosis (for example, coxiella, bartonella, brucella, toxoplasmosis, psittacosis)

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission services for infectious diseases provided outside of Specialist Infectious Diseases Paediatric Centres and routine vaccinations of children and babies.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 18C

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Paediatrics HIV – Providers are required to upload data to the Integrated Screening Outcomes Surveillance Service (ISOSS) – Children’s HIV and AIDS Reporting System (CHARS)

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity via CDS data.

131. Specialist services for complex liver, biliary and pancreatic diseases in adults

[Programme of Care – Internal Medicine, CRG – Hepatobiliary and Pancreas]
[Programme of Care – Blood & Infection, CRG – Infectious Diseases]

Service summary

Specialist services for complex liver, biliary and pancreatic diseases in adults include treatment of a defined list of conditions and a defined list of procedures provided by Specialist Hepatobiliary Centres including outreach when delivered as part of a provider network.

Other relevant service(s):

- 9. Adult specialist endocrinology services
- 65. Specialist services for adults with infectious diseases
- 68. Islet transplantation services (adults)
- 69. Liver transplantation service (adults and children)
- 85. Pancreas transplantation service (adults)
- 94. Radiotherapy services (adults and children)
- 105. Specialist cancer services (adults)

About the condition/service

Hepato-pancreato-biliary (HPB) services treat patients who have disorders of the liver, bile ducts and pancreas. A large volume of HPB services are delivered in local hospitals but, because of the complexity and high cost of care, delivery in conjunction with or at specialist tertiary centres may be necessary. Such conditions include hepatitis C (about 10,000 cases each year), serious complications of cirrhosis (about 3,000 cases each year) and complex liver, biliary and pancreatic surgery (about 9,000 cases each year).

How the service is organised

Surgical and medical HPB services are provided in Specialist Hepatobiliary Centres; Hepatitis C (HCV) services are delivered through Operational Delivery Networks. Some services are delivered through outreach arrangements in more local hospitals.

What NHS England directly commissions in line with national standards (specifications and policies)

There is a specific Service delivering Total Pancreatectomy with Islet Auto Transplant Service (TPIAT), for chronic pancreatitis which is commissioned in a small number of specialised centres, for the population of England.

This service is in the highly specialised portfolio.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications)

ICBs commission the following specialist services for complex liver, biliary and pancreatic disease from Specialist Hepatobiliary Centres, including services delivered on an outreach basis as part of a provider network:

- Treatment with curative intent for all tumours (malignant and benign) involving the liver, bile ducts and pancreas
- Treatment with palliative intent for all tumours (malignant and benign) involving the liver, bile ducts and pancreas using surgery or complex interventional radiological procedures where simple radiological/endoscopic treatments are not feasible
- Acute or chronic liver failure requiring escalation to Level 2 or Level 3 dependency care
- Management of complex portal hypertension requiring TIPSS (transjugular intrahepatic portosystemic stent shunting) insertion
- All strictures (narrowing) of the bile ducts and pancreatic ducts of any aetiology requiring surgery, complex biliary interventions (endoscopic and interventional radiological)
- Biliary manometry
- Patients with chronic hepatitis C viral infection. This includes patients with hepatitis C requiring direct acting antivirals, patients co-infected with HIV, presence of haemophilia, chronic kidney disease 3-6 and/or cirrhosis.
- Drug therapies for patients with chronic hepatitis B viral infection
- Complications of acute pancreatitis requiring endoscopic, radiological and/or surgical intervention
- Chronic pancreatitis requiring endoscopic, radiological and/or surgical intervention
- Liver, biliary and pancreas trauma, including iatrogenic bile duct injuries following laparoscopic cholecystectomy
- Clinical genetics services for patients with benign and malignant hereditary HPB disorders

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- Management, monitoring and surveillance of cirrhosis, alcoholic liver disease, NASH (non-alcoholic steatohepatitis), NAFLD (non-alcoholic fatty liver disease) not requiring intervention
- Prevention and identification of viral hepatitis B
- Treatment excluding drugs for viral hepatitis B
- Prevention and identification of viral hepatitis C
- Simple gallstone disease without suspicion of gallbladder cancer
- Acute and chronic pancreatitis not requiring surgery
- Initial diagnostic investigations of suspected HPB cancers under the direction of the designated HPB specialist MDT

- Diagnosis and initial assessment of jaundice
- Identification and surveillance of populations at risk of HPB cancers

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 19Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activity using CDS data.

132. Specialist services for haemophilia and other related bleeding disorders (adults and children)

[Programme of Care – Blood & Infection, CRG – Specialised Blood Disorders]

Service summary

Specialist services for haemophilia and other related bleeding disorders include all care provided by Specialist Haemophilia Centres including inpatient care where the cause of admission is related to a bleeding disorder. The service includes outreach when delivered as part of a provider network. This applies to provision in adults and children.

About the condition/service

Bleeding disorders are medical conditions in which the blood fails to clot properly. These conditions are rare in the general population, affecting about 24,000 people in the UK. Most are genetically inherited.

Bleeding disorders include:

- Haemophilia A and B (classified as mild, moderate or severe)
- Von Willebrand disease (classified as Type 1, Type 2 and Type 3, with Type 3 being severe)
- Factor deficiencies I, II, V, VII, X, XI and XIII
- Platelet disorders
- Acquired (non-inherited) haemophilia

There are two main forms of haemophilia – A and B – both of which are inherited in such a way that they mainly affect males. The most common is haemophilia A (deficiency of clotting factor VIII), which affects between 1 in 5,000 and 1 in 10,000 males. Haemophilia B (deficiency of clotting factor IX) is less common and affects about 1 in 40,000 males.

Von Willebrand disease is a deficiency or a defect of the coagulation protein, von Willebrand factor, it is more common that haemophilia but usually a less severe bleeding disorder. It affects at least 1 in 1,000 of both sexes.

When treatment is indicated, which is usually in the more severe levels of disease, this is primarily achieved by replacing the missing clotting factor/s. Various clotting factor concentrates are available as well as fresh frozen plasma which contains mixed clotting factors. Replacement may be given ‘on demand’ to treat a bleeding episode or, for more severe disorders, prophylactically to prevent bleeding. A new therapeutic avenue using biological bypassing agents is now emerging in the field of bleeding disorders.

Women with bleeding disorders need individualised specialist care when they give birth to prevent excessive bleeding. Where it is known that a woman is going to give birth to a baby with a bleeding disorder the obstetrician, midwife and haemophilia team work together to minimise any risks to the mother and baby, for example by avoiding forceps delivery.

How the service is organised

The standard service model for haemophilia services was set out in the Health Service Guidance HSG(93)30 ‘Provision of Haemophilia Treatment and Care’. This stated that there should be two different levels of haemophilia provision:

- Comprehensive Care Centres provide specialist diagnosis and care
- Haemophilia Centres provide a local, shared care service

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national service standards (service specifications and policies)

ICBs commission specialist services for haemophilia and other related bleeding disorders from both Comprehensive Care Centres and Haemophilia Centres where the cause of admission is the bleeding disorder. This includes services delivered on an outreach basis as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other activity for patients with bleeding disorders. For example, if an adult patient with a bleeding disorder needs a hip replacement, the ICB commissions the hip replacement and NHS England commissions any blood products needed to support haemostasis for that episode. In addition, ICBs commission services for patients with immune conditions relating to bleeding, for example, idiopathic thrombocytopenic purpura. NHS England commissions all surgery for children with bleeding disorders.

Changes to service commissioner

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

Identification Rules information

NCBPS service code(s)

- 03Z (valid for use in 2022/23 but will be split into adults and children rules in 2023/24)
- 03X (adults)
- 03Y (children)

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal

- Patient Level Contract Monitoring via Data Landing Portal
- Regular recording of patient information and treatments onto the United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO) database

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. All Haemophilia patients (with the exception of those that refuse) should be recorded on the United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO) database. The content of this database should be cross-referenced with reported provider activities.
2. The IR software tool should be used to identify inpatient activity using CDS data.
3. The IR software tool should be used to identify outpatient activity using CDS data.

133. Specialist services for severe personality disorder in adults

[Programme of Care – Mental Health, LD & Autism, CRG –Tier 4 Personality Disorder Services]

Service summary

Specialist services for severe personality disorder in adults includes inpatients and bespoke packages of care for intensive day care services (as an alternative to admission) provided by Specialist Centres. In addition, the service includes associated non-admitted care including outreach when delivered as part of a provider network.

About the condition/service

Personality disorders are "... deeply ingrained and enduring behaviour patterns, manifesting as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels and, particularly, relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance."

About 450 individuals each year need access to this service.

How the service is organised

The service is delivered at Specialist Centres.

The Specialist Centres provide intensive 'wrap around' interventions (24 hours a day, seven days a week) that ensure therapeutic assessment, engagement, containment, treatment and step down for adults with personality disorders (PDs). The decision to refer a patient to a Tier 4 PD Service is made on the basis of severity of their condition quantified by using an instrument developed by the National Personality Disorder Development Programme, which measures factors associated with diagnosis, pervasiveness, complexity, risk and unmanageability of PD. Patients who score 7, 8, 9 or 10 on the 10 point scale on the instrument are considered appropriate for referral to Tier 4. Interventions can be on an inpatient basis or through a bespoke care package. The Specialist Centres also provide access to or provision of expert specialist treatments for presenting co-morbidities, for example, eating disorders; substance misuse, etc.

The key role of Tier 4 PD outreach services is to ensure suitable treatment and care management is in place and provided for individuals leaving residential tier 4 services **and** to act to reduce the likelihood of individuals requiring admission to Tier 4 residential services.

The outreach service works collaboratively with colleagues from a range of services and agencies across the whole pathway, developing and supporting provider networks, which are required to contain and manage risk issues while meeting the complex needs of the client group.

The outreach service:

- Provides timely, appropriate specialist assessments for those people whom referrers consider to require Tier 4 PD interventions and manage admissions to residential services
- Provides focused time-limited services to actively develop and support local PD care pathways, including arranging and ‘brokering’ pathways back into local services
- Works collaboratively with all Tier 3 services, including providing consultation and support and ensuring there is seamless transition between the specialised and local elements of the pathway
- Agrees effective joint working arrangements with local teams to enhance capacity and confidence, particularly as points of transition for service users
- Develops and supports the wider multi-agency workforce and professional/family and carer networks towards effective and best practice when working with PD
- Works with PD services across all tiers in pursuit of continual service development and appropriate step down/step up provision at each point on the pathway
- Establishes and develops a PD network across the geographical area served, linking to other such networks to share learning and inform service improvement
- Informs future commissioning by collating and sharing regular detailed information regarding needs and prevalence of complex PD populations
- Implements effective transitional care services that consider the special needs of young adults making the transition from children’s to adult services
- Ensure service user involvement and collaboration is core to service planning, delivery and evaluation

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist services (Tier 4 services) for severe personality disorder in adults from Specialist Centres. This includes inpatients and bespoke packages of care for intensive day care services (as an alternative to admission). In addition, the service includes associated non-admitted care including outreach when delivered as part of a provider network.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission personality disorder services for patients requiring care in Tier 1, Tier 2 or Tier 3 services.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 22T

Data flows

The data flows that are used to support this service are:

- Mental Health Services Data Set via Strategic data collection service.
- Aggregate Contract Monitoring via Data Landing Portal
- service

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and MHSDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

The IR software tool does not include a rule for this service. All NHS commissioned providers of mental health services are required to collect and submit the Mental Health Services Data Set to the Strategic Data Collection Service (SDCS) cloud. Activity is identified via usage of Specialised Mental Health Service Category Codes, which are published in the document 'Mental Health Price Activity Matrix (MH PAM) Template (Schedule 2B)'. Providers must identify the commissioner of this activity using either the NHS England Regional ODS Code as per Schedule 6 of the provider's contract, or the Provider Collaborative ODS Code, as per the document 'Determining the NHS-led Provider Collaborative.

134. Specialist services to support patients with complex physical disabilities (excluding wheelchair services) (adults and children)

[Programme of Care – Trauma, CRG – Rehabilitation, Disability and Spinal Cord Injury]

Service summary

Specialist services to support patients with complex physical disabilities (including those with a combination of physical, sensory, intellectual, learning or cognitive disabilities) include the specialist assessment for, and provision of (if indicated):

- Prosthetics
- Specialist augmentative and alternative communication aids
- Specialist environmental controls

This applies to provision in adults and children.

A. PROSTHETICS (LIMBS)

About the condition/service

Prosthetics is a specialist service for all major upper and lower limb amputees and people with congenital limb deficiencies, who have a potential to use prostheses to help them mobilise or improve upper limb function.

The number of amputee and limb deficient people in England is about 45,000. Each year about 4,000 major lower limb amputations, 200 upper limb amputations and 150 congenital upper and lower limb amputations are referred to about specialist centres.

The service provides lifelong care to people with a congenital limb deficiency or who have had major limb amputations. Pre-amputation, re-amputation and antenatal consultations are also provided as required.

How the service is organised

Prosthetic services are provided by about 30 specialist centres across England and include workshops and manufacturing facilities. Some services are provided by satellite centres with all satellite centres being linked to a specialist centre.

Specialist centres provide:

- Specialist assessment and review
- Prescription, provision and maintenance of prosthetic limbs
- High tech prosthetic components, for example, microprocessor units and silicone cosmeses
- Specialist gait re-education and gait analysis
- Combined clinics with surgeons

- Pain management and psychological support including antenatal consultations
- Educational, vocational, leisure, mobility and driving advice

Assessments are carried out in specialist centres by a multi-disciplinary team that includes: a rehabilitation physician specialising in prosthetics, prosthetists, physiotherapists, occupational therapists, nurses, psychologists, counsellors and any other specialist that may be appropriate for any specific case.

There are different arrangements for veterans requiring prosthetics services.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (services specifications and policies)

ICBs commissions all prosthetics services.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission any standard therapies (for example, physiotherapy, occupational therapy) required by the patient that take place outside the prosthetics service.

How the activity for this service is identified

This service includes specified activity.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

B. SPECIALIST WHEELCHAIRS (INCLUDING COMPLEX POSTURAL SEATING AND POWERED WHEELCHAIR CONTROLS)

Change of service commissioner

From April 2015, ICBs (previously CCGs) are the responsible commissioner for all wheelchair services except those for amputee armed forces personnel.

C. SPECIALIST AUGMENTATIVE AND ALTERNATIVE COMMUNICATION AIDS

About the condition/service

The Office of the Communication Champion estimates that approximately 6,000 children and adults require assessment and provision by specialist communication services each year.

Communication is fundamental to independence, achievement and quality of life. A communication system enables people who have lost, or never had speech or language to interact with their world, often allowing them to engage and be successful in education, vocation and work.

Augmentative and alternative communication (AAC) equipment allows for:

- Output of synthesised (artificial) voice, digitised (recorded) voice or text
- A vast array of ways in which vocabulary is organised and selected by the user
- Many different means of accessing and controlling the equipment

People requiring specialist AAC assessment have a combination of physical, sensory, intellectual, learning or cognitive disabilities. This includes children and adults born with a communication impairment (for example, cerebral palsy, developmental disorders, learning disabilities and other disorders such as autism) and children and adults who become communication impaired (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson’s, Alzheimer’s, multiple sclerosis or motor neurone disease).

How the service is organised

Centres may be NHS or voluntary sector (funded via NHS or education sources). Assessment models and the services offered vary but most provide:

- A multi-disciplinary team including specialist speech and language therapists, clinical scientists and technologists, occupational therapists, specialist teachers and access to physiotherapists, psychologists and others
- Technological and engineering facilities for customisation and modification to the individual
- An assessment and loan bank of possible technologies offering a diverse range of solutions
- An extremely wide range of software, vocabulary packages and resources
- Expertise in procurement and equipment management
- An ability to issue, monitor, maintain, recall and refurbish equipment
- An ability to manage, aggregate and analyse user information to enhance the service and streamline day to day operations
- An ability to integrate services and equipment with other assistive technologies such as environmental controls
- An ability to educate and train a wide range of stakeholders from the user, families, spoke service members and local team members
- An ability to take account of co-morbidity issues such as postural support needs

Referrals for an AAC needs assessment originate from local services, including health care professionals in the community and acute medical settings, staff within the education sector, staff within the social care sector and specialist and local rehabilitation teams.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions services for patients that require specialist assessment for AAC aids:

- Where there is a severe/complex communication difficulty associated with a range of physical and/or cognitive, learning and sensory deficits.
- Where goals are achieved by the input of a multi-disciplinary team to include speech and language therapists, clinical scientists, occupational therapists and education professionals (as a minimum), with specific competencies and access to a wide range of specialist equipment.
- Where individuals require multiple assistive technologies, integrated into a single means of access and functionality (for example communication, environmental control, computer access and/or powered wheelchair control)
- Where communication solutions are dependent upon special engineering and adaptation.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission AAC aids for those patients who do not meet the criteria for specialist AAC aids.

How the activity for this service is identified

This service includes specified activity.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

D. SPECIALIST ENVIRONMENTAL CONTROLS

About the condition/service

There are about 6,000 users of environmental control systems (ECS) in England. These systems enable people with profound physical disability to gain a degree of personal independence, often enabling them to continue living in their own homes with carer support and relying on their ECS to achieve single switch access to operate multiple functions such as:

- Summoning help in an emergency or calling a carer
- making and receiving telephone calls
- controlling door access for visitors and the EC user
- adjusting room temperature, ventilation and lighting
- adjusting position in riser/recliner chair or profiling bed
- operating electrical appliances in home (television, satellite, audio visual equipment)
- computer control and access method

A significant proportion of users make use of these technologies to provide safety and security, gain remunerative employment, maintain social contacts and access information and services. The current EC equipment has a modular format with systems prescribed and assembled to meet individual need. However, they are only available from specialist suppliers and may require a customised means of access to accommodate the individual's functional abilities.

Most people requiring ECS have significant upper limb impairments that mean they are unable to use standard controls, for example remote-control handsets or telephones. Many are neurological conditions resulting in tetra-paresis, often with a progressive component varying from moderate to rapid and combined with fatigue. The commonest diagnoses are: multiple sclerosis, spinal cord injury (level C5/6 & above), motor neurone disease, cerebral palsy, muscular dystrophy, severe arthritis and acquired brain injury. Besides having severe physical impairments, some of the users may also have co-existing cognitive and communicative impairment.

How the service is organised

The specialist centres providing ECS: conduct assessment of the individual's needs, usually in their place of residence; prescribe equipment solutions to meet these needs; and undertake or oversee their installation. A stock of relevant equipment is available to demonstrate ECS and computer access to patients and carers and, if needed, a trial can be arranged.

The services are also responsible for: on-going support of the equipment, including initial tuition; clinical review with additions and modifications to suit changing needs; equipment maintenance; and service support, including emergencies.

Specialist ECS services achieve the required medical and technical competencies through the multi-disciplinary approach of clinical scientists, clinical technologists, specialist occupational therapists and input from medical personnel (most commonly rehabilitation medicine consultants). They work closely with the community and other specialist teams who may be involved with individual patients. This is especially needed for patients who require multiple assistive technologies that need integration into a single means of access (for example, environmental control, computer access, communication aid and/or powered wheelchair control).

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions specialist environmental controls.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any services relating to a patient's specialist environmental control but commission any general health services required by that individual.

What local authorities commission

Local authorities commission non-specialist environmental controls.

How the activity for this service is identified

This service includes specified activity.

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- Prosthetics: 05P
- Specialist augmentative and alternative communication aids: 05C
- Specialist environmental controls: 05E

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring
- Limb Prosthetic reporting via Data Landing Portal
- Augmentative and Assistive Communication reporting via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data.

How to use the Identification Rules

The IR software tool contains no Identification Rule for this service. Providers are required to identify activity and attribute the relevant NCBPS service code within all relevant commissioning dataflows.

135. Specialist paediatric surgery services

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist paediatric surgery services include services provided by Specialist Paediatric Surgery Centres including outreach when delivered as part of a provider network. The service includes:

- Management of rare surgical conditions in children
- Specialist surgery in neonates (neonatal surgery)
- Provision of specified specialist paediatric surgical procedures during childhood
- Surgical management or procedures for more common paediatric surgical conditions when a child requires specialist pre-operative, anaesthetic or post-operative care

Other relevant service(s):

- 72. Major trauma services (adults and children)
- 112. Specialist gynaecology services for children
- 136. Specialist paediatric urology services
- 139A. Surgery for complex obesity in children

About the condition/service

Most children who require routine surgical procedures can be cared for by their local children's surgical service. These non-specialist services may be provided by General Surgeons and/or Urologists (who also provide adult surgical care) or Specialist Paediatric Surgeons (who also provide the specialist surgical care for children).

Specialist paediatric surgical care is required for patients under the age of 18 when: the surgery is complex (for example, oesophageal atresia repair); the surgical condition being managed is rare (for example, anorectal malformations) and/or when a baby or child has complex co-morbidities (for example, inguinal hernia repair is normally a routine non-specialist procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidities). The same group of patients may also require the input of specialist paediatric radiology services. Specialist paediatric surgical procedures are normally provided by a surgeon registered under the sub-speciality Paediatric Surgery on the GMC specialist register.

Congenital abnormalities are uncommon. About 3% of newborns have a major physical abnormality. Many of these do not require surgical intervention. Individual congenital conditions requiring intervention in the neonatal period are rare (for example, gastroschisis, one of the commonest abnormalities, in which an infant's intestines stick out of the body through a defect on one side of the umbilical cord, has an incidence of about 1 in 2,500). Less severe abnormalities are more common (for example, inguinal hernias have an incidence of about 1%) but do not always require specialist care, unless the child has a significant co-morbidity.

Specialist paediatric anaesthesia services are required in a number of children undergoing diagnostic or interventional radiological procedures, for example, brain MRI in neonates, small infants or those with complex co-morbidity (for example, cystic fibrosis); percutaneous CT or ultrasound guided drainage of obstructed kidneys or difficult central venous cannulation; angiography; angioplasty; embolisation and thrombolysis; percutaneous cholangiography; nephrostomy.

How the service is organised

Services are delivered by Specialist Paediatric Surgery Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialised paediatric surgery services from Specialist Paediatric Surgery Centres in England, including services delivered on an outreach basis as part of a provider network. The service includes:

- Management of rare surgical conditions in children
- Specialist surgery in neonates (Neonatal Surgery)
- Provision of specified specialist paediatric surgical procedures during childhood
- Surgical management or procedures for more common paediatric surgical conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine surgery for children who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Inguinal hernia repair in children (Inguinal herniotomy)
- Circumcision
- Orchidopexy for the undescended testis

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23X

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to the NCBPSPIC or NCBPSNIC service.
3. The IR software tool should be used to identify outpatient activity using CDS data.

136. Specialist paediatric urology services

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist paediatric urology services include services provided by Specialist Paediatric Urology Centres including outreach when delivered as part of a provider network. The service includes:

- Management of rare urological conditions in children
- Provision of specified specialist urological procedures during childhood
- Surgical management or procedures for more common urological conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

Other relevant service(s):

- 28. Bladder exstrophy service (children)
- 72. Major trauma services (adults and children)
- 112. Specialist gynaecology services for children
- 127. Specialist renal services for children
- 135. Specialist paediatric surgery services

About the condition/service

Most children who require routine surgical procedures can be cared for by their local children's surgical service. These non-specialist services may be provided by General Surgeons and/or Urologists (who also provide adult surgical care) or Specialist Paediatric Surgeons (who also provide the specialised surgical care for children)

Specialist paediatric urological care is required for patients under the age of 18 when: the surgery is complex (for example, bladder augmentation); the surgical condition being managed is rare (for example, posterior urethral valves) and/or when a baby or child has complex co-morbidities (for example, circumcision is normally a routine non-specialist procedure but requires specialist surgical and anaesthetic input when the child has complex co-morbidities). The same group of patients may also require the input of specialist paediatric radiology services. Specialist paediatric urological procedures are normally provided by a surgeon registered as a Specialist Paediatric Surgeon on the GMC specialist register.

How the service is organised

Services are delivered by Specialist Paediatric Urology Centres. These services are normally linked with Specialist Paediatric Surgical Centres.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialist paediatric urology services from Specialist Paediatric Urology Centres, including services delivered on an outreach basis as part of a provider network:

- Management of rare urological conditions in children
- Provision of specified specialist urological procedures during childhood
- Surgical management or procedures for more common urological conditions when a child requires specialist pre-operative, anaesthetic or post-operative care.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission routine surgery for children who do not have complex co-morbidities that make the surgery more complex. Such procedures might include:

- Circumcision
- Orchidopexy for the undescended testis

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 23Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be sued to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to the NCBPSPIC or NCBPSNIC service code.
3. The IR software tool should be used to identify outpatient activity using CDS data.

137. Spinal cord injury services (adults and children)

[Programme of Care – Trauma, CRG – Rehabilitation, Disability and Spinal Cord Injury]

Service summary

Spinal cord injury services include services provided by Spinal Cord Injury Centres. This applies to provision in adults and children.

About the condition/service

A spinal cord injury (SCI) is an injury to the spinal cord resulting from trauma, disease or infection. Complete injuries result in tetraplegia or paraplegia below the level of the injury and incomplete injuries result in neurological impairment affecting mobility, bladder and bowels. Patients with high-level injuries may require long term ventilation.

The incidence of SCI in the UK is estimated at between 12 and 16 per million with the majority of cases caused by trauma.

The aim of the service is to:

- Provide acute management and rehabilitation of people with SCI
- Provide ongoing management of people with SCI
- Promote optimal outcomes, leading to reduced mortality and morbidity
- Support patients to maximise their potential for independent living and for return to employment or education, hobbies and activities of daily living
- Optimise autonomy and health in people with SCI

How the service is organised

Spinal cord injury services are provided by Spinal Cord Injury Centres (SCICs) in England. Most services are delivered directly on site at the centres, but provision may also include:

- Acute outreach, both face to face and by telephone, to newly injured patients and those caring for them
- Visits to the patient’s home, local area and local services, as part of planning for reintegration
- Outreach clinics in suitable locations

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions all activity for Spinal Cord Injury patients provided by the SCIC’s host provider, including:

- any part of the initial admission to the SCIC’s host provider following injury, wherever in the provider the patient is situated
- any part of the initial admission to the SCIC’s host provider following injury, even if the patient is treated for another related or non-related condition during

that spell (for example, hand injury, epilepsy). Occasionally the initial admission may be interrupted by a temporary transfer to another setting.
- any further admission or attendance for SCI-related care, wherever the treatment is located in the SCIC's host provider (for example, cystoscopy, tendon transfer), where a SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint care arrangement
- any further admission of the SCI patient for non-SCI-related care, if an SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint care arrangement

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission:

- Services for patients treated in or by SCI Centres who do not have a spinal cord injury as defined above, except where this service is defined elsewhere as a service commissioned by NHS England. Examples of services commissioned by ICBs might include patients without SCI having treatment for pressure sores.
- Patients admitted to SCICs with injury to the spinal column but intact neurology (with the exception of up to two nerve roots)
- Patients with progressive disease, except where this is covered by a service defined elsewhere as a service that is commissioned by NHS England, for example, patients with spinal tumours. However, if spinal cord dysfunction has arisen from the effects of a benign tumour that has been primarily managed by an appropriate specialty, or from a tumour that has been adequately treated and is now deemed to have a benign course, or if the patient has a significant life expectancy, the patient may transfer to the SCIC for rehabilitation and lifelong follow up. At this point, NHS England commissions the patient's care.
- A&E attendance following spinal cord injury up until a decision to admit
- Assisted conception services and sperm storage, with the exception of electro-ejaculation, which is part of the specialist SCI service
- Any further admission or attendance of a person with SCI for non-SCI-related care when the patient is treated by a clinician who is not an SCI clinician and there is no shared care agreement, except where the service is defined elsewhere as a service commissioned by NHS England
- People with SCI treated in centres (specialist or non-specialist) that are not recognised SCICs, except where formal sub-contract arrangements have been put in place with an SCIC or the service is defined elsewhere as being commissioned by NHS England
- Delivery (obstetrics) and care of the new-born
- Patients who remain in a SCIC after they are clinically fit for discharge
- Care in the community, including the provision, maintenance and replacement of equipment required to support the patient in the community, except where this is defined as a service commissioned by NHS England

- The provision of disability equipment, except where this is defined as a service commissioned by NHS England

Change of service commissioner

There are plans to review whether this service should be delegated to ICBs in the future.

Identification Rules information

NCBPS service code(s)

- 06A

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Critical care activity via SUS
- Uploading of information into the British Spine Registry
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- Long stay patient reporting via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. Any critical care activity associated with 1 above are required to be identified locally and attributed to specialised commissioning.
3. The IR software tool should be used to identify outpatient activity using CDS data.

138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)

[Programme of Care – Blood & Infection, CRG – Blood and Marrow Transplantation]

Service summary

Stem cell transplantation services for juvenile idiopathic arthritis and related connective tissue include services provided by Highly Specialist Stem Cell Transplant Centres for juvenile idiopathic arthritis and related connective tissue. This provision applies to children.

Other related services:

- 22. Autoimmune paediatric gut syndromes service
- 29. Haematopoietic stem cell transplantation services (adults and children)
- 100. Severe combined immunodeficiency and related disorders service (children)
- 129. Specialist rheumatology services for children

About the condition/service

Juvenile idiopathic arthritis is an autoimmune disorder.

The service is participating in a European study evaluating the clinical effectiveness of stem cell transplant services for this disease as a treatment option when other more conventional treatment options have been exhausted. The increased use of monoclonal antibody therapies as a treatment for juvenile idiopathic arthritis has resulted in fewer patients being referred for stem cell transplantation.

This service is in the highly specialised portfolio.

How the service is organised

The service treats about one child each year.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions stem cell transplantation services for children with juvenile idiopathic arthritis and related connective tissue disorders from Highly Specialist Stem Cell Transplant Centres for juvenile idiopathic arthritis and related connective tissue**.**

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- P23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal Transplant activity via local data flows

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Stem Cell Transplant Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPSP23 service code within all relevant commissioning dataflows.

139. Stickler syndrome service (adults and children)

[CRG –Genomic Medicine]

Service summary

Stickler syndrome services include services provided by Highly Specialist Stickler Syndrome Centres (including specialist laboratory services). This provision applies to adults and children.

Other relevant service(s):

- 12. Adult specialist ophthalmology services
- 120. Specialist ophthalmology services for children

About the condition/service

Stickler syndrome is an inherited disorder of connective tissue associated with cleft palate, deafness and arthropathy. It is the commonest inherited cause of rhegmatogenous retinal detachment in children (where fluid passes into the space between the retina and the retinal pigment layer). Although the systemic features are widespread, the sight-threatening complications are generally the most serious, particularly the risk of giant retinal tear, which is frequently bilateral and, if untreated, can lead to blindness.

This service is in the highly specialised portfolio.

How the service is organised

The service is an outpatient diagnostic service that focuses on genetic testing to establish the patient's sub-classification of the disease. The service sees about 100 new patients each year and their families.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions diagnostic services for patients with Stickler syndrome from Highly Specialist Stickler Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plans developed by the Highly Specialist Stickler Syndrome Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 20C

Data flows

The data flows that are used to support this service are:

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Stickler Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPS20C service code within all relevant commissioning dataflows.

139A. Specialist morbid obesity services for children

[Programme of Care – Women & Children, CRG – Specialised Surgery in Children]

Service summary

Specialist morbid obesity services for children includes services provided by Specialist Paediatric Morbid Obesity Centres. The service includes all bariatric surgical procedures and the associated care, as well as medical care provided by these centres for complex patients unsuitable for or not requiring surgery. This applies to provision in children.

Other relevant service(s):

- 109. Specialist endocrinology services for children
- 135. Specialist paediatric surgery services

About the condition/service

Currently, secondary prevention treatments for obesity include behaviour modification interventions such as diet: exercise and lifestyle; referral to specialist weight-loss clinics; drug therapy; low and very low-calorie diets; and behaviour modification therapies. Surgery to aid weight reduction may be considered when all other non-invasive measures have been tried but have failed and the patient has been adequately counselled and prepared for surgery.

Bariatric surgery is one component of the multimodality lifetime treatment pathway of specialist morbid obesity, which consists of multidisciplinary medical assessment and management of co-morbidities, lifestyle and dietary improvements, nutritional replacement, and lifelong follow up care.

How the service is organised

Surgery for complex obesity in children is delivered in a very small number of NHS providers.

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (service specifications and policies)

ICBs commission complex obesity surgery services from Specialist Paediatric Morbid Obesity Centres. This includes all bariatric surgery and associated care delivered by the Specialist Centre, including medical care and specialist weight management care for patients unsuitable for or not requiring surgery.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs are responsible for commissioning:

- medical weight management services
- in adults, bariatric surgery and associated care, including medical care and specialist weight management for patients unsuitable for or not requiring surgery

What local authorities commission

Local authorities commission local weight management services, commonly known as ‘tier 2 services’. In some localities local authorities also commission the medical weight management services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 35Z

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Paediatric critical care activity via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal
- The registration of patients on the National Bariatric Surgery Registry

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by specified centres.

How to use the Identification Rules

1. Providers of bariatric surgery are required to provide regular updates to the National Bariatric Surgery Registry and the information in this registry should be cross-referenced to other data flows to ensure consistency.
2. The IR software tool should be used to identify inpatient activity using CDS data.
3. Any critical care activity associated with 2 above should be captured by the paediatric intensive care rule.
4. Outpatient attendances associated with the initial assessment (used to establish appropriateness for surgery) and the subsequent provision of clinical care before and after Inpatient surgery should be identified locally and attributed to NCBPS35Z service code within all relevant commissioning dataflows.

139AA. Termination services for patients with medical complexity and or significant co-morbidities requiring treatment in a specialist hospital

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Women & Children, CRG – Specialised Women's Services]

Service summary

This service covers the provision of surgical and medical abortion when the pregnant person has co-morbidities that indicate the need for care in a National Health Service (NHS) hospital setting, typically with input from a multi-disciplinary team.

About the condition/service

Many women with co-morbidities, such as uncontrolled epilepsy, diabetes, heart conditions or cancer who need access to termination services, cannot be treated in a stand-alone community abortion clinic, and must be managed within a hospital setting where there is swift access to backup care and specific clinical expertise in the event of an emergency.

As the number of younger women with co-morbidities increases at a population level this is reflected in the pregnant population, both among those continuing and those ending pregnancies.

How the service is organised

To be determined

What Joint Committees (NHS England and Integrated Care Boards (ICBs)) commission in 2023/24 in line with national standards (specifications and policies)

ICBs commission specialised services for abortion where co-morbidities necessitate hospital-based termination from Specialist Termination Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission all other termination services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- NCBPS04H

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

To be determined

How to use the Identification Rules

The IR software tool does not contain a mechanism to identify this activity. Providers are required to identify activity locally and attribute NCBPS04H service code within all relevant commissioning dataflows.

139B. Uterine transplantation services (adults)

Whilst this section refers specifically to 'women', from an anatomical point of view it may also relate to trans men and individuals who identify as non-binary and who retain natal female reproductive organs.

[Programme of Care – Women & Children, CRG – Specialised Women's Services]

Service summary

Uterine transplantation services include services provided by Highly Specialist Uterine Transplant Centres. This applies to provision in adult women.

About the condition/service

About 1 in 5,000 women are born without a womb and some lose their wombs because of illness, for example, because of cervical cancer. Uterine transplantation offers an opportunity for these women to have their own children.

There has only been one documented uterine transplant leading to a successful term pregnancy in the world to date.

How the service is organised

To be determined

What NHS England directly commissions in line with national standards (specifications and policies)

Although there are plans to develop a uterine transplant programme in England, this will initially be funded from charitable monies (outwith the NHS) and it is unlikely that the procedure will be considered for commissioning by the NHS for several years.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

This is to be determined but it is unlikely that ICBs will be the responsible commissioner for any element of the procedure.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- NCBPS04U

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Critical care activity via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Patient Level Contract Monitoring via Data Landing Portal

How the activity for this service is identified

To be determined

How to use the Identification Rules

The IR software tool does not contain a mechanism to identify this activity. Providers are required to identify activity locally and attribute NCBPS04U service code within all relevant commissioning dataflows.

140. Vein of Galen malformation service (adults and children)

[Programme of Care – Women & Children, CRG – Paediatric Neurosciences]

Service summary

Vein of Galen malformation services include services provided by Highly Specialist Vein of Galen Malformation Centres. This provision applies to adults and children.

Other relevant service(s):

- 119. Specialist neuroscience services for children

About the condition/service

Vein of Galen Malformations (VGMs) are extremely rare abnormalities in the blood vessels in the brain leading to excess blood flow which can result in cardiac problems.

VGMs usually occur in fetuses or new-born babies, although sometimes these problems do not present until later in life.

This service is in the highly specialised portfolio.

How the service is organised

Treatment for VGMs in children involves injecting acrylate or placing a coil into the blood vessels to restore arteriovenous equilibrium.

The service treats about 10 new babies and children each year.

What NHS England directly commissions in line with national standards (specifications and policies)

NHS England commissions services for adults and children with vein of Galen malformations from Highly Specialist Vein of Galen Malformation Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs do not commission any elements of this service.

How the activity for this service is identified

Activity is identified via local data flows, which apply to Highly Specialist Vein of Galen Malformation Centres only.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- A23

Data flows

The data flows that are used to support this service are:

- Admitted Patient Care CDS via SUS
- Outpatient CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
  Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Vein of Galen Malformation Centres only.

How to use the Identification Rules

The IR software tool does not contain a mechanism to identify this activity. Providers are required to identify activity locally and attribute NCBPSA23 service code within all relevant commissioning dataflows.

141. Integrated veterans’ mental health and wellbeing service

[CRG – Armed Forces]

Service summary

Integrated veterans’ mental health and wellbeing service include services provided by Integrated Veterans’ Integrated Mental Health Wellbeing Centres.

About the condition/service

The integrated veterans’ mental health and wellbeing service provides services for veterans with complex mental health problems – including post-traumatic stress disorder – primarily associated with military service-related trauma. The service is known as Op Courage.

How the service is organised

The service treats about 5000 patients each year.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions integrated veterans’ mental health and wellbeing services for veterans from Integrated Veterans’ Mental Health Wellbeing service providers.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs have overall responsibility for commissioning comprehensive services for veterans, including mental health services.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 22X

Data flows

The data flows that are used to support this service are:

- Referral activity via local data flows and the national Mental Health Services Data Set (MHSDS).
- Assessment activity via local data flows and the MHSDS.
- Treatment programme activity via local data flows and the MHSDS.
- Follow-up activity via local data flows and the MHSDS
- Aggregate Contract Monitoring via Data Landing Portal

How the activity for this service is identified

Activity is identified via local data flows and the national Mental Health Services Data Set, which apply to Integrated Veterans’ Mental Health and Wellbeing service providers only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers already delivering this service are required to continue the data collection and reporting processes currently in use for this service.

142. Wolfram syndrome service (adults and children)

[Programme of Care – Internal Medicine, CRG –Specialised Endocrinology]

Service summary

Wolfram syndrome services include services provided by Highly Specialist Wolfram Syndrome Centres. This provision applies to adults and children.

Other relevant service(s):

- 109. Specialist endocrinology services for children

About the condition/service

Wolfram syndrome is a very rare inherited disorder. It is a progressive neurodegenerative disorder with a debilitating and life-threatening association of diabetes, blindness, deafness and brain disease.

This service is in the highly specialised portfolio.

How the service is organised

Both the adult and paediatric services run clinics that undertake assessment of all patients in a multidisciplinary structure. Patients are assessed and reviewed by all the specialities appropriate to their needs during the clinic.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions services for adults and children with Wolfram syndrome from Highly Specialist Wolfram Syndrome Centres.

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plan developed by the Highly Specialist Wolfram Syndrome Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- Q23

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS

- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly Specialist Wolfram Syndrome Centres only.

How to use the Identification Rules

The IR software tool does not include a methodology for identification of this service. Providers are required to identify activity locally and attribute NCBPSQ23 service code within all relevant commissioning dataflows.

143. DNA nucleotide excision repair disorders service (adults and children)

[Programme of Care – Internal Medicine, CRG – Specialised Dermatology]

Service summary

DNA nucleotide excision repair disorders services include services provided by Highly Specialist DNA Nucleotide Excision Repair Disorders Centres. This applies to provision in adults and children.

Other relevant service(s):

- 61. Specialist dermatology services

About the condition/service

DNA nucleotide excision repair disorders include patients with Xeroderma Pigmentosum (XP), Cockayne Syndrome (CS) and Trichothiodystrophy (TTD) These are rare inherited multi-organ disorders and patients have specific, complex and special needs. Although the underlying diseases are not curable at present, there is potential to significantly improve health and quality of life through a comprehensive, expert patient focussed service.

This service is in the highly specialised portfolio.

How the service is organised

This is provided by a rare disease centre, with a multidisciplinary clinical and molecular diagnostic service to co-ordinate the care and management of children and adults, and young people transitioning between paediatric and adult services.

What NHS England directly commissions in line with national standards (service specifications and policies)

NHS England commissions services for adults and children DNA nucleotide excision repair disorders from Highly Specialist DNA Nucleotide Excision Repair Disorders Centres

What Integrated Care Boards (ICBs) commission in line with local specifications and policies

ICBs commission the local care recommended in the management plans developed by the Highly Specialist DNA Nucleotide Excision Repair Disorders Centres.

Change of service commissioner

There are no plans to review commissioning arrangements for this service.

Identification Rules information

NCBPS service code(s)

- 24B

Data flows

The data flows that are used to support this service are:

- Outpatient CDS via SUS
- Admitted Patient Care CDS via SUS
- Aggregate Contract Monitoring via Data Landing Portal
- Highly Specialised data template via Data Landing Portal

How the activity for this service is identified

Activity prescribed as specialised is identified via the identification rules described below and reported via local and CDS data. Activity is undertaken and should be identified/reported by Highly DNA Nucleotide Excision Repair Disorders Centres only.

How to use the Identification Rules

1. The IR software tool should be used to identify inpatient activity using CDS data.
2. The IR software tool should be used to identify outpatient activity using CDS data.

Appendix A – National Audits, registries and datasets

Providers/clinical teams involved in the provision of specialised services are required to make regular data submissions to the following national audits, registries and datasets.

Service specification	**Service code**	**Service description**	**National audit, registry or dataset**
A01/S/a	NCBPS10Z	Cystic Fibrosis (adults)	UK Cystic Fibrosis patient registry
A01/S/b	NCBPS10Z	Cystic Fibrosis (children)	UK Cystic Fibrosis patient registry
A01	NCBPS13G	Pulmonary Hypertension	National Pulmonary Hypertension Audit and registry
A01	NCBPS29M	Adult Highly Specialist Respiratory Services: Interstitial Lung Disease	UK Idiopathic Pulmonary Fibrosis Registry (part of the UK Interstitial Lung Disease Registry)
A01	NCBPS29S	Respiratory: severe and difficult to control asthma	UK Severe Asthma registry hosted by Queens University Belfast formerly the British Thoracic Society difficult Asthma registry
A02/S/a	NCBPS19T	Liver Transplantation Service (Adults)	Liver Transplant Database (NHS Blood and Transplant)
A02/S/a	NSCBPS19Z	Specialist Services for Complex Liver, Biliary and Pancreatic Diseases in Adults	Hepatitis C Patient Registry and Treatment Outcomes System
A02/S/a	NSCBPS19Z	Specialist Services for Complex Liver, Biliary and Pancreatic Diseases in Adults	Intestinal Transplant Dataset (NHS Blood and Transplant)
A02/S/a	NSCBPS19Z	Specialist Services for Complex Liver, Biliary and Pancreatic Diseases in Adults	International Intestinal Transplant Registry
A03/S/a	NCBPS27B	Islet Transplantation Service	Pancreas and Islet Transplant Database (NHS Blood and Transplant)
A03/S/a	NCBPS27C	Pancreas Transplantation Service	Pancreas and Islet Transplant Database (NHS Blood and Transplant)
A03/S/a	NCBPS27Z	Adult Specialist Endocrinology Services	British Association of Endocrine and Thyroid surgeons surgical registry

A03/S/a	NCBPS27Z	Adult Specialist Endocrinology Services	National Congenital Anomaly and Rare bone disease registry
A03/S/a	NCBPS27Z	Adult Specialist Endocrinology Services	UK Acromegaly Register
[A04/S/a] 170004/S	NCBPS30Z	Vascular Surgery	The National Vascular Registry (now live, replaces National Vascular Database)
A05	NCBPS35Z	Severe and complex obesity	National Bariatric Surgery Registry
A05	NCBPS13B	Cardiology Electrophysiology and ablation services	Heart Failure Database (NICOR)
A05	NCBPS13E	Cardiac Surgery	Adult Cardiac Surgery (NICOR)
A05	NCBPS13E	Cardiac Surgery	UK TAVI dataset (v3.9) (NICOR)
A05	NCBPS13F	Cardiology: PPCI	Myocardial Ischaemia National Audit Project (MINAP) (NICOR)
A05	NCBPS13F	Cardiology: PPCI	Adult Percutaneous Intervention (PCI) Database (NICOR)
A05	NCBPS13N	Heart and Lung Transplantation Service: Heart and Lung Transplantation	Cardiothoracic Dataset (NHS Blood and Transplant)
A06	NCBPS11A	Atypical Haemolytic Uraemic Syndrome Services	National aHUS register
A06/S/a	NCBPS11B	Renal Dialysis	UK Renal Registry
A06/S/a	NCBPS11B	Renal Dialysis	National Renal dataset (v2.2)
A06/S/a	NCBPS11T	Renal transplantation	Kidney Transplant Dataset (NHS Blood and transplant)
A06/S/a	NCBPS11T	Renal transplantation	UK Renal Registry
[A07] 170077S	NCBPS12Z	Intestinal failure	National Intestinal Failure Registry
A07	NCBPS33A	Colorectal: Faecal incontinence	National Pelvic floor Registry (now operated by NHSD)
A07	NCBPS33C	Colorectal Transanal Endoscopic Microsurgery (TEMS)	National Bowel Cancer Audit (NBOCAP)
A07	NCBPS33D	Distal Sacrectomy	National Bowel Cancer Audit (NBOCAP)
A07	NCBPS01J	Colorectal: Anal cancer	National Bowel Cancer Audit (NBOCAP)
A07	NCBPS01J	Colorectal: Anal cancer	Royal college of Pathologists Minimum data set

A09	NCBPS26Z	Specialised Rheumatology	British Isles Lupus Assessment Group Biologics Registry (BILAG-BR)
A09	NCBPS26Z	Specialised Rheumatology	UK MYOACT Registry for patients with myositis
A09	NCBPS26Z	Specialised Rheumatology	UK Primary Sjogren's Syndrome registry
A09	NCBPS26Z	Specialised Rheumatology	UKIVAS Vasculitis registry
B01	NCBPS01R	Radiotherapy	Radiotherapy Data set NCRASenquiries@phe.gov.uk NHS Standard Contract: Approved Collection
B01	NCBPS01R	Brachytherapy and molecular radiotherapy	Radiotherapy Data set includes Brachytherapy reporting) NCRASenquiries@phe.gov.uk NHS Standard Contract: Approved Collection
B01	NCBPS01S	Stereotactic radiosurgery	Radiotherapy Data set NCRASenquiries@phe.gov.uk NHS Standard Contract: Approved Collection
B02	NCBPS01C	Chemotherapy	Systemic anti-Cancer Therapy Data Set https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set NHS Standard Approved Collection
B02	NCBPS01C	Chemotherapy	Patient Registry for Cannabis Based Products (where medicinal cannabis products are used to treat chemotherapy-induced nausea and vomiting when other therapies have failed)
B03	NCBPS01M	Specialist Cancer Services Head and Neck Cancer	Head and Neck Cancer Audit
B03	NCBPS01I	Malignant mesothelioma	National Lung Cancer Audit (LUCADA) – annual
B03	NCBPS01J	Specialist Cancer Services - Anal Cancer	**PLACEHOLDER** Multinational Anal Squamous Cell Carcinoma Registry and Audit (MASCARA)
B03	NCBPS01N	Specialised kidney, bladder and prostate	National Prostate Cancer Audit & BAUS Prostate Database, Bladder and Renal- BAUS Databases

B03	NCBPS01U	Oesophageal and gastric cancer	National Oesophago-gastric cancer audit - annual
B04	NCBPS01P	PET-CT	Diagnostic imaging dataset https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/diagnostic-imaging-data-set NHS Standard Contract: Approved Collection
		All cancer services	National Cancer waiting times monitoring dataset https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/cancerwaitingtimescwt NHS Standard Contract: Approved Collection
		All cancer services	Cancer Outcomes and Services Dataset NCRASenquiries@phe.gov.uk NHS Standard Contract: Approved Collection
D01/S/b	NCBPS05C	Alternative and Augmentative Communication aids	Regional Alternative and Augmentative communication aids database
D01	NCBPS07Z	Specialised rehabilitation for patients with highly complex needs	UK Rehabilitation Outcomes Collective (UKROC) http://www.ukroc.org/
D02	NCBPS09Z	Major Trauma	Trauma Audit and Research network (TARN) where associated with a major trauma patient https://www.tarn.ac.uk/Content.aspx?ca=4 NHS Standard Contract: Approved Collection
D02	NCBPS09Z	Specialist Burns Care Services (adults and children)	International Burns Injury Database (IBID)
D02	NCBPS09Z	Specialist Burns Care Services (adults and children)	National Burn Bed Bureau
D03	NCBPS06A	Spinal Cord Injury Services	National Spinal Cord Injury Database
D03	NCBPS06A/Z	Complex Spinal Surgery Services	British Spine Registry

D04	NBCPS08O	Adult Specialist Neurosciences Services: Neurology	Patient Registry for Cannabis Based Products
D04	NCBPS08R	Neurosciences (impatient) Interventional Radiology	Sentinel Stroke National Audit Project (SSNAP)
D04	NCBPS08S	Neurosurgery	UK Shunt registry
D04	NCBPS08S	Neurosurgery	Neurosurgical National Audit Programme (Society of British Neurological Surgeons (SBNS) Database)replaces British skull base national acoustic neuroma audit
D04	NCBPS43A	Neurosciences Inherited White Matter Disorders Diagnostic and Management Service for Adults	Inherited White Matter Disease Registry
D05	Many	Adult Critical Care	Intensive Care National Audit and Research Centre Adult Critical Care Case Mix Programme
D05	Many	Adult Critical Care	National Cardiac Arrest Audit (ICNARC)
D05	Many	Adult Critical Care	National Emergency Laparotomy Audit (NELA)
D05	Many	Adult Critical Care	Infection in Critical Care Quality Improvement Programme (ICCQIP)
D07	NCBPS31Z	Specialised Pain	National Neuromodulation Registry
D10	NCBPS34A/R	Specialised Orthopaedic Services	National joint registry NHS Standard Contract: Approved Collection
D10	NCBPS34A/R	Specialised Orthopaedic Services	**PLACEHOLDER** National Knee Joint Revision Database
D11	NCBPS28Z	Hyperbaric oxygen service	British Hyperbaric Association (annual)
D11	NCBPS28Z	Hyperbaric oxygen	UK Hyperbaric Oxygen Treatment Registry (part of the International Hyperbaric Oxygen Treatment Registry, currently hosted by Kings College London)
E01/S/a	NCBPS20Z	Medical genetics	UK Genetic testing Network
E02/E03/E05/E07		All relevant paediatric specialised services	National Intestinal Failure Registry

E02	NCBPS15Z	Cleft lip and palate	Cleft Registry & Audit NEtwork. (CRANE) crane@rcseng.ac.uk NHS Standard Contract: Approved Collection
E02	NCBPS23Q	Paediatric Orthopaedic Services	British Spine Registry
E02/S/c	NCBPS23X	Paediatric surgery	Neonatal outcomes audit of hypospadias (NOAH)
E02	NCBPS35Z	Morbid obesity	National Bariatric Surgery Registry
E03	NCBPS12D	Small Bowel Transplantation Service (Children)	Intestine Transplantation Dataset (NHS Blood and Transplant)
E03	NCBPS13T	Liver Transplantation Service (Children)	Liver Dataset (NHS Blood and Transplant)
E02	NCBPS20B	Bardet-Biedl Syndrome Service	Bardet-Biedl Registry
E03/S/a	NSCBPS23S	Paediatric renal services	Kidney Transplant Dataset (NHS Blood and transplant)
E03/S/a	NSCBPS23S	Paediatric renal services	UK Renal Registry
E03/S/a	NSCBPS23S	Paediatric renal services	National Renal dataset (v2.2)
E03/S/a	NSCBPS23S	Atypical Haemolytic Uraemic Syndrome Services	National aHUS register
E03	NCBPS23T	Paediatric respiratory	National Paediatric Difficult Asthma registry
E03/S/g	NCBPS23T	Paediatric respiratory	British Thoracic Society Pneumonia audit
E04	NCBPS23M	Specialist Neuroscience Services for Children	Patient Registry for Cannabis Based Products
E04	NCBPS23M	Specialist Neuroscience Services for Children	UK Shunt registry hosted by Cambridge University – quarterly data submission
E04	NCBPS23M	Specialist Neuroscience Services for Children	Orion CESS Registry hosted by Cambridge University https://orioncloud.org)

E04	NCBPS43C	Inherited White Matter Disorders Diagnostic and Management Service for Children	Inherited White Matter Disease Registry
E05/S/a	NCBPS13J	Pulmonary Hypertension Service for Children	National Pulmonary Hypertension Audit and Registry
E05/S/a	NCBPS13N	Heart and Lung Transplantation Service: Heart and Lung Transplantation	Cardiothoracic Dataset (NHS Blood and Transplant)
E05/S/a	NCBPS13X	Adult Congenital Heart Disease	National Congenital Heart Disease Audit
E05/S/a	NCBPS13Y	Adult Congenital Heart Disease Surgical Services	National Congenital Heart Disease Audit
E05/S/a	NCBPS23B	Paediatric cardiac services	National Congenital Heart Disease Audit
E07/S/a	NCBPSPIC	Paediatric Intensive care	Paediatric Intensive Care Audit Network database (PICANET)
E08/S/a	NCBPSNIC	Neonatal critical care	BADGERNET information system
E09	NCBPS04A	Specialised Women's Services	British Society for Endoscopy (BSGE) Endometriosis database
E09	NCBPS04D	Specialised Women's Services	British Society of Urogynaecology (BSUG) database
E09	NCBPS04A/D	Specialised Women's Services	National Neuromodulation Registry
E09	NCBPS04D	Specialised Women's Services	British Association of Urological Surgeons (BAUS) stress incontinence database
Many	Many	Rare diseases register	National Congenital anomaly and rare disease registration service (NCARDRS) hosted by Public Health England
F01	NCBPS02Z	Blood and marrow transplant	British Society of Bone and Marrow transplant data base
F02	NCBPS03T	Thrombotic Thrombocytopenic Purpura	United Kingdom Thrombotic Thrombocytopenic Purpura (TTP) Registry (managed by University College Hospitals London)
F02	NCBPS03Z	Haemophilia	UKHCDO National Haemophilia database

F02	NCBPS03Z	Haemophilia	UKHCDO triennial audit (comprehensive care centres only)
F03	NCBPS14A	HIV (adults)	HIV and AIDS reporting system (HARS)
F03	NCBPS14A	HIV (adults)	The UK collaborative HIV cohort study
F03	NCBPS14C	HIV (children)	National Surveillance of HIV in Pregnancy and Childbirth (ISOSS)
F03	NCBPS14C	HIV (children)	Children's HIV AIDS Reporting (CHARS) replaces CHIPS data collected by ISOSS and HARS
F05	NCBPS38S/38T	Haemoglobinopathies	National Haemoglobinopathy Registry
F06	NCBPS16Y	Paediatric immunology and infectious diseases	European society for Primary immunodeficiency
F06	NCBPS16Y	Paediatric immunology and infectious diseases	National Surveillance of HIV in Pregnancy and Childbirth (ISOSS)
F06	NCBPS16X	Immunology	UK Primary immunology deficiency registry
F06	NCBPS16X/Y	Immunology	National Immunoglobulin Database/ IVIG

Summary of changes – January 2023

Section	Change
Background (Prescribed Specialised Services Advisory Group)	No change
The purpose of the Manual	This section has been updated to reflect the Health and Care Act 2022.
Commissioning responsibilities of Integrated Care Boards	A new section has been added to describe the commissioning responsibilities of Integrated Care Boards and to explain how this is set out in this version of the Manual.
Detailed information about the Identification Rules	This section has been updated with more recent information.
Appendix B - High Cost Devices	Appendix B - High Cost Devices has been removed as information on High Cost Devices is found in the National Tariff Payment System Guidance
All chapters	Programme of Care has been added and CRGs updated. The 'What NHS England commissions' and 'What CCGs commission 'sections have been updated to reflect the fact that some services will be commissioned by Joint Committees NHS England and Integrated Care Boards) in 2023/24 New sections have been added as set out in the introduction to the document. The 'Why the service is commissioned by NHS England' section has been removed. The 'Change of service commissioner' section has been updated and includes information on services that may be delegated to Integrated Care Boards in the future. The 'Identification rules' section has been updated throughout the manual,
Multiple chapters	A number of services were originally classified as 'highly specialist'. The majority of these services are delivered

Section	Change
	in numerous providers and there continues to be confusion between highly ‘specialist’ services and highly ‘specialised’ services, the word 'highly' has been removed from multiple services to avoid confusion with services in the highly 'specialised' portfolio. Activity data has been updated throughout several chapters. Information on ‘Other relevant services’ has been updated for several chapters.
Multiple chapters	Where gender-specific terminology has been used to describe a service, there is an explanatory note to confirm that these services also relate to individuals who have transitioned or are non-binary but retain natal sexual characteristics.
1.Adult ataxia telangiectasia services	The ’How the service is organised' section has been updated’
2. Adult congenital heart disease services	No changes
2A. Adult oesophageal gastric services in the form of gastro-electrical stimulation for patients with intractable gastroparesis	The name of the service has been changed from ‘Adult highly specialist oesophageal gastric services in the form of gastro-electrical stimulation for patients with intractable gastroparesis’ to ‘Adult oesophageal gastric services in the form of gastro-electrical stimulation for patients with intractable gastroparesis’ The term 'specialist' has been removed as NHS England has commissioning responsibility for the whole service.
3. Adult specialist pain management services	The name of the service has been changed from ‘Adult highly specialist pain management services’ to ‘Adult specialist pain management services’
4. Adult specialist respiratory services	The name of the service has been changed from ‘Adult highly specialist respiratory services’ to ‘Adult specialist respiratory services’.

Section	**Change**
	The 'About the condition/service' and the 'How the service is organised' sections have been updated for Severe Asthma and Interstitial Lung Disease. Information on 'Management of central airway obstruction' has been added.
5. Adult specialist rheumatology services	The name of the service has been changed from 'Adult highly specialist rheumatology services' to 'Adult specialist rheumatology services'
6. Adult secure mental health services	No changes
7. Adult specialist cardiac services	The 'About the condition/service' section has been updated for 'complex interventional cardiology services' and for 'primary percutaneous coronary intervention (PPCI) services for st-elevation myocardial infarction.
8. Adult specialist eating disorder services	No changes
9. Adult specialist endocrinology services	No changes
10. Adult specialist intestinal failure services	No changes (This service has previously been removed and has been merged with 101. Severe intestinal failure services)
11. Adult specialist neurosciences services	Information on a dedicated service for patients with Inherited white matter disorders has been added.
12. Adult specialist ophthalmology services	No changes
13. Adult specialist orthopaedic services	No changes
14. Adult specialist pulmonary hypertension services	The 'About the condition/service' section has been updated
15. Adult specialist renal services	The 'About the condition/service' section has been updated. The chapter has been updated to include information on a Cystinosis service commissioned by NHS England.
16. Adult specialist services for people living with HIV	The name of the service has been changed from 'Adult specialist services for patients infected with HIV' to Adult specialist services for people living with HIV' to reflect more acceptable

Section	**Change**
	terminology. This terminology has been updated throughout this section. The ‘About the condition/service’ section has been updated. The ‘What NHS England commissions’ section has been clarified to reflect the fact that NHS England is responsible for the payment for ARVs used for post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) This section has also been update to clarify where PEP and PrEP drugs are delivered. The ‘What local authorities commission’ section has been updated to clarify that Local authorities also commission sexual health and genitourinary medicine (GUM) services including the delivery of PEP and PrEP drugs.
17. Adult specialist vascular services	No changes
18. Adult thoracic surgery services	No changes
19. Alkaptonuria service (adults)	No changes
19A. Alpha 1 antitrypsin services (adults)	New reference added to the Manual for this line.
20. Alström syndrome service (adults and children)	The ‘How the service is organised’ section has been updated.
21. Ataxia telangiectasia service for children	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
21A. Atypical haemolytic uraemic syndrome services (adults and children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
22. Autoimmune paediatric gut syndromes service	No changes
23.Autologous intestinal reconstruction service for adults	The ‘About the condition/service’ section has been updated.
24. Bardet-Biedl syndrome service (adults and children)	The ‘How the service is organised’ section has been updated.

Section	**Change**
25. Barth syndrome service (adults and children)	Name changed from ‘Barth syndrome service (male adults and children) to ‘Barth syndrome service (adults and children) The ‘About the condition/service’ section has been updated.
26. Beckwith-Wiedemann syndrome with macroglossia service (children)	The ‘About the condition/service’ section has been updated.
27. Behçet’s syndrome service (adults and adolescents)	The ‘About the condition/service’ section has been updated.
28. Bladder exstrophy service (children)	The ‘About the condition/service’ section has been updated.
29. Haematopoietic stem cell transplantation services (adults and children)	The name of the service has been changed from ‘Blood and marrow transplantation services (adults and children)’ to ‘Haematopoietic stem cell transplantation services (adults and children)’.
30. Bone conduction hearing implant service (adults and children)	No changes in content
31. Pain-related complex cancer late effects rehabilitation service (adults)	The name of the service has been changed from ‘Breast radiotherapy injury rehabilitation service‘ to Pain-related complex cancer late effects rehabilitation service (adults). This service has been re-specified, however maintains the very specialist scope. The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
32. Children and young people's inpatient mental health service	The name of the service has been changed from ‘Tier 4 child and adolescent mental health services’ to ‘Children and young people's inpatient mental health service’ to reflect an update in terminology.
33. Choriocarcinoma service (adults and adolescents)	No changes
34. Chronic pulmonary aspergillosis service (adults)	The ‘How the service is organised’ section has been updated.
35. Cleft lip and palate services (adults and children)	No changes
36. Cochlear implantation service (adults and children)	No changes

Section	Change
37. Complex childhood osteogenesis imperfecta service	No changes
38. Complex Ehlers Danlos syndrome service (adults and children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
39. Complex neurofibromatosis type 1 service (adults and children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
40. Complex spinal surgery services (adults and children)	No changes
41. Complex tracheal disease service (children)	No changes
42. Congenital hyperinsulinism service (children)	The ‘About the service/condition’ section has been updated.
43. Craniofacial service (adults and children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
44. Cryopyrin associated periodic syndrome service (adults and children)	The ‘How the service is organised’ section has been updated.
45. Cystic fibrosis services (adults and children)	No changes
46. Diagnostic service for amyloidosis (adults and children)	The ‘How the service is organised’ section has been updated. The name of the service has been changed from ‘Diagnostic service for amyloidosis (adults)’ to ‘Diagnostic service for amyloidosis (adults and children) to reflect the scope of the service.
47. Diagnostic service for primary ciliary dyskinesia (adults and children)	The chapter has been updated to reflect that NHS England commissions management and treatment services for children with PCD and ICBs do not commission any elements of the pathway.
48. Diagnostic service for rare neuromuscular disorders (adults and children)	The ‘How the service is organised’ section has been updated.
49. Encapsulating peritoneal sclerosis treatment service (adults)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.

Section	**Change**
50. Epidermolysis bullosa service (adults and children)	The ‘How the service is organised’ section has been updated.
51. Extra corporeal membrane oxygenation service for adults with respiratory failure	No changes
52. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure	No changes
53.Ex-vivo partial nephrectomy service (adults)	The ‘How the service is organised’ section has been updated.
54. Fetal medicine services (adults and adolescents)	No changes
55. Gender dysphoria services (children and adolescents)	The name of this service has been changed from ‘Gender identity development services for children and adolescents’ to ‘Gender dysphoria services (children and adolescents) to reflect an update in terminology used for the services. This has been reflected through the chapter.
56. Gender dysphoria services (adults)	The name of this service has been changed from ‘Gender identity services (adults)’ to Gender dysphoria services (adults) to reflect an update in terminology used for the service. This has been updated throughout the chapter.
56ZA. Ovarian and testicular cryopreservation for patients receiving gonadotoxic treatment who are at high risk of infertility and cannot store mature eggs or sperm	New chapter added to the Manual for this service
56A Hand and upper limb transplantation (adults)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
57. Heart and lung transplantation service (including mechanical circulatory support (adults and children)	No changes in content
58. Specialist adult gynaecological surgery and urinary surgery services for females	The name of this service has been changed from ‘Highly specialist adult gynaecological surgery and urinary surgery services for females’ to ‘Adult

Section	Change
	specialist gynaecological surgery and urinary surgery services for females' The 'How the service is organised' section has been updated.
58A. Specialist adult urological surgery services for men	No changes
59. Specialist allergy services (adults and children)	The name of this service has been changed from 'Highly specialist allergy services (adults and children' to 'Specialist allergy services (adults and children')
60. Highly specialist colorectal surgery services	This service has been transferred to 106A. Specialist colorectal surgery services.
61. Specialist dermatology services (adults and children)	The name of this service has been changed from 'Highly specialist dermatology services (adults and children) to 'Specialist dermatology services (adults and children). The 'About the condition/service' section has been updated. The 'How the service is organised' section has been updated to include information on services for Stevens-Johnson syndrome (SJS) and toxic Epidermal Necrolysis (TEN). The 'Change of service commissioner' section has been updated to remove reference to the future commissioning of a service for patients with Stevens-Johnson syndrome and toxic epidermal necrolysis from April 2019.
62. Specialist metabolic disorder services (adults and children)	The name of this service has been changed from 'Highly specialist metabolic disorder services (adults and children) to 'Specialist metabolic disorder services (adults and children).
63. Specialist pain management services for children	The name of this service has been changed from 'Highly specialist pain management services for children' to Specialist pain management services for children.'

Section	**Change**
64. Specialist palliative care services for children and young adults	The name of this service has been changed from ‘Highly specialist palliative care services for children and young people’ to ‘Specialist palliative care services for children and young people.’
65. Specialist services for adults with infectious diseases	The name of this service has been changed from ‘Highly specialist services for adults with infectious diseases’ to ‘Specialist services for adults with infectious diseases.’
66. Hyperbaric oxygen treatment services (adults and children)	No change
67. Insulin-resistant diabetes service (adults and children)	The ‘How the service is organised’ section has been updated.
68. Islet transplantation service (adults)	The ‘How the service is organised’ section has been updated.
69. Liver transplantation services (adults and children)	No change
70. Lymphangioleiomyomatosis service (adults)	No changes
71. Lysosomal storage disorder service (adults and children)	The ‘About the condition/service’ section has been updated.
72. Major trauma services (adults and children)	No changes
73. McArdle’s disease service (adults)	The ‘About the condition/service’ section has been updated.
74. Mental health services for Deaf Children and Adults	No changes
75. Mitochondrial donation service	No changes
76. NF2-schwannomatosis service (adults and children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
77. Neuromyelitis optica service (adults and adolescents)	The ‘About the condition/service’ section has been updated.
78. Neuropsychiatry services (adults and children)	No changes
79. Ocular oncology service (adults)	The ‘How the service is organised’ section has been updated.
80. Ophthalmic pathology service (adults and children)	The ‘How the service is organised’ section has been updated.
81. Osteo-odonto-keratoprosthesis service for corneal blindness (adults)	The ‘How the service is organised’ section has been updated.
82. Paediatric and perinatal post mortem services	No changes

Section	**Change**
83. Paediatric cardiac services	The 'About the service/condition' section has been updated.
84. Paediatric intestinal pseudo-obstructive disorders service	No changes
85. Pancreas transplantation service (adults)	The 'About the condition/service' section has been updated
86. Paroxysmal nocturnal haemoglobinuria service (adults and adolescents)	The 'About the condition/service' section has been updated
87. Positron emission tomography-computed tomography services (adults and children)	No changes
88. Primary ciliary dyskinesia management service (adults and children)	The 'About the condition/service' section has been updated. The 'How the service is organised' section has been updated.
89. Primary malignant bone tumours service (adults and adolescents)	The 'How the service is organised' section has been updated.
90. Proton beam therapy services (adults and children)	The 'About the condition/service' section has been updated. The 'How the service is organised' section has been updated.
91. Pseudomyxoma peritonei service (adults)	The 'How the service is organised' section has been updated.
91A. Psychological medicine inpatient services for severe and complex presentations of medically unexplained physical symptoms (adults)	New reference added to the Manual for this line.
92. Pulmonary hypertension service for children	The 'About the condition/service' section has been updated. No changes
93. Pulmonary thromboendarterectomy service (adults and adolescents)	The 'About the condition/service' section has been updated. The 'How the service is organised' section has been updated.
94. Radiotherapy services (adults and children)	No changes
95. Rare mitochondrial disorders service (adults and children)	No changes
96. Reconstructive surgery service for adolescents with congenital malformation of the female genital tract	This service has been removed because it has been merged with 58. Highly specialist adult gynaecological surgery and urinary surgery services for females.

Section	**Change**
97. Retinoblastoma service (children)	The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.
98. Specialist secure forensic mental health services for young people	The name of the service has been changed from ‘Tier 4 specialist forensic mental health services for young people’ to ‘Specialist secure forensic mental health services for young people’ to reflect updated terminology. The ‘About the condition/service’ section has been updated.
99. Severe acute porphyria service (adults and children)	The ‘How the service is organised’ section has been updated.
100. Severe combined immunodeficiency and related disorders service (children)	No changes
101. Severe intestinal failure service (adults)	No changes
102. Severe obsessive compulsive disorder and body dysmorphic disorder service (adults and adolescents)	No changes
103. Small bowel transplantation services (adults and children)	The ‘About the condition/service’ section has been updated.
103A. Specialist adult haematology services	A new chapter added to the Manual for this service. This includes information on a service for patients with idiopathic multicentric Castleman disease and also a service for patients with thrombotic thrombocytopenic purpura (TTP).
104. Specialist burn care services (adults and children)	The ‘How the service is organised’ section has been updated to include information on services for Stevens-Johnson syndrome (SJS) and toxic Epidermal Necrolysis (TEN). The ‘Change of service commissioner’ section has been updated to remove reference to transfer of funds associated with the commissioning of a service for patients with Stevens-Johnson syndrome and toxic epidermal necrolysis.

Section	**Change**
105. Specialist cancer services (adults)	No changes
106. Specialist cancer services for children and young adults	The name of the service has been changed from 'Specialist cancer services for children and young people' to Specialist services for children and young adults' to update the name in line with clinical practice.
106A. Specialist colorectal surgery services (adults)	The 'What NHS England Commissions' section updated to include ileoanal pouch formation. The 'What Clinical Commissioning Groups commission' section has been updated to remove ileoanal pouch procedures. The 'Change of service commissioner' section updated to reflect ileonal pouch formation has been moved and will require a transfer of funds from ICBs (previously CCGs).
107. Specialist dentistry services for children	No changes
108. Specialist ear, nose and throat services for children	No changes
109. Specialist endocrinology services for children	The name of this service has been changed from 'Specialist endocrinology and diabetes services for children' to 'Specialist endocrinology services for children' This is because the majority of paediatric diabetes services are provided locally, with occasional specialist input from paediatric endocrinology services. The chapter has been updated in line with this change.
110. Specialist gastroenterology, hepatology and nutritional support services for children	No changes
111. Clinical genomic services (adults and children)	No changes
112. Specialist gynaecology services for children	No changes
113. Specialist haematology services for children	No changes

Section	Change
114. Specialist haemoglobinopathy services (adults and children)	This chapter has been rewritten to reflect the new model of care commissioned as part of the national services review of haemoglobinopathy services.
115. Specialist immunology services for adults with deficient immune systems	No changes
115A. Specialist immunology services for children with deficient immune systems	No changes
115B. Specialist maternity care for adults diagnosed with abnormally invasive placenta	The name of this service has been changed from ‘Specialist maternity care for women diagnosed with abnormally invasive placenta’ to ‘Specialist maternity care for adults diagnosed with abnormally invasive placenta’ to make the name of the service gender neutral.
116. Specialised mental health services for Deaf adults	No changes
117. Specialist morbid obesity services	This service was removed because it was previously commissioned by CCGs. NHS England continues to commission a service for children under 139A. Specialist morbid obesity services for children.
118. Neonatal critical care services	The name of this service has been changed from ‘Specialist neonatal care services’ to ‘Neonatal critical care services’ to reflect the service more closely.
119. Specialist neuroscience services for children	No changes
120. Specialist ophthalmology services for children	No changes
121. Specialist orthopaedic services for children	No changes
122. Paediatric critical care services	The name of this service has been changed from ‘Specialist paediatric intensive care services’ to ‘Paediatric critical care services’ to reflect the service more closely.
123. Specialist paediatric liver disease service	No changes
124. Specialist perinatal mental health services (adults and adolescents)	The name of this service has been changed from ‘Specialist perinatal mental health services’ to ‘Specialist

Section	**Change**
	perinatal mental health services (adults and adolescents)'.
125. Specialist plastic surgery services for children	No changes
126. Specialist rehabilitation services for patients with highly complex needs (adults and children)	No changes
127. Specialist renal services for children	The chapter has been updated to include information on a Cystinosis service commissioned by NHS England.
128. Specialist respiratory services for children	No changes
129. Specialist rheumatology services for children	No changes
130. Specialist services for children with infectious diseases	No changes
131. Specialist services for complex liver, biliary and pancreatic diseases in adults	The chapter has been updated to include information on the Total Pancreatectomy with Islet Auto Transplant Service (TPIAT).
132. Specialist services for haemophilia and other related bleeding disorders (adults and children)	No changes
133. Specialised services for severe personality disorder in adults	No changes
134.Specialist services to support patients with complex physical disabilities (excluding wheelchair services) (adults and children)	No changes in content
135. Specialist paediatric surgery services	No changes
136. Specialist paediatric urology services	No changes
137. Spinal cord injury services (adults and children)	No changes
138. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders (children)	No changes
139. Stickler syndrome service (adults and children)	The name of this service has been changed from 'Stickler syndrome diagnostic service (adults and children)' to 'Stickler syndrome service (adults and children)' to better reflect the scope of the service (no change in commissioning responsibility).

Section	**Change**
139A Specialist morbid obesity services for children	No changes
139AA. Termination services for patients with medical complexity and or significant co-morbidities requiring treatment in a specialist hospital	The name of this service has been changed from ‘Termination services for expectant mothers with significant comorbidities that require either or both critical care and medical support’ to ‘Termination services for patients with medical complexity and or significant co-morbidities requiring treatment in a specialist hospital’ in line with the service specification for the service and the reference to treatment only being in a specialist setting.
139B. Uterine transplantation services (adults)	The name of this service has been changed from ‘Uterine transplantation services (adult women)’ to ‘Uterine transplantation services (adults)’ to make the service name gender neutral.
140. Vein of Galen malformation service (adults and children)	The ‘About the condition/service’ section has been updated.
141. Veterans’ integrated mental health and wellbeing service	The name of the service has been changed from ‘Veterans’ mental health complex treatment service’ to ‘Veterans’ integrated mental health and wellbeing service’ to better reflect the terminology used by the profession.
142. Wolfram syndrome service (adults and children)	The ‘How the service is organised’ section has been updated.
143. DNA nucleotide excision repair disorders service (adults and children)	The name of the service has been changed from ‘Xeroderma pigmentosum service (adults and children)’ to ‘DNA nucleotide excision repair disorders service (adults and children)’ to more accurately reflect the broader scope of services (no change in commissioning responsibility as two other DNA disorders in addition to XP are already within commissioning responsibility of NHS England)’ The ‘About the condition/service’ section has been updated. The ‘How the service is organised’ section has been updated.

Changes to previous versions of the Manual and to the Identification Rules are available on request.

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First published May 2013
Published to Name, in electronic format only.