**Service Specification No.** | E3j
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**Service** | Paediatric Medicine – Specialised Allergy Services
**Commissioner Lead** | Barbara Howe
**Provider Lead** |  
**Period** | 12 months
**Date of Review** |  

1. **Population Needs**

1.1 **National/local context and evidence base**

- Allergic diseases are amongst the most common diseases in Western society affecting up to 30% of the UK population (20 million) at some time in their lives. The prevalence of allergic diseases including eczema, asthma, allergic rhinitis and food allergy have risen dramatically over the past 30 years and recent robust primary care data suggests almost 40% of children have an allergic diagnosis. For the majority (95%) of patients, allergic diseases can be managed by primary or other non-specialist allergy services with routine therapies (e.g. topical steroids (ointment, inhaler, nasal spray), antihistamines) coupled with advice (e.g. information regarding natural history, avoidance strategies, allergy management plans). A specialist service is, however, required for management of children with rare, severe or complex multi-system allergic disease as described below. The specialist Paediatric Allergy service will provide the service for the top tier of complex and severe allergy. We expect the rest of the paediatric allergy service to be funded by provision through local commissioning arrangements.
- Approximately 5% of patients with allergies are suitable for Clinical Commissioning Group (CCG) commissioning, leaving approximately 0.1% requiring referral to a specialist centre, with half of those currently receiving specialist interventions such as immunotherapy or investigation for drug allergy.

- A number of published reports indicate that provision for severe, multi-system or complex allergy is appropriate for national commissioning arrangements:

- *Allergy: the unmet need*, Royal College of Physicians, 2003 [http://old.rcplondon.ac.uk/pubs/books/allergy/](http://old.rcplondon.ac.uk/pubs/books/allergy/).


- The model suggested for both adult and paediatric services was set out in a recent report by the House of Lords Committee on Science and Technology (*see above*) and further reinforced by a follow up report by the Royal College of Physicians (*Allergy services: still not meeting the unmet need - see above*).

- There is broad consensus that all children with severe/complex allergic disease should be seen in the context of a specialist paediatric service (*Children’s National Service Framework* [1] and Department of Health 2004 [2]) to take into account the special requirements of paediatric service provision (*Royal College of Paediatrics and Child Health Allergy care pathways* [3]; National Service Framework for Children [4]; National Institute for Health and Clinical Excellence (NICE): *Food allergy for children* [5]; World Allergy Organisation (WAO) *Diagnosis and Rationale for Action against Cow’s Milk Allergy* (DRACMA) guidelines [6].

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2. [www.nhsconfed.org/Publications/reports/Pages/Children-young-people-health.aspx](http://www.nhsconfed.org/Publications/reports/Pages/Children-young-people-health.aspx)
3. [Royal College of Paediatrics and Child Health Allergy care pathways](http://www.rcpch.ac.uk/allergy)
5. [NICE food allergy for children](http://www.guidance.nice.org.uk/CG116)
6. [DRACMA WAO milk allergy guideline](http://www.worldallergy.org/publications/WHO_DRACMA_guidelines.pdf)
A networked hub and spoke structure is envisaged with specialist paediatric allergy centres based in teaching hospitals integrating with secondary and primary care services. Centres would be staffed by specialist paediatric allergists with support from nursing, dietetic, psychological and administrative services. Specialist allergy services would see patients because of the rarity or complexity of their conditions. Cases are defined as specialised because they will have been triaged from primary or secondary care through referral guidance, patient pathways or failure of diagnosis or treatment.

Although other paediatric specialties provide services which overlap to a degree with those provided by the specialist in allergic disease, paediatric allergy services meet a defined need for these complex and highly specialised diseases that is not met by organ-based specialities.

National Context
Specialist services in Paediatric Allergy are currently provided in a small number of dedicated units that have highly skilled staff and integrated services for children with complex primary allergic diseases. A larger proportion of children, often with less severe allergic disease are managed by general paediatricians with or without a specific interest in allergy, in District General Hospitals (DGHs). Delivery of the specialist services requires dedicated multi-disciplinary teams, requiring specialist laboratory-based testing, and dietary, psychological, and medical management. Key interdependencies link other tertiary paediatric and adult specialities and disciplines. Paediatric Allergy complements other co-located services such as gastroenterology, respiratory, ear nose and throat (ENT), ophthalmology, dermatology, immunology and infectious diseases, and general paediatrics, as well as immunology laboratories and adult allergy and clinical immunology services. The Royal College of Physicians (RCP) and parliamentary reports all emphasise the importance of training, education, and support as additional tasks for specialist centres. This is further elaborated on in the Royal College of Paediatrics and Child Health (RCPCH) allergy care pathways publications and outlines the need to establish networks with primary care and all other stakeholders. This latter is the focus of the Kennedy report “Getting it right for children and young people”. It is anticipated that the specialist clinics would provide the paediatric allergy champions for a region.

National Policies
Policies relevant to this specification are:


- Long term conditions

- Rare diseases


National Guidelines

National guidelines have been developed by NICE (http://www.nice.org.uk/) for allergic disorders and include the following:

- Food allergy in children and young people (CG116)
- Venom anaphylaxis - immunotherapy Pharmalgen (TA246)
- Anaphylaxis (CG134)
- Atopic eczema in children (CG57)
- Asthma (uncontrolled) - omalizumab (TA133)
- Asthma (in children) - corticosteroids (TA131)
- RCPCH care pathways http://www.rcpch.ac.uk/allergy/
- European Academy of Allergy and Clinical Immunology (EAACI) guidelines – Declaration on immunotherapy http://eaaci.net/resources/immunotherapy-declaration.html

National guidelines have been developed by the British Society for Allergy and Clinical Immunology (BSACI)7 for many allergic disorders and include the following:


7 http://www.bsaci.org/index.php?option=com_content&task=view&id=117&Itemid=1
BSACI have also worked in partnership with primary care to develop specific guidance for primary care enabling appropriate referrals and care pathways with the majority of patients treated locally by their GPs:

- Several other BSACI guidelines are in development.

The BSACI and Association of Anaesthetists have published joint guidelines on anaphylaxis during general anaesthesia:


The Resuscitation Council UK have worked in partnership with BSACI and have published joint guidance on the emergency treatment of anaphylaxis:


The WAO has developed guidelines on milk allergy www.worldallergy.org/publications/WAO_DRACMA_guidelines.pdf.

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8 http://www.bsaci.org/index.php?option=com_content&task=view&id=64&Itemid=74
There is ample evidence that specialist allergy treatment benefits patients:


Guidelines for best paediatric to adult care transition practice have been developed and should be a key component of a paediatric specialist service:


### 2. Scope

#### 2.1 Aims & Objectives of the service: Paediatric Allergy

The provider shall ensure that Specialist Paediatric Allergy centres provide:

- a family-centred service that is accessible and provides equity of access to specialist care throughout the country.
- a high quality care service, according to best practice guidelines defined by authoritative bodies such as RCPCH and BSACI.
- a sustainable service for children with severe and complex allergies that meets the needs of the regional population that incorporates the views of patients and provides effective use of resources.
- holistic, multi-disciplinary patient-focused care for children with allergic diseases
- the expertise required for the investigation, clinical assessment, treatment and management of patients with suspected and established allergic diseases.
- integrated care with primary, secondary and other care providers and ensure close links with other expert centres at national and international levels.
- training and expertise including ability to communicate complex allergy issues with healthcare professionals as well as children and families, including safeguarding issues
- access to National Institute of Health Research (NIHR) portfolio clinical trials in
allergy and to lead improvement in child health in the NHS through underpinning research.

- support, advice, expertise and training for the local/regional network.
- integration of patient care between regional / national specialised centres and local services through the use of standardised shared-care protocols, ensuring that support is delivered as close to patients' homes as possible, whilst access to specialist services is maintained e.g. desensitisation immunotherapy
- increased awareness of best practice in the diagnosis and management of these rare conditions through active engagement and shared care with local providers.

The objectives of the service will be to:

Ensure the provider addresses individual needs for control of allergy, including self-administration/home therapy and (when indicated) desensitisation immunotherapy. The service will deliver the aim to improve both life expectancy and quality of life for children with allergy by:

- preventing acute and chronic allergic symptoms.
- halting the progress of complications if present and where possible.
- reversing previous psychological damage and disability when possible.
- recognising complications early and managing them optimally, particularly those not amenable to first line therapy.
- delivering safe and effective allergen immunotherapy.
- developing approaches to management, based on individual needs, for the life-long management of allergic disease, including self-management/home therapy when possible. Consistent, evidence-based and equitable decision-making about use of off license therapies in refractory or relapsing disease

2.2 Service description/care pathway: Paediatric Allergy

- The provider shall deliver a diagnostic package for the investigation of suspected allergic diseases, including: initial consultation and follow-up in a dedicated paediatric allergy clinic; specialised allergy homes; regular outpatient consultations; and ongoing monitoring including tests.
- The provider shall ensure that all centres and home care programmes should be working towards accreditation.
- The provider shall ensure the management of those allergies requiring other tests, food/drug provocation challenges, and respiratory / ENT / gastro-intestinal investigation and desensitisation where indicated. Specifically this will require:
  - diagnostic services for the management of complex and rare allergies.
The provider shall ensure that the following procedures are provided by Specialist Allergy Centres as appropriate:

- Complex skin testing using drugs/food/venom/latex (skin prick/intradermal).
- Component-resolved and other in-vitro specialist diagnostic testing.
- Allergen challenges – e.g. food, drug or other allergen challenges for high-risk patients where necessary.
- Radiology - access to appropriate paediatric radiology services
- Specialised Immunology Laboratory services with Clinical Pathology Accreditation (CPA) or equivalent for allergy testing.
- Methods to investigate allergen-induced asthma including: computerised spirometry, exhaled nitric oxide (NO) where necessary.
- Access to bronchoscopy services for investigation of resistant asthma.
- Access to endoscopy services for patients with eosinophilic enteropathies.
- Access to diagnostics for rare and emerging allergic diseases through European/USA laboratories.

The provider shall provide hospital-based outpatient and day-care with access to in-patient facilities. This will comprise:

- Regular dedicated allergy outpatient clinics for assessment and follow-up.
- Adequate clinical space in relation to the number of patients being treated.
- Adequate space for patients receiving infusions or training.
- A safe working environment for staff.
- Access to an appropriately staffed day-case facility that can perform food and drug provocation challenges, and provide immunotherapy and biologic infusions. This service should be supported by clear guidelines, protocols, and pathways for patient care.

The provider shall provide support to other clinical specialties for complications of severe and multi-system allergic diseases including:

- ENT, respiratory medicine, gastroenterology, ophthalmology, dermatology, immunology & infectious diseases, haematology/ oncology, paediatrics, clinical genetics, rheumatology.

The provider shall have appropriate pharmacy facilities including:

- Appropriate storage and dispensing facilities for drugs and immunotherapeutic products.
- Pharmacy storage facilities for immunological therapies and good documentation of dispensing to individual patients.
The provider shall provide patient self-care as an option in the patient’s management based on the patients’ wishes, abilities and circumstances, to include:

- Provision of information about when to seek advice for new or severe symptoms suggestive of poor control, new sensitivities or increased risk of severe reactions.
- Competency testing (for example in use of adrenaline auto-injector devices).
- Training for the administration of rescue medication at home. The self-care options offered will be based on the patient’s and their family’s wishes, abilities and circumstances. The self-care training and monitoring package will form part of the commissioned service.
- Provision of home therapy as a package of care on a named patient basis including, where necessary, nursing supervision, deliveries of consumables to patients/new treatments (e.g. monoclonal antibodies or cytokines) on a named patient basis, where there is a suitable evidence base. This includes day case attendance, nursing supervision, the drug, pumps for subcutaneous or intravenous use, monitoring by biochemical tests, specialised immunopathological tests and medical follow-up.

The provider shall ensure that the Paediatric Specialist Allergy services should be provided by a multi-disciplinary team that includes:

- At least two Consultant Paediatric Allergists with experience in the management of patients with complex/specialised allergy and who maintain up-to-date Allergy continuing professional development (CPD) in their area of practice.
- Physicians, dieticians and nurses trained in Paediatric Allergy or who have had long specialist experience in the practice of paediatrics and who maintain up-to-date Allergy CPD.
- There should be no single-handed practice unless fully supported by network governance structures and regular multi-disciplinary team (MDT)/network meetings.

The provider shall also ensure that:

- Allergen immunotherapy/desensitisation therapy should be provided in conjunction with specialist nurses in an established allergy centre.
  - There are mechanisms to ensure there is documented consent before undertaking drug or food provocation, and there is documented consent and risk assessment before initiating treatment such as immunotherapy or biologics.
  - The provider shall provide transition services:
    - for children with complex allergy before referral to adult services based on
the framework recommended by the Department of Health.  

- Transfer arrangements and preferences should be discussed with the child and their family up to 12 months in advance. Shared protocols between child and adult services should be established.

- The provider shall maintain the following links:
  - Secondary care links
  - Depending on the nature of the allergic disease, services are involved in shared care in relation to general medical needs, delivery of drugs.
  - Secondary providers will be integrated with well-defined service delivery specifications and referral pathways linked within the network.
  - Availability in core hours (e.g. 0900-1800) Monday-Friday for telephone advice for non-urgent cases, 24-hour service for emergency support;
  - Timely review/assessment of non-urgent cases in clinic setting (for immediate care see paediatric intensive care unit (PICU) service specification)
  - Development of guidelines and policies to standardise care across local/regional network
  - Primary care links
  - Care plans of allergy patients are shared with primary care.
  - Home therapy and management is arranged in liaison with CCGs.
  - Clinic letters are sent to GPs and other specialties involved in a patient’s care.
  - Private sector and third sector links
  - The service shall maintain a strong liaison with patient groups involved in allergic disorders to enable further community support and continuity of care.

Referral processes and sources

- Referrals can be made from both primary and secondary care as follows:
- Due to the complex nature of severe allergies, tertiary referrals come from secondary care centres (general paediatricians) or other tertiary or specialist paediatricians (particularly dermatology, respiratory, ENT, gastroenterology and accident and emergency).
- Primary Care Physicians (Tier 1) shall refer patients directly to the service when standard approaches to management fail, or the patient meets specialist referral criteria, though these cases will require screening by the centre to ensure the referral requires specialist input or whether it can be managed through CCG-commissioned local or regional allergy services which may be provided for the
local population by the same facility. A care pathway with referral guidance should be developed.

**Equity of access to services**

Patients with rarer diseases requiring referral to a national specialist centre or centres should have equitable access and distance to travel wherever possible, taking account of geographical issues.

**Location(s) of Service Delivery**

- At present, there are approximately 19 paediatric centres in the UK (7 of which are staffed by paediatric immunology specialists and 12 by paediatric allergy specialists and some of which are co-located with the adult service). ([Royal Colleges of Physicians Report 2010](http://www.nelm.nhs.uk/en/NeLM-Area/News/2010---June/24/Allergy-services-still-not-meeting-the-unmet-need-Joint-report-of-RCP-and-RCPath-Working-Party-June-2010/)).

**Days/hours of operation**

- The provider shall ensure that services are available during office hours.
- The provider shall ensure that there is a written agreed patient pathway for dealing with out of hours emergencies and a system for giving out-of-hours advice, particularly in relation to advice on matters such as anaphylaxis, drug, latex and anaesthetic allergy.

**Response time & detail and prioritisation**

- As per national waiting time targets.

**Service user/ carer information**

- The provider shall ensure that centres will provide (in collaboration with patient organisations where they exist):
  - Written disease-specific information leaflets.
  - Periodic educational events for patients.
  - Periodic educational events for GPs.
  - Information to patients and staff about patient support organisations.
- The provider shall ensure that Specialist Centre Staff support patient groups with membership of Medical Advisory panels.
- The provider shall ensure that where possible patient information should be standardised nationally or across networks. National guidelines and patient information in many areas of allergy have already been developed by BSACI and
the Anaphylaxis Campaign to harmonise care.

- Shared protocols and guidelines have already been developed in professional networks and in some multi-centre regional groups to harmonise care and should be used to underpin policy development with patient group involvement. Patient organisations have a large resource of information sheets which could be adapted and adopted in collaboration.

- General Paediatric care

  When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children’s Services (attached as Annex 1 to this specification)

2.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

*Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

Specifically, this service is for children and young people up to 19 years of age with allergic disease requiring specialised intervention and management, as outlined within this specification.

2.4 Any Acceptance and exclusion Criteria:

Inclusion Criteria

Individuals requiring specialist allergy services would be characterised by:

- Increased risk of death because of severity of the allergy (anaphylaxis, angioedema, drug allergy, brittle asthma).
- Persisting poor quality of life despite routine therapies with restrictions to daily activities at home, school or work (severe eczema / atopic dermatitis) with a major allergic component such as asthma, hay fever (allergic rhinoconjunctivitis) and chronic urticaria.
- Requirement for safe allergen immunotherapy: Immunotherapy has been reintroduced into the UK with tighter controls and recommendations and should only be performed by experienced health care professionals in specialised centres with direct access to resuscitation facilities (CSM Update – desensitising

- Rare diseases leading to allergic symptoms requiring complex investigations and therapies (mastocytosis, food protein induced enteropathy syndrome (FPIES), eosinophilic enteropathies).
- Diseases with allergic symptoms but where the cause is unclear and specialist input is required to make a specific diagnosis, identify triggers, optimise management and prevent further recurrences.

The provider shall ensure that management of the following conditions is provided by specialist allergy services:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACUTE ALLERGY</strong></td>
<td></td>
</tr>
<tr>
<td>Complex Anaphylaxis</td>
<td>Multiple or severe allergies (Clinical Guidance from NICE: guidance.nice.org.uk/cg134) recommends a specialist allergy referral for all presentations to A&amp;E with suspected anaphylaxis and likewise for children or young people with multiple or severe food allergy (both IgE mediated and non-IgE mediated) (Food Allergy (guidance.nice.org.uk/cg116) comorbid asthma, growth failure or nutritional compromise or unclear cause.</td>
</tr>
<tr>
<td>Drug allergy</td>
<td>All (BSACI Guidelines 2009 &amp; 2010 (including antibiotic, muscle relaxants, non steroidal anti-inflammatory drugs (NSAIDs), general anaesthetics and local anaesthetics)</td>
</tr>
<tr>
<td>Bee and wasp venom allergy (NICE 2912)</td>
<td>All (The Technology appraisal from NICE published in 2012 (<a href="http://www.nice.org.uk/guidance/TA246">www.nice.org.uk/guidance/TA246</a>)</td>
</tr>
<tr>
<td>Vaccine allergy</td>
<td>All (BSACI Guidelines 2009)</td>
</tr>
<tr>
<td>Latex allergy</td>
<td>If signs of anaphylaxis (BSACI position paper 2004)</td>
</tr>
<tr>
<td><strong>SEVERE ATOPIC DISEASE</strong></td>
<td></td>
</tr>
<tr>
<td>Severe atopic dermatitis</td>
<td>Unresponsive to conventional therapy with allergic triggers (NICE CG57)</td>
</tr>
<tr>
<td>Severe allergic asthma</td>
<td>Unresponsive to conventional therapy including aspirin sensitive and severe</td>
</tr>
</tbody>
</table>
### Exclusion Criteria
- Patients with less severe allergy who do not require specialist review
- Symptoms such as chronic fatigue syndrome without evidence of allergy

### Exit Criteria
Patients will leave the service when:
- Their allergic disease is controlled and suitable for self-management or management by non-specialised allergy services or primary care physicians.
- Their allergen immunotherapy course is completed and no further follow-up is indicated.
- Transition to specialist adult services

### 2.5 Interdependencies with other services
The provider shall have access to related services required for the optimal care of patients with allergic conditions. This will include:

- **Co-located services** – The provider shall deliver close input from specialist paediatric allergy dietetic services - essential for the management of food allergy. The provider shall ensure access to social workers, play specialists, psychologists and respiratory physiotherapy/speech therapy for selected patients to complete the package of holistic care required for complex allergy patients.

- **Interdependent services** – Paediatric allergy specialists must liaise closely with colleagues in a range of specialties, including respiratory medicine, ENT surgery, dermatology, haematology, oncology, infectious diseases, gastroenterology and ophthalmology and behavioural medicine. Radiology as well as close support from a high-quality, accredited diagnostic immunology laboratory providing a range of routine and specialist allergy assays, are required.
- **Access to in-patient beds** under direct supervision of the paediatric allergy service or admission pathways should be established with individualised care plans where necessary.

### 3. Applicable Service Standards

#### 3.1 Applicable national standards

The provider shall ensure that allergic disorders are managed according to best practice guidelines and position statements as defined by:

- RCPCH (Royal College of Paediatrics and Child Health) National Allergy Care Pathways, BSACI, NICE guidelines and others.
- Collaboration with other expert centres at national and international levels.
- Where appropriate, all clinic letters should be copied to patients.
- The provider shall provide a means of collating workload data on inpatient and home therapy workload linked to ICD10 coding including population of a national or local specialist workload monitoring tool (for example, a web-based database).
- The provider shall provide data for the national/network dashboard for recording outcomes, process or proxy measures.
- The provider shall act as an ambassador for the service and support patient and professional organisations improving support and care for conditions under their remit.
- The provider shall develop regional care pathways or comply with national care pathways and referral criteria.
- The provider shall ensure that specialist centre staff support peer accreditation processes by acting as inspectors.
- The provider shall have active participation in training and development of the next generation of specialist allergists to ensure continuity of future service provision.
- The provider shall ensure that Paediatric Allergy Specialists maintain expertise by fulfilling the CPD requirements of the Royal College of Paediatrics and Child Health or equivalent undertaking team based practice.
- The provider will ensure that the centre has an active role in audit.
- The provider will ensure that NIHR approved clinical research can be delivered within its service.
The provider will ensure that:


- Each network develops a regional patient pathway for access to specialist allergy services which ensures that only patients with appropriate allergic disease or associated complications are referred.

4. Key Service Outcomes

Expected Outcomes - Paediatric Specialist Allergy

Patient related outcomes

The provider shall demonstrate the efficacy of desensitisation/immunotherapy by monitoring for (for example):

- Significant improvement in Quality of Life (using validated tools such as PADQLQ, HRQOL and EQ5D measures).
- Improvement in symptom scores.
- Reduction in time away from school and work.
- Reduction in medication use in patients (e.g. in severe hay fever undergoing pollen subcutaneous and sublingual immunotherapy and severe insect venom allergy).
- Successful tolerance to future allergen exposure.

- The provider shall demonstrate the efficacy of the service in excluding drug allergy e.g. to penicillin allowing use of beta-lactam antibiotics for severe chronic conditions such as bronchiectasis and the outcome of desensitisation to drugs such as penicillin when other antibiotics are not effective.
- The provider shall demonstrate the efficacy of exclusion of food allergy in children on previously restricted diets resulting in fewer allergic reactions, healthcare service visits, and by discharging patients with appropriate self-management plans where indicated.
- The provider shall monitor the % patients on omalizumab for asthma reviewed by allergist before commencing therapy and proportion continuing on therapy after 16 week assessment as per NICE guidance (where relevant).
The provider shall demonstrate an improvement in symptom score, medication use and emergency attendances of patients on omalizumab for asthma by assessing these parameters before commencing therapy and after 16 weeks as per NICE guidance and at regular intervals if the therapy continues.

The provider shall demonstrate an improvement in symptom score, medication use and emergency attendances of patients with severe allergic eczema where allergen avoidance and eradication is instigated (e.g. food avoidance diets, reduction in bacterial load on skin using antiseptics).

The provider shall ensure an improvement in patient confidence and effectiveness in the management of their allergies through a public engagement strategy for the service to ensure that patient views of the service are measured (where necessary in collaboration with patient organisations). The provider shall undertake PREM (Patient Related Experience Measures) surveys for patients and carers on an annual basis and achieve >75% satisfaction and act on any deficiencies identified.

The provider shall ensure that there are defined arrangements for maintaining expertise in the management of rare diseases where there are less than 5 patients per network. This may be achieved by ensuring that there are nominated individuals with expertise across the range of rare disorders per network and through regular educational meetings and through appropriate protocols or guidance.

**Clinical governance**

- The provider shall ensure that they actively participate in regional network clinical meetings, to review and compare practice and share expertise in these rare conditions. A minimum attendance requirement at 50% of network meetings (from a minimum of three meeting per annum per network) will be necessary.

- The provider shall ensure mandatory participation in regional and national allergy audits.

- The provider shall ensure that all services in a network share and compare their dashboard performances in a process of continuous quality improvement. The dashboard elements to be defined by the Immunology and Allergy CRG but to include:
  - Engagement and communication with GPs.
  - Involvement of patients in their care.

**Coding and Activity monitoring:**

- The provider shall develop an approach to improving the recording and collection of routine activity and performance data.

- The provider shall ensure that out-patient as well as in-patient activity for diagnosed patients should be measured using hospital systems to detect patients with the relevant ICD (where one exists).

- There should be a mechanism to collect data on activity related to patients...
treated at home.

- The provider shall deliver continual CPD and networking to keep abreast of new developments in allergy diagnostics and therapy as there are regular developments in the specialty.
- The provider shall deliver a means for populating national and international disease registries.

**Accreditation:**

- All centres should participate in any UK accreditation scheme that is developed and in the interim be encouraged to engage with any European accreditation schemes e.g. GALEN.
- All patients with a complex or severe allergic disease should be monitored regularly for development of disease progression and complications.
ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

- This specification annex applies to all children’s services and outlines generic standards and outcomes that would fundamental to all services.

- The generic aspects of care:
  The Care of Children in Hospital (HSC 1998/238) requires that:
  
  o Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
  o Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimise complications and mortality.
  o Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
  o Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
  o Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

- All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

- The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

- Services should therefore be organised and delivered through “integrated pathways of care" (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004)
Interdependencies with other services

All services will comply with Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical InterDependencies – DH

- Imaging
  
  o All services will be supported by a three-tier imaging network (‘Delivering quality imaging services for children’ Department of Health 13732 March 2010). Within the network:
    
    ▪ it will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
    ▪ robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements
    ▪ robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
    ▪ common standards, protocols and governance procedures will exist throughout
    ▪ All radiologists, and radiographers will have appropriate training, supervision and access to CPD
    ▪ All equipment will be optimised for paediatric use and use specific paediatric software

- Specialist Paediatric Anaesthesia
  
  o Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training. All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training and should maintain the competencies so acquired. These competencies include the care of very young/ premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).
  
  o As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.
  
  o Specialist acute pain services for babies and children are organised within
existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neurosciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

- **References**
  1. GPAS Paediatric anaesthetic services. RCoA 2010 [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
  2. CCT in Anaesthesia 2010
  3. CPD matrix level 3

- **Specialised Child and Adolescent Mental Health Services (CAMHS)**

  The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

  Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following

  - Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply ([http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx](http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx))
  - Staffing profiles and training - essential QNIC standards should apply.
  - The child/young person’s family are allowed to visit at any time of day taking account of the child/young person’s need to participate in therapeutic activities and education as well as any safeguarding concerns.
  - Children and young people are offered appropriate education from the point of admission.
  - Parents/carers are involved in the child/young person’s care except where this is not in the best interests of the child/young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
  - Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in
the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal Colleges

- Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)
  - There must be at least two Registered Children’s Nurses (RCNs) on duty 24 hours a day in all hospital children’s departments and wards.
  - There must be an Registered Children’s Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of two RCNs in total).
- Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.
- All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children’s Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).
- Each hospital which admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002).”Facing the Future” Standards, Royal College of Paediatrics and Child Health.
- Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).
- Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).
Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- ensuring that people who use services are aware of how to raise concerns of abuse.
- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- having effective means of receiving and acting upon feedback from people who use services and any other person.
- taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
  - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
  - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
  - reporting the alleged abuse to the appropriate authority
  - reviewing the person’s plan of care to ensure that they are properly supported following the alleged abuse incident.
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- taking into account relevant guidance set out in the Care Quality Commission’s Schedule of Applicable Publications
- ensuring that those working with children must wait for a full Criminal Records
Bureau (CRB) disclosure before starting work.
  - Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010
  - All children and young people who use services must be
    - fully informed about their care, treatment and support.
    - able to take part in decision making to the fullest extent that is possible.
    - asked if they agree to their parents or guardians being involved in decisions they need to make.

(Outcome 4I Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

Key Service Outcomes

- Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

- Poorly planned transition from young people’s to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:
  - all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

- The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:
  - A16.1 Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
  - A16.3 Toys and/or books suitable to the child’s age are provided.
  - A16.8 There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult
Patients; the segregated areas contain all necessary equipment for the care of children.

A16.9 A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.

A16.10 The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this.

A16.13 When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.

A16.14 Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.

A18.10 There are written procedures for the assessment of pain in children and the provision of appropriate control.

- All hospital settings should meet the *Standards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).

- There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:
  
  - a choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users’ needs;
  - food and hydration that meet any reasonable requirements arising from a service user’s religious or cultural background;
  - support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs;
  - for the purposes of this regulation, “food and hydration” includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
  - that providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

- All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

- All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate.

- All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). For children, these should include specific
arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensure that staff handling medicines have the competency and skills needed for children and young people’s medicines management
- ensure that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

- Many children with long term illnesses have a learning or physical disability. Providers should ensure that:
  - they are supported to have a health action plan
  - facilities meet the appropriate requirements of the Disability Discrimination Act 1995
  - they meet the standards set out in *Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children’s to adult health services*. Department of Health Publications, 2006, London