Service Specification
No. E10a 4

Service Complex Gynaecology Services – Severe Endometriosis

Commissioner Lead Jacquie Kemp

Provider Lead

Period 12 Months

Date of Review

1. Population Needs

1.1 National/local context and evidence base

- Severe endometriosis is defined as either deeply infiltrating endometriosis or rectovaginal endometriosis. Deeply infiltrating endometriosis exists where the disease invades at least 5mm below the tissue surface and can occur in a variety of sites, such as; bladder, pelvic sidewalls, ovaries, pelvic brim, bowel surface and diaphragm. Rectovaginal endometriosis is endometriosis which involves the rectovaginal septum area (rectovaginal septum, vagina, uterosacral ligaments, rectum). This service specification concerns only severe endometriosis as is given in this definition and which has an annual incidence of around 5,000 new cases per year.

- Endometriosis is a disease in which deposits of hormone responsive abnormal tissue develop outside of the womb (uterus). These deposits usually form on the peritoneum (the shiny lining tissue) of the pelvis, close to the uterus, fallopian tubes or ovaries. The endometriotic deposits respond to the cyclical female hormones by increasing in size and bleeding each month. Bleeding on the
peritoneal surface is abnormal and causes scarring of the peritoneum and adherence to surrounding structures. In severe disease the fallopian tubes, ovaries and bowel all stick to the back of the uterus tethering the pelvic organs together causing chronic severe pain. The endometriotic deposits can also grow through tissue layers like a tumour, which can result in endometriosis growing into the bowel, bladder or ureter (the tubes carrying urine from the kidney to the bladder). In addition to pain this causes abnormal function of the affected organ.

- The cause of the disease remains unknown but many theories exist. Treatment involves medical methods to suppress the female hormones or surgical treatment to destroy or remove the disease or the affected pelvic organs. Medical treatment is only of benefit in mild cases. Surgical excision is the recommended treatment in moderate or severe disease (ref 1). Removing endometriosis from the pelvic tissues requires considerable surgical skill and expertise, as it is often close to vital structures like the ureter, bladder or bowel. It is best performed using laparoscopic surgery as this enables excellent visualisation of the deep pelvis which facilitates the very delicate surgery required. In contrast open surgery often results in incomplete excision of the disease. Incomplete excision will result in inadequate treatment, with failure to resolve symptoms and makes repeat surgery even more difficult.

- National criteria (British Society of Gynaecological Endoscopy [BSGE]; www.bsge.org.uk) now exist on the standards of service and expertise required to undertake surgical excision of advanced endometriosis and this is driving the establishment of endometriosis centres where such work can be undertaken by specialist teams.

- Using UK population statistics 2005/6, there were 10.5million women between the ages of 15 and 45 years. The prevalence of endometriosis is 3% - 10% (ref’s 2-7) of this group, so the disease burden ranges from 0.3 to 1 million cases. The prevalence of severe endometriosis ranges from 5-30% of affected patients, giving a cohort of 15,000 to 300,000 women within this 30-year age span. This amounts to 500 to 10,000 new cases per year. A reasonable conservative estimate is therefore 5000 women with severe disease in the UK requiring treatment each year.

- Currently there are 13 accredited BSGE Endometriosis Centres in England offering integrated endometriosis care catering for women with severe disease, and 15 provisional BSGE centres trying to develop the same service standards. Optimal levels would be to have 30 centres in England delivering services for severe endometriosis who are BSGE Accredited Endometriosis Centres or who are Centres that can meet the standards set out in this specification. Each centre is expected to treat approximately 100 cases of severe endometriosis a year.
References

2. Scope

2.1 Aims and objectives of service

- The aim of the service is to provide patient centred specialist care for women with severe endometriosis, which improves their quality of life.
- The service will achieve this aim by:
  - Clearly defining and explaining the extent of the disease
  - Providing appropriate counselling and psychological support
  - Providing a nurse specialist who will interface between patient and specialist team
  - Individualising care based on the patient’s specific symptom complex and preferences
  - Taking account of the patient’s fertility needs
  - Providing high quality treatment and care to relieve symptoms of endometriosis
  - Assessing quality of life before, and at intervals after, treatment
The aim of surgical treatment is to remove endometriosis and relieve symptoms of the disease, whilst incurring the lowest possible morbidity.

The service will achieve this aim by:
- Providing complex laparoscopic surgical excision of all endometriosis irrespective of site
- Operating jointly, as required, with a second gynaecologist, a named colorectal surgeon and/or urologist
- Retaining pelvic structures unless there is an objective reason to remove them
- Maintaining a detailed surgical database to include detail of surgery and any complications
- Working with pain management specialists
- Keeping the use of open surgery to the minimum

2.2 Service description/care pathway

- Summary of the service provided is explained in the following steps:
  - Referral from primary or secondary care (including detailed clinical information, investigation results and laparoscopic images)
  - Initial outpatient assessment in specialist endometriosis clinic by endometriosis nurse, information, counselling and explanation will be given. Quality of life questionnaire will be completed. Renal and pelvic ultrasound performed if required. Other investigations organised as needed, which may include diagnostic laparoscopy.
  - Review appointment with consultant gynaecologist in endometriosis clinic and treatment decision made and pre-operative preparation organised.
  - Multidisciplinary discussion of cases that require combined surgeon input.
  - Elective surgical inpatient spell
  - Elective outpatient follow-up at three months by consultant and six months by nurse, with quality of life assessments at 6, 12 and 24 months post surgery.
  - Discharge to secondary, or primary, care after six months follow up
  - Management of any complications or recurrence as required
The specialised service in more detail:

- Laparoscopic surgery for severe or recto-vaginal endometriosis is considered to be a specialised service due to its complexity and high risk of morbidity. The British Society for Gynaecological Endoscopy has established criteria (see reference in section 6) for centres carrying out such work and accredits departments that reach its standards. The criteria include:
  o working in a multi-disciplinary team with a named colorectal surgeon and nurse specialist
  o holding a dedicated endometriosis clinic
  o operating on a minimum number of patients per year
  o submitting operative and quality of life outcome data to a national database

- These criteria are designed to ensure quality care to women with complex surgical needs to minimise the risk of surgical complication and maximise the opportunity to deliver the best outcomes. Effective experienced care such as this will reduce the cost to the taxpayer by reducing the current experience of multiple less adequate procedures, long-term medication, multiple hospital investigations and recurrent admissions.

- **Referral**
  Patients with known severe disease, which has not been adequately treated or has recurred, are likely to be referred by primary care clinicians. Gynaecologists in secondary care who identify severe endometriosis or rectovaginal disease at laparoscopy or open surgery will refer patients from secondary care to an Endometriosis centre. Laparoscopic images of suitable quality and format will be included with the referral wherever they are available as this will prevent the need for repeat laparoscopic pelvic survey after referral.

- **Primary outpatient assessment**
  Patients will be seen by the endometriosis specialist nurse at the first visit, and a full review of symptoms including completion of a quality of life questionnaire will be completed. Where investigations are incomplete or additional ones are needed these can be performed or booked. Ideally the nurse should be able to complete (or organise) a pelvic and renal ultrasound if not supplied with the referral. Detailed literature about surgical treatment will be given to the patient along with a discussion about the likely next step. If a diagnostic laparoscopy is required this will be organised direct by the nurse. Such a primary assessment will ensure that patients are fully informed and investigated before they attend the consultant clinic. This will optimise use of the consultant clinic. In some cases (long travel distance or clear understanding of expected management) patients may be seen in the consultant clinic at the first attendance. Careful scrutiny of the referrals by the endometriosis specialist nurse will optimise this arrangement.
Consultant specialist assessment

The patient will attend the endometriosis clinic for review by the Gynaecologist, who will carry out any examination needed, discuss the clinical findings and investigation results and explain treatment options. If the patient wishes to proceed with laparoscopic surgical excision of the endometriosis, this will then be booked and signed consent taken in the clinic. Any preoperative preparation, such as gonadotrophin receptor hormone agonist (GNRH; injection to suppress endometriosis) or bowel preparation will be arranged from the clinic visit.

Patients who choose medical treatment, which can be delivered in secondary, or primary, care will be referred back to those providers. Some patients may choose no treatment and can be referred back to primary care.

Multidisciplinary Team (MDT) discussion

Severe endometriosis or rectovaginal endometriosis may require surgery on the retroperitoneal structures, ureters, bladder or bowel, or a combination of all. In such cases it will be necessary to discuss the case and plan surgery with colorectal surgeons and urologists as a minimum. In units with suitably effective radiology (MRI or endo-cavity ultrasound) this may also include a Radiologist. Additional members of the MDT could include pain management specialists and infertility specialists as required.

Inpatient surgical spell

Admission can be arranged according to local protocols but is usually on the day of surgery. Some patients will require surgery in two stages 12 weeks apart. The first stage is to drain adherent endomeriomas and strip out the cyst lining, followed by down regulation with a GNRH injection lasting 12 weeks. The second stage operation will remove all the adhesions and excise the endometriosis. The specific complex Laparoscopic surgical procedures which will be undertaken within an Endometriosis Centre include:

- First stage drainage and stripping of endometriomas and staging of endometriosis
- Laparoscopic excision of recto-vaginal endometriosis
- Laparoscopic excision of recto-vaginal endometriosis + skinning of rectal surface
- Laparoscopic excision of recto-vaginal endometriosis + disc resection of bowel
- Laparoscopic excision of recto-vaginal endometriosis + low anterior resection
- Laparoscopic excision of recto-vaginal endometriosis + low anterior resection + ileostomy
- Laparoscopic excision of recto-vaginal endometriosis + low anterior resection + colostomy
- Laparoscopic excision of ureteric endometriosis +/- Ureteric re-implantation
o laparoscopic partial bladder cystectomy for endometriosis
o laparoscopic excision of diaphragmatic endometriosis
o laparoscopic excision of other bowel endometriosis
o laparoscopic excision of pelvic sidewall endometriosis

• A more detailed tariff code is required to ensure there is appropriate costing for this surgery as current iterations are not sufficiently specific.

• **Outpatient review and discharge from the service**
Patients will be followed up and examined at three months post surgery in the specialist endometriosis clinic. They will have contact details of the endometriosis specialist nurse and make contact if problems develop. At six months the endometriosis nurse will review the patient and obtain a completed quality of life questionnaire. The same questionnaire will be completed at 12 and 24 months post surgery and mechanisms (telephone or website submission) for this need to be in place. After the six month review the patient is discharged back to primary care. Some patients will have ongoing symptoms and will require referral to other specialists (Urologists, colorectal surgeons and pain management specialists), this may be within the endometriosis centre or back in local secondary care dependent on circumstances. Patients with complications will require individualised follow up.

• **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 women who fulfil the severe endometriosis definition as outlined within this specification section 1.5.
2.4 Any acceptance and exclusion criteria

Acceptance criteria

- The service will accept referrals from GPs and secondary care clinicians in Gynaecology and Colorectal surgery. The service will also accept referrals from other providers, particularly when the referring service is not accredited to undertake the clinical role the service requires.

- The service will accept referrals for patients who meet one of the following criteria:
  - women with a diagnosis of severe endometriosis
  - non-severe endometriosis refractory to treatment

- Referrals into the service will be assessed by a named consultant.

- Eligible women will be referred using a defined referral system that can be audited for waiting times.

- A discharge plan will be prepared explaining support and facilities required at home.

- Appropriate referrals to specialist colleagues will be documented and GP informed of any transfer of care.

Exclusions

- Patients that have pelvic pain but do not have endometriosis.
- Non-severe endometriosis that is responding to treatment.
- Patients with gynaecological cancer; their care is covered in the cancer services specifications.

2.5 Interdependencies with other services

- Co-located services
  Secondary care facilities to deal with the inpatient care of patients undergoing complex laparoscopy and laparotomy. Suitable laparoscopic theatre equipment to undertake complex laparoscopic surgery (high definition camera stacks with multiple monitors; preferably integrated laparoscopic theatres, suitable laparoscopic instrumentation for tissue sealing and dissection). Recovery
facilities and ability to care for critically unwell patients (Intensive therapy Unit). Colorectal surgeons available to attend surgery or operate with the gynaecologist as required. Urologist available to attend surgery or operate with the Gynaecologist as required.

- **Interdependent services**
  Interdependent services include chronic pain management service and Clinical Imaging.

- **Related services**
  Patients with persisting pain or other symptoms may require ongoing investigation for other causes. These can be arranged by the secondary care referrer or GP as appropriate.

3. **Applicable Service Standards**

3.1 **Applicable national standards e.g. NICE, Royal College**

- BSGE (www.bsge.org.uk) ‘Criteria for a BSGE recognised centre for laparoscopic treatment of women with recto-vaginal endometriosis’

4. **Key Service Outcomes**

- Eligible women will be referred using a defined referral system that can be audited for waiting times.
- There will be an agreed planned and mapped pathway of care for women with severe endometriosis (see appendix).
The provider will be expected to use evidence based approaches and to demonstrate efficiencies whenever possible.

Appropriate referrals to specialist colleagues will be documented and GP informed of any transfer of care.

A discharge plan will be prepared explaining support and facilities required at home.

5. Location of Provider Premises

The current list of accredited BSGE Endometriosis Centres and Provisional Endometriosis Centres can be found at [www.bsge.org.uk](http://www.bsge.org.uk)
## Service Pathway – Complex Gynaecology Management of Severe Endometriosis

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<tr>
<th>Referral Pathway type/source</th>
<th>Service Delivery</th>
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<td>Primary</td>
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### Outpatient Appointment (Detail? Assessment, MDT, Single Clinician etc)
- Specialist Endometriosis clinic in BSGE accredited Endometriosis Centre: Consultant Gynaecologists and Endometriosis Specialist Nurse (primary appointment may be by Specialist Nurse, dependent on local pathway)
- Full review of referral information and laparoscopic images/clinical assessment/MDT discussion
- Supply of detailed patient information sheets, contact details of Endo Nurse and expected treatment plan. Collect primary Quality of Life data.

### Investigations/procedures needed
- Transvaginal Ultrasound/Renal Ultrasound/MRI/Other rectal ultrasound
- Repeat Laparoscopy dependent on referral detail and time from primary diagnosis

### Treatment Strategy (please provide detail)
- **Inpatient:** Joint Laparoscopic surgery by Specialist Gynaecologist and Colorectal Surgeon.
  - Two Stage: 1. Primary drainage and stripping of enometriomas, GNRH down regulation. 2. Then bowel prep and excisional surgery (+/- hysterectomy)
  - Single Stage: GNRH down regulation, bowel prep followed by excisional surgery (+/- hysterectomy)
- **Outpatient:** Medical management
  - Expectant management
  - Management with hormonal treatment
  - Specialist pain management Service colorectal or urological review

### Follow up (detail)
- Endometriosis Specialist Consultant clinic or Endometriosis Specialist Nurse Clinic
  - Primary follow up with clinical examination
  - Secondary follow up with Quality of Life data

### Further investigations/treatments required (detail)
- Continuing symptoms or new development may require repeat investigations
- Patient surgical findings, procedure, complications and all Quality of Life data to be entered on database (e.g. BSGE Endo database) and audited. To include two year follow up Quality of Life data.

### Second treatment episode if needed (detail)
- Recurrence of symptoms requiring repeat excisional surgery, adhesiolysis or hysterectomy
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 minimize 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 Inter-Dependencies – Department of Health
• Imaging
  o All services will be supported by a 3 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 the network.
    ▪ All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development
    ▪ 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 neuro-sciences 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 persons 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 persons 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 College

- 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 2RCNs 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 who 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:
o Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.

o Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.

o Ensuring that people who use services are aware of how to raise concerns of abuse.

o Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.

o Having effective means of receiving and acting upon feedback from people who use services and any other person.

o 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.

o 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.

o 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.

o Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.

o Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.

o Taking into account relevant guidance set out in the Care Quality Commission’s Schedule of Applicable Publications

o Ensuring that those working with children must wait for a full CRB disclosure before starting work.

o 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
  o Fully informed of their care, treatment and support.
  o Able to take part in decision making to the fullest extent that is possible.
  o Asked if they agree for their parents or guardians to be 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:
  o 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:
  o 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.
  o A16.3 Toys and/or books suitable to the child’s age are provided.
  o 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
  o Patients; the segregated areas contain all necessary equipment for the
    care of children.
  o 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;
  - 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.
o 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:
  
  o They are supported to have a health action plan
  o Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
  o 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, 2006, London