E10/S/a

NHS STANDARD CONTRACT
FOR COMPLEX GYNAECOLOGY- SEVERE ENDOMETRIOSIS

SCHEDULE 2- THE SERVICES A. SERVICE SPECIFICATIONS

Service Specification No.	E10/S/a
Service	Complex Gynaecology – Severe Endometriosis
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Severe endometriosis for the purpose of this specification is defined as either deeply infiltrating endometriosis or recto-vaginal 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. Recto-vaginal endometriosis is endometriosis which involves the recto-vaginal septum area (recto-vaginal septum, vagina, utero-sacral ligaments, rectum). There are many classification systems for endometriosis but none are universally accepted. The definition used here would accord with grade 3 and 4 disease used in the revised American fertility Score. (1). Whilst minor and moderate endometriosis can be managed in all gynaecology departments, this service specification concerns only severe endometriosis, which has an annual incidence of around 5,000 new cases in the UK 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 (2). 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 with two skilled laparoscopic surgeons working together, as this enables excellent visualisation of the deep pelvis which facilitates the very delicate surgery required and joint expertise enables joint decision making during critical steps of the operation. 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 workload 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 multidisciplinary teams.

Using UK population statistics 2005/6, there were 10.5 million women between the ages of 15 and 45 years. The prevalence of endometriosis is 3% - 10% (3-8) 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 or 3,000 annually in England alone.

Currently there are 17 accredited British Society of Gynaecological Endoscopy (BSGE) endometriosis centres in England offering integrated endometriosis care catering for women with severe disease, and 20 provisional BSGE centres aspiring to develop the same service standards. Optimal levels would be to have 30 centres in England (or 50 for the UK) delivering services for severe endometriosis who are BSGE Accredited Endometriosis Centres or which 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.

The overarching principle for surgical excision of severe endometriosis in a specialist centre is that all endometriosis is to be removed, irrespective of site. This accords with national guidance (2) and is considered by current experts to be the most effective treatment. This principle is driving a more standardised surgical approach to these complex cases. There still remains some variation in practice with regard to selection of patients who need a segmental rectal resection and this reflects the clinical controversy in this aspect of the surgery. However recent high quality reviews have concluded that its use should be limited to

selected cases and that a less aggressive approach to removal of the disease from the rectum carries less morbidity without reducing the benefits to the patient (9, 10).

Currently consultants have achieved specialist training in this type of complex laparoscopic surgery by attending national and international courses and/or by working directly with experienced colleagues in the UK and abroad. The expertise gained, supported by the Royal College of Obstetricians and Gynaecologists (RCOG) training programme, has driven the development of specialist endometriosis centres and is providing a sustainable training system for complex laparoscopic surgery.

References

1. American Fertility Society. Revised American Fertility Society classification: 1985. Fertil Steril 1985;43:351– 2.
2. Green Top Guideline. No 24. RCOG. 2006.
3. Ballweg ML. Impact of endometriosis on women's health: comparative historical data show that the earlier the onset, the more severe the disease. Best Pract Res Clin Obstet Gynaecol 2004;18:201-18.
4. Prystowski JB, Stryker SJ, Ujiki GT, Poticha SM. Gastrointestinal endometriosis. Incidence and indications for resection. Arch Surg 1988;123:855–88.
5. MacAfee C, Hardy-Greer H. Intestinal endometriosis: a report of 29 cases and a survey of the literature. J Obstet Gynaecol Br Empire 1960;67:539–55.
6. Weed JC, Ray JE. Endometriosis of the bowel. Obstet Gynaecol 1987;69:727–30.
7. Chapron C, Jacob S, Dubuisson JB, Vieira M, Liaras E, Fauconnier A. Laparoscopically assisted vaginal management of deep endometriosis infiltrating the rectovaginal septum. Acta Obstet Gynaecol Scand 2001;80:349-54.
8. Jenkins S, Olive DL, Haney AF. Endometriosis: pathogenetic implications of the anatomic distribution. Obstet Gynaecol 1986;67:335-8.
9. De Cicco C, Corona R, Schonman R, Mailova K, Ussia A, Konnickx P: Bowel resection for deep endometriosis: a systematic review. BJOG 2011;118:285-291.
10. Mauleman C., Tomassetti C, D'Hoore A, Van Cleynenbreugal B, Penninckx F, Vergote I, D'Hooge T: Surgical treatment of deeply infiltrating endometriosis with colorectal involvement. Hum Reprod Update 2011;17:311-326.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	√
Domain 2	**Enhancing quality of life for people with long-term conditions**	√
Domain	**Helping people to recover from episodes of ill-**	√

NHS England E10/S/a
Gateway Reference 01369

3	**health or following injury**	
Domain 4	**Ensuring people have a positive experience of care**	√
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	√

All women with severe endometriosis who require surgery will have nationally standardised treatment pathway (see appendix) enabling them to:

- Access laparoscopic surgery with two skilled appropriately trained laparoscopic surgeons working together, in line with the criteria used for BSGE accreditation criteria
- Experience MDT assessment and care in line with BSGE guidance
- Have a clear understanding of their entry and exit from the Severe Endometriosis pathway
- Experience integrated pathway where all relevant primary/community/secondary treatment providers are aware of their treatment responsibilities
- Experience treatment to referral waiting times to see consultant that are audited in line with the NHS 18 week RTT targets

Patient reported outcome measures (PROMs) will be used to assess the individual symptoms and the global quality of life score measured at a single point in time would be used to audit outcome. Comparison from pre-operation to 2 years post operation will be expected to show improvement. These PROMs are built into the core structure of BSGE endometriosis centres and will be audited.

Appropriate referrals to specialist colleagues will be documented and GP informed of any transfer of care. Area Teams will be alerted to any adverse audit information.

Direct patient access to an endometriosis specialist nurse will be used to help the patient feel supported in the management of her condition and can be assessed as a sub-indicator.

3 Aims and objectives of service

3.1 Aims of the service

The aim of the service is to provide patient centred specialist care for women with severe endometriosis, improving 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 all 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
- Recording PROMs on relevant clinical domains and quality of life
- Working with pain management specialists
- Keeping the use of open surgery to the minimum

3.2 Service description/care pathway

3.2.1 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/video)
- Initial outpatient assessment in specialist endometriosis clinic by endometriosis nurse, information, counselling and explanation will be given. Primary 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 plus pre-operative preparation organised.
- In selected cases primary appointment may be with consultant and local negotiations will be needed to clarify such pathways
- Multidisciplinary discussion of cases which require colorectal and or urology surgeon input.
- Elective surgical inpatient spell
- Elective outpatient follow-up at three months by consultant and six months by nurse, with PROMs including quality of life assessments at 6, 12 and 24 months post surgery.
- Ideally discharge to secondary, or primary, care after six months follow up, with

subsequent PROMs collected in non-face to face consultation
- Management of any complications, morbidity or recurrence as required

3.2.2 The specialised service in more detail:

Laparoscopic surgery for deeply infiltrating endometriosis or for 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 (http://www.bsge.org.uk/ec-requirements-BSGE-accredited-endometriosis-centre.php) for centres carrying out such work and accredits departments that reach its standards. The criteria include:

- Working in a multi-disciplinary team with a named colorectal surgeon and nurse specialist
- Holding a dedicated endometriosis clinic
- Operating on a minimum number of patients with severe endometriosis each year
- Submitting operative and quality of life outcome data to a national database
- Audit their outcomes

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 deeply infiltrating endometriosis or recto-vaginal disease at laparoscopy, or open surgery, will refer patients from secondary care to an Endometriosis centre. Laparoscopic images and or video, of suitable quality and format will be included with the referral wherever they are available as this may 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 **i**f 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 supress 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. Some patients may need review by the fertility team prior to any surgical treatment; this can be organised by the primary referral source.

MDT discussion
Severe deeply infiltrating endometriosis or recto-vaginal 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, unless there is long travel distances involved. Some patients will require surgery in two stages 12 weeks apart. The first stage is to drain adherent endometriomas and where appropriate 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:

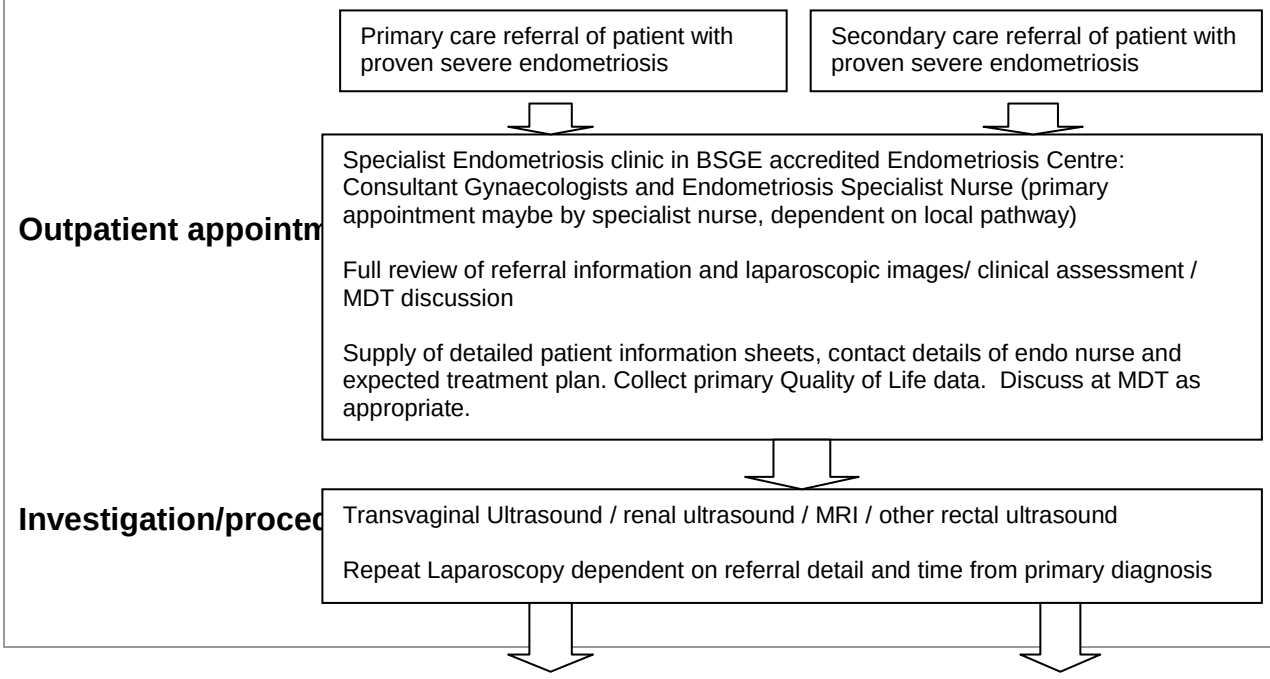
- First stage drainage and stripping of endometriomas and staging of endometriosis
- laparoscopic excision of pelvic sidewall endometriosis
- laparoscopic excision of recto-vaginal endometriosis
- laparoscopic excision of recto-vaginal endometriosis + skinning of rectal surface
- laparoscopic excision 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/re-anastamosis
- laparoscopic partial bladder cystectomy for endometriosis

- laparoscopic excision of diaphragmatic endometriosis
- laparoscopic excision of other bowel endometriosis

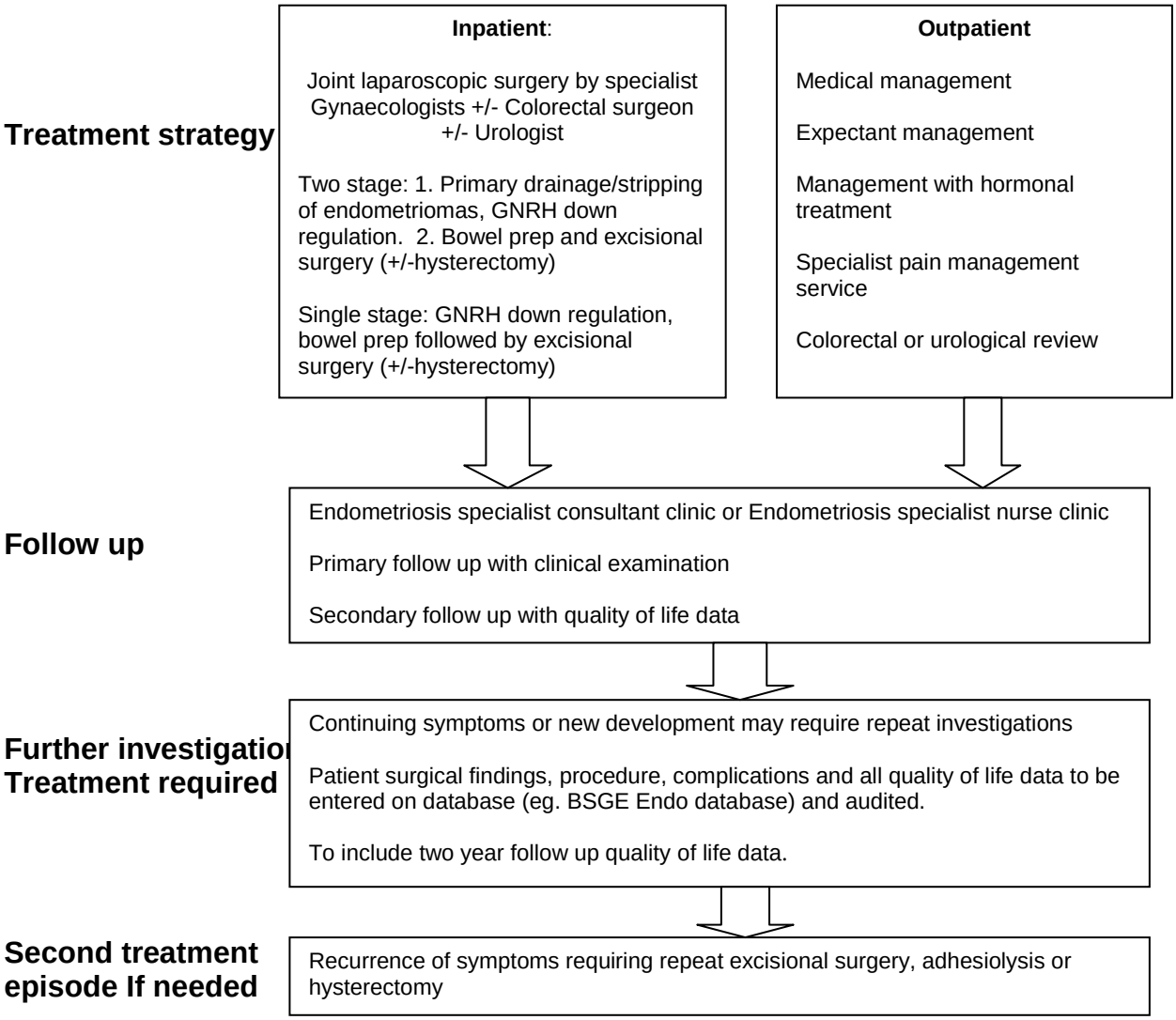
Outpatient review and discharge from the service

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 for non face to face consultations (telephone or website submission) 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.

Figure 1. The management of severe endometriosis pathway



NHS England E10/S/a
Gateway Reference 01369



3.3 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 1.1.

In exceptional cases young women under 18 years may be referred to the service. It is recognised that in the upper age groups 16 - 18 years they can be treated in either a

paediatric or adult setting and, where possible should be able to choose, provided appropriate safeguarding and facilities are in place. Wherever possible, overnight facilities for parents or carers should also be available.

This advice is based on the consensus document: Key components of developmentally and age appropriate care to support transition for adolescents and young adults : Service Specification Proposal (2013) prepared by an expert reference group supported by NHS IQ at the request of the National Clinical Director for Children, Young People and Transition to Adulthood.

3.4 Any acceptance and exclusion criteria and thresholds

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

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

3.5 Interdependencies with other services/providers

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.

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. A second experienced laparoscopic Gynaecologist to operate with the primary surgeon on all complex cases.

Interdependent services

Interdependent services include chronic pain management service and Clinical Imaging.

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

Data Submission
PROMs and quality of life data along with surgery details and complications will be recorded on a live database, such as the BSGE endometriosis database, which will be available for audit.

4. Applicable Service Standards

4.1 Applicable national standards

- BSGE (www.bsge.org.uk) 'Criteria for a BSGE recognised centre for laparoscopic treatment of women with recto-vaginal endometriosis'
- RCOG (2006) 'The investigation and management of endometriosis' Green-top guideline 24
- ESHRE (2005) 'Guidelines for the diagnosis and management of endometriosis' Human Reproduction vol.20, issue 10, pp2698-2704

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements See Appendix 1

Appendix One

Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
% of cases entered on BSGE database	>70%	% seen recorded in database	Audit to assess reasons for non-compliance
Compliance with BSGE criteria for laprascopic surgery for severe endometriosis	100%	Reported within national audit reports	Audit to evaluate causation and any change in practice
Domain 2: Enhancing the quality of life of people with long-term conditions			
Quality of life score.	Improvement in median score for population by at least 20% at 2 years post surgery	Global quality of life to be measured at 6, 12 and 24 months post surgery.	Audit of QOL scores for whole patient group and change in surgical practice where appropriate.
Record standard dataset of patient symptoms on national database for audit.	>75%	Proportion of patients having surgery for severe endometriosis with symptom questionnaire pre operatively and at 6, 12 and 24 months post surgery.	Audit of symptom questionnaires for whole patient group to evaluate causation and remedial action
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Ensure adequate follow up of surgical cases for severe endometriosis	>75%	Proportion of patients who were followed up for 2 years post surgery for severe endometriosis	Audit to evaluate causation and remedial action

NHS England E10/S/a
Gateway Reference 01369

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 4: Ensuring that people have a positive experience of care			
Patient feedback	>50%	Proportion of patient completing anonymous feedback questionnaire at completion of treatment	Audit to evaluate causation and remedial action
Access to operation in timely fashion	>90%	Surgery within 18 weeks of referral to specialist centre	Audit to evaluate causation and remedial action
Adequate preparation for surgery	>90%	Given date for surgery at least 4 weeks in advance	Audit to evaluate causation and remedial action
Limit changes in planned treatment time	<10%	Proportion of patients who have surgery date changed once issued	Audit to evaluate causation and remedial action
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Surgery performed by appropriately experienced team	100%	Confirmation of two skilled laparoscopic surgeons for all cases	Audit to evaluate causation and remedial action/ loss of service.
Surgical environment fit for safe surgery	100%	Surgery to be undertaken in theatres designed to undertake complex laparoscopic surgery	Audit to evaluate causation and remedial action/ loss of service.

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 (Health Service Circular 1998/238) requires that:

- 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.
- 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.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- 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 (DH)

Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DH 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

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.1 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) training2 and should maintain the competencies so acquired3 *. 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).

As well as providing 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.

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. Guidelines for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
2. Certificates of Completion of Training (CCT) in Anaesthesia 2010
3. Continuing Professional Development (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)
- 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:

- 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.
- Participates 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 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 of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- 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.

Implimentation 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 hydraton that mett any reasonable reuirements 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:

- 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, 2006, London.

NHS England E10/S/a
Gateway Reference 01369

Change Notice for Published Specifications and Products developed by Clinical Reference Groups (CRG)

Amendment **to the Published Products**

Product Name	Complex Gynaecology- Severe Endometriosis
Ref No	**E10/S.a**
CRG Lead	Anthony Smith

Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
	Put the previous year's specification in a new specification template, this has created a new section linked to the National Outcome Framework and domains	Section 2 and appendix 2	To ensure consistency of specification formatting	CRG	January 2014
	Revise the classification definition of the disease	Section 1	Further clarity	CRG	January 2014
	Revised treatment and updated training	Section 1- last 2 paragraphs	Further clarity	CRG	January 2014

	requirements and evidence updates				
	Revise the coding sections to better reflect treatment activity.	Section 3.2 paragraph 7	Further clarity	CRG	January 2014
	Incorporate a new section for audit and governance	Section 3.2	Further clarity	CRG	January 2014