NHS England

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	**E10/S(HSS)a**
Service	**Gestational Trophoblastic disease (Choriocarcinoma - all ages)**
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

The UK Gestational Trophoblastic Disease (GTD) Service is an internationally renowned, multi-disciplinary team which provides both clinical and psychological care, for women diagnosed with GTD and specialist advice for health care professionals involved in giving care to this patient group.

GTD is a spectrum of rare pregnancy related disorders comprising the premalignant conditions of complete (CHM) and partial hydatidiform moles (PHM) through to the malignant invasive mole, choriocarcinoma and placental site trophoblastic tumour (PSTT). Sixty years ago, most women could expect to die of GTD. Fortunately this situation has been reversed by the progressive discovery of effective therapies and appropriate management protocols together with a very sensitive biomarker of the disease activity (human chorionic gonadotrophin; hCG).

The UK national GTD service was designated in 1984 and has played a leading international role in developing these therapies, management protocols and biomarker assays and currently cures more than 98% of affected women.

Evidence Base.

- GTD is a rare disease so centralised care is necessary to ensure adequate skill levels in the teams that manage it otherwise high cure rates cannot be achieved.
- Indeed, data from a recent survey for GTD survival in countries that do not have centralised care including the USA show considerably lower survival rates (Kohorn et al 2009 International Society for the Study of Trophoblastic Disease (ISSTD) conference Cochin and J Reprod Med 2013 in press).

- Similar improved survival results have been seen with other curable malignancies. Thus, testicular cancer cure rates have been shown to be significantly higher when the disease is managed in specialised centres than in district general hospitals (Harding et al Lancet 1999, 341, 999-1002)

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 3	**Helping people to recover from episodes of ill-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**	√

See appendix 2 but briefly:

Outcomes: Deaths as % of new cases

In addition to National Key Performance Indicators (KPI), e.g. waiting times, infection control etc; further service specific KPIs will monitor that:

- Counselling is offered to all patients during first course of chemotherapy;
- All patients have a named key worker on day of admission;
- Patient's GP is informed of admission within 24 hrs;
- All patients are issued with diary of treatment events on first discharge;
- Maximum 14 day turn around on histopathology specimens;
- Local to residence chemotherapy administration where feasible is established within three weeks of first admission

3. Scope

3.1 Aims and objectives of service

- To provide centralised comprehensive health care for women with Gestational Trophoblastic Disease (GTD)
- To provide a world-class screening, diagnostic and treatment facility across the UK for the management of GTD, identifying and treating patients with malignant forms of GTD to achieve a cure rate ≥ 98% whilst minimising morbidity and psychological sequelae.

- To provide accurate (expert) diagnosis.
- To monitor GTD patients for relapse or new episodes of the disease
- To advise/teach nationally and internationally on the management of GTD
- To minimise complications (late effects) of treatment in this young fertile group of women
- To provide excellent patient experience.

3.2 Service description/care pathway

Women diagnosed with GTD, or where GTD is suspected, will be formally registered, using the official registration form, with one of the national screening centres. This will include the diagnosis of:

- Complete hydatidiform mole (classical type, androgenetic, no other foetal tissue)
- Partial hydatidiform mole (usually triploid, other foetal tissues present)
- Twin pregnancy with Complete or Partial hydatidiform mole
- Limited macroscopic or microscopic molar change judged to require follow-up
- Aypical placental site nodule.
- Referrals are also accepted in writing, or verbally in emergencies, for the diagnosis of:
- Choriocarcinoma
- Placental site trophoblastic tumour
- Persistently raised HCG of unknown cause

The provider will provide:

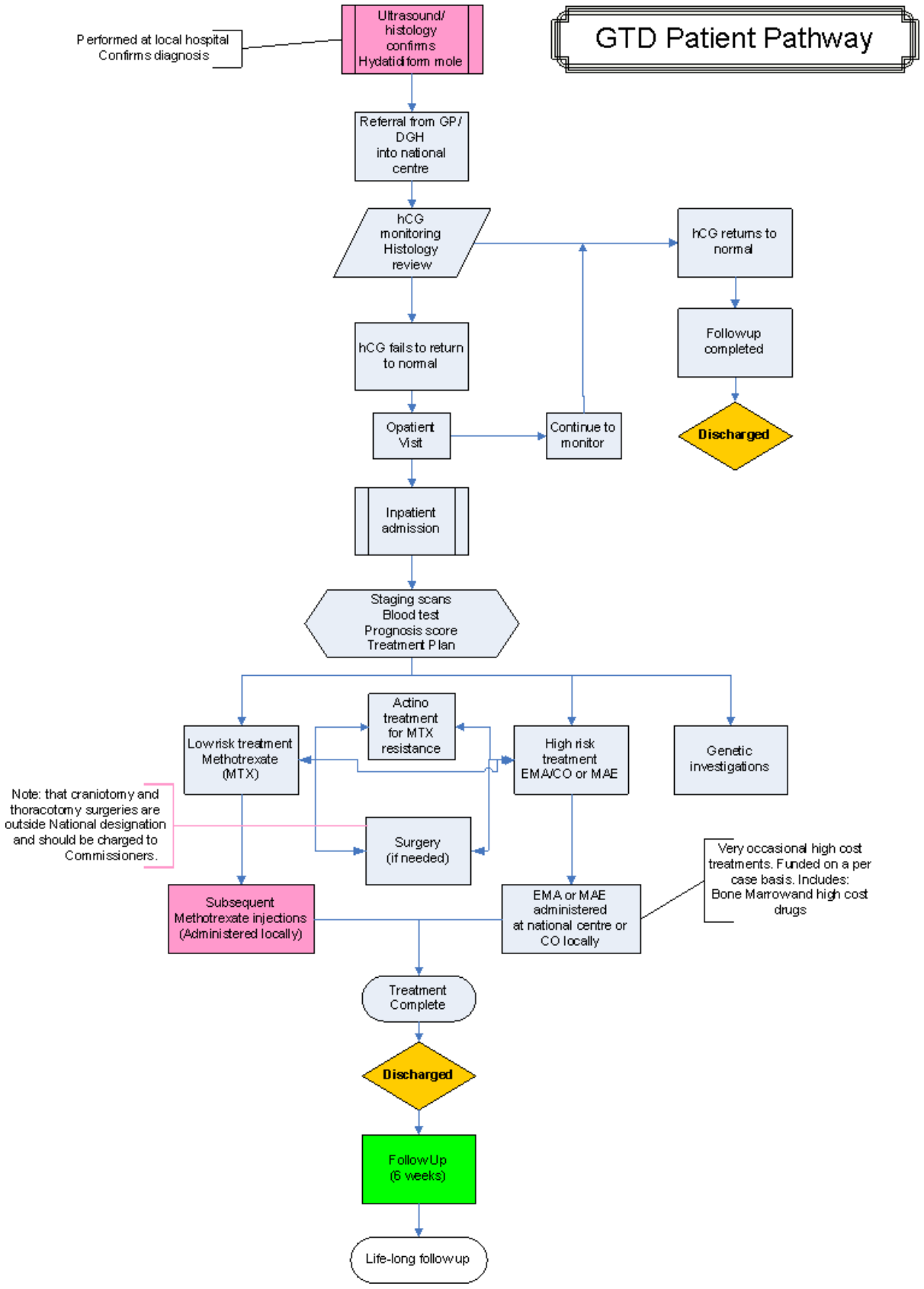
- A registration facility for molar pregnancies and other GTD events. • registration within 72 hours of referral receipt with written information sent to patient, GP and referring Gynaecologist at this point;
- Emergency telephone referral facility 24 hours a day, 7 days a week;
- A comprehensive monitoring facility including regular patient communication regarding results and progress;
- Acomprehensive treatment facility including neurosurgical, thoracic, gynaecological, urological surgery, interventional radiology, radiotherapy, intensive care and high dose chemotherapy.
- Communications at each stage of the patient journey in accordance with the service information pathway. The provider will work with NHS England to ensure sufficient considerations are given to communications;
- A comprehensive discharge process;
- A disease specific hCG assay with maximum 48 hour turnaround of commented results;
- An efficient optimal patient pathway including a robust hCG monitoring protocol identifying those women “at risk”, with timely intervention and treatment;
- 24/7 access to clinical advice;
- a telephone advisory/ results service for patients and health professionals;

- Multi-disciplinary patient support including monthly drop-in sessions and a monthly support group;
- An internationally leading service and reference centre;
- GTD related education and support to patients and carers through information
- booklets, websites, telephone advisory service, drop-in sessions, and counselling;
- GTD related education and support to health professionals through annual study days, information sheets, telephone advisory service and websites;
- Central pathology review with expertise available to ensure a specialist pathological opinion within 7 days of receipt of appropriate materials;
- Genetic analysis; confirmation of pathological diagnosis anddiscrimination between gestational & non-gestational tumours as appropriate;
- Investigation of recurrent molar pregnancies;
- Annual audit of patient experience with an action plan on patient feedback;
- Patient inclusion in service design by consultation during structured drop-in sessions and annual surveys;
- Regular audit of provider assurance and governance processes.

Risk management:

- Weekly multi-disciplinary team meetings to optimise clinical care and psychological support.
- National External Quality Assessment Scheme (NEQAS): to minimise analytical errors e.g. imprecision and bias. Monitored by daily Internal Quality Controls (IQC). All assays are registered, as required by Chemical Pathology Accreditation (CPA), with an appropriate NEQAS scheme;
- Cross-site (Charing Cross/Sheffield) meetings to harmonise service delivery;
- Datix (is a single incident reporting system for all incidents including accidents, complaints, claims and Patient Advice and Liaison Service (PALS) activities). Each incident is investigated and a report issued with remedial action if appropriate.

Figure 1. The GTD service pathway



Service model, **Data Management , Audit and Governance**

The patient is sent information on molar pregnancy, a sample kit with instructions and information on the advisory and support services offered. These include a telephone advisory service, manned during office hours (30,000+ calls per annum), 24 hour emergency access to an on-call clinician & rapid access to counselling. Also, an invitation to attend a monthly drop-in session where they can meet other women suffering molar pregnancy, learn more about their condition, future pregnancies and have the opportunity for face to face contact with staff to discuss any personal concerns.

Pathology is requested for review. Patients found to be non-molar on review are discontinued from follow-up once normal hCG levels are achieved. If review confirms a third molar pregnancy patients are invited to the centre for a consultation with both a service consultant and consultant geneticist. The patient is offered further genetic investigation, advice and counselling regarding future pregnancy.

The referring consultant retains responsibility for the patient's on-going clinical care, with Patient's invited to call the specialist centre directly for on-going advice and interpretation of results. The specialist centre liaises closely with the local health care providers (GP/gynaecologist) during the monitoring period, with commented results and immediate alert to any problems arising. Patients are monitored every two weeks, with serum & urine hCG measurements until levels return to normal and then by urine samples only, every four weeks until follow-up is complete. Because of possible relapse with a future pregnancy, hCG samples are requested on two occasions after each future pregnancy.

For patient's requiring admission to the specialist centre, responsibility for their clinical management passes to the specialist centre oncology team. Patients are seen in the outpatient clinic by a consultant and Clinical Nurse Specialist. They undergo blood tests, pelvic ultrasound and chest x-ray to facilitate a prognostic score, determining if low or high risk chemotherapy is indicated. Some women will require further imaging. The initial admission is dependant on the patient medical status. The specialist centre liaises closely with the local health care providers (GP/gynaecologist/oncology team) for on-going care.
Following the initial admission, the centre endeavours to arrange on-going treatment(s) local to patient residence. During chemotherapy treatment the patient is seen at the national centres regularly the frequency depending on the nature and complexity of the treatment given.

Monitoring during treatment involves at least serum hCG analysis. When the patients are at home, this is done at the local hospital phlebotomy clinics or the GP practice and forwarded by the local laboratories to the centre for analysis using the pre-paid kits provided. The national providers will liaise closely with the local health care providers (GP/gynaecologist/oncology team). A full blood count (FBC), Liver (LFTs) and kidney function (U&Es) tests are also necessary prior to each course of chemotherapy.

Data management is handled through existing electronic systems at Charing Cross and Sheffield that have been tailored for automation of tumour marker surveillance, ease of clinical audit, activity reporting and to facilitate compliance with local and national governance. These systems are already supported by dedicated IT staff.

Referral processes and sources

Referrals can be made by any doctor who has diagnosed the patient with a GTD event using a registration form for molar pregnancies (see Appendix 3) that is available:

- online at http://www.hmole-chorio.org.uk/clinicians_info_registration.html or by
- by directly contacting the Advisory services in London or Sheffield (Appendix 3) or by
- secure online registration system available at https://nww.h-mole.nhs.uk/.

Non molar referrals can be made by telephone, letter or email.

Discharge criteria and planning

Active discharge planning is commenced on admission or prior to elective admission as per provider discharge policy. GTT procedure Appendix 4

Tumour marker follow-up (hCG) is life-long for both low and high risk patients.

Patient-Centred Services

The patient is at the heart of the GTD service. Each patient is assigned a key worker, is offered counselling and where appropriate the necessary Teenage and Young Adult (TYA) support and paediatric support including play specialists. Clear communication with the patient and all associated teams within and external to the centre is essential and is the key to the service's successful operation.

Operational Delivery Network (ODN)

Regular satisfaction surveys of various aspects of the ODN are carried out in the GTD service including the patients, their GPs and referring gynaecologists so that improvements in the overall service are enabled. Over the years this has lead to the introduction of many patient driven changes to service delivery, information enhancement and improved patient experience.

3.3 Population covered

The service is accessible to all patients with GTD.

There are approximately 120 new patients per year.

This is a UK service covering Scotland, Northern Ireland, England and Wales. Three centres have been designated for hCG monitoring and registration of new patients with GTD: Ninewells Hospital in Dundee for Scottish patients, Weston Park Hospital (Sheffield Teaching Hospitals NHS foundation Trust) in Sheffield for those women living in the north of England, central and north Wales and Charing Cross Hospital (Imperial College Healthcare NHS Trust) in London for all other regions. Treatment, if necessary, is given either in Sheffield for women in north England, central and north Wales or London for those in the rest of the UK.

3.4 Any acceptance and exclusion criteria and thresholds

The criteria for registration/referral acceptance are either pathological confirmation of GTD or clinical suspicion of GTD in the absence of pathological evidence. Referrals are accepted from consultant gynaecologists, GPs or any clinician who suspects a diagnosis of GTD following discussion with the specialist centre. Patients physically seen by the service include those identified:

- By the monitoring process as requiring further treatment
- As placental site or epitheliod trophoblastic tumours or choriocarcinomas
- With persistently raised and/or unexplained elevated hCG levels
- As having multiple molar pregnancies
- With atypical placental site nodules

Patients identified for intervention through the hCG monitoring protocol will meet one or more of the following criteria:

- Serum hCG > 20, 000 IU/L at >4 weeks post evacuation
- Rising hCG i.e. 2 consecutive rising serum samples
- HCG plateau i.e. 3 consecutive serum samples not rising or falling significantly
- Heavy haemorrhage and/or severe abdominal pain
- HCG still abnormal at 6 months post evacuation

There is no exclusion criteria providing patients reside within the areas covered by the UK scheme.

3.5 Interdependencies with other services/providers

i) Co-located Services

The effective running of the GTD service requires effective teamwork between a number of departments within the hospital including, gynaecology, histopathology, radiology, thoraco-abdominal surgery, liver surgery, neurosurgery, intensive care, psychiatry, palliative care/pain control, paediatrics and a high dose transplantation centre. Within the hospital the service is supported by a full range of ancillary services, including a comprehensive translating service, designated clinical nurse specialist, counselling specialist, paediatric play specialists, accommodation facilities for relatives, TYA services and the various other support services including a Maggie's Centre are available. The Sheffield centre is the regional TYA centre and Charing Cross is a designated TYA unit with all necessary links in place for TYA services across the country.

ii) Interdependent Services

Externally, good relationships have been built between the national centres, patient's GPs and other oncology units to deliver the centrally designated treatment close to the patient's home. There are protocols in place for chemotherapy to be administered in many local oncology units. Whilst patients are receiving treatment locally, the direction and prescription of their clinical care remains with the national centre at all times.

iii) Related Services -

The following local outside services may be engaged either before referral, during shared care treatment or after completion of therapy: Gynaecology, Oncology, Radiology, GP, Phlebotomy (tumour marker monitoring), TYA principle treatment centres (PTC), psychiatric, fertility and social workers.

iv) Data Submission: Monthly activity reports. Annual workload analysis.

Referring centres: All obstetric and gynaecology units, gynae/onc centres and any other NHS facility where the diagnosis of GTD is suspected

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

See Appendix 2

All clinical services, including treatment protocols must be in accordance with appropriate clinical guidelines and National Standards e.g. NICE/ NCAT(National Cancer Action Team), Nursing & Midwifery Council: National Standard of Conduct, Performance & Ethics for Nurses & Midwives, acute oncology, safe-guarding children and TYA(Teenage & Young Adults).

All medical laboratory services (e.g. hCG analysis) must be provided in an appropriately regulated environment, operated according to nationally accepted quality standards(UK-NEQAS-United Kingdom National External Quality Assessment Service) and have Clinical Pathology Accreditation (CPA).

The two national centres have considerable expertise in developing high standards of clinical care / maintaining databases of patients with GTD where fertility preservation is important. Moreover, Charing Cross has the world's largest experience with GTD and has an international reputation for establishing new standards of care in this area.

Potential aspirational standards for the next year will include development of:

- Shorter follow-up protocols
- An application for i-phone and android phones to provide patients and their doctors with easily accessible information about GTD and its therapy.

5. Applicable quality requirements and CQUIN goals

5.1 Applicable CQUIN goals (See Schedule 4 Part E)

The GTD service is a highly specialised service and the quality standard goals will be determined by the two national centres in dialogue with the commissioners.

For 2013/14 the GTD service will propose to:

- Audit length of hCG surveillance required following uterine evacuation of a molar pregnancy to determine shortest, safest length thus reducing costs and enhancing the patient experience.

- Re-evaluate the impact of high dose chemotherapy to determine whether we should continue this high cost intervention in selected patients

6. Location of Provider Premises

The Provider's Premises are located at:

- Imperial College Healthcare NHS Trust (Charing Cross Hospital) London

- Sheffield Teaching Hospital NHS Foundation Trust (Weston park Hospital)

7. Individual Service User Placement

The provision of high dose chemotherapy and other services required in selected patients will be managed on a per patient basis.

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			
Deaths	< 2% overall	Deaths as a percentage of all new cases	Audit to evaluate causation and change in practice
Domain 2: Enhancing the quality of life of people with long-term conditions			
Maximising fertility rates	> 80%	Proportion of patients who are attempting pregnancy that are succeeding, assessed through questionaires/telephone interview	Audit to evaluate causation and change in practice where feasible
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Counselling offered to all patients	>98%	Proportion of patients offered counselling	Audit to evaluate causation and remedial action
Domain 4: Ensuring that people have a positive experience of care			
All patients to have a named key worker on day of admission	> 98%	Proportion of patients who were assigned a named key worker on day of admission	Audit to evaluate causation and remedial action
Patient's GP is informed of admission within 24 h of admission	> 95%	% patient's GPs informed in this time frame	Audit to evaluate causation and remedial action
All patients to see consultant on day or within 24 h of admission	>98%	% patients who saw consultant within 24 h admission	Audit to evaluate causation and remedial action
Establishing local chemotherapy / shared care within two weeks of first admission	> 90%	% of patients achieving this where appropriate	Audit to evaluate causation and remedial action
Annual patient survey	100% offered survey	% patients achieving this	Audit to evaluate causation and remedial action
All patients on chemo offered patient diary on 1st discharge	>98%	% patients achieving this	Audit to evaluate causation and remedial action

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Compliance with all relevant national KPIs including infection control and waiting times	As per national KPIs	As per national KPIs	As per national KPIs
Maximum 14 day turn around time on histopathological specimens	> 90%	% of total MOGCT pathology specimens not reported in this time	Audit to evaluate causation and remedial action

Appendix Two

Imperial discharge procedure for Gestational Trophoblastic Tumours

Low risk. Within 48 hours of admission:

- Organise the administration of the methotrexate (MTX) injections local to patient residence. Contact the GP to discuss, fax the referral letter, protocol and the three subsequent treatment schedules. If the GP unable to administer, contact the local oncology unit and refer to an appropriate oncologist, then fax the referral letter and treatment schedules. Provide information on methotrexate administration
- Order three courses of MTX and folinic acid tablets from pharmacy to be prepared as a To Take Away (TTA)
- Educate the patient on the safe storage and transport of drugs

Prior to discharge:

- Arrange six week out-patient appointment (OPA), give copy of letter, treatment schedules, spillage kit, purple sharps in and any other TTA's to patient
- Arrange for patient to see the clinical co-ordinator the day before discharge to collect blood test instructions for once or twice weekly hCG testing, and a letter requesting full blood count (FBC) and urea & electrolyte's (U&E's) test to be done the day before each cycle of treatment using local phlebotomy provision
- Give advice (verbal and written) on contraception, caution in the sun, alcohol consumption and exercise
- Ensure appropriate transport arrangements are in place
- Minimal/no vaginal bleeding
- Adequate storage facilities identified for methotrexate and other drugs

Upon completion of treatment:

- Arrange a six week follow-up OPA with repeat pelvic ultrasound (if required) (and chest
- X ray if lung metastases identified on pre treatment CXR)
- Give advice (verbal & written) on long term hCG monitoring, future pregnancy advice and any other issues raised
- Post six week clinical check-up
- Discharge from clinic to continue postal follow-up of hCG

High risk:

- Organise the administration of the CO infusions local to patient residence. Contact the local oncology unit to discuss and refer to an appropriate oncologist, fax the referral letter and protocol;
- Ensure all take away drugs are available;
- Educate the patient on the safe storage and use of prescribed drugs;
- Arrange a two week out-patient appointment
- Ensure appropriate transport arrangements are in place.
- Give written information, including copies of patient letters on the above including discharge after in-patient stay.

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 (HSC) 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 minimise 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

Imaging

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 the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to continuous performance development (CPD)
- 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) training 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 an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (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 Providing Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal Collage of Anaesthetists (RCoA) 2010 www.rcoa.ac.uk
2. Certificate for completion of training (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 specialist 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. National Institute for Health and Care Excellence. (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:
    - Taking 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 Clinical Records Bureau 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.

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.
- 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
- Ensures 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.