NHS England

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	D06/S(HSS)a
Service	Stevens-Johnson syndrome and toxic epidermal necrolysis (SJS-TEN), all ages
Commissioner Lead	
Provider Lead	
Date of Review	

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1. Population Needs

1.1 National/local context and evidence base

Stevens-Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN) are severe muco-cutaneous reactions, usually to drugs, characterized by blistering and epithelial sloughing. The two terms describe phenotypes within a severity spectrum, in which SJS is the less extensive form and TEN is the more extensive. The incidence of SJS-TEN (all ages) is approximately one to two cases per million per year.

Although rare, SJS-TEN is a devastating disease. The published mortality for SJS is less than 10%, with the figure rising to 30% for TEN, and overall SJS-TEN mortality is about 22%. There is also an appreciable acute morbidity including multi-organ failure. In a series of 87 SJS-TEN patients (Revuz *et al.*), 97% developed erosive mucous membrane lesions; oral involvement was observed in 93% of patients, ocular in 78%, genital in 63%, and all three sites in 66%.[16] Respiratory tract epithelial necrolysis can occur resulting in bronchial obstruction and ventilatory compromise; necrolysis of gastrointestinal epithelium leads to profuse diarrhoea; acute kidney injury may occur due to hypoperfusion and acute tubular necrosis. 74% have eye involvement which can be severe, early detection is key to improved outcomes. Survivors of the acute illness often develop significant long-term sequelae, related to skin and mucosal scarring and disfigurement and psychological trauma.

As noted above severe SJS-TEN has a high case fatality ratio but is very rare. Early diagnosis is difficult because SJS-TENS has a wide differential diagnosis of superficially similar conditions requiring very different management, including immune bullous disease, bullous lupus and staphylococcal scalded skin syndrome. Delay in diagnosis worsens prognosis because disease-specific protocols have not been started promptly. Patients are often referred to other specialists for diagnostic confirmation, critical care or multidisciplinary

input, sometimes requiring emergency transfer between hospitals. Patients may stay in critical care for weeks, and suffer lifelong sequelae.

Three studies and a systematic review of TEN cases have demonstrated that rapid admission to a Burns Centre is associated with improved survival, whilst delayed transfer is accompanied by increased mortality

The national Burns database iBID recorded, in 2012, thirteen adults with SJS-TEN of whom 6 died, and one child with SJS who survived (case fatality ratio 46%).

A retrospective survey of British Dermatologists, co-ordinated by the British Association of Dermatologists (BAD), identified 66 cases seen between June 2013 and June 2014. Twenty one of these patients died (case fatality 32%). The age distribution was:

<10 yrs	10 – 18 yrs	18 – 30 yrs	30 – 50 yrs	50 – 70 yrs	>70 yrs
10	2	14	15	12	13

The length of stay was:

1 – 5 days	6 – 10 days	11 – 15 days	16 – 20 days	20 – 30 days	>30 days
18	15	11	10	9	3

The setting in which they were managed was:

Adult ICU	Paeds ICU	Burns Unit	HDU	Ward	Other
17	4	10	10	21	4 (spinal unit, CCU)

This service specification sets out the agreed pathway for referral and multidisciplinary care of patients with SJS-TEN. In 2013, the Specialised Dermatology and Burns CRGs formed a working group to address the need for a structured national service with clear referral and management pathway, outcome measures and robust data collection. All agreed that care must be multidisciplinary, in an age appropriate critical care setting and involve professionals with skills in skin loss diagnosis and complex wound management, in a small number of expert centres. This would facilitate audit and research to improve outcomes. Major Burns and Dermatology Centres are generally not co-located, and this is further complicated when considering paediatric care. Therefore the pathway must take into account local service configurations and should incorporate remote access to expert opinions including secure image transfer.

A national guideline for acute management of TEN in adults has been produced by the BAD with input from the British Burn Association and the British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS). This specification will ensure the implementation of this guideline throughout England, and also facilitate the development of a guideline for children.

SJS-TEN patient management should be carried out in a small number of centres each with appropriate specialist expertise. In this way, standardised care will be delivered to provide high quality care with improved clinical outcomes. Establishing a national network of SJS-TEN centres will enable the implementation of appropriate governance structures, including: case registration on a national database; case conferences for case validation and standardisation of care; regular audits against defined standards of care; opportunities for training and continuing professional development.

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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	✓

Survival

There is a significant mortality from SJS-TEN. Sometimes the degree of external and internal damage and subsequent physiological disruption is so rapid and overwhelming that death seems unavoidable. The validated SCORTEN tool predicts the probability of survival and allows comparison of expected and actual mortality.

Visual impairment

The ocular surface is involved in 74% of cases, which can lead to permanent visual impairment. Early intervention minimises ocular damage.

Mucosal scarring

Involvement of the oral, genital, and urological mucosae requires expert input from the relevant specialties to minimise risk of permanent disability.

Skin scarring

Survivors may sometimes be left with scarring requiring medical or surgical treatment. Pigmentary alterations are stigmatising and can result in severe psychological damage. Outcomes will be measured using validated scores including the Vancouver Scar Scale and Patient Observer Scar Assessment Scale (POSAS). Because the condition is relatively superficial, the deep scarring and contractures seen after burns are not a feature of SJS-TEN.

Psychological damage to patients

Survivors carry not only physical but also emotional scars as a result of being struck down in their prime by devastating illness. There is a real fear of it happening again. Outcomes will

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be measured using an appropriate validated quality of life measure.

Length of hospital stay; Length of ICU/PICU/HDU stay

Expert care and avoidance or prompt treatment of complications should reduce length of stay.

3. Scope

3.1 Aims and objectives of service

This highly specialist service for patients with SJS-TEN who have an actual or predicted skin loss to more than 30% Body Surface Area will provide the following at a small number of paediatric and adult specialist centres:

- to ensure prompt referral and transfer of eligible patients whilst minimising inappropriate referrals

- accurate diagnosis with the appropriate multispecialty input including support from age appropriate anaesthesia, critical care, dietetics, pain team, ophthalmology, ENT, urology, immunology, gynaecology, physiotherapy and psychology teams

- prompt and expert management of complex skin wounds (which resemble burns) with attention to fluid and electrolyte loss, sepsis, mucosal damage, pain and nutritional compromise.

3.2 Service description/care pathway

Patients with SJS-TEN must be cared for in either an age-specific Burns Centre or Specialised Dermatology centre co-locating with an age-specific Intensive Care Unit. All patients presenting to a Specialised Dermatology centre with SJS-TEN must be seen within 12 hours by a burns surgeon with experience of managing SJS-TEN. All patients presenting to a Burns Centre with SJS-TEN must be seen within 12 hours by a consultant dermatologist with experience of managing SJS-TEN.

https://www.england.nhs.uk/wp-content/uploads/2013/06/a12-spec-dermatology.pdf
https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/d06-spec-burn-care-0414.pdf

Care must be multidisciplinary, in an age-appropriate critical care setting and involve professionals with skills in skin loss diagnosis and in complex wound management, in a small number of expert centres.

The agreed pathway, summarised below, largely reflects current practice, but with much more interaction between Burns and Dermatology specialists, and national co-ordination. Dermatological expertise is essential for diagnosis, and well established fast-track pathways used for severe burns should be used.

Given the acute nature of TEN, and the importance of early recognition of the condition, the

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following must be available within 12 hours of presentation in a specialist centre:

Review by a consultant dermatologist with experience of managing SJS-TEN
AND
Review by a consultant burns surgeon with experience of managing SJS-TEN

- Review by a consultant ophthalmologist with experience of managing SJS-TEN ocular disease must be available within 24 hours. The facility to use amniotic membrane transplant must be available in the specialist centre.

- To facilitate confirmation of the diagnosis histologically, access to a consultant dermatopathologist to interpret biopsies and frozen sections must be available within 24 hours.

- Appropriate laboratory and diagnostic services, such as biochemistry, haematology, microbiology and radiology must be available on site to support care of the acutely unwell patient.

- Access to other specialties such as respiratory medicine, gastroenterology, gynaecology, urology, oral medicine, microbiology, pain team, dietetics, physiotherapy, psychology and pharmacy must be available as required to meet the specific needs of the patient.

- Environment: the patient must be cared for in an environment that can be temperature and humidity-controlled. An ambient temperature of 25 - 28° is optimal. Patients should be barrier-nursed in a side room for optimum infection control purposes. Patients should be managed on a pressure-relieving mattress.

- Nursing: patients must be cared for by nurses experienced in the management of skin fragility disorders (such as epidermolysis bullosa, pemphigus vulgaris) or burns. Nurses must be trained in the specific moving and handling requirements of patients with skin fragility or absent epidermis. They should also be trained in wound care and dressings of burns/skin failure.

- Intensive care specialists: ITU physicians experienced in the management of the physiological consequences of acute skin failure must be available to advise on this aspect of care.

- Specialist centres must have the ability to deliver parenteral nutrition.

- Specialist centres must have the ability to implement and maintain faecal management systems.

- Specialist centres must have the ability to step up and step down intensity of care

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according to progression/remission of the disease process. The expertise of those caring for these patients must be the same regardless of the location of care.

- Patients will be repatriated to local dermatology, Burns Facility or Burns Unit when healing is apparent and critical care is no-longer required.

- Further care and rehabilitation following repatriation will be supported by advice from the Specialist centre, but is not contractually included in the Specialist service.

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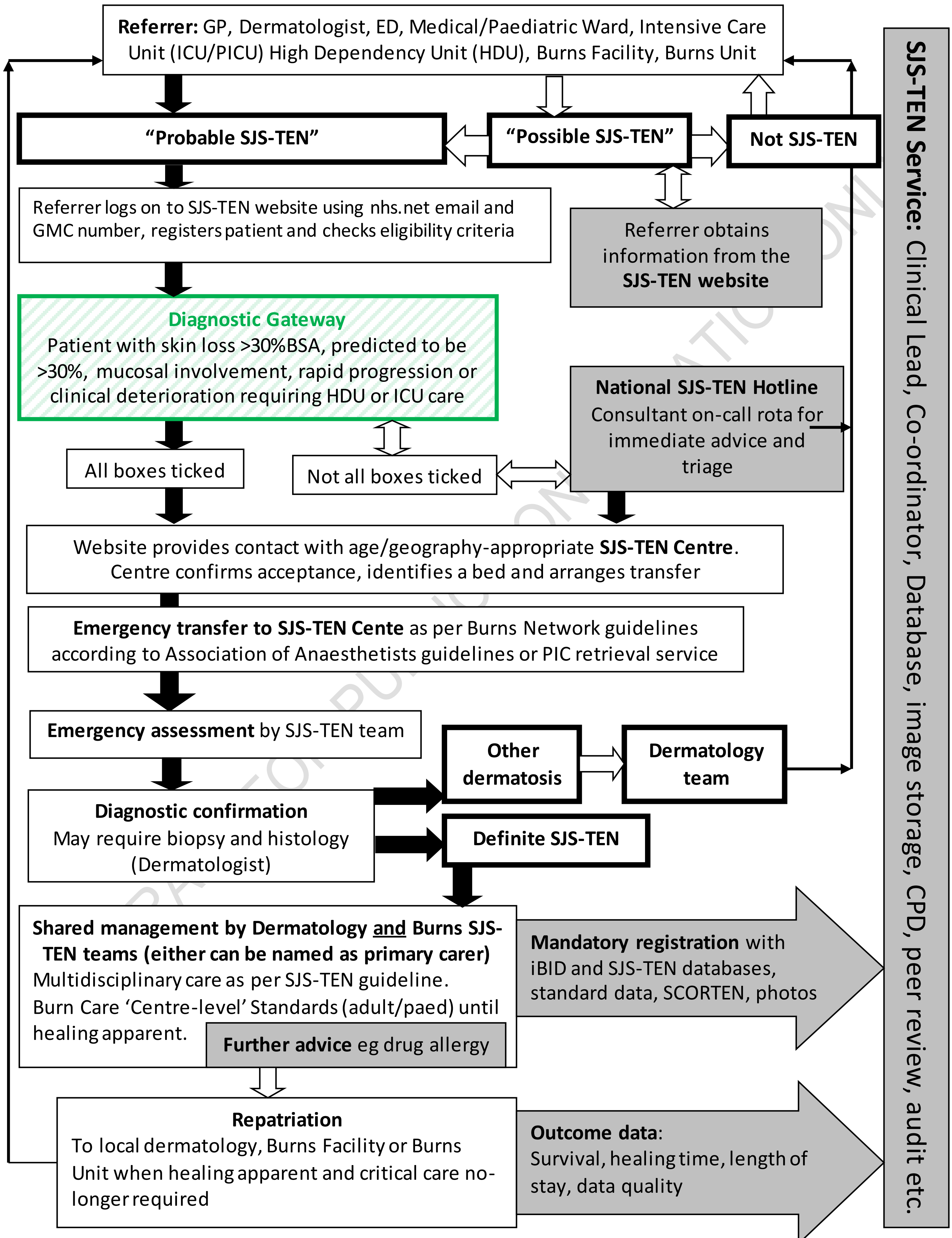
Referral pathway for SJS-TEN

Bold black arrows = fast track pathway; shaded boxes = national SJS-TEN service



3.3 Population covered

The service outlined in the 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 or Scotland, but INCLUDES patients resident in Wales or Scotland who are registered with a GP practice in England.

Patients with suspected or confirmed SJS-TEN and skin loss ≥ 30% Body Surface Area (BSA) or requiring critical care for skin loss due to SJS-TEN. All ages.

3.4 Any acceptance and exclusion criteria and thresholds

The service is accessible to all patients of the English NHS with SJS-TEN. The accepting centre (specialised centre) must have an 'automatic acceptance' policy. Patients must not be refused admission due to non-availability of beds.

3.5 Interdependencies with other services/providers

Critical adjacencies are related to:

- Specialist critical care and anaesthesia
- Specialised Dermatology
- Paediatric and adult Burn centre level care
- Nurses skilled in dressing changes to large areas of skin loss
- Other related specialties including ENT, ophthalmology, gynaecology, gastroenterology urology, oral medicine
- Pain team
- Psychology
- Scar management
- Intensive care

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

UK guidelines for the management of Stevens-Johnson syndrome/toxic epidermal necrolysis in adults 2015. British Association of Dermatologists. D Creamer, SA Walsh, P Dziewulski et al. (in press, British Journal of Dermatology and Journal of Plastic, Reconstructive and Aesthetic Surgery)

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British Association of Dermatologists. Audit points, dataset and methodology in quality standards in Dermatology

http://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=1437

The BAD has commissioned a group of members to define a minimum dataset in Dermatology that can be used to characterise the quality of a service and be a tool for comparison between services. This has been divided into quantitative and qualitative measures. This document concerns itself with defining the quantitative measures.

In 2010, the government published its vision for the NHS "Transparency in Outcomes – a Framework for the NHS". This proposed an NHS Outcome Framework with 5 domains:

1. Preventing people from dying prematurely
2. Enhancing quality of life for people with long-term conditions
3. Helping people recover from episodes of ill health or following injury
4. Ensuring people have a positive experience of care
5. Treating and caring for people in a safe environment and protecting them from avoidable harm

The quantitative measures were mapped to these 5 domains.

Stevens-Johnson syndrome and toxic epidermal necrolysis	
Audit points	
Point 1	
Description	The diagnosis of SJS-TEN must be made by a consultant dermatologist and a burns consultant in all patients.
Data items	1.Status and specialty of senior opinion at diagnosis
Collection methodology	Evidence will be obtained through review of hospital records of all SJS-TEN cases, commencing 24 months prior to the date of registering the audit.
NHS England Domains	1, 2, 3, 4, 5.
Point 2	
Description	A skin or mucosal biopsy for histopathology and direct immunofluorescence must be taken in all patients with suspected SJS-TEN.
Data items	1.Skin or mucosal histology report
Collection methodology	Evidence will be obtained through review of hospital records of all SJS-TEN cases, commencing 24 months prior to the date of registering the audit.
NHS England Domains	1, 2, 3, 4, 5.
Point 3	
Description	A SCORTEN assessment must be made at the time of diagnosis in all patients within 48 hours of presenting and result must be clearly documented in the notes.

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	http://www.nature.com/jid/journal/v115/n2/full/5600766a.html
Data items	SCORTEN risk factors: 1.Age 2.Malignancy 3.Heart rate (beats per minute) 4.Serum urea 5.% body surface loss 6.Serum bicarbonate 7.Serum glucose

Burns Care Standards 2013
http://www.britishburnassociation.org/downloads/National_Burn_Care_Standards_2013.pdf
Adult Critical Care standards
https://www.ficm.ac.uk/sites/default/files/Core%20Standards%20for%20ICUs%20Ed.1%20(2013).pdf
Paediatric Critical Care standards (http://www.england.nhs.uk/wp-content/uploads/2013/07/eo7sa-paed-inten-care.pdf
http://picsociety.uk/wp-content/uploads/2015/08/PICS-CICstandards-V5-D24-20150716-PICS-VERSION.pdf
Acutely ill patients in hospital
http://pathways.nice.org.uk/pathways/acutely-ill-patients-in-hospital
Drug Allergy *(http://pathways.nice.org.uk/pathways/drug-allergy)*
(http://pathways.nice.org.uk/pathways/drug-allergy#content=view-info-category%3Aview-quality-standards-menu)

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

There is a requirement to hold national audit meetings involving all designated centres on an annual basis.

Each centre must ensure that:-
1. All practitioners participate in continuous professional development and networking
2. Patient outcome data is recorded and audited across the service
3. All centres must participate in the national audit commissioned by NHS England.

Audit meetings should address:
- Clinical performance and outcome
- Process-related indicators e.g. efficiency of the assessment process, prescribing policy, bed provision and occupancy, outpatient follow-up etc.
- Stakeholder satisfaction, including feedback from patients, their families, referring clinician and General Practitioners doctors and GPs.

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

To be agreed with the Commissioner.

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6. Location of Provider Premises
The Provider's Premises are located at: To be agreed. It is expected that there would be 4 adult and 3 paediatric centres nationally.
7. Individual Service User Placement
Not applicable.

References

1. Schulz JT, Sheridan RL, Ryan CM et al. A 10-year experience with toxic epidermal necrolysis. J Burn Care Rehabil 2000; 21:199-204.

2. McGee T, Munster A. Toxic epidermal necrolysis syndrome: mortality rate reduced with early referral to regional burn center. Plast Reconstr Surg 1998; 102:1018-22.

3. Palmieri TL, Greenhalgh DG, Saffle JR et al. A multicenter review of toxic epidermal necrolysis treated in U.S. burn centers at the end of the twentieth century. J Burn Care Rehabil 2002; 23:87-96.

4. Mahar PD, Wasiak J, Hii B et al. A systematic review of the management and outcome of toxic epidermal necrolysis treated in burns centres. Burns 2014; 40:1245-54

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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			
Reduced in-hospital mortality from SJS-TEN	Mortality 20% or more than predicted	SCORTEN predicted v actual mortality	External peer review
Domain 2: Enhancing the quality of life of people with long-term conditions			
All patients undergo psychological assessment	80%	Audit of clinical records	External peer review
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Length of ICU and PICU stay	6 weeks	Hospital activity data	External peer review
Domain 4: Ensuring that people have a positive experience of care			
No formal complaints from patient or family	>10% of patients	Hospital reports	Report to CQC
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
No never events	Zero	StEIS	Root cause analysis

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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

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- 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) training 2 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

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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

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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.

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- 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.

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.

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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 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.

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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. Improvng the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London.

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