SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No:	170043S
Service	Stevens-Johnson syndrome and toxic epidermal necrolysis (SJS-TEN), all ages
Commissioner Lead	*For local completion*
Provider Lead	*For local completion*

1. Scope

1.1 Prescribed Specialised Service

This service specification covers the provision of services for Toxic Epidermal Necrolysis (TEN) and Stevens-Johnson syndrome (SJS) (all ages).

1.2 Description

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.

1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

The service is accessible to all patients of the NHS in England with SJS-TEN. CCGs commission the local care recommended in the management plans developed by HSS centres as well as all other dermatology services. CCGs commission care for patients at Specialist Burn Care Centres once the burn care episode is complete.

2. Care Pathway and Clinical Dependencies

2.1 Care Pathway

Patients with SJS-TEN must be cared for in either an age-specific Burns Centre or Specialised Dermatology Centre co-located 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 patient pathway, summarised below, reflects close working 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.

Referral into the Service:

- The 24 hour SJS-TEN advice line will be manned by a rotation of consultants from the Specialist Centres.
- Clinical images from the referrer will be reviewed by the on-call consultant who will make a decision regarding the need for transfer to SJS-TEN Specialist Centre following discussion with the referring clinician.

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

- The accepting centre (specialised centre) must have an 'automatic acceptance' policy. Patients must not be refused admission due to non-availability of beds. All services will need to work together to ensure that patients are allocated to the geographically nearest centre .

- 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.

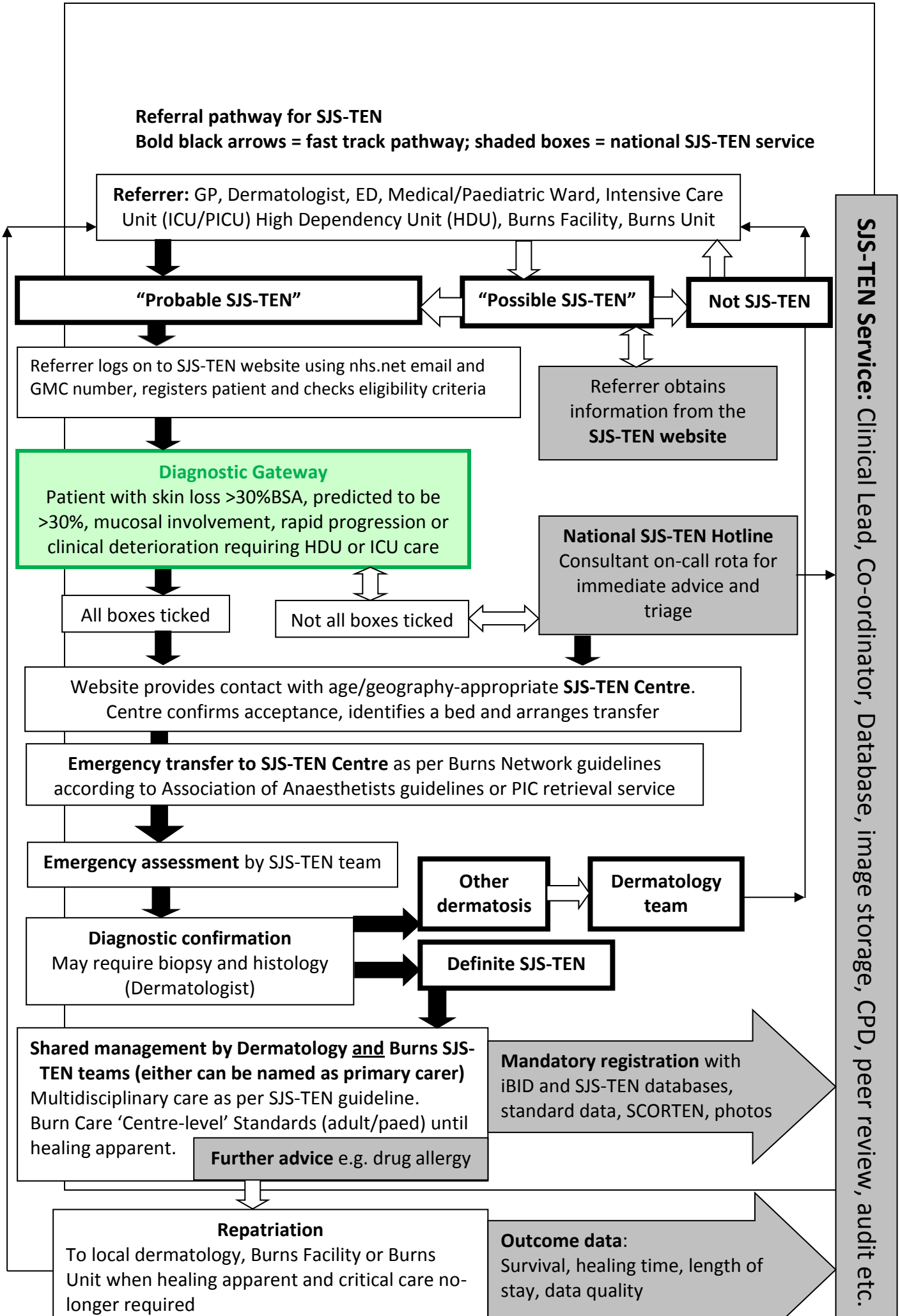
- Specialist centres must have the ability to implement and maintain faecal management systems.

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

Please note that access to treatment will be guided by any applicable NHS England national clinical commissioning policies.


Referral pathway for SJS-TEN
Bold black arrows = fast track pathway; shaded boxes = national SJS-TEN service
Referrer: GP, Dermatologist, ED, Medical/Paediatric Ward, Intensive Care Unit (ICU/PICU) High Dependency Unit (HDU), Burns Facility, Burns Unit
"Probable SJS-TEN"
"Possible SJS-TEN"
Not SJS-TEN
Referrer logs on to SJS-TEN website using nhs.net email and GMC number, registers patient and checks eligibility criteria
Referrer obtains information from the SJS-TEN website
Diagnostic Gateway
Patient with skin loss >30%BSA, predicted to be >30%, mucosal involvement, rapid progression or clinical deterioration requiring HDU or ICU care
All boxes ticked
Not all boxes ticked
National SJS-TEN Hotline
Consultant on-call rota for immediate advice and triage
Website provides contact with age/geography-appropriate SJS-TEN Centre. Centre confirms acceptance, identifies a bed and arranges transfer
Emergency transfer to SJS-TEN Centre as per Burns Network guidelines according to Association of Anaesthetists guidelines or PIC retrieval service
Emergency assessment by SJS-TEN team
Other dermatosis
Dermatology team
Diagnostic confirmation
May require biopsy and histology (Dermatologist)
Definite SJS-TEN
Shared management by Dermatology and Burns SJS-TEN teams (either can be named as primary carer)
Multidisciplinary care as per SJS-TEN guideline.
Burn Care 'Centre-level' Standards (adult/paed) until healing apparent.
Further advice e.g. drug allergy
Mandatory registration with iBID and SJS-TEN databases, standard data, SCORTEN, photos
Repatriation
To local dermatology, Burns Facility or Burns Unit when healing apparent and critical care no-longer required
Outcome data:
Survival, healing time, length of stay, data quality
SJS-TEN Service: Clinical Lead, Co-ordinator, Database, image storage, CPD, peer review, audit etc.

2.2 Interdependence with other Services

Critical adjacencies are either paediatric or adult and related to:

- Specialist critical care and anaesthesia
- Specialised dermatology
- Burn centre level care
- Nurses skilled in dressing changes to large areas of skin loss
- Other related specialties including ENT, ophthalmology
- Pain team
- Psychology
- Scar management
- Intensive care

Non critical adjacency (consultation would expect to be within 6 hours)

- Gynaecology, gastroenterology, urology, oral medicine

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

The NHS England contract includes provision for the service to treat eligible patients from overseas under S2 and aligned referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of this contract.

Trusts performing procedures on patients outside of S2 arrangements and aligned referral arrangements will need to continue to make the financial arrangements directly with the governments involved, separately from their contract with NHS England.

NHS England commissions the service for the population of England. Commissioning on behalf of other devolved administrations is reviewed annually, and a current list is available from NHS England commissioners.

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

3.2 Population Needs

The incidence of SJS-TEN (all ages) is approximately one to two cases per million per year.

3.3 Expected Significant Future Demographic Changes

No growth expected in total numbers of patients apart from that due to improved coding and identification of patients.

3.4 Evidence Base

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%. 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 (Gueudry et al.), 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 Clinical Reference Groups (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). An appendix covering management in children is in preparation. This specification will ensure the implementation of this guideline throughout England.

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; clinical trials to resolve uncertainties; opportunities for training and continuing professional development.

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim 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:

- 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 may resemble burns) with attention to fluid and electrolyte loss, sepsis, mucosal damage, pain and nutritional compromise.

NHS Outcomes Framework Domains

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**	✓

4.2 Indicators Include:

Number	Indicator	Data Source	Outcome Framework Domain	CQC Key question
Clinical Outcomes				
101	% Difference in SCORTEN predicted mortality vs actual mortality.	IBID	1	Safe, effective, caring, responsive

102	Average length of stay	Provider /HES	3, 4, 5	safe, caring, effective
103	Mortality rate - 1 year	SJS-TEN Database	1	Safe, effective, caring, responsive
104	% of patients undergoing psychological assessment	SJS-TEN Database	2	Safe, effective, caring, responsive
105	% of patients presenting with SJS-TEN seen within 12 hours by a Burns surgeon.	SJS-TEN Database	1, 3	Safe, effective, caring, responsive
106	% of patients presenting with SJS-TEN seen within 12 hours by a consultant Dermatologist	SJS-TEN Database	1, 3	Safe, effective, caring, responsive
107	% of patients presenting with SJS-TEN seen within 24 hours by a consultant Ophthalmologist	SJS-TEN Database	1, 3	Safe, effective, caring, responsive
Patient Experience				
201	Number of formal complaints from families	Provider	4	Safe, effective, caring, responsive
202	Patient feedback	Self declaration	4	Safe, effective, caring, responsive
Structure and Process				
301	Lead clinician	Self declaration	1, 2, 3, 4, 5	Well-led
302	24 access to specialist advice	Self declaration	1,2,3,4	Safe, effective, caring, responsive
303	Access to dermatopathologist	Self declaration	1,2,3,4	Safe, effective, caring, responsive
304	Nursing staff	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive
305	Facilities and support	Self declaration	5	Safe, effective
306	SCORETEN assessment	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive
307	Clinical guidelines	Self declaration	1, 2, 3, 4, 5	Safe
308	Patient pathways	Self declaration	1,2,3,4	Safe, effective, caring, responsive
309	Data submission	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive
310	Audit	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive

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 impact on patients
Survivors carry not only physical but also emotional scars as a result of being affected by such a devastating illness. There is a real fear of it happening again. Outcomes will be measured using an appropriate validated quality of life measure.

Length of hospital stay; Length of Intensive Care Unit (ICU) / Paediatric Intensive Care Unit (PICU) / High Dependency Unit (HDU) stay
Expert care and avoidance or prompt treatment of complications should reduce length of stay.

Detailed definitions of indicators, setting out how they will be measured is included in schedule 6.

4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C

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 GPs.

4.4 Applicable CQUIN goals are set out in Schedule 4D

To be agreed with the Commissioner.

5. Applicable Service Standards

5.1 Applicable Obligatory National Standards
Not applicable

5.2 Other Applicable National Standards to be met by Commissioned Providers
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. Br J Dermatol. **2016** Jun;174(6):1194-227 and J Plast Reconstr Aesthet Surg. **2016** Jun;69(6):e119-53)

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.

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)

5.3 Other Applicable Local Standards
Not applicable

6. Designated Providers (if applicable)

To be agreed. It is expected that there would be 4 adult and 2-3 paediatric centres nationally.

7. Abbreviation and Acronyms Explained

The following abbreviations and acronyms have been used in this document:

SJS - Stevens-Johnson syndrome
TEN - toxic epidermal necrolysis
BSA - Body Surface Area
ICU - Intensive Care Unit
PICU - Paediatric Intensive Care Unit
HDU - High dependency Unit
iBID - International Burn Injury Database
SCORTEN - SCORe of Toxic Epidermal Necrosis

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) training[2] and should maintain the competencies so acquired[3]*. 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.

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 person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents / carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child / young person.

Applicable national standards e.g. NICE, Royal 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 2 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 that 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
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participating in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.

- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications.
- Ensuring that those working with children must wait for a full 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.

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.

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 offering 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 is 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:

- 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.