



Department  
of Health

# Prescribed Specialised Services Advisory Group

Recommendations to Ministers

March 2015

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<b>Author: Innovation Growth and Technology Directorate/ Medicines, Pharmacy and Industry Division/ MPI-CCE / 17090</b>
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<b>Contact details:</b>  PSSAG Secretariat Room 2E14 Quarry House Quarry Hill Leeds LS2 7UE  sarah.samuel@dh.gsi.gov.uk

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# Prescribed Specialised Services Advisory Group (PSSAG)

## Recommendations to Ministers

**Prepared by the PSSAG Secretariat, Department of Health**

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# Introduction

Since its last report was published in May 2014, the Prescribed Specialised Services Advisory Group (PSSAG) has continued to provide advice to Ministers on specialised services and held meetings on 16 May 2014 and 30 September 2014. This report presents PSSAG's recommendations from both meetings and sets out Ministers' decisions on each of the recommendations it made.

In deciding whether it would be appropriate for a health service to be nationally commissioned by NHS England the Secretary of State must have regard to four statutory factors (as set out in section 3B(3) of the National Health Service Act 2006 as amended by the Health and Social Care Act 2012). These are:

- The number of individuals who require the provision of the service or facility;
- The cost of providing the service or facility;
- The number of persons able to provide the service or facility; and
- The financial implications for Clinical Commissioning Groups if they were required to arrange for the provision of the service or facility.

Before deciding to make regulations requiring NHS England to commission such services, the Secretary of State must (a) obtain appropriate advice for that purpose, and (b) consult NHS England. PSSAG was established by the Department of Health in 2013 to provide the Secretary of State with this advice.

The specialised services directly commissioned by NHS England are listed in Schedule 4 to the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, 'the Regulations'. Ministers obtained advice on the initial list of specialised services to be commissioned by NHS England from 1 April 2013 (set out in the Regulations) from an independent stakeholder group, the Clinical Advisory Group (CAG), established in June 2011 to provide Ministers with this advice.<sup>ii</sup> Following advice from PSSAG and consultation with NHS England, the list of specialised services set out in Schedule 4 was amended with effect on 1 April 2014 to add two new services.<sup>iii</sup>

It is NHS England's responsibility to determine how these services are commissioned. Service descriptions for each of the specialised services are set out in NHS England's 'Manual for prescribed specialised services' (first published November 2012 and updated in January 2014).<sup>iv</sup> The Manual should be considered alongside service specifications, NHS England commissioning policies and the technical requirements NHS England imposes on providers. (References in this report to service descriptions are to the descriptions given in the Manual.)

# Prescribed Specialised Services Advisory Group (PSSAG)

PSSAG is a Department of Health expert committee that was established in 2013 to provide ongoing advice to Ministers on whether services are specialised and should be nationally commissioned by NHS England, rather than locally commissioned by Clinical Commissioning Groups (CCGs).

Membership of the group includes representatives from the Royal Colleges and CCGs, lay members to represent the interests of patients and the general public, and members with financial and technical expertise who can offer assistance with matters relating to coding and how the specialised elements of a service can be separately identified. The full PSSAG membership is at Annex A.

Evidence and supporting information on services currently prescribed in legislation for direct commissioning by NHS England and any new services identified as potentially suitable for such commissioning, is made available to PSSAG from a range of sources. These may include Clinical Reference Groups (CRGs)<sup>v</sup>, patient groups, clinicians, commissioners and members of the public. The proposals the Group considers are in large part generated by NHS England through its CRGs.

PSSAG's work programme will also include review of services previously identified by the CAG for "early review". These services were generally recommended by CAG for review in two to three years once the new commissioning arrangements were established. The majority of these were services that CAG recommended for commissioning by NHS England in the first instance with a view to elements being considered for commissioning by CCGs in the future. In addition, CAG recommended three services for commissioning by CCGs in the first instance with a view to elements being considered for commissioning by NHS England in the future.<sup>vi</sup>.

## Process

PSSAG considers four specific questions:

1. Whether the services currently included on the list of prescribed specialised services set out in legislation should continue to be commissioned by NHS England.
2. Whether there are services currently commissioned by NHS England, which would be more appropriately commissioned by CCGs.
3. Whether there are services currently commissioned by CCGs, which would be more appropriately commissioned by NHS England.
4. Whether there are innovative new treatments and interventions that are not part of existing services and which should be commissioned by NHS England.

When considering if a service is specialised or not the group must review existing services and assess new ones on the basis of the four factors within the National Health Service Act 2006 which are:

- The number of individuals who require the provision of the service or facility;

- The cost of providing the service or facility;
- The number of persons able to provide the service or facility; and
- The financial implications for Clinical Commissioning Groups if they were required to arrange for the provision of the service or facility.

In developing its advice, PSSAG may also consider such matters as:

- How activity can be identified to enable separate contracting, monitoring and payment;
- Likely running costs associated with separate and direct commissioning;
- Defining elements of service to be commissioned; and
- The number of provider contracts NHS England is likely to need to develop to directly commission the service.

As part of the process in advising the Secretary of State about statutory prescribed services, the group will also consider proposals from NHS England on the formulation of its service descriptions and will provide advice to Ministers on whether the service descriptions (and any proposed changes) are appropriate in respect of the prescribed service.

## Public consultation

At PSSAG's meeting in September 2014 it was asked to consider proposals from NHS England that renal dialysis services and morbid obesity surgery services should no longer be commissioned nationally by NHS England. PSSAG considered the two services against the four statutory factors and concluded that they were not appropriate for national commissioning by NHS England.

PSSAG therefore recommended to Ministers that commissioning responsibility for these two services should transfer to CCGs. In addition to the statutory consultation with NHS England required by the Health and Social Care Act 2012, Ministers requested an additional, wider, public consultation on the logistics and timing of the transfer of these two services.

The public consultation ran from 27 November 2014 to 9 January 2015. A Government Response to the consultation was published on 3 February 2015.<sup>vii</sup>

## Outcomes

This report sets out the recommendations that PSSAG made at its May 2014 and September 2014 meetings on the services to be directly commissioned by NHS England. Ministers have accepted the recommendations set out in this report, with the exception of the recommendation for commissioning of renal dialysis services.

In accordance with the Health and Social Care Act 2012 a formal consultation with NHS England was carried out on the proposed changes. NHS England's response to the consultation confirmed that it was in agreement with PSSAG's recommendations, but that it felt commissioning responsibility for renal dialysis services and morbid obesity surgery services

should transfer to CCGs from April 2016. This was in line with the feedback received from the Department's public consultation.

Ministers are in agreement that commissioning responsibility for morbid obesity surgery services should transfer from NHS England to CCGs from April 2016. With regard to the transfer of commissioning responsibility for renal dialysis services, the Department became aware that NHS England had provided an incorrect patient population figure to PSSAG when presenting this proposal. Ministers therefore requested that the proposal be reconsidered by PSSAG taking the correct patient population figure into account.

In its response to the statutory consultation with NHS England, NHS England also recommended that transfer of commissioning responsibilities from CCGs to NHS England for i) management services for adults with primary ciliary dyskinesia, ii) specialist adult haematology services, and iii) some aspects of specialist paediatric intensive care services should all take place from April 2016 rather than April 2015. NHS England advises that this is necessary to allow time to ensure a safe and effective transfer of commissioning responsibilities for all of these services. Ministers agreed with this recommendation.

PSSAG's recommendations, along with the formal consultation with NHS England and the Department's public consultation on the proposed transfer of commissioning responsibility for renal dialysis services and morbid obesity surgery services, will inform the development of the necessary statutory instruments to amend Schedule 4 of the Regulations, setting out the specialised services for which NHS England will have commissioning responsibility both from April 2015 and April 2016.



# 1. Adult Attention Deficit Hyperactivity Disorder

## Service summary and proposal

Guidance issued by the National Institute for Health and Care Excellence (NICE) sets out the basis on which Clinical Commissioning Groups (CCGs) should commission services for adults with attention deficit hyperactivity disorder (ADHD). PSSAG considered a proposal from NHS England (with support from the Board members of the UK Adult ADHD Network, UKAAN) that NHS England should commission Highly Specialist Centres that could support CCG-funded specialist adult ADHD services on an outreach basis. This would include a tertiary diagnostic and second opinion service.

## View of PSSAG

PSSAG is of the view that further information is needed before it can take a decision on this proposal. PSSAG will therefore re-consider this proposal at a future meeting.

## Suggested changes

PSSAG do not advise changes at this time.

## 2. Adult haematology services

### Service summary and proposal

Adult specialised haematology services are not currently prescribed in regulations, and CCGs commission all adult haematology services (except in a few prescribed cases). NHS England currently commissions the majority of haematology services for children and young people and all rare cancer services. In September 2013, PSSAG considered a proposal from NHS England that it should commission a highly specialist haematology service for adults, to provide for greater alignment between the adult and children's services (which were already prescribed). This would include the following rare conditions:

- Thrombotic thrombocytopenic purpura (TTP) - a rare blood disorder resulting in clots that cause damage to the kidney, heart and brain.
- Langerhans' cell histiocytosis (LCH) - a cancer-like condition in which an abnormal increase in immune cells causes organ damage.

### View of PSSAG and Ministers

PSSAG agreed, on the basis of the four statutory factors, that adult specialised haematology services are suitable for commissioning by NHS England, rather than by CCGs, particularly with respect to the small number of individuals requiring the provision of the service, the high cost of providing the service, the very small number of individuals with the expertise to treat these patients and the significant financial risk to CCGs if they were required to provide the service. PSSAG recommended that NHS England commission an adult highly specialist haematology service including the aforementioned rare conditions. Ministers agreed with PSSAG's advice and made the decision for commissioning responsibility for adult specialised haematology services to transfer to NHS England from 1 April 2015.

### Update

At the September 2014 meeting, NHS England informed PSSAG that it would be unable to take on commissioning responsibility for adult specialised haematology services until 1 April 2016. This was due to the transfer of the service proving more difficult than initially envisaged. The relevant Clinical Reference Groups will work together during 2015/16 to ensure NHS England is able to take on commissioning responsibility for these services from April 2016.

## 3. Adult highly specialist pain management services

### Service summary and proposal

Adult highly specialist pain management services include services provided by Adult Highly Specialist Pain Management Centres

PSSAG considered a proposal from NHS England that it change the wording of the service description for “Adult highly specialist pain management services” to read “For specified interventions, the service includes condition specific MDT specialised assessment and management including procedure costs (including devices), specialist pain-specific psychological and behavioural interventions, inpatient care, follow up and rehabilitation.”

### View of PSSAG

PSSAG agreed that this would be a better description of the services currently being commissioned by NHS England.

### Suggested changes

NHS England to update the service description as set out in the proposal.

## 4. Adult specialist cardiac services

### Service summary and proposal

Adult specialist cardiac services include:

- All cardiac surgery activity;
- Complex cardiac electrophysiology services;
- Provision of complex device therapy;
- Inherited heart disease services;
- Complex invasive cardiology services;
- Primary percutaneous coronary intervention (PPCI) services for ST-elevated myocardial infarction; and
- Provision of cardiac magnetic resonance imaging (cardiac MRI).

PSSAG considered a proposal from NHS England to change the term “complex invasive cardiology services” within the service description to “complex interventional cardiology procedures”. This term was proposed as better reflecting the terminology used to describe the specialised service being commissioned.

### View of PSSAG

PSSAG agreed that this would be a better description of the services currently being commissioned by NHS England.

### Suggested changes

NHS England to update the service description as set out in the proposal.

## 5. Adult specialist neurosciences services

### Service summary and proposal

Adult specialist neurosciences services encompass all services provided by Adult Neurosciences or Neurology Centres. These include:

- All neurosurgery activity;
- All interventional procedures within neuroradiology;
- Inpatient neurology;
- Specialist diagnostics (including neurophysiology, neuroradiology); and
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care).

NHS England also currently commissions all neurology outpatients at Adult Neurosciences or Neurology Centres. From April 2015, it will only commission outpatients that have been referred by a consultant.

NHS England commissions all inpatient services, whether or not the services are specialist, from Adult Neurosciences or Neurology Centres. CCGs commission non-specialist services delivered outside of Adult Neurosciences or Neurology Centre.

PSSAG considered a proposal from NHS England for CCGs to commission non-specialist inpatient neurology services from Adult Neurosciences or Neurology Centres.

### View of PSSAG

PSSAG agreed that discussions on the proposals for adult specialist neurosciences would be postponed to a future meeting, when more detailed proposals could be provided.

### Suggested Changes

PSSAG advised no suggested changes at this time.

## 6. Adult specialist ophthalmology services

### Service summary and proposal

Adult specialist ophthalmology services include services provided by Adult Specialist Ophthalmology Centres, including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex procedures only. Adult specialist ophthalmology services also include the provision of artificial eyes to adults and children.

PSSAG considered a proposal from NHS England to amend the term “Adult Specialist Ophthalmology Centres” within the service description to “Adult Specialist Ophthalmology Networks” as this term better described the way services are provided under the current commissioning arrangements.

### View of PSSAG

PSSAG agreed that this would be a better description of the services currently being commissioned by NHS England.

### Suggested changes

NHS England to update the service description as set out in the proposal.

## 7. Adult specialist renal services

### Service summary and proposal

Adult specialist renal services include:

- All dialysis services (including plasma exchange for patients with acute kidney injury);
- Outpatient assessment and preparation for renal replacement at Adult Specialist Renal Centres including procedures relating to establishing renal access prior to dialysis; and
- All transplant-related care provided by Adult Specialist Renal Centres and all transplantation activity provided by Adult Renal Transplant Centres.

PSSAG considered a proposal from NHS England that commissioning responsibility for renal dialysis services should transfer from NHS England to CCGs. NHS England would retain commissioning responsibility for renal transplantation services for adults.

### View of PSSAG

PSSAG agreed that, on the basis of the four statutory factors, renal dialysis services did not require national commissioning by NHS England. The patient population was high – information provided by NHS England, gave a figure of about 45,000 individuals requiring renal dialysis per annum. Whilst the total cost of delivering renal dialysis services was high, the cost in individual cases was not considered to be high. There were many people able to provide renal dialysis, with some activity taking place outside of specialist centres, and PSSAG felt that there would be no specific financial risk to CCGs of having to commission this service. NHS England confirmed that CCGs would receive appropriate budgets to commission the service and were confident that the funding could be disaggregated.

### Update

The Department has since become aware that the patient population figure provided by NHS England as part of the proposal was incorrect. The figure provided was 45,000 individuals requiring renal dialysis per annum. The correct figure is nearer to 23,000 individuals requiring renal dialysis per annum.

In light of this Ministers have asked NHS England to refer the proposals back to PSSAG for reconsideration using the correct patient population figure.

## 8. Bone anchored hearing aid services and Middle ear implantable hearing aid services

### Service summary and proposal

The Specialised Ear Surgery Clinical Reference Group has advised that the term ‘bone anchored hearing aid device’ relates to a device made by a specific manufacturer. It has also advised that it would make clinical sense to combine the separately prescribed services for bone anchored and middle ear devices into a single prescribed service covering bone conduction hearing implants for all ages.

PSSAG considered a proposal from NHS England that the service description for the new Regulation be:

“Bone conduction hearing implant (BCHI) services include multi-disciplinary assessment, surgical implantation and rehabilitation (including maintenance of the implant). This applies to provision in adults and children.”

### View of PSSAG

PSSAG agreed that, given the commercial overtones of the current prescription, it would be appropriate for it to be amended. PSSAG accepts the clinical sense of combining the current prescriptions for bone anchored hearing and middle ear devices into a single prescription covering bone conduction hearing implants for all ages.

### Suggested changes

PSSAG advised ministers to replace the current prescribed services for “bone anchored hearing aid services” and “middle ear implantable hearing aid services” with “bone conduction hearing implant services”.

NHS England to update its service descriptions accordingly.



## 9. Fetal alcohol spectrum disorders

### Service summary and proposal

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing a continuum of birth defects caused by maternal consumption of alcohol during pregnancy.

Services for FASD are not currently prescribed in regulations, and CCGs commission all services for patients with FASD. PSSAG considered a proposal for NHS England to commission a highly specialist FASD service for all ages, including outreach when delivered as part of a provider network.

### View of PSSAG

PSSAG agree that, on the basis of the four statutory factors, highly specialist FASD services for all ages would not be appropriate for national commissioning by NHS England.

The Paediatric Medicine Clinical Reference Group confirmed to PSSAG that it did not feel on the basis of the four statutory factors that FASD services were appropriate for national commissioning by NHS England. There was understood to be a lack of incidence and prevalence data, leading to uncertainty around the potential number of referrals per year. PSSAG were of the view it would be very difficult to identify the sub-set of patients who would benefit from referral to a specialist centre. There are no bio-markers for FASD that could be used to identify such patients.

### Suggested changes

PSSAG did not advise changes to the prescribed services. CCGs to remain responsible for commissioning services for patients with FASD.

# 10. Highly specialist colorectal surgery services

## Service summary and proposal

Highly specialist colorectal surgery services include the following services for adult patients when provided by Highly Specialist Colorectal Surgery Centres:

- Surgical management for complex inflammatory bowel disease; and
- Complex surgical interventions for faecal incontinence.

PSSAG considered a proposal to change the wording of the regulation from “Highly specialist colorectal surgery services” to “Specialist colorectal surgery services” and the terminology within the NHS England service description from “Highly specialist colorectal surgery.....” to “Specialist colorectal surgery....”

NHS England advised that this service is more common than what would normally be described as a “highly” specialised service. Therefore, the proposed terminology would better describe the service currently being commissioned by NHS England.

## View of PSSAG

PSSAG agreed that this would be a better description of the services currently being commissioned by NHS England.

## Suggested changes

PSSAG advised that the statutory prescribed service needed to be more accurate and recommended replacing the current prescribed services “Highly specialist colorectal surgery services” with “Specialist colorectal surgery services”.

NHS England to update the service description accordingly.

# 11. Maternal care – abnormally invasive placenta

## Service summary and proposal

CCGs commission all maternity care, except where the woman has a condition in which her care falls within a specialist service commissioned by NHS England, for example, cystic fibrosis.

Abnormally invasive placenta is a condition in which the placenta invades too deeply or attaches too strongly to the uterine wall. The placenta can also attach to and invade into adjoining organs, potentially leading to massive haemorrhage. It is the most common cause of peripartum hysterectomy. Incidence is increasing as a result of increasing rates of caesarean section, older childbearing, and In Vitro Fertilisation (IVF);

PSSAG considered a proposal from NHS England for maternity care services for women with abnormally invasive placenta to be commissioned by NHS England.

## View of PSSAG

Services for abnormally invasive placenta - PSSAG agreed that this service could be appropriate for national commissioning on the basis of the four statutory factors in principle, but only for those patients accessing services after being identified as likely to have an abnormally invasive placenta.

PSSAG requested that the views of the presidents of the Royal College of Midwives and the Royal College of Obstetricians and Gynaecologists, and the National Clinical Directors for Diagnostics and Maternity and Women's Health at NHS England be sought on the potential size of patient population for this service, how it would be defined, and whether this could fundamentally change the patient pathway and routine ante-natal care.

PSSAG agreed that if the requested information confirms that the patient population is low and can be defined, the Group will be content to allow the Chair to make the decision to recommend this service for national commissioning by NHS England on its behalf, rather than this proposal being brought back to a future meeting.

## Suggested changes

PSSAG did not recommend changes at this time, subject to any view Professor Sir Ian Gilmore may take on receiving the requested evidence described above.

# 12. Practitioner Health Programme

## Service summary and proposal

The NHS Practitioner Health Programme (PHP) aims to improve the mental health and social functioning of doctors and dentists, aid them to return to and/or retain work, reduce the risk to patients and the public, and reduce the need for regulatory involvement. It does this by providing confidential treatment for doctors and dentists with mental health or addiction problems who cannot access mainstream NHS services.

The NHS PHP consists of a primary care led multidisciplinary team of clinical experts with the specialist knowledge, skills and expertise to cater for this particular patient group. The competencies required have been defined and approved by the Royal College of General Practitioners, Royal College of Psychiatry, and the Faculty of Occupational Medicine.

NHS England does not currently commission any services for doctors and dentists who cannot access mainstream NHS services. PSSAG considered a proposal from the NHS Practitioner Health Programme for NHS England to commission these services.

## View of PSSAG

PSSAG was of the view that, on the basis of the four statutory factors, it is unable to recommend the PHP service for national commissioning by NHS England.

PSSAG recognised the importance of the service and the potential for patient risk as well as service disruption caused by sick doctors unable to access appropriate treatment. PSSAG suggested that this area may benefit from an independent national review, looking at what services are already in place for doctors and dentists across the country. The review could also make recommendations on the most appropriate service specification for providing support to this vulnerable group of practitioners. It was suggested that the Royal Medical Benevolent Fund might have an interest in such a review.

## Suggested changes

PSSAG did not advise changes to be made at this time. The Department is considering PSSAG's suggestion that a review in this area would be helpful.

## 13. Primary Ciliary Dyskinesia management services for adults

### Service summary and proposal

Primary Ciliary Dyskinesia (PCD) is a rare hereditary disorder of ciliary dysfunction leading to multisystem abnormalities. Chronic infection of the upper and lower airway is the most common symptom. Without appropriate specialised treatment, progressive chronic lung disease and bronchiectasis develop.

NHS England commissions highly specialised management centres for management of PCD in children. NHS England also commissions diagnostic services for all patients with PCD.

PSSAG considered a proposal from NHS England (with significant patient group input) for NHS England to commission management services for adults with PCD. This would offer continuity of specialised care into adulthood.

The proposed NHS England commissioned service would be specifically for:

1. Transition of paediatric patients with a confirmed diagnosis of PCD;
2. Adult patients with a confirmed diagnosis of PCD made by the PCD Diagnostic Service; and
3. Adult patients with clinically suspected PCD but indeterminate results of investigations by the adult or paediatric PCD Diagnostic services.

### View of PSSAG

PSSAG agreed that, on the basis of the four statutory factors, this service was appropriate for national commissioning.

According to the information provided, the number of individuals requiring the service was low; the cost of providing the service was understood to be high; the number of persons able to provide the service was low with five or fewer providers able to provide the service, and the Group agreed there would likely be financial implications for CCGs if they were required to provide the service.

PSSAG therefore recommended that NHS England should commission a management service for adults with primary ciliary dyskinesia.

### Suggested changes

PSSAG recommended that NHS England take on responsibility for commissioning management services for adults with primary ciliary dyskinesia, and that the Regulations be amended as necessary to reflect this commissioning responsibility.

### Update

In its response to the statutory consultation, NHS England has advised that the transfer of commissioning responsibility for this service should be postponed until 1 April 2016, to allow time to develop a national service specification and identify funding. Ministers agreed that the transfer should take place from April 2016.

# 14. Severe alpha 1 anti-trypsin deficiency services

## Service summary and proposal

Alpha 1 anti-trypsin deficiency is a rare genetic condition that usually affects the lungs and liver. The condition frequently causes disability and can shorten life expectancy.

PSSAG considered a proposal, put forward by NHS England's Specialised Respiratory CRG and with extensive input from the Alpha 1 Alliance (a charity formed to provide information and support to sufferers of the condition):

- NHS England to commission severe alpha 1 antitrypsin deficiency services from Highly Specialist Highly Specialist Respiratory Centres; and
- CCGs to commission all care for patients with alpha 1 anti-trypsin deficiency not delivered by the specialist centre including: pulmonary rehabilitation, acute admissions, exacerbation management, smoking cessation, oxygen therapy, all community care e.g. case management, primary and secondary care clinic consultations, testing for family members of index cases.

## View of PSSAG

PSSAG agreed that the patient population is small and the costs are relatively modest (at £5,000 per patient per year). However, PSSAG questioned whether all the relevant expertise was concentrated in only three to five centres and believed there were likely to be more centres in the UK with combined liver and lung expertise. The Group is also of the view that there would be little burden to CCGs if they were to continue to fund the care of patients with alpha 1 anti-trypsin deficiency. The main expense would be in transplantation and this is already designated as specialised activity to be commissioned by NHS England.

PSSAG agreed that if there are new developments in treatment, such as a licensed augmentation therapy, a proposal could be brought back to PSSAG for consideration.

PSSAG noted that several of its members had been sent a report directly by the Alpha 1 Alliance. PSSAG is confident that it gave fair and objective consideration to the proposals in this case. Members' concerns about the direct contact were noted and it was confirmed that such contact should go through the PSSAG secretariat.

## Suggested changes

PSSAG recommended no changes be made at this time.

## 15. Severe intestinal failure service / Adult specialist intestinal failure services

### Service summary and proposal

PSSAG considered a proposal from NHS England to change the wording of the regulations in relation to these services, specifically that the prescribed service “adult specialist intestinal failure service” be removed from the regulations on the basis that these services are encompassed within “severe intestinal failure service”.

### View of PSSAG

PSSAG received confirmation from the Specialised Colorectal Services CRG that “adult specialist intestinal failure service” was encompassed within “severe intestinal failure service” and that amending the regulations to remove “adult specialist intestinal failure” did not alter the scope of the service being commissioned. Based on this confirmation PSSAG agreed that there was no need for a distinct prescribed service in the statutory requirements, and that a change in the wording of the regulations should be made.

### Suggested changes

PSSAG advised the removal of the separate prescribed service “adult specialist intestinal failure” from the list of prescribed services.

NHS England to update its service descriptions accordingly.

# 16. Severe paediatric chronic fatigue syndrome/myalgic encephalopathy

## Service summary and proposals

Paediatric Chronic Fatigue Syndrome (CFS)/Myalgic Encephalopathy (ME) is a debilitating condition characterised by disabling and persistent fatigue. Children with severe CFS/ME are rarely able to leave the house, are dependent on mobility equipment, and need help with basic self-care.

The National Institute for Health and Clinical Excellence guidelines state that children with severe CFS/ME should be assessed and treated at home by specialist services. NHS England does not currently commission services for children with severe CFS/ME.

PSSAG considered a proposal, put forward by a Consultant Paediatrician at the Royal Hospital for Rheumatic Diseases. The proposal was for NHS England to commission services for children with severe CFS/ME from Highly Specialist Chronic Fatigue Syndrome/Myalgic Encephalopathy Centres, including assessment and intensive follow-up treatment provided in the patient's home. CCGs would commission all other services for paediatric CFS/ME.

## View of PSSAG

PSSAG is of the view that there are significant problems with how severity is defined in the context of 'severe CFS/ME', and how this cohort of patients is identified. The size of the patient population stated in the proposal would be appropriate for specialised commissioning but the Group has concerns about the reliability of the data provided.

PSSAG has requested additional information related to this proposal, specifically:

- The criteria and thresholds intended for referral and how many patients would be estimated to fulfil these criteria per annum; and
- Any work that has been done on outcome data or audits, and how and whether this group of patients will be seen by Child and Adolescent Mental Health Services (CAMHS).

Once this information had been obtained, PSSAG would also find it useful to take the views of the Royal College of Paediatrics and Child Health, the Royal College of Psychiatrists, and the Association for Young People with CFS/ME before discussing the proposal again.

## Suggested changes

PSSAG suggested no changes be made at this time.



# 17. Specialist burn care services

## Service summary and proposal

Specialist burn care services include all burn care delivered by Burn Centres, Burn Units and Burn Facilities delivered as part of a provider network. This covers the whole pathway for children and adults including:

- Specialist assessment ;
- Admission to a Centre, Unit or Facility; and
- Rehabilitation and surgical reconstruction.

PSSAG considered a proposal from NHS England to change the wording within the NHS England service description from "...Burn Centres, Burn Units and Burn Facilities delivered as part of a provider network." to "...Burn Centres, Burn Units and Burn Facilities delivered as part of an Operational Delivery Network." and to insert a new bullet point "Outreach" into the list of elements of the care pathway.

## View of PSSAG

PSSAG agreed with this proposal.

## Suggested changes

NHS England to update the service description accordingly.

# 18. Specialist immunology services for patients with deficient immune systems

## Service summary and proposal

Specialist immunology services include services provided by Highly Specialist Immunology Centres, including outreach when delivered as part of a provider network, for the following:

- All primary immunodeficiencies;
- Autoimmune and auto inflammatory disease where there is associated immunodeficiency;
- Complex autoimmune and vasculitic conditions as shared care; and
- Auto inflammatory syndromes

Services include provision of cytokines and other immunomodulatory therapies for the above conditions.

PSSAG considered a proposal from NHS England to allow different entries to be included in NHS England's Manual reflecting the differentiation between adult and children's services. NHS England proposed splitting the current regulation which applies to 'all ages' into two separate regulations representing adult and children's services.

## View of PSSAG

PSSAG agreed with this proposal.

## Suggested changes

PSSAG recommended that provision be made for two distinct prescribed services: one being adult specialist immunology services and the other paediatric immunology services.

NHS England to update its Manual of prescribed specialised services as proposed to replace the current service description for "Specialist immunology services for patients with deficient immune systems" with new distinct service descriptions for the adult and children's services.

# 19. Specialist morbid obesity services

## Service summary and proposal

Specialist morbid obesity services include services provided by Specialist Morbid Obesity Centres. The service includes all bariatric surgical procedures and the associated care, as well as medical care provided by these centres for complex patients unsuitable for or not requiring surgery. This applies to provision in adults and children.

PSSAG considered a proposal from NHS England that NHS England should no longer commission morbid obesity services for adults and that these services should instead be commissioned by CCGs. NHS England would continue to commission morbid obesity surgery services for children.

## View of PSSAG

PSSAG agreed that, on the basis of the four statutory factors, this service does not require commissioning by NHS England. Figures provided by NHS England showed that the number of operations undertaken per year was around 8,000. NHS England reported that there are 138 surgeons able to deliver obesity surgery services. NHS England confirmed that specialist morbid obesity surgery and associated activity was covered by national tariffs and that CCGs would receive appropriate budgets. PSSAG therefore felt that there would be no specific financial risk to CCGs in having commissioning responsibility for this service.

PSSAG considered that this could be a complex issue for CCGs to take on and to mitigate this it was of the view that providers and commissioners at all levels need to work in partnership. PSSAG agreed that consideration should be given to whether CCGs should continue to use the national service specification and associated access policy to commission this service, noting that the future direction of travel might be to invest in Tier 3 obesity services and thus prevent patients needing care at Tier 4 level.

PSSAG also recommended that NHS England explore options for putting Key Performance Indicators (KPIs) in place for both commissioners and providers, and that any KPIs would need to reflect the direction towards Tier 3 services. PSSAG suggested that NHS England would need to provide CCGs with information about waiting lists for surgery.

## Suggested changes

PSSAG advised that statutory prescribed services be amended to omit specialised morbid obesity services for adults. PSSAG recommended that NHS England amend its service description to make it clear that severe and complex obesity services only includes children and not adults.

# 20. Specialist ophthalmology services for children and young people

## Service summary and proposal

Specialist ophthalmology services for children and young people include services provided by Specialist Paediatric Ophthalmology Centres, including outreach when delivered as part of a provider network. The service includes management of rare conditions and complex or high risk procedures only.

PSSAG considered a proposal from NHS England to amend the term “Specialist Paediatric Ophthalmology Centres” within the service description to “Specialist Paediatric Ophthalmology Networks” as this term better described the way services are provided under the current commissioning arrangements.

## View of PSSAG

PSSAG agreed that this would be a better description of the services currently being commissioned by NHS England.

## Suggested changes

NHS England to amend the service description accordingly.

## 21. Specialist paediatric critical care services

### Service summary and proposal

NHS England commissions most paediatric critical care services under the service prescribed in Regulations as “specialist paediatric intensive care services”. Some paediatric critical care services – including some transport services – are commissioned by CCGs.

In September 2013, PSSAG considered a proposal from NHS England that the latter should commission the transfer of all non-ventilated children into Level 2 and 3 critical care facilities and repatriation of children from paediatric critical care to the hospital nearest to their home area or to a Level 2 unit. NHS England also proposed that the terminology used to describe the service should be aligned with that used in adult and neonatal critical care services.

### View of PSSAG and Ministers

PSSAG agreed, on the basis of the four statutory factors, that transfer of non-ventilated children into Level 2 and 3 critical care facilities and repatriation of children from paediatric critical care to the hospital nearest to their home area or to a Level 2 unit were appropriate for commissioning by NHS England. This was agreed at PSSAG’s meeting in September 2013. Ministers agreed with PSSAG’s advice and made the decision for commissioning responsibility for these services to transfer to NHS England from 1 April 2015.

### Update

NHS England informed PSSAG at its September 2014 meeting that NHS England would be unable to take on commissioning responsibility for these services until 1 April 2016.

The transfer of commissioning responsibility for these services has proved more difficult than originally envisaged. The Paediatric Intensive Critical Care CRG has given further consideration to the proposal and is working to confirm activity levels, identify and map the current transport provider commissioning pattern, and identify associated funding. NHS England advised that this is a complex piece of work and could not be completed in time for a transfer from April 2015.

## 22. Specialist services to support patients with complex physical disabilities

### Service summary and proposal

The current service description for this service is as follows:

‘Specialist services to support patients with complex physical disabilities (including those with a combination of physical, sensory, intellectual, learning or cognitive disabilities) include the specialist assessment for, and provision of (if indicated):

- Prosthetics (limb and artificial eyes);
- Specialist wheelchairs (including complex postural seating and powered wheelchair controls) (PSSAG has already advised that this element of the service should be commissioned by CCGs from April 2015);
- Specialist augmentative and alternative communication aids; and
- Specialist environmental controls.

This applies to provision in relation to adults and children.’

PSSAG considered a request from the Complex Disability CRG for PSSAG’s understanding as to whether the provision of recreational/sports limbs is included within the service description as detailed above, given that these prostheses might not meet a specific health need but rather a recreational need.

The CRG is seeking this clarification because the provision of recreational/sports limbs was not specifically discussed by the Clinical Advisory Group.

### View of PSSAG

PSSAG’s view was that it would not consider the provision of recreational/sports limbs to be within the currently prescribed service. If NHS England wanted this service to be prescribed a proposal on the provision of recreational/sports limbs would need to be put to PSSAG at a future meeting.

### Suggested changes

PSSAG did not advise changes at this time.

## 23. Spina Bifida

### Service summary and proposal

Spina bifida is a developmental congenital disorder caused by the incomplete closing of the embryonic neural tube, affecting the development of the spinal cord and the vertebrae, muscles, and skin which would usually enclose it. This damage to the spinal cord results in disruption in communication between the brain and the parts of the body served by nerves arising from the cord below the lesion, in a similar way to an acquired spinal cord injury.

PSSAG considered a proposal from NHS England for specialist services for adults with spina bifida to be separately regulated and for NHS England to commission those specialist services for adults with spina bifida that are not already prescribed elsewhere.

NHS England already commissions all specialist care from Adult Neurosciences and Neurology Centres, regardless of patient diagnosis.

CCGs would commission:

- Outpatients who have not been referred by a consultant;
- Non-specialist procedures from Spina Bifida Centres; and
- Ongoing local and community care for adults with spina bifida from providers that are not Spina Bifida Centres.

### View of PSSAG

PSSAG was of the view that it could not make a decision on the commissioning of spina bifida services without additional information.

PSSAG was presented with conflicting views from two Clinical Reference Groups (CRGs). The advice of the Spinal Cord Injury CRG was that spina bifida patients were not best served by its services due to the high incidence of cognitive difficulties associated with spina bifida. The Neurosciences CRG advised that the majority of services for spina bifida patients were generally currently commissioned correctly. In light of these differing views, PSSAG has requested further detail on cost and the specialisms required to treat the urology needs of patients with spina bifida.

### Suggested changes

PSSAG advised no changes be made at this time.

# References

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<sup>i</sup> SI 2012/2996. Copies of legislation may be purchased from HMSO. Additionally, a copy of this statutory instrument, in its original form, is available at: <http://www.legislation.gov.uk/ukSI/2012/2996/contents/made>. There are other amendments to this statutory instrument but they are not listed here as they are not relevant. Further, relevant amendments to SI 2012/2996 are in the process of being made at the time of publication of this document and will be available at [www.legislation.gov.uk](http://www.legislation.gov.uk).

<sup>ii</sup> National commissioning of specialised services: report from the Clinical Advisory Group for Prescribed Services: <https://www.gov.uk/government/publications/national-commissioning-of-specialised-services-report-from-the-clinical-advisory-group-for-prescribed-services>

<sup>iii</sup> The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) (No. 2) Regulations 2014 available at: <http://www.legislation.gov.uk/ukSI/2014/452/introduction/made>

<sup>iv</sup> The latest version of the Manual for Prescribed Specialised Services is available at: <http://www.england.nhs.uk/wp-content/uploads/2014/01/pss-manual.pdf>. A postal copy may be requested by telephoning 0300 311 22 33 (Monday to Friday 8am to 6pm, excluding English Bank Holidays) or writing to the Board at PO Box 16738, Redditch, B97 9PT,

<sup>v</sup> NHS England's Clinical Reference Groups (CRG) cover the full range of specialised services and are responsible for providing NHS England with clinical advice regarding the services commissioned by NHS England. The CRGs are made up of clinicians, commissioners, Public Health experts and patients and carers, and are responsible for the delivery of key 'products' such as service specifications and commissioning policies, which enable NHS England to commission services from specialist providers through the contracting arrangements overseen by its Area Teams

<sup>vi</sup> National commissioning of specialised services: report from the Clinical Advisory Group for Prescribed Services: <https://www.gov.uk/government/publications/national-commissioning-of-specialised-services-report-from-the-clinical-advisory-group-for-prescribed-services>.

<sup>vii</sup> Arrangements for the transfer of commissioning responsibilities for renal dialysis and morbid obesity surgery services from NHS England to Clinical Commissioning Groups: government response to consultation is available at: <https://www.gov.uk/government/consultations/transferring-services-from-nhs-england-to-ccgs>.