Department of Health

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(Via Chief Executive’s Bulletin)
Chief Executives of Primary Care Trusts
Chief Executives of NHS Trusts and Foundation Trusts
Chief Executives of Strategic Health Authorities

Dear Colleague

Subject: CHANGES TO THE PORTFOLIO OF NATIONALLY COMMISIONED SERVICES FROM APRIL 2007

This letter gives information about the transfer of NSCAG to the NHS in April 2007 and gives details of ten changes to the portfolio of the National Specialist Commissioning Advisory Group (NSCAG) from 2007/08.

Transfer of NSCAG to the NHS in April 2007

It has been agreed that the national commissioning function as carried out by NSCAG should transfer to the NHS in April 2007. On its transfer, NSCAG will become known as the National Commissioning Group (NCG) and will become a standing committee of the, as yet to be established, National Specialised Services Commissioning Group (NSSCG), a committee that will include representation from each of the ten Specialised Commissioning Groups, currently being established in the ten Strategic Health Authorities (SHAs).

The SHA Chief Executives have agreed that the NCG will be hosted by NHS London and will transfer in April 2007.

The current NSCAG budget is funded from two sources:

- an element historically funded from DH, a small percentage of which relates to services that NSCAG commissions on behalf of Scotland, Wales and Northern Ireland
- an element recovered from PCTs, generally on a baseline allocation basis, for services that have transferred from PCT to national commissioning.

The full NSCAG budget will transfer from DH to the NHS on 1 April 2007 and will incorporate the appropriate uplift for 2008/08. The funding will be added to PCT baselines and PCTs will then be expected to contribute towards the budget for nationally commissioned services, agreed each year by the NSSCG. Further details of the transfer, including the governance arrangements and an Allocation Working Paper setting out the financial details, will follow in the New Year.

Changes to the NSCAG Portfolio

Four services, which were formerly commissioned by PCTs, have been designated by Ministers and will be commissioned on a national basis from April 2007; these are:

- the severe obsessive compulsive disorder and body dysmorphic disorder service for adolescents and adults
- the secure forensic mental health and learning disability service for young people
- the pulmonary hypertension service for children
- the rare mitochondrial disease service for adults and children.

The following changes to commissioning arrangements will also take place from April 2007:

- there will be a return of responsibility to PCTs for designating centres for deep brain stimulation for severe Parkinson's disease
- there will be an extension to the nationally commissioned liver transplantation service to include live adult to adult liver transplantation
- there will be an extension to the extra corporeal membrane oxygenation service for adults
- there will be an extension of one year to the period of designation for the national commissioning of lysosomal storage disorders, from April 2007 to March 2008
- there will be an increase in the budget for the lysosomal storage disorders service to take account of new enzyme replacement therapies and the additional patients receiving treatment
- a fourth centre – Birmingham Children's Hospital NHS Trust – will be designated for the treatment of children with lysosomal storage disorders

Further information about these changes can be found in Annex A, with background details on NSCAG provided in Annexes B and C. Further information about NSCAG can be found at: www.advisorybodies.doh.gov.uk/NSCAG

Funding mechanisms

The methodology of transferring funding from PCTs to NSCAG was agreed at the Financial Issues Group meeting on 24 October 2006. All costs in this letter are quoted at 2006/07 price levels.

An Allocation Working Paper (AWP), notifying PCTs of resource adjustments to their 2007/08 allocations resulting from the above changes to NSCAG's portfolio, will also be issued in December.

Yours sincerely

Fiona Marley
Head of Commissioning

NSCAG

ANNEX A: CHANGES TO THE PORTFOLIO OF THE NATIONAL SPECIALIST COMMISSIONING ADVISORY GROUP (NSCAG) FROM 2007/08

1. Severe obsessive compulsive disorder and body dysmorphic disorder service for adolescents and adults

Patients with obsessive compulsive disorder (OCD) suffer from obsessions (intrusive thoughts or disorders) and compulsions (repetitive behaviours). Body dysmorphic disorder is closely related to OCD and is incorporated into the designation.

This service is being nationally designated and commissioned because of the considerable expertise required in the treatment of these conditions. The anticipated volume is 200 cases per annum.

Treatment provided by the four centres will be in line with the NICE guidance[1] and will be for patients with the very severe form of the disease, defined as “Level 6” in the guidance, and who have not responded to standard treatments.

Four centres have been designated:

- East and North Hertfordshire NHS Trust (adult inpatients and outpatients)
- South London and Maudsley NHS Foundation Trust (adult inpatients and outpatients; adolescent outpatients)
- South West London & St George’s Mental Health NHS Trust (adult inpatients and outpatients)
- The Priory Hospital North London[2] (adult inpatients and adolescent inpatients).

In addition to treatment at these four centres, it is anticipated that one or two patients per annum may require neurosurgical treatment at Ninewells Hospital, Dundee.

Commissioning responsibility will pass from PCTs to NSCAG and current NHS expenditure – £2.80m – will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs as part of their overall contribution to the NSCAG budget.

2. Secure forensic mental health and learning disability service for young people

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[1] Inpatient care or intensive treatment programmes/CAMHS Tier 4, OCD with risk to life, severe self-neglect or severe distress or disability (from Obsessive Compulsive Disorder: Core interventions in the treatment of obsessive compulsive disorder and body dysmorphic disorder, NICE, November 2005)

[2] The Priory Group Limited is an independent provider of acute and secure mental health, neuro-rehabilitation and specialist educational services.

NSCAG already commissions a secure forensic mental health service for young people from five units. These units are unable to meet the needs of young people with learning disabilities because of the vulnerability of this client group and the specialist nature of their needs.

This service is being nationally designated and commissioned because the current spot-purchasing arrangements by PCTs mean that there are wide variations in referral, assessment and access to appropriate services, resulting in some patients not receiving effective treatment. These placements are also very high cost, placing considerable financial risks on individual PCTs. The estimated volume is 5-8 new placements per annum.

The service will be for young people who have learning disabilities, who need medium secure inpatient provision and who meet the forensic or equivalent risk criteria of the current secure forensic mental health service.

The two designated units are adjacent to existing medium secure mental health provision for young people: it is hoped that this will help to prevent marginalisation of young people with learning disability.

Two centres have been designated:

- Northumberland, Tyne and Wear NHS Trust (NTW) (seven beds from April 2008)
- St Andrew's Hospital, Northampton[3] (10 beds from April 2007).

Commissioning responsibility will pass from PCTs to NSCAG and current NHS expenditure – £4.56m – will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs as part of their overall contribution to the NSCAG budget.

Since the seven beds at NTW will not be available until April 2008, NSCAG will use this element of the budget to spot-purchase beds during 2007/08.

3. Pulmonary hypertension service for children

Pulmonary hypertension (PH) is a high pressure in the circulation of blood through the lungs, leading to progressive heart failure.

This service for children is being nationally *commissioned* because of the considerable expertise required to treat children. The service for adults and children is already nationally designated.

The service for adults will not be nationally commissioned because the numbers of patients involved are too large to meet the NSCAG criteria. For children, the estimated national caseload is 350.

One centre has been designated:

- Great Ormond Street Hospital for Children NHS Trust (GOSH).

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[3] St Andrew's is a not-for-profit charitable organisation, specialising in the provision of specialist mental health care.

Commissioning responsibility will pass from PCTs to NSCAG and current NHS expenditure – £2.72m[4] – will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs as part of their overall contribution to the NSCAG budget.

4. Rare mitochondrial disease service for adults and children

Mitochondria are small organelles – present in every cell in the body – whose function is to process the cell's energy. Mitochondrial disease can therefore affect any cell process. It commonly presents as muscle weakness but any body system – including liver, pancreas and kidney – can be affected, and the range of neurological symptoms is very wide.

The diagnostic and neurological treatment elements of this service are being nationally designated and commissioned because of the considerable expertise required to treat patients. The estimated volume is 590 outpatient appointments per annum.

This designation does not alter the current pattern of clinical management of mitochondrial disorders. Much of the work of investigating and managing mitochondrial disorders will continue to take place outside the NSCAG service, for example in paediatric metabolic services.

Three centres have been designated:
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Oxford Radcliffe Hospitals NHS Trust
- University College London Hospitals NHS Foundation Trust.

Commissioning responsibility will pass from PCTs to NSCAG and current NHS expenditure – £2.80m – will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs as part of their overall contribution to the NSCAG budget.

5. Return of responsibility for designating centres for deep brain stimulation for severe Parkinson's disease to PCTs

Deep brain stimulation (DBS) involves passing an electrode into the subthalamic nucleus of the brain. The electrode is connected by a thin wire to a stimulator, which is placed under the skin of the chest and generates electrical impulses that block the abnormal brain activity responsible for the slowness and absence of movement, stiffness of limbs and involuntary movements in Parkinson's disease (PD). The patient passes a hand-held magnet over the stimulator to turn it on and off as required. The advantages of DBS are that the amount of stimulation is adjustable and, unlike older forms of surgery for PD, it does not destroy any parts of the brain.

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[4] This sum is for 2007/08 only and may need to be revisited for 2008/09 and beyond.

In January 2001, Ministers confirmed the designation of centres providing DBS for severe PD. Unlike most NSCAG services, the service costs for DBS for severe PD were not funded by NSCAG but by PCTs according to the usual NHS commissioning arrangements. The purpose of NSCAG designation was to manage in a controlled way the introduction of new centres across the country.

At the same time, a trial, PD SURG, commenced to establish the optimal timing for intervention with DBS in the treatment of severe PD. Any centre involved in the trial had to be designated. The Medical Research Centre is the trial sponsor, and £14,000 has been paid towards the cost of each DBS device and procedure from DH through the Excess Treatment (Subvention) Fund for patients enrolled in the trial. The recruitment phase of the trial ended in December 2006.

The number of centres providing DBS for severe PD has grown from five in 2001 to 10 in 2006 and no further centres are expected to apply to be designated prior to April 2007. NSCAG's involvement will cease from April 2007.

6. Extension to the nationally commissioned liver transplantation services to include live adult to adult liver transplantation

NSCAG commissions adult cadaveric liver transplantation from six centres across England. Although the number of liver transplants undertaken in the UK over the past six years has been fairly constant, the number of eligible patients waiting for a transplant at any one time has increased significantly, from 152 in 2000 to 360 in 2005. At least 10% of those listed for transplantation die before a suitable cadaver organ becomes available. Receiving an organ from a live donor will be life-saving, with a minimum 50% probability of survival at five years post-transplant.

The estimated number of live adult to adult liver transplants that will be undertaken per annum is 50. All the existing liver transplant centres plan to put themselves forward to be designated to undertake this procedure. They are:

- Cambridge University Hospitals NHS Foundation Trust
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- King's College Hospital NHS Trust
- University Hospital Birmingham NHS Foundation Trust
- The Royal Free Hampstead NHS Trust
- Leeds Teaching Hospitals NHS Trust

The estimated additional costs of the extension of the liver transplantation service to include live adult to adult liver transplantation is £2.89m per annum. This funding will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs to NSCAG as part of their overall contribution to the NSCAG budget.

7. Extension to the extra corporeal membrane oxygenation service for adults

Extra corporeal membrane oxygenation (ECMO) rests the lungs of adults with potentially reversible respiratory failure by oxygenating the blood through an artificial lung machine. During the process, the effects of volutrauma (damage to the lungs), barotrauma (damage to the ear) and oxygen toxicity, which are associated with prolonged conventional or high frequency ventilation, are minimised.

A single designated centre, University Hospitals of Leicester NHS Trust, has been undertaking a trial[5] of ECMO for adults. This commenced in July 2001 and reached its target number of 180 patients in August 2006. Analysis of the patient survival data has now begun, with full trial results expected in 2007/08. During 2007/08, patients who would have been previously randomised to conventional treatment will have access to ECMO at the single designated centre.

The estimated cost of these additional patients in 2007/08 is £1.09m. This funding will be incorporated into the NSCAG budget for 2007/08 and transferred pro rata to baseline allocations from PCTs to NSCAG as part of their overall contribution to the NSCAG budget.

Once the full trial results are known, decisions will need to be made about whether the service should continue and, if so, whether further centres should be designated to improve geographical access. Any increase in the number of centres would have further financial implications.

8. Extension of the designation period for the national commissioning of lysosomal storage disorders (for adults and children)

Services for the diagnosis and assessment of patients with lysosomal storage disorders are nationally designated and commissioned at the following centres, with Birmingham Children's Hospital NHS Trust becoming a further centre in April 2007 (see section 10 below):

- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester and Manchester Children's University Hospitals NHS Trust
- Great Ormond Street Hospital for Children NHS Trust
- Salford Royal NHS Foundation Trust
- The Royal Free Hampstead NHS Trust
- University College London Hospitals NHS Foundation Trust.

It was previously agreed that the national commissioning of lysosomal storage disorders should be for a two-year period only, from April 2005 to March 2007. In light of the introduction of a number of new enzyme replacement therapies (ERTs) – one of which is not expected to be licensed until early 2007 – it has been agreed that lysosomal storage disorders should be commissioned nationally for a further year, from April 2007 to March 2008.

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[5] CESAR trial: Conventional Ventilation or ECMO for Severe Adult Respiratory Failure. As the name suggests, the trial is a randomised control trial of ECMO versus conventional treatment.

9. Increase in the budget for the lysosomal storage disorders service to take account of new enzyme replacement therapies and the additional patients receiving treatment

Given that it has been agreed that national commissioning of lysosomal storage disorders should continue for a further year until March 2008 (see section 8 above), NSCAG has been putting in place arrangements to continue to commission the service. These arrangements include assessing the impact of two new enzyme replacement therapies (ERTs).

During 2006/07, a new ERT, Alglucosidase Alfa (Myozyme), was licensed for the treatment of infant-onset and late-onset Pompe's disease:

- the infant-onset form of the disease is fatal without Alglucosidase Alfa, with most deaths occurring within one year of birth. On average, four to five affected babies are born annually
- the late-onset form of the disease is not always fatal. Complications, for example, respiratory failure, can cause serious morbidity or death. Treatment with Alglucosidase Alfa can delay or prevent patients needing a ventilator. It is estimated that there are 50 English patients who will require Alglucosidase Alfa for the late-onset form of the disease.

A further ERT, Idursulfase (Elaprase), for Mucopolysaccharidosis II (Hunter's Syndrome), is expected to be licensed in early 2007. Individuals with Hunter's Syndrome typically survive until late childhood. Idursulfase seems to improve the physical condition but without preventing the cognitive decline that leads to early death. It is estimated that there are 30 children expected to meet clinical guidelines for treatment.

The financial impact of (a) the full-year effect of these two new ERTs, (b) the full-year effect of patients who have been initiated on the five existing ERTs during 2006/07 and (c) the anticipated number of patients who will be initiated on the five existing ERTs during 2007/08, is estimated at £21.3m. It has been agreed that the current budget for ERTs of £58m be transferred from PCTs to NSCAG based on the allocations transferred in 2005/06 and 2006/07, i.e. £45m on an historical usage basis (for patients identified prior to 1 April 2005) and £13m pro rata to baseline allocations. The additional sum of £21.3m will all be transferred pro rata to baseline allocations and will be incorporated into the NSCAG budget as part of PCTs' overall contribution to the NSCAG budget.

10. Designation of a fourth centre for children with lysosomal storage disorders

There are currently three centres designated by NSCAG to treat children with lysosomal storage disorders:

- Cambridge University Hospitals NHS Foundation Trust
- Central Manchester and Manchester Children's University Hospitals NHS Trust
- Great Ormond Street Hospital for Children NHS Trust.

In order to improve access, particularly for children living in the West Midlands, a further NSCAG centre has been designated at Birmingham Children's Hospital NHS Trust.

Funding for this fourth centre for children will be identified from within the overall NSCAG budget for lysosomal storage disorders. There is no additional funding requirement from PCTs associated with the designation of this Trust as an additional provider.

Further information

Further information on the above services should be addressed to the lead commissioner in the NSCAG team, as follows:

Severe obsessive compulsive disorder and body dysmorphic disorder service for adolescents and adults	patrick.hobbs@dh.gsi.gov.uk
Secure forensic mental health and learning disability service for young people	chad.whitton@dh.gsi.gov.uk
Pulmonary hypertension service for children	jeremy.glyde@dh.gsi.gov.uk
Rare mitochondrial disease service for adults and children	patrick.hobbs@dh.gsi.gov.uk
Return of responsibility for designating centres for deep brain stimulation for severe Parkinson's disease to PCTs	fiona.marley@dh.gsi.gov.uk
Extension of the liver transplant programme to include live adult to adult liver transplantation	patrick.hobbs@dh.gsi.gov.uk
Extension to the extra corporeal membrane oxygenation service for adults	jeremy.glyde@dh.gsi.gov.uk
• Extension of the designation period for the national commissioning of lysosomal storage disorders (for adults and children) • Increase in the allocation for the lysosomal storage disorders service to take account of new therapies and the additional patients receiving treatment • Designation of a fourth centre for children with lysosomal storage disorders	sarah.watson@dh.gsi.gov.uk

ANNEX B: BACKGROUND TO THE NATIONAL SPECIALIST COMMISSIONING ADVISORY GROUP (NSCAG)

NSCAG was set up to advise Department of Health (DH) Ministers on which NHS services are best commissioned nationally, rather than locally, to ensure a high quality of clinical care and equity of access for patients as well as securing value for money.

The Advisory Group is currently chaired by Professor Rod Griffiths, President of the Faculty of Public Health, and was established in 1996. Members represent a broad range of interests including clinical practice, management, commissioning, public health and research and development.

The commissioning team who support the work of the Advisory Group are currently sited within DH but will be transferring to the NHS in April 2007.

NSCAG services are generally those that:

- relate to a clearly defined group of patients
- relate to a condition which is so rare that the national caseload is unlikely to be above 400, and would not normally exceed 1,000
- are capable of being provided by a small number of centres, which between them can meet the needs of the national caseload
- place a significant financial burden, when cases arise, on PCTs' funds.

The total NSCAG budget for 2005/06 is £222million. An additional £58million is managed as a separate drugs budget on behalf of PCTs for enzyme replacement therapy (ERT) and substrate reduction therapy (SRT) for patients with lysosomal storage disorders (LSDs).

ANNEX C: SERVICES COMMISSIONED BY THE NATIONAL SPECIALIST COMMISSIONING ADVISORY GROUP

Service designated and funded by NSCAG:

- Alstrom syndrome in adults and children
- Amyloidosis service
- Bladder exstrophy service for children
- Choriocarcinoma service
- Complex tracheal disease in children
- Craniofacial surgery service for congenital craniofacial disorders
- Epidermolysis bullosa service for children
- Epidermolysis bullosa service for adults
- Extra corporeal membrane oxygenation service for adults
- Extra corporeal membrane oxygenation service (ECMO) service for neonates and infants and children
- Extra corporeal membrane oxygenation (ECMO) / Ventricular assist devices (VADs) (bridge to heart transplant) service for children
- Heart and lung transplantation service for adults and children
- Liver transplantation service for adults and children
- Lysosomal storage disorders
- Mental health service for Deaf children and adolescents - Inpatient service
- Ocular oncology service for adults
- Ophthalmic pathology service
- Osteo odonto keratoprosthesis
- Pancreas transplantation service
- Persistent hyperinsulinaemic hypoglycaemia of infancy
- Primary ciliary dyskinesia (diagnostic service)
- Primary malignant bone tumours service
- Pseudomyxoma peritonei service
- Pulmonary thromboendarterectomy service
- Rare neuromuscular diseases service
- Reconstructive surgery in adolescents for congenital malformation of the female genital tract
- Retinoblastoma service
- Secure forensic mental health service for young people
- Severe combined immunodeficiency and related disorders service
- Severe intestinal failure service
- Small bowel transplantation service for adults
- Small bowel transplantation service for children
- Specialist paediatric liver
- Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders
- Telemental health service for Deaf children and adolescents
- Vein of Galen malformation in children
- Ventricular assist devices as bridge to transplant for adults

Services designated by NSCAG but not funded:

- Deep brain stimulation for Parkinson's disease service
- Pulmonary hypertension service