

**DH AND SCG MEETING**

**Friday 4 July 2003 from 10.30am - 3.00pm, Olivier Room, 4<sup>th</sup> Floor, Wellington House,  
133-155 Waterloo Road, London SE1 8UG**

**AGENDA**

- 1 Welcome and Apologies for absence
- 2 Minutes of the meeting of 25 April 2003 **Attachment, Item 2**
- 3 Matters arising
- 4 Overview and Scrutiny for Health Guidance (Meredith Vivian) **Attachment, Item 4(i)&(ii)**
- 5 Patient and Public Involvement (Barbara Gill) **Attachment, Item 5**
- 6 Commissioning Dental Services (Pam Scoular)
- 7 Children's Services (Claire Phillips and Jane Scott)
- 8 UK Genetic Testing Network report (Jacquie Westwood) **Attachment, Item 8**
- 9 Foundation Trusts (Mirella Marlow and Julia Stallibrass) **Attachment, Item 9**
- 10 Annual Report (Julia Stallibrass)
- 11 Pulmonary Hypertension Commissioning Guidance (Paul Maubach) **Attachment, Item 11**
- 12 Photodynamic Therapy (Paul Maubach) **To Follow**
- 13 Enzyme Replacement Therapy (Julia Stallibrass) **Attachment, Item 13**
- 14 Commissioning Specialised Services - A Common Framework (Barbara Gill) **Attachment, Item 14**
- 15 NSCAG reports (Edmund Jessop) **Attachment, Item 15**
- 16 Renal Transplantation and Desensitisation FOR INFORMATION ONLY **Attachment, Item 16**
- 17 AOB

**Updates**

These updates are attached for information only; they will not be discussed unless a decision is required.

NOTES OF THE QUARTERLY MEETING OF THE DH AND  
SPECIALISED COMMISSIONING GROUPS ON 25 APRIL 2003

1 WELCOME AND APOLOGIES FOR ABSENCE

**Apologies:**

Kendall Bird	Thames Valley LSCG
Deirdre Evans	Scotland
Rachel Ferris	West of England LSCG
Jaki Meeking	South SCG
David Russell	Yorkshire LSCG
Chris Wolvin	Mersey & Cheshire LSCG

**Present:**

Carl Ashworth	Greater Manchester LSCG
Alison Brewis	KSS LSCG
Geoffrey Carroll	DH/Eastern SCG
John Develing	Cumbria & Lancashire LSCG
Cathy Edwards	NORCOM LSCG
Jackie Ellis	DH
Barbara Gill	London SCG
Peter Graham	Peninsula LSCG
Mirella Marlow	KSS LSCG
Paul Maubach	West Midlands SSA
Mike Maunder	Northern LSCG
Peter Saggars	Eastern SCG
Mark Satchell	Central South Coast LSCG
Julia Stallibrass	DH
Hong Tan	London SCG
Chris Theaker	EMCOM LSCG
Jacqui Westwood	London SCG
Julie Woodin	DHSC (Midlands & East)

**Attending for Specific Items:**

Sandra Barrow	PASA (PASA, item 5)
Jonathan Burrill	PASA (PASA, item 5)
Jane Deller	London Genetics Network Co-ordinator (accompanying Jacqui Westwood)
Steve Dunn	DH (Foundation Trusts, item 13)
Edmund Jessop	DH/NSCAG (NSCAG, item 20)
Charles Lister	DH (Haemophilia, item 15)

2 NOTES OF THE MEETING OF 24 JANUARY 2003

The notes were agreed to be correct.

### 3 MATTERS ARISING FROM NOTES OF MEETING OF 25/04/03

#### Item 4: Financial Flows

**Agreed action:**

Julia Stallibrass from the DH drew the meeting's attention to a workshop that was being organised by the DH on Financial Flows in mid-May or early June. She asked for names from those interested in sending a representative. Further details will be circulated as soon as possible.

To circulate further details of the DH workshop on Financial Flows planned for mid May/early June as soon as possible. (*Julia Stallibrass*)

#### Item 5: Cleft Lip and Palate Services

**Agreed action:**

To draft a proforma to apply to Cleft Lip and Palate Services development plans to incorporate care standards and seek CIGs' and Paul Woods' (DH) comments and input. (*Chris Theaker*)

To apply proforma to individual Cleft Lip and Palate services development plans. (*All SCGs*).

#### Item 7: HTLV Services

**Agreed action:**

To seek DH funding for HTLV services for 2003/04 and 2004/05. (*Julia Stallibrass and Edmund Jessop*)

To visit the HTLV services provider - St Mary's Hospital, London. (*Edmund Jessop - DH, Hong Tan - SCG representative*)

#### Item 14: Spinal Cord Injuries Services Review (South England)

**Agreed action:**

To circulate final report when completed. (*Mirella Marlow*)

#### Item 15: National Databases

**Agreed action:**

To convene a meeting to discuss national databases and the possibility of a common approach to funding. (*Julia Stallibrass*)

#### Item 16: SCG National Workshop

**Agreed action:**

To arrange a facilitated workshop on Local Delivery Plans, SCG decision making, SCG Governance arrangements. (*Julia Stallibrass*)

#### Item 20: Paediatric Spinal Cord Injury Services Survey

**Agreed action:**

To link with work being lead by Rosemary Manson on Paediatric Spinal Deformities including Scoliosis. (*Kendall Bird*)

#### 4 NATIONAL DEVELOPMENT GROUP FOR SPECIALISED MENTAL HEALTH SERVICES

**Agreed action:**

To convey concerns to the DH regarding the role of NDG and its relationship to SCGs. (*Julia Stallibrass*)

#### 5 PURCHASING & SUPPLY AGENCY PRESENTATION ON CARDIO-VASCULAR SERVICES

Sandra Barrow and Jonathan Burrill from the Purchasing and Supply Agency gave a presentation on their work with cardiovascular services and referred to the first two national frameworks they had negotiated on ICDs and Heart Valves. National frameworks are the foundation stone of purchasing and supply contracts and give information on all the companies in the field, listing their products and prices. PASA are developing a price benchmarking database which will be available to NHS trusts. In addition, PASA are establishing 28 Supply and Management Confederations coterminous with SHAs. These are based on local NHS trusts but the meeting felt that it would be beneficial for local commissioners to be involved as well. In discussion it was emphasised how important it was to understand and incorporate Supply and Management Confederation plans for particular services into Local Delivery Plans.

**Agreed action:**

To send PASA contact details for SCGs so that PASA can keep commissioners informed of local Supply and Management Confederations' activities so as to facilitate co-operation. (*Julia Stallibrass*)

#### 6 POSITRON EMISSION TOMOGRAPHY

Commissioners reported on progress around the country on developing a strategic approach to planned and controlled introduction of PET services. The South SCG were particularly well advanced – a conference had been held, the five LSCGs were now considering their positions (although revenue funding was unlikely until 2004/05 at the earliest) and clinicians were developing protocols. London were mapping all services, both research and NHS, and looking at future plans. SCGs in the North had agreed to work together on PET planning with David Russell as the lead. West Midlands and East Midlands SCGs agreed they needed to set up a process forthwith to tackle the issue.

**Agreed action:**

To adopt a local approach (i.e. South, London, West Midlands/Eastern, North) to the consideration and development of PET services. (*All SCGs*)

To send South SCG's clinical protocols to DH for wider comment/ circulation. (*Jaki Meekings*)

To circulate London's mapping exercise. (*Barbara Gill*)

#### 7 DBS FOR SEVERE PARKINSON'S DISEASE

Geoffrey Carroll from the DH gave a brief background – standards for DBS for severe Parkinson's disease had been developed; the PD SURG trial in the first wave centres had taken some time to get off the ground and had not really commenced until January 2002; delays in organising the first wave centre visits by the review team (consisting of Professor Williams, Mr Varma, Kendall Bird and a nurse specialist) had been so delayed that submission of a self-assessment questionnaire had been substituted. These self-assessment questionnaires were now being analysed.

The meeting agreed that it was important to complete the process and produce an independent assessment of each centre against the standards.

**Agreed action:**

To assemble a peer review team (neurologist, neurosurgeon, nurse and host commissioner) to visit each first wave centre to review against their completed self assessment questionnaire. (*Julia Stallibrass*)

To nominate a lead commissioner for the peer review process - possibly London or West Midlands. (*Barbara Gill and Paul Maubach respectively*)

To seek host commissioners' views on development of second wave centres at Hope Hospital, Sheffield and Kings College and the National Hospitals, London. (*Carl Ashworth and Barbara Gill respectively*)

## **8 AUDIT OF SPECIALISED SERVICES COMMISSIONING REPORT**

**Agreed action:**

To report back on the Audit Commission's benchmarking exercise on a high volume specialised service in KSS LSCG. (*Mirella Marlow*)

To find out if the National Audit Commission plan to revisit specialised services commissioning since their 1977 report. (*Julia Stallibrass*)

To check access to Minimum Data Set information i.e. individual patient data. (*Julia Stallibrass*)

To invite the NHS Information Authority to the next meeting. (*Julia Stallibrass*)

## **9 STEREOTACTIC RADIOSURGERY**

Cathy Edwards from NORCOM LSCG described the problems at the Sheffield stereotactic radiosurgery service, in particular the existing waiting list for treatment. Despite additional capacity having been created there was uncertainty as to whether it would be sufficient to meet demand. The situation was exacerbated by the fact that patients were being referred at different points in the care pathway; some providers referred patients pre the work-up stage or with inadequate work-up test reports. To encourage more appropriate referrals the centre would be devising a new pricing structure which would separately identify and cost treatment with/without work-up. It is hoped that the resultant reduction in inappropriate referrals will contribute to reducing waiting lists to a more acceptable level.

Commissioners agreed to support the new pricing structure subject to the production of a zero net impact statement and the circulation of the care pathway and referral guidelines to commissioners and providers. It was also felt to be important that the national stereotactic radiosurgery service (ie the London and the Sheffield centres and the corresponding specialised commissioning groups: London and NORCOM) should work together.

**Agreed action:**

To circulate a zero net impact statement on the proposed creation of a 2 tariff pricing structure, plus notice of the new pricing structure, plus a copy of the care pathways to commissioners, cancer networks and referring providers and clinicians such as those in Neurosciences centres. (*Cathy Edwards*)

To seek support for a clinical study on treatment for cerebral metastases and trigeminal neuralgia. *(Geoffrey Carroll)*

To draw up common referral criteria for cerebral metastases and trigeminal neuralgia for the Sheffield and London centres. *(Cathy Edwards and Barbara Gill)*

#### 10 GENETIC TESTING NETWORK

Jacquie Westwood from London SCG introduced the paper and asked for comments on the Genetic Testing Network plan. A pilot in education and training will soon be commencing in the South West and regional genetic centres will be receiving a proforma to apply for membership of the national Genetic Testing Network in the next week or so.

The meeting agreed that the Genetic Testing Network should be a standing item for future meetings.

#### 11 NEWBORN SCREENING FOR HAEMOGLOBINOPATHIES

##### Agreed action:

To circulate details of the forthcoming conference when known *(Julia Stallibrass)*

#### 12 TEMPLATES & DOCUMENTATION TO SUPPORT COMMISSIONING

##### Agreed action:

To set up a small working group to produce a paper clarifying the brief and proposing a way forward for consideration at a future meeting. *(Barbara Gill)*

#### 13 FOUNDATION TRUSTS

Steve Dunn from the DH gave a presentation on Foundation Trusts. Comments from the meeting centred on two issues. Firstly, how to achieve the appropriate public/patient representation on Foundation Trusts' Boards for specialised services (most specialised service activity will be provided to non-local patients so public/patient representation on Boards will need to reflect this wider patient constituency). Secondly, how to ensure that service developments, new services and changes in service provision are achieved by agreement with the appropriate commissioning body which in the case of specialised services will not be with the local PCT but rather with the Level 1, Level 2 or even "national" specialised commissioning group.

##### Agreed action:

To draft and circulate for comment a paper highlighting the issues and possible problems of Foundation Trusts in relation to specialised services commissioning. *(Mirella Marlow)*

To arrange a national DH workshop for specialised service commissioners. *(Steve Dunn and colleagues)*

#### 14 PAEDIATRIC & CONGENITAL CARDIAC CARE

The meeting reported on the various arrangements around the country to assess the provision of paediatric congenital cardiac care services against the PCCC standards. These exercises are sometimes led by the DHSCs and sometimes by SCGs. In the North a proforma and a scoring system has been used which the Midlands & East are also going to use.

**Agreed action:**

To report on the DH arrangements for reviewing PCCC services, particularly the DHSC's role, and identify the DH lead dealing with PCCC. (*Julia Stallibrass*)

**15 HAEMOPHILIA SERVICES**

Charles Lister from the DH reported on the additional central funding agreed under the Spending Review for haemophilia services and specifically recombinant clotting factors (£13m in 2003/04, £21m in 2004/05 and £53m in 2005/06). Three issues had to be addressed: organising the prioritisation of patients to receive recombinant factors (ie from the youngest to the eldest); deciding on the criteria for allocation of funding to PCTs (ie capitation versus actual patient numbers in each PCT); and agreeing the purchasing mechanism for the clotting factors. Charles reported it has been decided that there will be national contracting via PASA in Years 1, 2 and 3 for clotting factors purchased by the additional funding and by Year 4 for all clotting factors; the additional funding will be included in PCTs' overall allocation; and funding will be on the basis of actual patient numbers. Consequently a data collection exercise is being carried out on existing caseload by PCT.

Paul Maubach from West Midlands SCG reported that PASA was conducting an audit of existing clotting factor contracts and their expiry dates to see if the programme for national contracting of all clotting factors could commence earlier than Year 4.

Commissioners agreed that they supported the national framework approach and asked to be involved in the validation of the data.

Commissioners were concerned about wastage of clotting factors and the need for measures to tackle this problem.

**Agreed action:**

To give lead commissioners' names to Charles Lister, so data collection can be validated by SCGs. (*Julia Stallibrass*)

**16 WORKFORCE DEVELOPMENT CONFEDERATIONS**

Jackie Ellis from the DH reported on the varying engagement of WDCs with SCGs/LSCGs across the country and the concern of commissioners about the fact that WDCs did not tend to consider the training and education needs of specialist staff providing specialised services.

Mike Maunder from Northern SCG reported a relatively positive experience with his local SCG (both WDCs were represented on the SCG and communications were good possibly due to the fact that the two reps had previously been involved in specialised services) but some commissioners reported poor or no linkages with their WDCs. Barbara Gill from London SCG reported that the London WDCs were involved in the specific service reviews rather than the SCG.

It was agreed that it would be helpful if the DH could raise the issue with WDCs.

**Agreed action:**

To circulate lead WDCs for particular specialised services. (*Julia Stallibrass*)

To input into SHA workforce development plans due for completion in July 2003. (*All SCGs*)

To report back on DH progress in raising WDCs' awareness of education and training needs for specialised services. (*Julia Stallibrass*)

## **17 ENZYME REPLACEMENT THERAPIES**

Paul Maubach from West Midlands SCG introduced the paper by Daphne Austin, which is planned to be circulated to meeting of SHAs and the Regional Directors of Public Health in the near future. The meeting supported the paper and agreed that the issues around extremely expensive treatments for chronic disease, such as Enzyme Replacement Therapy (ERT), need to be addressed at a national level.

Several commissioners stated they have or were planning to have risk sharing consortia for ERT (eg North West, West Midlands and London).

### **Agreed action:**

To redraft paper on ERT in the light of the meetings' comments (*Paul Maubach and colleagues*)

To submit to DH for consideration. (*Julia Stallibrass*)

## **18 SPECIALISED SERVICES ADVISORY GROUP**

There were no new service proposals put forward to be considered by SSAG.

## **19 GUIDANCE ON COMMISSIONING ARRANGEMENTS FOR SPECIALISED SERVICES**

Julia Stallibrass from the DH gave a brief presentation.

### **Agreed action:**

To provide a timetable against which guidance requirements must be met. (*Julia Stallibrass*)

To submit proposals to the DH for an appropriate name for Level 1 SCGs. (*All SCGs*)

## **20 NSCAG/SPECIALISED SERVICES ADVISORY GROUP**

### **20.1 HTLV – application to NSCAG**

Edmund Jessop reported that the DH had agreed to fund this service in 2003/04 and 2004/05 to help establish the service and support the development of two further clinics in Birmingham and Manchester. Thereafter the service will be funded by the NHS. Hong Tan will act as the SSG representative.

### **20.2 Inherited Disorders of Connective Tissue – application to NSCAG**

Edmund Jessop introduced this item.

### **Agreed action:**

To report back on a visit to the service providers. (*Edmund Jessop – DH, Hong Tan – SCG representative*)

To ask NSCAG to raise at the meeting it is arranging for clinicians, the possibility of drafting text for inclusion in the Specialised Services National Definitions set. (*Edmund Jessop*)



**20.3 Pancreatic Transplantation – application to NSCAG**

Edmund Jessop introduced this item.

**Agreed action:**

To report back on the outcome of NSCAG's June meeting regarding this application. (*Edmund Jessop*)

**21 ANY OTHER BUSINESS**

## HEPATITIS C SERVICES UPDATE

### Hepatitis C - taking forward *Hepatitis C Strategy for England*

#### Seminar for Specialised Commissioning Groups on 25 February 2003

A summary of the main points arising from discussion at the seminar will be e-mailed to all Specialised Commissioning Groups in the next few weeks with a link to powerpoint presentations from the seminar speakers on the Department of Health website.

#### Action plan to implement *Hepatitis C Strategy for England*

The Department of Health will be publishing an action plan to take forward implementation of *Hepatitis C Strategy for England* in the next few months. As proposed in the Chief Medical Officer's infectious disease strategy, *Getting Ahead of the Curve*, this will form part of a blood-borne viruses action plan.

Gerry Robb  
DH