SERVICE SPECIFICATION FOR THE NATIONAL PULMONARY HYPERTENSION SERVICE (NPHS)

1. PURPOSE OF THE SPECIFICATION

1.1 Regulation of the commissioning of the investigation and management of pulmonary hypertension following the designation of the service by NSCAG.

1.2 The specification has been developed to enable PCTs, Specialised Services Commissioning Groups (SSCGs)/LSCGs and the lead commissioners for Consortia to make service level agreements in 2003/4 for NPHS. The specification should be used by all commissioners to ensure consistency in agreements.

1.3 This specification will be used by the PCTs and SSCG’s to monitor the performance and quality of the providers of NPHS.

1.4 The commissioners of the service will make decisions about funding prostaglandin and other related drug treatments for individual patients within five working days of the request having been made by one of the centres.

1.5 The specification has been developed to take account of agreements, related to:

- management of pulmonary hypertension based on the Recommendations on the Management of Pulmonary Hypertension in Clinical Practice by the British Cardiac Society (publication in Autumn 2001 in Heart)
- draft European guidance (in press)
- clinical outcomes: mandatory for specialised services as part of each SSCG’s monitoring programme
- discussions with NPHS centres on benchmarking of prices and content of pulmonary hypertension care packages.
- standards and accreditation for NPHS

2. CLINICAL PRACTICE: INDICATIONS AND VOLUME

2.1 Indications for assessment and treatment of pulmonary hypertension have been developed to guide referring clinicians and for the purpose of service level agreements. Appropriate referrals are based on current international evidence, taking account of changes in clinical practice and changes in clinical indications for specific diseases after discussion with the designated providers of the service.

2.2 The categories are as follows:

2.2.1 Patients referred for investigation to establish or exclude a diagnosis of pulmonary hypertension.
2.2.2 Treatment and follow-up of pulmonary hypertension which is:

- Pulmonary arterial including familial, primary, and PH associated with connective tissue diseases, exposure to toxins, portal hypertension, shunts associated with congenital heart disease and HIV
- Thromboembolic where surgical pulmonary thromboendarterectomy is not immediately indicated
- Miscellaneous causes such as sarcoidosis which may respond to current drug therapies for pulmonary hypertension

2.2.3 The providing centres will be those detailed in Appendix 1.

2.3 The clinical protocol attached at Appendix 3 is based on the British Cardiac Society guidance and will provide the basis for selection of patients for whom management by the NPHS is judged appropriate.

Note: Total predicted activity sets the expected ceiling based on an estimated incidence (new cases) of 4 per million population per annum and prevalence (patients with the disease being treated in English centres) of 20 per million.

3. REFERRAL OF PATIENTS

3.1 The PCTs/SSCGs will expect and encourage their local consultants to refer to those provider units that the Consortium/collective commissioning teams have contracted with in 2003/4 (for full details see Appendix 1):

- Newcastle
- Cambridge
- Sheffield
- London

3.2 Referral of patients may be elective or non-elective.

3.3 Providers for specific disease types are detailed in Appendix 1.

4. PATIENT PATHWAY

4.1 Unless agreed otherwise between PCT and Provider a typical sequence of care will include an initial outpatient assessment, admission for investigation, admission for initiation of treatment, after care, and routine follow-up in outpatients, including re-admission if necessary.

4.2 Patient care may be transferred back to the referring hospital, but pulmonary hypertension care will need to continue at the NPHS centre.

Note: Rare clinical exceptions to this approach must be agreed in advance with lead purchasers.

The lead purchaser will monitor with support from referring clinicians lengths of stay and the outcomes detailed in section 5.
4.3 The NPHS consultant must report back to the referring consultant and GP on the progress of the patient. They should be informed at all stages of the patient’s treatment and on how to access advice. The quality of communication between NPHS providers and referring consultants will be monitored.

4.4 There should be arrangements for direct 24 hour emergency access after discharge.

4.5 The follow-up process must run for the life time of the patient, until lung transplantation or for a period of time agreed with the referring clinician. A clinical review will be required after treatment is established between referring and provider clinicians to enhance communication, to plan further treatment and to agree on any transfer arrangements.

4.6 Delays in planned or agreed transfers should be audited. The clinical quality, timing and effect in terms of cost to secondary care hospitals of these transfer arrangements will be monitored.

5. CLINICAL OUTCOMES, INFORMATION AND AUDIT, AND CLINICAL GOVERNANCE

5.1 A national database has been co-ordinated by Dr Simon Gibbs, Hammersmith Hospital and is currently funded by NSCAG. Pulmonary hypertension data for England and Wales will be analysed by one centre, working with the other centres to produce clinical outcome comparisons (with casemix analysis).

5.2 As a minimum, for the purposes of the SLA the consortia will want to monitor outcomes by each provider separately but duplication of data collection will be avoided. Rapid progress on outcome analysis using the database with risk modelling to follow will avoid the need for separate direct reporting to the consortia.

Note: These outcome measures include:

- Pulmonary Function Tests
- Six minute walk (distance in metres)
- Echocardiography – reduction in peak pulmonary artery pressure
- Chest X-Ray – reduction in cardiothoracic ratio.
- Quality of Life measures (v Papworth protocol)
- Survival at 6 months and 1 year on prostaglandins and analogues

Definitions and further detail on timing (i.e. interim reports on NPHS outcomes) and additional within centre data requirements to be agreed by NPHS clinicians and SSCGs.

5.3 Regular and documented clinical audit should be carried out and results reported to the lead PCTs/SSCGs.

Note: Proposed audit topics for 2003/4 should be agreed with the commissioners and will focus on monitoring of clinical demand, and the use of the specific clinical outcome measures outlined in 5.2.
5.4 A database of all NPHS activity will be maintained. Information on casemix, activity, and the agreed results of the programme should be transferred to the commissioners every quarter no later than 21 days after the end of the previous quarter.

5.5 Note: Each provider must share the clinical results of the NPHS programme with all referring clinicians including them in annual education and audit reviews (with emphasis on improving communication and collaboration between secondary care and NPHS units).

5.6 There should be arrangements in place for continuous review of patients by the Provider on a long-term basis.

6. STANDARDS

6.1 The NPHS committee has agreed standards of care for pulmonary hypertension with NSCAG (Appendix 4). A programme of data collection, analysis and accreditation has been developed by NSCAG with the NPHS national committee in 2001/2.

Centres should prepare for re-assessment/review of accreditation and will need to pay close attention to key areas where there may be difficulty in compliance with the national standards. (To be completed by September 2003 led by specialised services commissioners/NSCAG working with the NPHS committee.)

6.2 Standards for staffing and facilities are laid down by the Standards of Care and amendments will be agreed by the SSCGs with the NPHS National Committee (Appendix 4) for incorporation within this service specification (after the current 2003/4 commissioning intentions round).

6.3 NPHS centres must meet the minimum standards for specialist units. The purchaser will monitor against these standards and expect providers to provide evidence in support.

6.4 Each pulmonary hypertension centre should manage at least 40 patients per year to encourage a high standard of care in investigation, treatment and follow-up of patients.

6.5 The Provider will treat only those patients for whom the condition is included in the service agreement. (see sections 2 and 3).

7. STAFFING AND FACILITIES

7.1 NPHS centres must provide 24-hour on-call cover. There should be appropriately trained specialised medical and nursing staff.

7.2 Each centre should have a named designated person acting as lead clinician.

7.3 There should be a full range of support staff including radiologists, pathologists, cardiac and lung function technicians, social workers, paramedic support, physiotherapy, pharmacy and palliative care.

7.4 Strategies for prevention, control and treatment of complications of pulmonary hypertension should be defined and updated.
Note: Supportive therapies are included in all NPHS packages and are subject to audit.

7.5 Beds in NPHS centres should be in a designated ward with dedicated beds. This could be part of a larger facility for the treatment of patients with cardiothoracic disease.

7.6 Children should be treated at Great Ormond Street Hospital for Children and, where judged appropriate and only after assessment at GOSH, treated through shared care arrangements at other centres only with a joint clinical care plan.

7.7 The NPHS centre should be able to perform on-site all procedures connected to the management of pulmonary hypertension or confirm to the lead purchaser that alternative appropriate arrangements have been made with another centre.

8. QUALITY ASSURANCE

8.1 The Provider must work to written quality standards and provide monitoring information to the lead purchaser.

8.2 The Provider unit must fulfil the requirements of Your Guide to the NHS.

8.3 The centre must enable the patient’s, carer’s and advocate’s informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children.

8.4 Good quality information should be made available to patients. Written information (which has been evaluated by patients) should be available at the point of referral in NPHS centres and should be used to reinforce clinical communication and to inform patients about all aspects of the condition and treatment and its effects on daily living.

8.5 The patient’s contact with the unit in terms of attendance for day care and local shared care should be planned in consultation with the patient. The care plan should include the likely timescale for treatment.

8.6 The Pulmonary Hypertension Association provides a national patient-run support group and should be informed by commissioners of significant difficulties with the provision of a clinical service at any NPHS centre.

8.7 The environment of the NPHS centre should afford privacy.

8.8 The NPHS centre should have a policy on death and bereavement which is culturally sensitive and considers the needs of staff as well as patients.

8.9 A clearly defined after-care programme should be developed with the patient and the referring provider unit.

8.10 Discharge should be planned and agreed with all parties concerned, though responsibility for effective discharge lies with the consultant.

8.11 Post-discharge care should be agreed with the GP and secondary services.
9. RESEARCH

9.1 National analysis and audit including outcome data analysis, coordinated through the NPHS Database in collaboration with SSCGs will be essential.

9.2 All experimental treatments with future funding implications should be agreed with the commissioners as pilot studies and will require prior approval. The proposed treatment protocol must have received the approval of the relevant ethical committees.
Appendix 1

NATIONAL PULMONARY HYPERTENSION CENTRES

2003/4

<table>
<thead>
<tr>
<th>Centre</th>
<th>Provider Units</th>
<th>Lead Clinician</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newcastle</td>
<td>Freeman Hospital</td>
<td>Professor Paul Corris</td>
</tr>
<tr>
<td>Sheffield</td>
<td>Royal Hallamshire Hospital</td>
<td>Dr David Kiely</td>
</tr>
<tr>
<td>Cambridge</td>
<td>Papworth Hospital</td>
<td>Dr Joanna Pephe-Saba</td>
</tr>
<tr>
<td>London</td>
<td>Hammersmith Hospital</td>
<td>Dr Simon Gibbs</td>
</tr>
<tr>
<td></td>
<td>Royal Brompton Hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(adult congenital heart disease)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Royal Free Hospital</td>
<td>Dr Gerry Coughlan</td>
</tr>
<tr>
<td></td>
<td>(connective tissue diseases)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Great Ormond Street Hospital for Children</td>
<td>Prof. Glennis Howarth</td>
</tr>
<tr>
<td></td>
<td>(children only)</td>
<td></td>
</tr>
</tbody>
</table>

Except where stated the provider units manage adults with pulmonary hypertension as specified in section 2.
NATIONAL PULMONARY HYPERTENSION SERVICE

COMMITTEE MEMBERS

Central Sheffield Hospitals NHS Trust
(Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF)
Dr David Kiely, consultant cardiologist
Iain Armstrong, nurse specialist
Lisa Needham, general manager

Great Ormond Street Hospital NHS Trust
(Great Ormond Street, London WC1N 3JH)
Professor Glennis Haworth, vascular biology and pharmacology unit (at Institute of Child Health)
Louise Peat, service manager
Sarah Watson, service development manager

Hammersmith Hospitals NHS Trust
(Hammersmith Hospital, Du Cane Road, London W12 0HS)
Dr Simon Gibbs, consultant cardiologist (Vice-chairman 2001-3)
Anne Hall, general manager

Royal Brompton and Harefield NHS Trust
(Royal Brompton Hospital, Sydney Street, London SW3 6NP)
Professor Tim Evans, consultant intensivist
Clare Robinson, service development manager (at Harefield Hospital)

Royal Free Hampstead NHS Trust
(Royal Free Hospital, Pond Street, London NW3 2QG)
Professor Carol Black, consultant rheumatologist
Dr Gerry Coghlan, consultant cardiologist
Kim Fleming, director of service development

Newcastle-upon-Tyne Hospitals NHS Trust
(The Freeman Hospital, High Heaton, Newcastle-upon-Tyne NE7 7DN)
Professor Paul Corris, professor of thoracic medicine (Chairman 2001-3)
Fiona Waldron, assistant director of business management

Papworth Hospital NHS Trust
(Papworth Everard, Cambridge, Cambridgeshire CB3 8RE)
Dr Joanna Pepke-Zaba, lead clinician, Pulmonary Vascular Diseases Unit.
Claire Tripp, acting service manager
PULMONARY HYPERTENSION SERVICE PROTOCOL

1.0 DEFINITION OF TERMS

Pulmonary Hypertension is defined as a mean pulmonary artery pressure >25 mm Hg at rest or 30 mm Hg with exercise. The classification of pulmonary hypertension is linked to the anatomy or the aetiology. These diagnostic categories are for the convenience of deciding on treatment. Primary Pulmonary Hypertension refers to pulmonary hypertension for which no cause can be identified. The term remains unchanged from the previous system of classification. Primary pulmonary hypertension is a form of Pulmonary Arterial Hypertension which also includes collagen vascular disease*, congenital systemic to pulmonary shunts*, portal hypertension*, HIV infection*, exposure to various drugs or toxins* and persistent pulmonary hypertension of the newborn*. Other types of pulmonary hypertension include Pulmonary Venous Hypertension*, Pulmonary hypertension associated with disorders of the respiratory system and / or hypoxaemia*, Pulmonary hypertension due to chronic thrombotic and / or embolic disease*, and Miscellaneous causes*.

*These hitherto have been called secondary pulmonary hypertension, a term without value for diagnosis and decisions on treatment.

2.0 GENERAL PRINCIPLES OF INVESTIGATION AND MANAGEMENT

These are presented here in brief, but full details are described in the British Cardiac Society Guidelines and Medical Practice Committee, Recommendations on the Management of Pulmonary Hypertension in Clinical Practice which is also approved by the British Thoracic Society and the British Society of Rheumatology.

Presentation and Investigation

2.1 The symptoms of pulmonary hypertension are relatively non-specific. Breathlessness is the most common.

2.2 Where the diagnosis of pulmonary hypertension is suspected a transthoracic echocardiogram should be performed to screen for pulmonary hypertension.

2.3 Referral of patients to a designated specialist centre should normally be made after an ECG, chest X-ray, simple spirometry and demonstration of pulmonary hypertension by echocardiography, but before cardiac catheterisation. Referral should not be delayed owing to the risk of early death from this condition.

2.4 The diagnosis should be confirmed at right heart catheterisation.

2.5 The aetiology of pulmonary hypertension should be sought in order to determine optimal treatment.
2.6 Acute vasodilator testing should be undertaken at the time of cardiac catheterisation. The response to acute vasodilator testing accurately identifies patients who may respond to long-term oral vasodilator treatment.

**Treatment**

2.7 All patients with primary or thromboembolic pulmonary hypertension should be treated with warfarin. Warfarin should be seriously considered in other types of pulmonary arterial hypertension where there are no contraindications.

2.8 Vasodilator therapy with oral calcium antagonists may improve symptoms, haemodynamics and survival in selected patients with pulmonary arterial hypertension who respond to an acute vasodilator test.

2.9 Patients with severe pulmonary hypertension which is primary, familial or caused by anorectic agents, connective tissue diseases, shunts associated with congenital heart disease, portal hypertension, sarcoidosis, HIV or chronic thromboembolic disease (either inoperable or as a bridge to pulmonary thromboendarterectomy) should be considered for long-term intravenous infusion of prostaglandins.

2.10 Patients with chronic proximal pulmonary thromboembolic disease should be considered for pulmonary thromboendarterectomy.

2.11 Lung or heart-lung transplantation should be considered in selected patients with pulmonary hypertension with disease which is severely symptomatic and progressive despite optimal medical and/or surgical treatment.

2.12 Controlled oxygen therapy may be indicated for those patients with sustained nocturnal hypoxaemia where arterial oxygen saturations are below an average of 90% on air and patients with chronic pulmonary disease associated with hypoxia and pulmonary hypertension.

2.13 Atrial septostomy may be considered in severe pulmonary hypertension refractory to prostaglandin therapy particularly if it is associated with recurrent syncope.

2.14 Women of child-bearing age with pulmonary hypertension require contraceptive advice.

2.15 Patients should receive a one-off pneumococcal immunisation and annual immunisation against influenza.

2.16 Patients with pulmonary hypertension require lifelong monitoring in a specialist centre with the instigation of appropriate therapies as the disease evolves. Submaximal exercise testing is a useful objective assessment since exercise capacity and severity of pulmonary hypertension are correlated. Patients with pulmonary hypertension caused by hypoxia, chronic heart failure and congenital heart disease will be followed up by other physicians and do not normally require monitoring in a specialist pulmonary hypertension centre.
3.0 MANAGEMENT STRUCTURE:

3.1 The Pulmonary Hypertension group at each centre is made up of specialist groups, which constitute the physicians, specialist nurses, radiologists, cardiac and lung function technicians, ward staff, and management support.

3.2 Each group will be appropriately trained in provision of the investigation and treatment of pulmonary hypertension.

3.4 There is already a national management group (Appendix 2), the NPHS Committee that will meet quarterly with the principal aims of ensuring:

- an equitable, accessible service
- the highest quality service.
- that activity is appropriately funded based on commissioning agreements
- that an up to date protocol is always available.
- that technical issues within the criteria above are addressed.

The Pulmonary Hypertension group within each centre will be made up of representatives of the constituent groups and with a named physician as director accountable to the Trust Medical Director.

4.0 GENERAL SEQUENCE OF STEPS FOR INVESTIGATION AND TREATMENT OF PULMONARY HYPERTENSION:

4.1 Referrals will be made to the named specialist in pulmonary hypertension.

4.2 The patient will usually be seen in outpatients or transferred from another hospital for further tests that may include lung imaging and cardiac catheterisation. The decision to perform investigations as an inpatient or an outpatient will depend on the clinical state of the patient and their proximity to a centre.

4.3 The admission of the patient will be co-ordinated by the consultant physician, pulmonary hypertension nurse and related junior medical staff whose duty it will be to ensure all on call pulmonary hypertension staff are aware of the referral.

4.4 On completion of the investigations a plan for the management of the patient will be discussed and presented to the patient. Arrangements will be made to commence drug therapy and / or refer for pulmonary thromboendarterectomy, lung transplantation or atrial septostomy.

4.5 The patient will be followed up life long or until surgery with regular review of their therapy.
## NATIONAL PULMONARY HYPERTENSION SERVICE – STANDARDS OF CARE

January 2003

<table>
<thead>
<tr>
<th>Core Standard</th>
<th>Definition &amp; Information Required</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. THE SPECIALIST TEAM</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Wherever possible patients with significant pulmonary hypertension (mean pulmonary artery pressure &gt;35 mm Hg or systolic pressure &gt;50) should be managed by NSCAG designated centres</td>
<td>Proportion of patients not referred to the specialist team</td>
<td>Data from Trust/GP information systems</td>
</tr>
<tr>
<td>1.2 Guidelines should be in place to ensure that the same clinical management protocols apply to all designated centres</td>
<td>National guideline document</td>
<td>Heart supplement</td>
</tr>
<tr>
<td>1.3 Patients should be managed by a specialist team led by a physician with a sub-specialty interest in pulmonary hypertension including a specialist pulmonary hypertension nurse (and home care team when on intravenous therapy)</td>
<td>Members of the team identified</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td>1.4 The specialist team should meet on a regular basis to discuss each patient during diagnostic and treatment phases of the care pathway</td>
<td>Record of team meetings with decisions documented</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td>1.5 The specialist team should be supported by adequate secretarial support to ensure good communication with referring hospitals, GPs and patients</td>
<td></td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>2. COMMUNICATION WITH PATIENTS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.1 At every stage patients should be offered clear, objective, full and prompt information in both written and verbal form. Each patient should receive information relevant to their case concerning the disease, diagnostic procedures, treatment options and effectiveness</td>
<td>Appropriate written and verbal information given to patients.</td>
<td>Examples of information leaflets</td>
</tr>
<tr>
<td>2.2 Patients and carers should have a point of contact at all times with a member of the team. They should receive clear advice about who they should contact in case of emergency</td>
<td>Each patient should have a list of the pulmonary hypertension team and a list of contact numbers</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td>3. ACCESS and DIAGNOSIS</td>
<td>National guidelines in place, urgent cases defined and doctors informed of referral procedures</td>
<td>Annual report of the National Pulmonary Hypertension Service</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>3.1</strong> There are nationally agreed guidelines, which facilitate appropriate and timely referrals from primary, secondary and tertiary care to specialist centres</td>
<td>Interval between receipt of referral and date patient first seen by a specialist</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.2</strong> There should be minimal delay between referral to a specialist centre and an outpatient consultant appointment. All patients referred urgently will be able to see a specialist at a one-stop hospital visit within one month of the specialist centre receiving their referral and those who are severely symptomatic should be seen within 2 weeks</td>
<td>Range and median distribution of times between date of referral for diagnostic imaging and imaging appointment</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.3</strong> Patients are able to access non-invasive imaging services within 3-5 working days (includes chest X-ray and echocardiography)</td>
<td>Range and median distribution of times between date of referral for diagnostic imaging and imaging appointment</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.4</strong> For appropriate patients, CT scanning and nuclear imaging should be performed within 14 days of the first appointment with a specialist physician unless decided otherwise between patient and physician</td>
<td>Range and median distribution of times between date of referral for CT scan / nuclear imaging and imaging appointment</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.5</strong> For appropriate patients, cardiac catheterisation and / or pulmonary angiography should be performed within 28 days of the first appointment with a specialist physician</td>
<td>Range and median distribution of times between date of referral for diagnostic imaging and imaging appointment</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.6</strong> The patient should have a full diagnosis and treatment plan within 14 days of their cardiac catheterisation</td>
<td>Range and median distribution of times between date of referral for diagnostic imaging and imaging appointment</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.7</strong> Where possible a named lead person (e.g. specialist nurse or trained counsellor) should be present with the patient when the final diagnosis is discussed</td>
<td>Documented lead individual</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td><strong>3.8</strong> The full diagnosis should be communicated to the referring consultant(s) and the GP within 3-5 working days of the definitive diagnosis being made</td>
<td>Guidelines to ensure communication with GP</td>
<td>Annual Trust report</td>
</tr>
<tr>
<td>4. TREATMENT</td>
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</tr>
<tr>
<td>4.1</td>
<td>There should be agreed best practice clinical guidelines covering all aspects of care based on published national guidelines. These should be regularly updated in accordance with evidence based medicine</td>
<td>Treatment guidelines in use</td>
</tr>
<tr>
<td></td>
<td>Number of patients who receive prostaglandin therapy</td>
<td>Delay in obtaining health authority / primary care group funding agreement for life-long therapy</td>
</tr>
<tr>
<td>4.2</td>
<td>For those patients who are eligible for prostaglandin therapy, this should be commenced within 6 weeks of the first appointment with a specialist physician. The delay should be a maximum of 8 weeks</td>
<td>Range and median distribution of times between date of decision to recommend prostaglandin therapy and its commencement</td>
</tr>
<tr>
<td>4.3</td>
<td>For those patients who are eligible for pulmonary thromboendarterectomy, referral should be received by Papworth Hospital within one week of pulmonary angiography</td>
<td>Range and median distribution of times between date of decision to refer and referral received.</td>
</tr>
<tr>
<td>4.4</td>
<td>For those patients who are eligible for lung transplantation, referral should be sent to the lung transplant centre within one week of the completed work-up</td>
<td>Range and median distribution of times between date of completed work-up and referral sent</td>
</tr>
<tr>
<td>4.5</td>
<td>Eligible patients should be encouraged to become part of nationally / internationally coordinated randomised trials</td>
<td>Proportion of patients offered randomised controlled trials</td>
</tr>
<tr>
<td>4.6</td>
<td>A palliative approach, involving symptom control, psychological, social and spiritual support to the patient and their carers should be provided throughout the course of the illness, regardless of whether they wish to receive active treatment</td>
<td>Evidence of palliative care protocols</td>
</tr>
<tr>
<td>5. FOLLOW-UP</td>
<td></td>
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<tr>
<td>-----------------</td>
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<td>---------------------------------</td>
</tr>
<tr>
<td><strong>5.1</strong></td>
<td>There should be clear nationally agreed protocols on follow-up within each specialist centre</td>
<td>Protocols for patient follow-up</td>
</tr>
<tr>
<td><strong>5.2</strong></td>
<td>Where appropriate, follow-up protocols and recommendations should be sent to referring physicians with whom shared-care is arranged. This applies particularly to patients for whom transport to a specialist centre may present difficulties</td>
<td>Evidence for documentation being sent to referring physician</td>
</tr>
</tbody>
</table>

| 6. MONITORING OUTCOMES |  |
|-----------------|-----------------|---------------------------------|
| **6.1** | Outcomes should be monitored. This requires routine audit and a proper infrastructure for data collection | a) Documentation of formal agenda of planned audits and reports of completed audits | Annual report of the National Pulmonary Hypertension Service |
| | | b) Participation of all centres in national audits | Audit participation |
| | | c) Evidence of systematic data collection and analysis infrastructure | Submission of annual data |
| **6.2** | Patient satisfaction with the quality of the service delivered should be monitored | Evidence of patient satisfaction | Annual patient satisfaction questionnaires |