

Guidance for the Referral of Patients Abroad for NHS Proton Treatment

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All relevant documents are available on the NSCT website including:

Latest version of the guidance document
Referral Form
Patient Information,
Travel & Accommodation Policies

Guidance for the Referral of Patients Abroad for NHS Proton Treatment

Proton Clinical Reference Panel (PCRP)

1. Introduction

1.1 Proton treatment is a highly specialised means of delivering radiotherapy dose to a target volume. The particular characteristic of proton beams means that comparatively little radiation is given to normal tissues. This is especially useful for cases where critical normal tissues impose dose constraints or considerations of potential late effects from irradiation of the normal tissues make even optimised photon options such as Intensity Modulated Radiotherapy (IMRT) unacceptable.

1.2 Worldwide experience and evidence of proven benefits and long term outcomes, outside the treatment of ocular malignancy, is still limited however. Clinical decisions as to the need or suitability for proton therapy are required as there are many factors other than dose distribution that are important to consider. Patients should have the opportunity to discuss the range of options with an expert in radiotherapy by referral to a Clinical Oncologist.

1.3 In May 2007, the final report of the National Radiotherapy Advisory Group (NRAG) contained a recommendation that the Department of Health facilitated the setting up of panel to review high priority clinical cases on behalf of Primary Care Trusts (PCTs). This concept was incorporated into the Cancer Reform Strategy published in December 2007 so that as from April 2008, suitable cases have been funded for treatment abroad by a service nationally commissioned by the National Specialised Commissioning Team (formerly NCG) The NSCT oversee the organisation of specialist services for the diagnosis and treatment of rare conditions in England. A Proton Clinical Reference Panel (PCRP) has been set up by the NSCT which manages the referral pathway and has the necessary knowledge of proton therapy to approve cases for consideration for treatment abroad so ensuring patients had appropriate and equitable access to high-energy proton therapy abroad. This guidance document outlines the process by which clinicians may refer cases to the panel.

1.4 The current arrangements for the treatment of ocular malignancy with low energy protons at Clatterbridge are unaffected and continue to be the funding responsibility of PCTs.

1.5 The Department of Health are also taking forward a strategy to commission high energy proton therapy in England. This service is expected to be available in about 5 years time.

1.6 For the time being, patients in England will still be referred abroad for proton therapy.

1.7 The capacity for Proton Therapy within Europe has been limited although there are new centres becoming available within the next few years, which may aid capacity. Treatment centres abroad have placed some constraints on who they will accept through the NHS funded route. Patients should be aware that assessment and treatment may take some time.

1.8 The Cancer Reform Strategy, NRAG and the NSCT only apply to England. The NSCT also commission Proton Beam Therapy on behalf of the National Service's Division Scotland and with agreement on a patient by patient basis with Wales and Northern

Ireland. The PCRPs have agreed to consider clinical cases and offer an opinion about referral abroad, using the same diagnostic and clinical criteria as in England. NSCT policies and process on funding of travel and accommodation apply to patients commissioned by the NSCT for England and on behalf of devolved administrations as agreed. Any updated policies on the management of patients from the devolved countries will be made separately available.

1.9 The NSCT have no funding responsibility for patients from the Channel Islands or the Isle of Man. The NSCT Proton Panel will consider a referral from the Channel Islands or the Isle of Man subject to confirmation from the patient's consultant that funding for the referral has been agreed. Confirmation of this would need to be sent with the clinical referral.

1.10 The referral forms and guidance for healthcare professionals and patients are available on the NSCT website. They may be updated or new documents be made available periodically. NSCT policies on funding patients travel and accommodation costs are also available on the websites. The referral forms ask for a significant amount of detail, reports and copies of imaging. Referrals will not be processed if the dataset is incomplete and this will therefore delay a panel decision. The dataset requested to support the referral process is also the minimum satisfactory for referral to the treatment centre. Any changes in process will be notified on the NSCT websites.

1.11 In England, this process replaced the old PCT approval mechanism. PCTs, Strategic Health Authorities (SHAs) and all NHS Trusts have been notified of this mechanism. This centralised NSCT process is therefore the only mechanism by which NHS funding for Proton Treatment abroad will be considered.

1.12 Other charged particle treatment such as Carbon Ion Therapy is not available through the NHS and should still be regarded as experimental.

2. Who can be referred and funded for treatment abroad?

2.1 The list in section 3 below contains the prioritised diagnostic categories and sites that have been agreed and funded as the very highest priority for referral for proton treatment abroad. The list is derived from the NRAG report, amounting to potentially 400 cases per annum. There is still a real concern about a lack of available treatment capacity in the next few years with specific restrictions on referral imposed by treatment centres for NHS funded cases. Over a period of time these criteria and the diagnosis list will be reviewed and may be expanded as larger capacity is available abroad and evidence of improved outcomes is demonstrated.

2.2 It is important to recognise that funding will not be approved outside the strict criteria of the approved diagnostic list (section 3 below) and with reference to the accompanying notes. The fact that a patient has a diagnosis on the approved list does not imply that protons will necessarily or always be the preferred radiotherapy option. It should be noted that final decision to accept cases for treatment after approval from the PCRPs is made by the treating centre.

2.3 Some additional and over-riding principles for approval and funding are important. These are:

2.3.1 Treatment should be given with curative intent.

2.3.2 Patients will have good performance status either 0 or 1 (WHO - Appendix 2)

2.3.3 No other coincident diagnoses that are likely to either limit 5 year survival or make a prolonged period abroad difficult to manage from a practical point of view

2.3.4 There should be no metastatic disease

2.3.5 Re-treatment cases will not be accepted

2.3.6 There are weight limits on the treatment couches in treatment centres. The weight of adult patients at the time of referral should be given and should not exceed 150kg.

2.4 The cases with the clearest indication are adult and paediatric patients with base of skull chordoma and chondrosarcoma or primary paraspinal tumours. Many of these tumours will have had some degree of surgical resection or debulking. It is clear that any advantage of proton treatment over optimal photon treatment may be dependent on the size and position of the tumour and target volume in relation to critical normal tissues and tolerance doses. In some cases the treatment centre may require further debulking surgery before they are accepted for treatment. Cases may be turned down when, in the panel's view, proton therapy would not confer any advantage. Some important additional factors on some specific issues are contained in the notes at the end of the guidance. The definition of 'paediatric' is taken as up to but not including the 16th birthday at the date of receipt of a complete referral to the panel. Equivalent diagnoses/tumours will not normally be approved in the adult age group.

2.5 A wide range of factors need to be taken into account in assessing if Proton Therapy confers any significant advantage over conventional radiotherapy or IMRT. The diagnosis alone is often not sufficient. These factors include the:

2.5.1 timing of radiotherapy in relation to other treatments

2.5.2 site of tumour

2.5.3 radiotherapy target volume,

2.5.4 target volume dose and dose gradients required

2.5.5 tumour and target volume proximity to critical dose limiting structures

2.5.6 patient age and performance status,

2.5.7 stage and pathology

2.5.8 presence, size and position of metallic implants

2.5.9 views of patients / parents

2.5.10 patients ability to travel

3. List of Approved Diagnoses

3.1 Adult

3.1.1 Base of Skull & Spinal Chordoma

3.1.2 Base of Skull Chondrosarcoma

3.1.3 Spinal & Paraspinal Bone and Soft Tissue Sarcomas (Non Ewing's)

3.2 Paediatric

3.2.1 Base of Skull & Spinal Chordoma

3.2.2 Base of Skull Chondrosarcoma

3.2.3 Spinal & Paraspinal 'adult type' Bone and Soft Tissue Sarcomas

3.2.4 Rhabdomyosarcoma

3.2.4.1 Orbit

3.2.4.2 Parameningeal & Head & Neck

3.2.4.3 Pelvis

3.2.5 Ependymoma

3.2.6 Ewing's Sarcoma

3.2.7 Retinoblastoma

3.2.8 Pelvic Sarcoma

3.2.9 Optic Pathway and other selected Low Grade Glioma

3.2.10 Craniopharyngioma

3.2.11 Pineal Parenchymal Tumours (not Pineoblastoma)

3.2.12 Esthesioneuroblastoma

4. Who should make the referral and be responsible for co-ordinating the process?

4.1 For adult and paediatric cases the referral MUST come from a Consultant Clinical Oncologist who has seen and assessed the patient. Discussions with patients and parents of children about the pros and cons of proton treatment, alternatives and assessments of the complexities of target volumes can only be made by a Clinical Oncologist being involved in the MDT decision and seeing the patient and family. Experience has shown there have been significant problems affecting the appropriate selection of patients and their management where this has not happened.

4.2 It is vital that BEFORE a referral is made:

4.3.1 A full Multi-Disciplinary Team (MDT) has considered the case

4.3.2 The pros and cons of Proton Treatment compared with conventional radiotherapy and / or IMRT has been discussed in each case with a Clinical Oncologist.

4.3.3 Some paediatric clinical trial protocols may preclude proton treatment. The early involvement of a Paediatric Clinical Oncologist where radiotherapy is a possibility in the treatment pathway is thus important and will avoid potential delays and conflicts.

4.3.4 The responsibility for the referral and communication with the proton treatment centre should remain with the referring consultant. Although there is a central administrative process for approving cases, it is important that this does not remove or devalue the direct knowledge, responsibility and relationship that exist with the clinical team who has met and assessed the wider issues for the patient.

4.3.5 Follow up and continuity of care rests with the referring centre. Treatment Centres may ask for detailed radiotherapy follow up data. Again, this makes a Clinical Oncologist the best primary managing consultant.

5. How to make a referral for treatment to the Proton Clinical Reference Panel

5.1 NSCT administrative rules mandate that a completed referral form (available on the NSCT and RCR websites) must be received before a case can be processed and considered for approval as well as imaging (including any encryption passwords). All relevant letters, summaries, operation reports, radiology / histology reports should also be available for the PCRCP and may be requested if not supplied at the outset, leading to delays.

5.2 Direct referral to a Proton Treatment centre should not be made until NSCT approval has been obtained.

5.3 Cases with diagnoses outside the list above will not be approved or funded and there

are some overriding principles that need to be met even within the approved list as detailed above.

5.4 All referrals must be sent to: leedsth-tr.ProtonNCG@nhs.net and not individual panel members. The replies will be from the Chair of the panel rather than individual panel members. If there are email problems the form can be faxed to 0113 2067561. The panel aim to meet a target of approval within 10 working days of receipt of a completed referral in 90% of cases that clearly meet pre-defined diagnostic criteria. Individual advice and support cannot be supplied routinely by panel members. However if there are administrative or clinical queries relating to referral, contact may be made with the administrative centre for guidance on the numbers and email given below.

5.5 Imaging information is important in the approval and referral process. The Imaging on CD-ROM should be sent by post to Leeds (see contact details below) as the location for co-ordinating the administrative side of the panel process. We suggest 2 sets of CD-ROMs are produced with up to date pre and post-operative imaging. One set should be sent to the panel and the other retained to send to the treatment centre (which must be sent by express / courier mail e.g. FedEx or UPS) if and when the case is approved. Experience has shown that there can be significant delays in packages arriving, especially to the USA due to Homeland Security procedures if standard postal routes are used. Post-operative imaging should be recent and we advise within 8 weeks of the referral. We cannot return imaging discs so provision for adequate extra copies to be made for sending to the proton treatment centre should be considered at the outset of the referral process. We are exploring improved ways in which images can be sent to the panel and also overseas for the future.

The following guidance shows what imaging is required:

5.5.1 Staging scans are not required to be sent to the panel unless there is significant uncertainty but reports should be included with the application to demonstrate that there is not metastatic disease.

5.5.2 **For adult cases** pre and post op MRI are required and the latest scan should be within 8 weeks of the referral. For some cases a pre-op CT may give additional helpful information.

5.5.3 **For paediatric cases** the following list details the imaging required:

5.5.3.1 Base of skull and spinal cordoma and chondrosarcoma: MRI at initial diagnosis + post op imaging. In addition, if there has been a long delay between post op imaging and referral, recent imaging (i.e. within 8 weeks).

5.5.3.2 Adult type paraspinal bone and tissue sarcomas, pelvic sarcomas: initial + post op MRI.

5.5.3.3 Rhabdomyosarcomas: initial MRI/CT (to assess bone destruction if available), post chemo imaging prior to definitive local treatment if available (patient should actually be referred earlier than this is available), post surgery imaging, again if available.

5.5.3.4 Ependymoma: initial pre-op MRI, immediate post op MRI to assess extent of resection. Where there has not been an initial complete macroscopic resection, imaging post chemo/second

surgery to confirm complete resection.

5.5.3.5 Optic pathway and other LGG's: initial diagnostic MRI, most recent MRI demonstrating the current extent of disease.

5.5.3.6 Craniopharyngiomas: initial diagnostic MRI, post op MRI and an up to date MRI if there has been a long delay between surgery and referral.

5.5.3.7 Pineal parenchymal tumours: initial and post op imaging

5.5.3.8 Ewings: initial diagnostic imaging, post induction chemo-pre op imaging and post op imaging if available

5.5.3.9 Esthesioneuroblastoma: pre and post op imaging

5.6 In setting up a national referral and review process it has been useful to be reminded of the legal consequences of data protection and the use of email and attachments. It is clear that no identifiable patient data should be sent by any means other than an *nhs.net* address to another *nhs.net* address. Email addresses that are *nhs.uk* and even more so *ac.uk* should not be used. Obtaining an nhs.net email is easy (<https://www.nhs.net>).

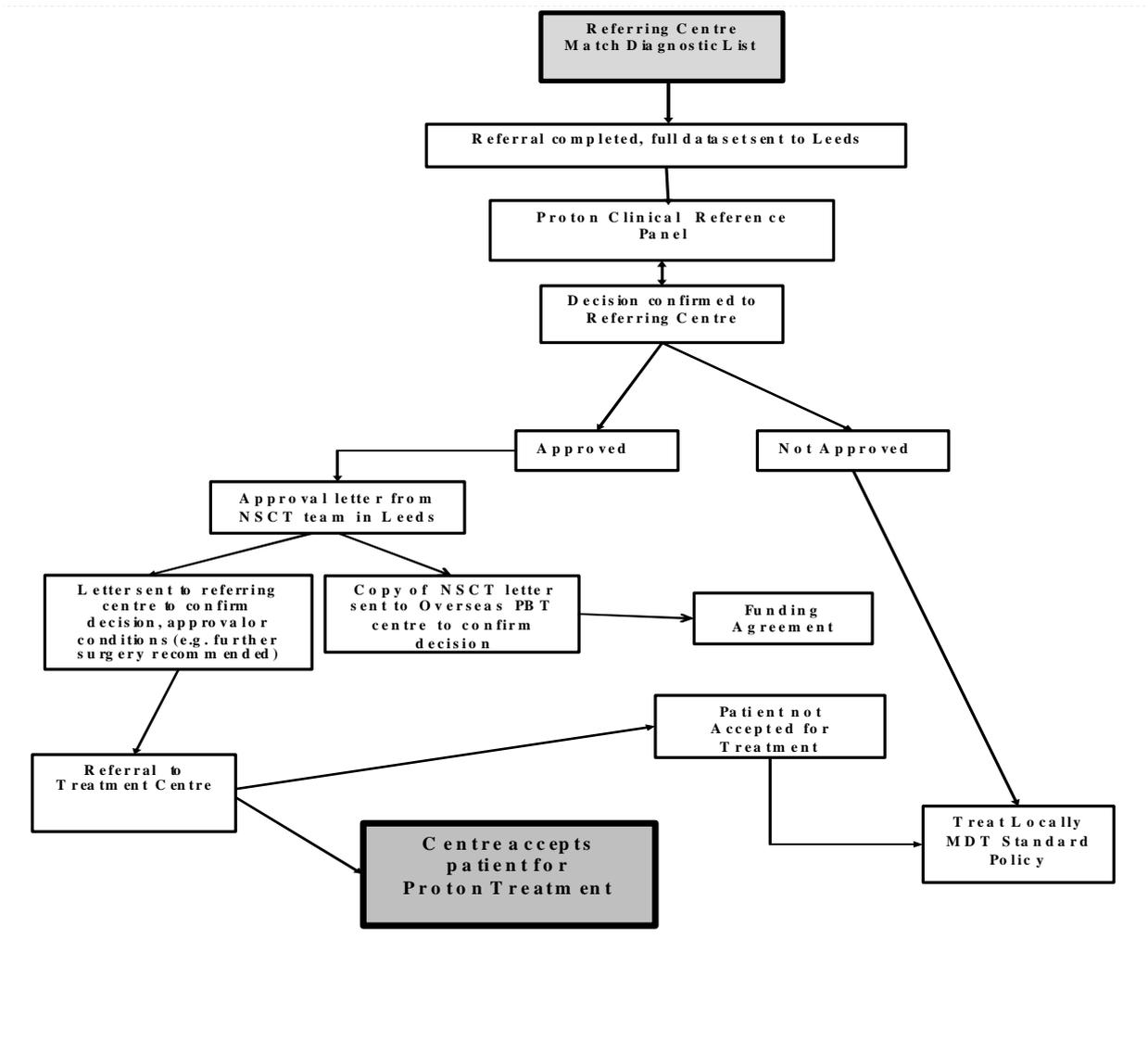
5.7 Specific pathways are being developed between the NSCT and treatment centres to ensure high quality care, good clinical liaison, administrative, accommodation and transport links. **In order to make arrangements with treatment centres clear and avoid false expectation for patients it is important that the referral to the PCRPs and approval is obtained BEFORE cases are discussed or referred to treatment centres.**

5.8 The NSCT will only fund treatment at selected centres. Referring clinicians will be directed as to which proton treatment centre a referral should be made after approval.

5.9 If a case is not approved and turned down for funding and the patient or referring consultant feel that relevant factors have not been taken into account that make a case exceptional within the wider context of other patients with the same diagnosis, then they may ask for consideration of the case under the NSCT's Individual Cases Policy. (Available on NSCT website).

5.10 The NSCT can only act in ways for which there is specific legal provision. There is no legal mechanism which empowers NSCT to make a retrospective payment. Such reimbursement could only be given as 'special' or 'ex gratia' payments, which are the subject of guidance from the Department of Health. According to this guidance, the NSCT can only make a payment after the event, when it acknowledges that there has been an error or maladministration.

6. Referral Pathway for Proton Treatment



7. What happens if the case is approved?

7.1 The referring clinician will be contacted once the panel has made a decision.

7.2 The panel will suggest a contact and which centre to refer to.

7.3 Once the referring clinician has sent the minimum referral data and images to the treatment centre there may be requests back for more details and they particularly may want to discuss any neurosurgical issues direct with the UK neurosurgeon. Treatment centres have quite strict acceptance criteria so it is important that patients are not led to believe that a referral will always lead to Protons being offered. A significant number of

cases have required further surgery before being accepted for treatment.

7.4 In the referral letter to the treatment centre it should be made clear that the patient has been approved by the NSCT and that it is an NHS referral.

7.5 After acceptance of a patient by the treatment centre the NSCT should be notified via the leedsth-tr.ProtonNCG@nhs.net address so that we are aware and the NSCT team can liaise with the treatment centre to make sure there are no problems with the direct funding arrangements for the treatment.

7.6 If a proton treatment centre cannot accept a case for whatever reason but still recommend protons are appropriate to consider, the case should be referred back to the Proton Clinical Reference Panel before any other arrangements are made. An alternative treatment centre may then be recommended.

7.6 The approval for treatment will lapse 3 months after the approval date if a referral to the treatment centre has not been made. Reapplication would then be necessary. If there are exceptional circumstances the referring clinician may contact the Chairman of the PCRCP.

7.7 Information for patients is available on the NSCT website.

7.8 Treatment centres have placed some specific limits on their acceptance of NHS patients. The NSCT will therefore direct where cases are referred to and approve the funding on that basis. The centres that we may approve sending patients to are:

7.8.1 Villigen, Switzerland: http://www.psi.ch/index_e.shtml

7.8.2 Jacksonville, Florida, USA: <http://www.floridaproton.org/>

7.8.3 Oklahoma USA: <http://www.procure.com/OurLocations/Oklahoma.aspx>

7.9 In the future the NSCT will potentially develop a wider base for referral bearing in mind the quality of treatment and care available, capacity, value for money and cost. New centres are being commissioned in Germany and the USA.

8. What about travel and accommodation?

8.1 The NSCT policy on funding of patient's travel and accommodation costs can be found on the NSCT website. It applies to and patient funded by the NSCT for proton therapy.

8.2 The NSCT will fund the treatment costs directly with the treatment centre. Arrangements have also been made with treating centres in Villigen and Florida to include accommodation costs as part of the package of care funded directly by the NSCT. When a patient is treated in the USA costs of car hire are also packaged into the costs funded directly by the NSCT.

8.3 Other travel and accommodation arrangements are the responsibility of the referring centre. Some guidelines and help on how to do this is either available via the web sites or via the NSCT administration office on the number shown below. Guidance should be sought from the NSCT and not the PBT treatment centres.

8.4 The referring NHS Trust will be expected to coordinate administrative arrangements

outside of those agreed as part of the NSCT package and reclaim costs from the NSCT. It includes one carer for adults and two parents or carers for paediatric patients. The patient should not be expected to take on this burden. There will be several appointments for assessment and planning before treatment starts and these are similar to those for conventional radiotherapy. This may require separate trips.

8.5 Experience has shown that oncology centres and radiotherapy departments are best suited to guide patients and undertake these arrangements as the processes involved in Proton treatment are similar to those for conventional radiotherapy. Referral through a Clinical Oncologist is mandatory for all patients. It is recommended that some administrative arrangements are made in referring oncology / radiotherapy centres to support his process.

8.6 Support may be required for patients to obtain passports, EU Health Insurance Cards, travel insurance (and occasionally) visas.

8.7 All billing and charges from the proton treatment centre should be made directly to the NSCT, as long as in the referral it is made clear this is an NHS and NSCT approved case. So, patients and referring centres should not have to get involved in these. However reimbursement for travel and accommodation expenses incurred by the referring Trusts should be made in accordance to the travel and accommodation guidelines (Reimbursement section) available on the NSCT website. Please note that the Clinical Reference Panel administration office do not deal with the financial arrangements or reimbursements so financial queries should be directed to the London NSCT administration. Contact details are:

9. What if further surgery or other concomitant treatment is required?

9.1 The nature and extent of surgery are vitally important for several reasons in determining outcomes and acceptance for proton treatment. This is because:

9.1.1 The volume of residual disease in many tumours (e.g. sarcoma, chordoma and chondrosarcoma) directly linked to the likelihood of cure.

9.1.2 Surgery can create adequate geometry and margins for tumour and target volumes and in particular the relationship with critical dose limiting structures, that allow high dose treatment to be planned.

9.2 If a proton treatment centre feels that more surgery is required before treatment is possible the case should be reviewed back in the referring MDT to assess if the required surgery is possible locally or if cross referral to another UK centre with the specialist techniques is necessary. In the event that this is not possible, surgery abroad may be considered necessary.

9.3 The NSCT cannot accept funding responsibility for further resection or surgery required in order to make a proton treatment possible, before a patient can be accepted by a treatment centre. If it is necessary for this to be arranged abroad, an E112 will be required for treatment within the EU or a direct application for PCT funding approval.

9.4 Surgical procedures for the placement of fiducial markers or intravenous access lines that are part of proton treatment delivery will be funded directly with treatment centre abroad by the NSCT.

9.5 If chemotherapy is required to be given concurrently with the proton treatment for paediatric patients, whilst the patient is abroad, it will be funded directly with the treatment centre abroad by the NSCT.

10. Notes on the Diagnostic List

10.1 The following notes are intended to help referring clinicians in discussions with patients and to select patients in whom there might be a benefit in considering Proton treatment within the current criteria.

10.2 Spinal Tumours There are two significant issues that may make these cases difficult or untreatable with Protons that referring clinicians should be aware of.

10.2.1 It is clear that proton centres recognise the importance of adequate debulking of tumours and the poor results with treatment with significant volumes of macroscopic disease such that further surgery will be suggested or cases rejected for treatment. If further surgery is required it may be suggested that this is done abroad as in many instances in our recent experience, surgeons in the UK have declared that they cannot undertake any further procedure. Under these circumstances approval and funding for the surgery will require the issue of an S2 for treatment within the EU or PCT approval for surgery in the USA.

10.2.2 The presence of any metal stabilisation rods or plates may have a major impact on the acceptance of cases for treatment. The outcomes of cases treated with significant metallic stabilisation in place have been shown to be very significantly worse such that cases may be reviewed on a case-by-case basis and often not accepted. There is some guidance that may make proton treatment more likely and which surgeons should be aware of. Ideally the position and type of any stabilisation should be planned prior to resection, with proton treatment in mind. The uncertainties of dose distribution in treatment planning close to the target volume and critical normal tissues such as spinal cord with cold spots in the shadow of metal and hot spots anteriorly and laterally can lead to significant underestimation of dose with current planning systems. This uncertainty is sufficient that conventional radiotherapy with IMRT solutions where dose distributions will be much more reliable may be preferred. Factors to be born in mind are:

10.2.2.i Titanium rather than stainless steel is preferred as it reduces artefact and improves accuracy of radiotherapy treatment planning.

10.2.2.ii Metal implants close to residual disease that will be within the radiotherapy target volume may make the patient unacceptable for treatment.

10.2.2.iii Transverse cross-links at the level of the tumour and in the plane of radiotherapy between longitudinal rods should be avoided.

10.2.2.iv Implants should be minimised but posterior rods for stabilisation or only one plate, situated away from the radiotherapy target volume may still allow treatment.

10.2.2.v Pedicular screws should be fixed at least 2 vertebral bodies cranial and caudal to the area of the tumour to avoid artefacts which may compromise treatment planning and dosimetry.

10.3 Chordoma and Chondrosarcoma of Base of Skull

Significant residual bulk disease may preclude patients from treatment with Protons. There is good evidence of good outcomes from surgery and post operative proton and conventional radiotherapy when the volume of residual disease is minimal. This volume appears to ideally be less than 25ml Experience has been that newer approaches to endoscopic skull base surgery and in some cases re-operation at specialist centres, including some abroad, has been recommended before patients have been accepted for proton treatment. In some cases decompression may be necessary to allow sufficient space between the brainstem and the target volume to allow scope for high dose proton treatment.

10.4 Sacral Tumours including Chordoma

Many bulky sacral Chordomas can only be resected with considerable morbidity and subsequent impact on quality of life. Given that these cases are ultimately not likely to be permanently curable, patients will often not wish to undergo such surgery. However a very positive approach to treatment should be considered with high dose radiotherapy recommended as a means of maximising local control for these patients. At present protons have little advantage over optimal conventional radiotherapy due to the site and size of the target volume. Whilst small investigational studies have used various approaches to charged particle therapy as a primary treatment modality, there is insufficient literature and evidence to support this approach as a standard policy to apply nationally. These inoperable cases would therefore not be approved or funded for treatment abroad. However it is strongly recommended that patients are referred to specialist centres in the UK for consideration of high dose IMRT if such treatment is not available in their local radiotherapy treatment centre.

10.5 General Paediatric Considerations

10.5.1 In recent years planning and modelling studies have predicted advantages for proton therapy compared with conventional radiotherapy in terms of reduction in long-term morbidity in some clinical scenarios. However, direct evidence of improved long term outcomes or late morbidity has not yet been demonstrated for protons in paediatric cancer. Even in countries with direct access to proton treatment only certain cases are referred and treated and it is in no way seen as routine yet. Therefore, whilst these modelling and other studies would suggest the potential for gain, it is hard to be absolute about arguments in individual patients. This is especially the case when there could be an impact on other aspects of complex and multimodality care pathways. The importance of timing of radiotherapy may mean that high quality photon treatment delivered at the optimum time, especially if close integration with chemotherapy is necessary, may outweigh any potential benefits of proton treatment. The upset for the wider family and fragmentation of healthcare and support should also be taken into account. In view of the considerable recent media and internet interest in proton therapy for children it is important for families to avoid an exaggerated impression of the potential benefits. These complex pros and cons should be clearly discussed in individual cases with parents. It is difficult to justify any undue pressure on parents or clinicians in making these choices.

10.5.2 Early referral in complex cases where multimodality therapy is a factor is encouraged so that the proton centre can schedule treatment and anaesthetic requirements ahead of time and good paediatric oncology links for each case

established with the treatment centre abroad. It may be that if radiotherapy is a possibility within a treatment pathway, and a case fits within the criteria, an early referral even before the absolute indication is terms of response and dose required is known may be sensible. Approval for protons may be conditional under these circumstances but administrative delays can be minimised when final details are known.

10.6 Paediatric Pelvic Sarcoma

This encompasses a range of diagnoses and specifically refers to tumours arising from the bony or soft tissues of the pelvis:

10.6.1 Ewing's Sarcoma

10.6.2 Osteosarcoma

10.6.3 Spindle Cell Sarcoma arising from the pelvis

10.6.4 Rhabdomyosarcoma – including those arising from the genito-urinary tract within the pelvis

10.7 Paediatric Ependymoma

The prognosis for patients with incompletely excised tumours is poor and in referring patients abroad it is almost certain that proton treatment centres and their associated neurosurgical teams will suggest more aggressive surgery. Therefore only completely resected ependymoma cases will only considered for approval within the NSCT criteria.

10.8 Paediatric Low grade Glioma

Whilst proton treatment may allow radiotherapy to be given with a potential for less late toxicity, it may still be advisable to defer radiotherapy treatment either by a period of 'observation' for disease which is non-progressive or by chemotherapy. Cases should be managed on an individual basis.

10.9 Retinoblastoma

Few children will now be treated with radiotherapy. It should be noted that access to proton treatment for this group will only be through referral from the designated specialist National centres of the Barts and the London NHS Trust and the Birmingham Children's Hospital NHS Foundation trust.

10.10 Air travel after neurosurgery

There is little evidence base for advice on air travel after craniotomy. There is some concern about unabsorbed air within the skull and the effects in travelling soon after clinical recovery. The most common advice seems to be to say patients should be fit to travel after 4-6 weeks, but if there is any doubt a lateral brow up x-ray should demonstrate if there is any air in the head.

10.11 General Adult Considerations

The whole issue of performance status is complicated. Advanced disease and poor performance status due to medical co-morbidity that is of a sort that is significantly life limiting, limits the ability to travel or deliver treatment and is likely to exclude the patient

from consideration anyway. The huge difficulties of travel abroad and accommodation, limited support and daily travel to the treatment centre is not to be underestimated and a degree of pragmatism is necessary by the referring clinician and patient in deciding if a referral for proton treatment is worthwhile.

11. Summary and Contact Details

- § High energy proton treatment is centrally funded through NSCT for limited patient groups for treatment abroad
- § Existing arrangements for ocular malignancy treatment at Clatterbridge are unaffected
- § A Clinical Reference Panel will review clinical details and imaging to approve referrals
- § Referral forms and guidance available on the NSCT website

<http://www.specialisedservices.nhs.uk/service/proton-beam-therapy>

- § Referrals and contact with treatment centres abroad should not be made until formal approval has been given by the NSCT for each case.
- § A Clinical Oncologist must see and refer all cases.
- § Referrals should be sent to the NSCT via nhs.net email to:

leedsth-tr.ProtonNCG@nhs.net

- § Imaging on CD-ROM should be sent to

Dr Adrian Crellin
Consultant Clinical Oncologist
NHS Specialised Services Proton Clinical Reference Panel
St James's Institute of Oncology
Level 4 Bexley Wing
St James's University Hospital
Beckett Street
LEEDS LS9 7TF

- § Contact Telephone and Fax numbers
Tel 0113 2068602
Fax 0113 2067561
adrian.crellin@nhs.net
- § If the case is approved the referring clinician will be informed and a suggested treatment centre and contact for referral will be given.
- § After approval the referring clinician will retain primary clinical responsibility (discussions with the patient, referral to the treatment centre and follow up care after treatment).
- § Funding covers treatment costs, basic level travel and accommodation. The NSCT Policy is available on the NSCT website. The referring centre will be responsible for making travel and accommodation arrangements. Advice on this is available if needed from the NSCT
- NSCTProton@nsct.nhs.uk
Tel: 020 7932 3937

Appendix 1. Referral Form – **Note the word version of this form can be downloaded from the NSCT website.**

Specialised Services

NSCT - Proton Overseas Programme - Referral Form

Surname	Referral Date
First Name	Gender Male / Female
DOB	

NHS number	Hospital number
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Address Postcode	GP Name Address
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Diagnosis / Site

Referring Clinical Oncologist	Telephone
Referring Centre	Fax
Centre Address	Email address

Surgeon	Telephone
Hospital	
Postal address	Email address

For Paediatric Patients:

Main carer(s):

Other siblings in family (gender and ages):

Family members (including ages) who will need to travel and lodge with patient:

History synopsis

Diagnosis - Date of diagnosis

Operations - Date of 1st operation
Procedure

Date of 2nd operation
Procedure

Chemotherapy

Clinical Summary

(should include Past Medical History and significant Co-morbidities)

For Adult Patients:

Weight

Language abilities or limitations:

Specific Clinical Factors

Neurological deficits

Mobility

Communication / language issues – abilities or limitations

WHO/ECOG Performance Status 0 1 2 (Delete as appropriate)

0 Fully active, able to carry on all pre-disease performance without restriction

1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work

2 Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours

3 Capable of only limited self-care, confined to bed or chair more than 50% of waking hours

Present medication:

Enclosures Checklist

Histology Report **Y / N**

Operation Report **Y / N**

Imaging CD-ROM **Y / N**

Radiology Reports **Y / N**

Willing to Travel **Y / N**

Email to: leedsth-tr.protonNCG@nhs.net

Fax: 0113 2067561

Help - Contact - 0113 2068602

PLEASE NOTE : It is an NSCT requirement that **THIS FORM and ALL supporting information** including relevant letters, summaries, operation reports, radiology / histology reports, imaging on CD-ROM are received before a case will be officially processed and considered.

Appendix 2

WHO / ECOG PERFORMANCE STATUS*

Grade	
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair

* As published in Am. J. Clin. Oncol.:

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.