



GIG
CYMRU
NHS
WALES

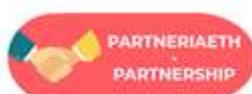
Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Specialised Services Commissioning Policy: CP148

Proton Beam Therapy for Children, Teenagers and Young Adults in the treatment of malignant and non-malignant tumours

April 2023

Version 1.12



Document information

Document purpose	Commissioning Policy
Document name	Proton Beam Therapy for children, teenagers and young adults in the treatment of malignant and non-malignant tumours
Author	Welsh Health Specialised Services Committee
Date first published	January 2018
Revision date	February 2023
Commissioning Team	Cancer & Blood
Target audience	Chief Executives, Medical Directors, Directors of Finance,
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document No	CP148
Review Date	2026

Contents

Policy Statement	4
Welsh Language.....	4
Decarbonisation	4
Disclaimer	4
1. Introduction	6
1.1 Plain Language Summary	6
1.2 Aims and Objectives	7
1.3 Epidemiology	7
1.4 Current Treatment.....	8
1.5 Proposed Treatment	8
1.6 What NHS Wales has decided.....	8
1.7 Relationship with other documents	9
2. Criteria for Commissioning	10
2.1 Inclusion Criteria – general principles.....	10
2.2 Criteria for treatment.....	11
2.3 Exclusion Criteria	11
2.4 Continuation of Treatment.....	12
2.5 Acceptance Criteria.....	12
2.6 Patient Pathway (Annex i)	12
2.7 Designated Centres	13
2.8 Exceptions.....	13
2.9 Clinical Outcome and Quality Measures	14
2.10 Responsibilities	15
3. Evidence	16
3.1 References	16
3.2 Date of Review.....	16
4. Equality Impact and Assessment.....	17
5. Putting Things Right:	18
5.1 Raising a Concern.....	18
5.2 Individual Patient Funding Request (IPFR)	18
Annex i Patient Pathway.....	19
Annex ii Paediatric indications suitable for conventional radiotherapy (photons or electrons).....	20
Annex iii Abbreviations and Glossary	21

1 **Policy Statement**

2 Welsh Health Specialised Services Committee (WHSSC) will commission
3 Proton Beam Therapy (PBT) for Children, Teenagers and Young Adults in
4 the treatment of malignant and non-malignant tumours in accordance with
5 the criteria outlined in this document.

6

7 In creating this document WHSSC has reviewed this clinical condition and
8 the options for its treatment. It has considered the place of this treatment
9 in current clinical practice, whether scientific research has shown the
10 treatment to be of benefit to patients, (including how any benefit is
11 balanced against possible risks) and whether its use represents the best
12 use of NHS resources.

13

14 **Welsh Language**

15 WHSSC is committed to treating the English and Welsh languages on the
16 basis of equality, and endeavour to ensure commissioned services meet the
17 requirements of the legislative framework for Welsh Language, including
18 the [Welsh Language Act \(1993\)](#), the [Welsh Language \(Wales\) Measure
19 2011](#) and the [Welsh Language Standards \(No.7\) Regulations 2018](#).

20

21 Where a service is provided in a private facility or in a hospital outside of
22 Wales, the provisions of the Welsh language standards do not directly apply
23 but in recognition of its importance to the patient experience the referring
24 health board should ensure that wherever possible patients have access to
25 their preferred language.

26

27 In order to facilitate this WHSSC is committed to working closely with
28 providers to ensure that in the absence of a Welsh speaker, written
29 information will be offered and people have access to either a translator or
30 'Language-line' if requested. Where possible, links to local teams should be
31 maintained during the period of care.

32

33 **Decarbonisation**

34 WHSSC is committed to taking assertive action to reducing the carbon
35 footprint through mindful commissioning activities. Where possible and
36 taking into account each individual patient's needs, services are provided
37 closer to home, including via digital and virtual access, with a delivery chain
38 for service provision and associated capital that reflects the WHSSC
39 commitment.

40

41 **Disclaimer**

42 WHSSC assumes that healthcare professionals will use their clinical
43 judgment, knowledge and expertise when deciding whether it is appropriate
44 to apply this policy.

45

1 This policy may not be clinically appropriate for use in all situations and
2 does not override the responsibility of healthcare professionals to make
3 decisions appropriate to the circumstances of the individual patient, in
4 consultation with the patient and/or their carer or guardian.

5
6 WHSSC disclaims any responsibility for damages arising out of the use or
7 non-use of this policy.

8

1 **1. Introduction**

2 This policy has been developed as a Commissioning Policy for the planning
3 and delivery of Proton Beam Therapy (PBT) for Children, Teenagers and
4 Young Adults (TYA) in the treatment of malignant and non-malignant
5 tumours for people resident in Wales. This service will only be
6 commissioned by WHSSC and applies to residents of all seven Health
7 Boards in Wales.

8

9 **1.1 Plain Language Summary**

For the sake of clarity, this document distinguishes between **Proton Beam Therapy (PBT)**, and all other types of radiotherapy which are grouped together as **conventional radiotherapy**.

Radiotherapy is the use of ionising radiation to treat cancer. Radiotherapy includes Proton Beam Therapy (PBT), which is provided by specialist centres. Radiotherapy also includes treatments provided by all British radiotherapy centres, such as conventional radiotherapy, Intensity Modulated Radiotherapy (IMRT), Image Guided Radiotherapy (IGRT), Stereotactic Radiotherapy (SBRT, SABR), Brachytherapy, Superficial radiotherapy, electron therapy, and Molecular Radiotherapy (i.e. therapeutic radioisotopes such as radioiodine).

10

11 Children are defined as individuals aged up to their 16th birthday. The age
12 limit applies to the start of treatment. Patients who transition between age
13 groups at any stage during the pathway should have their cancer managed
14 according to the original referral criteria assuming this is clinically
15 appropriate.

16

17 TYA patients are defined as individuals aged from their 16th to their 25th
18 birthday. There is an overlap between TYA and adult patients.

19

20 Most of the cancers affecting children differ from those affecting adults.
21 They occur in different parts of the body, appear differently under the
22 microscope and respond differently to treatment. Cancers in teenagers and
23 young adults (aged 16 to around 25 years old) are often 'paediatric-type'
24 and pattern of malignancies.

25

26 Cancer in children, teenagers and young adults encompasses a wide range
27 of individual diagnoses, each of which is treated according to specific clinical
28 protocols and treatments according to stage (extent of spread) and body
29 site. Around 40% are leukaemias and lymphomas (forms of blood cancer),
30 25% are brain tumours, with the remainder comprising a wide range of
31 other tumours. Treatment is frequently complex and intensive but cure

1 rates among children are much higher than for most adult cancers, and
2 overall more than 80% of children are completely cured.¹

3
4 Rarely, non-malignant conditions, for example desmoid fibromatosis, may
5 also require radiotherapy as part of their treatment regimens.

6
7 PBT refers to the use of high-energy proton beams instead of conventional
8 radiotherapy to treat cancer and tumours. PBT utilises a different method
9 of conformally targeting a high dose to a tumour compared to conventional
10 radiotherapy and may thus allow dose escalation to the treatment volume
11 when compared to conventional treatment. As a result of the characteristic
12 properties of PBT (i.e. to stop at a precise depth in tissue with little dose
13 beyond that point) it can allow treatment with reduced volumes of
14 irradiated normal tissues in nearly all situations when compared to
15 conventional radiotherapy. It is this property that allows treatment to be
16 delivered with potentially reduced risks of late side effects, and which can
17 permit escalation of radiation dose to radical levels for some tumours
18 situated next to sensitive structures such as the spinal cord or brain, where
19 conventional radiotherapy may be difficult.

20 21 **1.2 Aims and Objectives**

22 This policy aims to define the commissioning position of WHSSC on the
23 use of PBT for children and TYA in the treatment of malignant and non-
24 malignant tumours.

25
26 The objectives of this policy are to:

- 27 • ensure commissioning for the use of PBT is evidence based
- 28 • ensure equitable access to PBT
- 29 • define criteria for children and TYA in the treatment of malignant
30 and non-malignant tumours to access treatment
- 31 • improve outcomes for children and TYA in the treatment of
32 malignant and non-malignant tumours

33 34 **1.3 Epidemiology**

35 Paediatric cancer is relatively rare (less than 1% of all cancers)² with a
36 characteristic pattern of tumour types and incidence.

37
38 TYA cancer is also relatively rare (less than 1% of all cancers³) with a
39 characteristic pattern of tumour types and incidence. Although TYA patients
40 are defined as individuals aged from their 16th to their 25th birthday there
41 is inevitably an overlap between TYA and adult patients.

¹ [Gan H.-W. & Spoudeas H.A. \(2014\). Long-term follow-up of survivors of childhood cancer \(SIGN Clinical Guideline 132\). Archives of Disease in Childhood – Education and Practice, 99:138-143](#)

² [Children's cancers incidence statistics | Cancer Research UK](#)

³ [Young people's cancers statistics | Cancer Research UK](#)

1 There is also a spectrum of cancers that are more common in the paediatric
2 age group and occur with less frequency in the TYA definition group but
3 overlap.

4 5 **1.4 Current Treatment**

6 Standard pathways of care vary depending on the type of cancer and can
7 include chemotherapy, surgery and radiotherapy.

8
9 One third of survivors of childhood cancer report severe or life-threatening
10 complications up to 30 years after the diagnosis of cancer. This can be due
11 to side effects of cancer treatment, and radiotherapy is a significant
12 contributing factor.

13
14 Late effects of radiotherapy are related to a number of factors, including
15 the age of the child, the total dose of radiation, the volume of tissue treated
16 and the critical structures within the radiation field. Late effects of
17 radiotherapy can include effects on IQ, learning and memory, pituitary
18 dysfunction requiring life-long hormone replacement, risk of vascular
19 sequelae such as stroke, infertility, premature menopause, risk of cardiac,
20 renal and lung toxicity and the risk of secondary radiation induced
21 malignancy. These risks are particularly high in this age range due to the
22 vulnerability of growing tissues compared to mature adults.

23 24 **1.5 Proposed Treatment**

25 Proton Beam Therapy (PBT) is a potential alternative to conventional
26 radiotherapy. PBT provides radiation by delivering a beam of proton
27 particles rather than X-rays. The physical properties of protons result in a
28 significantly reduced radiation dose being deposited in the normal tissue
29 beyond the tumour. This is in contrast to X-rays where there is dose
30 extension beyond the tumour.

31
32 This leads to two main advantages. Firstly, the reduction in the volume of
33 normal tissue irradiated when treating tumours in children, teenagers and
34 young adults is expected lead to an improvement in the quality of survival
35 by reducing the long term side effects of treatment. Secondly, PBT may
36 have the ability to treat tumours which are adjacent to normal tissue where
37 the normal tissue tolerance would prevent X-ray radiotherapy from
38 delivering an effective dose. In this case PBT would be able to deliver an
39 effective dose of radiation to the tumour and avoid irradiating the
40 surrounding normal tissue beyond its tolerance thereby leading to
41 increased cure rates. This is particularly advantageous for radio-resistant
42 tumours where higher doses are required to optimise chance of cure.

43 44 **1.6 What NHS Wales has decided**

45 WHSSC has carefully reviewed the evidence of PBT for children and TYA in
46 the treatment of malignant and non-malignant tumours. We have

1 concluded that there is enough evidence to fund the use of PBT, within the
2 criteria set out in section 2.1.

3 4 **1.7 Relationship with other documents**

5 This document should be read in conjunction with the following
6 documents:

7 8 • **NHS Wales**

- 9 ○ All Wales Policy: [Making Decisions in Individual Patient Funding](#)
10 [requests](#) (IPFR).

11 12 • **WHSSC policies and service specifications**

- 13 ○ [WHSSC Specialised Services Service Specification: Proton Beam](#)
14 [Therapy –CP146](#)
15 ○ [WHSSC Specialised Services Commissioning Policy: Proton Beam](#)
16 [Therapy for Adults with cancer –CP147](#)

17 18 • **Relevant NHS England policies**

- 19 ○ [Proton Beam Therapy Service \(All Ages\) Service Specification](#)
20 ○ [Proton Beam Therapy for Children, Teenagers and Young Adults in](#)
21 [the treatment of malignant and non-malignant tumours](#)
22 ○ [Clinical Commissioning Policy: Proton Beam Radiotherapy \(High](#)
23 [Energy\) for Skull Base Tumour Treatment –NHS overseas](#)
24 [programme \(adult\)](#)

25 26 • **Other published documents**

- 27 ○ [All Wales National Standards for Teenager and Young People with](#)
28 [Cancer aged 16-24 years](#)
29 ○ [All Wales National Standards for Children with Cancer aged 0 to 15](#)
30 [years](#)

2. Criteria for Commissioning

The Welsh Health Specialised Services Committee has approved funding of Proton Beam Therapy (PBT) for Children, Teenagers and Young Adults (TYA) with malignant and non-malignant tumours, in line with the criteria identified in this policy.

Patients meeting all of the following criteria **and** subject to being approved by the UK National Proton Clinical Reference Panel will be routinely funded for high-energy proton treatment.

This arrangement will be kept under regular review.

The All Wales PBT Advisory Group (AWPROT), a subgroup of the Clinical Oncology Sub-Committee (COSC) of the Welsh Scientific Advisory Committee (WSAC), will be asked to scrutinise any new evidence to help inform WHSSC of any change to the list of indications included in this document.

2.1 Inclusion Criteria – general principles

Age

This policy is for children, teenagers and young adults up to their 25th birthday.

The age limit applies to the start of treatment. Those who transition between age groups at any stage during the pathway should have their disease managed according to the original referral criteria assuming this is clinically appropriate. There is an overlap between TYA and adult patients.

Prior to Proton Beam Therapy

Prior to PBT, the following should have taken place:

- Discussion by the appropriate specialist MDT.
- Comprehensive diagnosis and staging.
- Consultation with the children, teenagers and young adults and/or their carer/guardian where general radio-therapeutic issues and the relative merits of PBT compared with high quality conventional radiotherapy have been discussed and explained.

The final decision to offer PBT is made by a consultant clinical oncologist.

2.2 Criteria for treatment

For Proton Beam Therapy (PBT) to be routinely funded, Children, Teenagers and Young Adults (TYA) need to meet all of the following criteria:

- A principal cancer treatment centre MDT for children and/or TYA has confirmed that treatment with PBT is an appropriate treatment option.
- There is a clear indication for radiotherapy, and defined as curable (leading if cured to normal or near-normal life expectancy) with a reasonable disease specific 5 year survival expectation and no comorbidities likely to limit life expectancy to fewer than 5 years.
- Are under 25 years of age
- There is **no** evidence of distant metastases, with the exception of certain tumours which remain curable when metastatic. For example, metastatic intracranial germinoma, rhabdomyosarcoma and Ewing's Tumours with limited volume lung metastases that have demonstrated a good partial response on radiological reassessment after chemotherapy.
- Adequate performance status and medically sufficiently stable to undergo PBT without a delay which may lead to increased risk of recurrence or a compromise to cure rate and combined treatment pathways.
- If an adult over the age of 25 years is diagnosed with a typical paediatric diagnosis requiring radiotherapy and meeting all other (non-age-specific) criteria as above, they may be referred for PBT and individual cases will be considered by the panel.

Clinical trials

It is recognised that the eligibility criteria for PBT will evolve, partly as the result of clinical research and trials. Trials may be locally developed, national or international. Within the UK, it is assumed that PBT trials will be coordinated by CTRad's (the National Cancer Research Institute's Radiotherapy Clinical and Translational Research Working Group) Proton Beam Therapy Clinical Research Steering Committee (PBT-CRSC). Patients from Wales should have access to appropriate clinical trials. If new PBT indications are supported, for example based on clinical trial data or within NHS England through their Evaluated Commissioning Projects, access and funding for Welsh patients should be considered by AWPROT and WHSSC.

2.3 Exclusion Criteria

PBT for adults is covered in a separate WHSSC Policy: [Proton Beam Therapy for Adults with Cancer CP147](#).

Patients requiring radiotherapy for indications where there is no dosimetric advantage for protons over photons will be excluded (for example, total body irradiation (TBI), whole brain radiotherapy, extremity sarcomas (see

1 Annex ii for further details, although this list is not exhaustive. Some
2 referrals will need to be discussed with the PBT teams on a case-by-case
3 basis).

4
5 Ocular tumours suitable for low energy PBT are not covered in this policy.

6
7 See Annex ii for indications where patients' life expectancy is unlikely to
8 yield a significant clinical benefit with PBT.

9 10 **2.4 Continuation of Treatment**

11 Healthcare professionals are expected to review a patient's health at
12 regular intervals to ensure they are demonstrating an improvement to their
13 health due to the treatment being given.

14
15 If no improvement to a patient's health has been recorded then clinical
16 judgement on the continuation of treatment must be made by the treating
17 healthcare professional.

18 19 **2.5 Acceptance Criteria**

20 The service outlined in this specification is for patients ordinarily resident
21 in Wales, or otherwise the commissioning responsibility of the NHS in
22 Wales. This excludes patients who whilst resident in Wales, are registered
23 with a GP practice in England, but includes patients resident in England who
24 are registered with a GP Practice in Wales.

25 26 **2.6 Patient Pathway (Annex i)**

- 27 • Patients with paediatric and TYA cancers should all be considered by
28 appropriate specialist MDTs. For children the relevant MDT will be either
29 the paediatric MDT or the joint adult/paediatric neuro-oncology MDT.
- 30 • For TYA patients the referral will be made by the relevant disease site
31 MDT. Patients should be referred to the 'co-ordinating TYA MDT' which
32 will also need to provide support to patients and families at what will be
33 a disruptive time.
- 34 • Where radiotherapy is considered and patients are eligible according to
35 the criteria as listed above, consideration should be made by the MDT
36 for referral for PBT and this should be offered to patients.
- 37 • The responsible Clinical Oncologist attending the MDT should make the
38 referral to the relevant PBT National Clinical Panel (via the online referral
39 portal/imaging must be sent via the Image Exchange Portal) for case
40 review and a recommendation for Proton Treatment.

- 1 • If approved by the PBT National Clinical Panel:
- 2 ○ Where a patient is to be treated by either the Christie Hospital or
- 3 University College London Hospitals, the referral is forwarded
- 4 automatically via the portal. The proton beam centre will contact the
- 5 patient's local oncology team to confirm receipt of referral and
- 6 request any additional information that may be required.
- 7 ○ Where a patient is to be treated overseas, the referring clinician
- 8 should refer directly to the recommended treatment centre.
- 9 ○ PBT treatment will be funded directly by NHS England and recharged
- 10 to WHSSC.
- 11 • On completion of treatment, follow up will be by the referring treatment
- 12 centre.
- 13

14 **2.7 Designated Centres**

- 15 • The Christie NHS Foundation Trust
- 16 Wilmslow Road
- 17 Manchester
- 18 M20 4BX
- 19
- 20 • University College London Hospitals NHS Foundation Trust
- 21 235 Euston Road
- 22 London
- 23 NW1 2BU
- 24
- 25 • University of Florida Proton Therapy Centre
- 26 Jacksonville
- 27 USA
- 28
- 29 • West German Proton Therapy Centre Essen
- 30 Am Mühlenbach 1
- 31 45147 Essen
- 32 Germany
- 33

34 When both English centres are fully operational, overseas referral will

35 stop.

36

37 **2.8 Exceptions**

38 If the patient does not meet the criteria for treatment as outlined in this

39 policy, an Individual Patient Funding Request (IPFR) can be submitted for

40 consideration in line with the All Wales Policy: Making Decisions on

41 Individual Patient Funding Requests. The request will then be considered

42 by the All Wales IPFR Panel.

43

44 If the patient wishes to be referred to a provider outside of the agreed

45 pathway, an IPFR should be submitted.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43

Further information on making IPFR requests can be found at: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

2.9 Clinical Outcome and Quality Measures

The Provider should work to written quality standards and provide monitoring information to the lead commissioner.

The centre should 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, teenagers and young adults.

The PBT programme should aim to deliver the following:

- improved cancer survival and cure rates
- ability to minimise and reduce the short and long-term side effects of treatment
- delivery of accurately targeted therapeutic doses of radiation to tumours
- maintenance of good patient (and family) experience of treatment
- maintenance of safe integration with other aspects of treatment and interventions within the clinical pathway of care
- development of clear clinical outcome information to support further clinical and service development
- development of the UK based service, infrastructure, clinical protocols and pathways of care.

The Provider should:

- have a structured clinical outcomes collection and analysis programme
- audit practice to inform change
- report and learn from radiotherapy error and near-miss events, to inform practice
- prospectively collect an RTDS-compatible dataset for routine submission to the Welsh Cancer Intelligence Surveillance Unit or Public Health England
- collect relevant diagnosis specific data on clinical outcome measures
 - overall survival
 - progression free survival
 - tumour local control
 - acute and late toxicity
- patient satisfaction data

- 1 • describe links to clinical trials, national registries and academic
2 studies.

4 **2.10 Responsibilities**

5 The responsible clinician (a consultant clinical oncologist) from a relevant
6 specialist cancer MDT should refer all suitable patients to the UK National
7 Proton Clinical Reference Panel for approval.

8
9 Following the panel approval, the clinician will then apply to WHSSC for
10 funding for the treatment.

11
12 Referrers should:

- 13 • inform the patient that this treatment is not routinely funded outside
14 the criteria in this policy, and
15 • refer via the agreed pathway.

16
17 Clinicians considering treatment should:

- 18 • discuss all the non-PBT treatment options with the patient;
19 • advise the patient of any side effects and risks of the potential
20 treatment
21 • inform the patient that treatment is not routinely funded outside of
22 the criteria in the policy, and
23 • confirm that there is contractual agreement with WHSSC for the
24 treatment.

25
26 In all other circumstances an IPFR must be submitted.

1 **3. Evidence**

2 WHSSC is committed to regularly reviewing and updating all of its
3 commissioning policies based upon the best available evidence of both
4 clinical and cost effectiveness.

5 6 **3.1 References**

7 The indications for PBT described in this policy (section 2.1) are supported
8 by a comprehensive evidence review conducted by NHS England⁴.

9
10 There is extensive literature describing the dosimetric advantages of PBT
11 compared to conventional radiotherapy, which leads to less irradiation of
12 normal surrounding tissue. Particularly in young patients, who have many
13 years in which to accumulate and live with late radiotherapy toxicities, this
14 offers a great theoretical advantage. Due to this, PBT for young people is
15 internationally considered to be the treatment of choice. PBT has been used
16 for many years across the world safely, including within services
17 commissioned by the NHS Wales via the overseas programme. Given the
18 uncertainties regarding definite long term clinical gain (due to lack of long
19 term follow up data from randomised controlled trials in this group of
20 patients), clinicians and patients/guardians will discuss the pros and cons
21 of PBT versus PRT using a decision-making aid, which will offer a structured
22 format for discussion.

23 24 **3.2 Date of Review**

25 This document is scheduled for review before 2026 where we will check if
26 any new evidence is available. If no new evidence or intervention is
27 available the review date will be progressed.

28
29 If an update is carried out the policy will remain extant until the revised
30 policy is published.

31

⁴ <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2019/07/Interim-Policy-PBT-for-CTYA-for-malignant-and-non-malignant-tumours.pdf>

1 **4. Equality Impact and Assessment**

2 The Equality Impact Assessment (EQIA) process has been developed to
3 help promote fair and equal treatment in the delivery of health services. It
4 aims to enable Welsh Health Specialised Services Committee to identify and
5 eliminate detrimental treatment caused by the adverse impact of health
6 service policies upon groups and individuals for reasons of race, gender re-
7 assignment, disability, sex, sexual orientation, age, religion and belief,
8 marriage and civil partnership, pregnancy and maternity and language
9 (Welsh).

10

11 This policy has been subjected to an Equality Impact Assessment.

12

13 The Assessment demonstrates the policy is robust and there is no potential
14 for discrimination or adverse impact. All opportunities to promote equality
15 have been taken.

16

5. Putting Things Right:

5.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for [NHS Putting Things Right](#). For services provided outside NHS Wales the patient or their representative should be guided to the [NHS Trust Concerns Procedure](#), with a copy of the concern being sent to WHSSC.

5.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

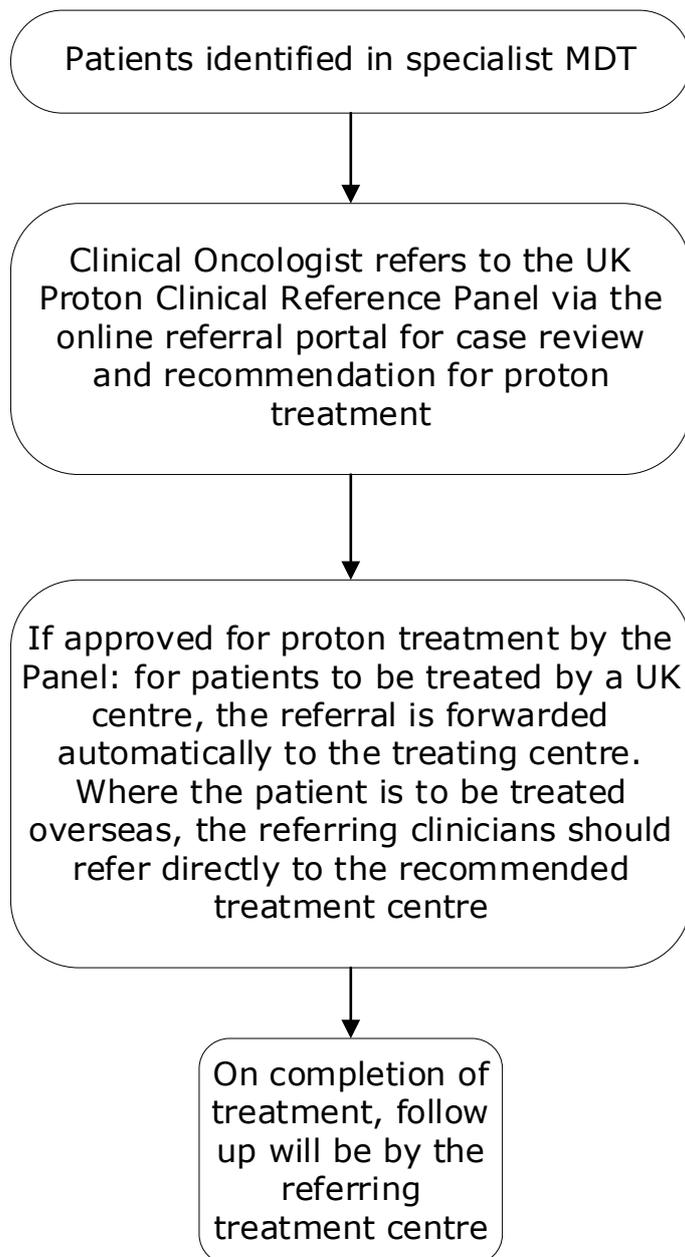
If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

1 **Annex i Patient Pathway**

2



3

4

1 **Annex ii Paediatric indications suitable for conventional**
 2 **radiotherapy (photons or electrons)**

Indications where patients' life expectancy unlikely to yield a significant clinical benefit with PBT	
Patients with biologically aggressive diseases with poor prognoses	Diffuse Midline Glioma (Including Diffuse Intrinsic Pontine Glioma - DIPG) High Grade Glioma CNS Atypical Teratoid Rhabdoid Tumour (ATRT) (incompletely resected, recurrent, poor performance status or unstable on chemotherapy)
Patients with extensive metastatic disease treated with purely palliative intent (i.e. for symptom control only) with limited life expectancy	Any anatomical site Variable number of fractionation regimes
Radical, Adjuvant and Palliative Indications where the anatomical site location and/or an extensive Radiotherapy Target volume renders PBT unlikely to yield a clinical benefit (no significant Organs at Risk sparing and/or integral dose benefit)	
Distal limb primary sites (without pelvic or thoracic extension)	e.g. Ewing's/Rhabdomyosarcoma/ Osteosarcoma Adult-type sarcomas Fibromatosis
Extensively wide RT Target volume	Total Body Irradiation (pre BMT conditioning- all disease indications) Total Nodal Irradiation Whole Brain RT e.g. Cranial Boost with TBI –CML/ALL BMT Primary Cerebral Lymphoma Palliative WBRT Whole Lung Irradiation (in absence of additional focal boost to e.g. chest wall/mediastinum/spine etc) e.g. Ewing's sarcoma RMS Wilms tumour Hodgkin's lymphoma Whole abdominal/Pelvic Irradiation e.g. Ruptured Wilms tumour Desmoplastic small round blue cell tumour
Superficial RT volume (preferentially treatable with Electrons or Orthovoltage radiation modalities)	e.g. Cutaneous/scalp lesions (includes benign (e.g. keloid) and malignant conditions)

3

4

1 **Annex iii Abbreviations and Glossary**

2 **Abbreviations**

3	IPFR	Individual Patient Funding Request
4	MDT	Multi-disciplinary Team
5	PBT	Proton Beam Therapy
6	TYA	Teenagers and Young Adults
7	WHSSC	Welsh Health Specialised Services Committee

8

9 **Glossary**

10 **Individual Patient Funding Request (IPFR)**

11 An IPFR is a request to Welsh Health Specialised Services Committee
12 (WHSSC) to fund an intervention, device or treatment for patients that
13 fall outside the range of services and treatments routinely provided across
14 Wales.

15 **Principal cancer treatment centre**

16 The principal treatment centre provides expertise and experience in the
17 management of an individual patient's particular type of cancer, which
18 includes the provision of multidisciplinary care, the coordination of an
19 individual's care with other appropriate locations and access to clinical trials
20 and research. Such centres will have defined clinical governance structures
21 and clear policies for transition to age-appropriate environments and
22 specialist teams.

23

24 **Welsh Health Specialised Services Committee (WHSSC)**

25 WHSSC is a joint committee of the seven local health boards in Wales. The
26 purpose of WHSSC is to ensure that the population of Wales has fair and
27 equitable access to the full range of Specialised Services and Tertiary
28 Services. WHSSC ensures that specialised services are commissioned from
29 providers that have the appropriate experience and expertise. They ensure
30 that these providers are able to provide a robust, high quality and
31 sustainable services, which are safe for patients and are cost effective for
32 NHS Wales.