The future of paediatric radiotherapy: notes from an inclusive meeting at The Royal College of Radiologists

8 February 2018

Introduction

In February 2018 The Royal College of Radiologists (RCR) hosted a stakeholder meeting to discuss the future of paediatric conventional (photon) radiotherapy services in England. The purpose of the day was to provide a neutral, safe, professional space to discuss and document the benefits and challenges around proposed changes to the provision of paediatric radiotherapy against a background of:

- The ongoing NHS England (NHSE) children and young people’s national cancer service review¹
- Two UK NHS proton beam therapy centres (opening 2018 and 2020)
- NHSE adult radiotherapy service specifications (Oct 2017)²
- The publication of the RCR *Good practice guide for paediatric radiotherapy* (second edition 2018).

The meeting was an opportunity for clinical and paediatric/teenage and young adult (TYA) oncologists, associated healthcare professionals and patient and family representatives to establish the key considerations that need to be taken into account in any reorganisation. There was additional representation from the Society and College of Radiographers (SCoR), the Institute of Physics and Engineering in Medicine (IPEM), charitable associations, the National Cancer Research Institute (NCRI) and NHSE Commissioning. Every UK Children’s Cancer and Leukaemia Group (CCLG) paediatric radiotherapy centre was represented. This paper is a summary of the discussions.

Current provision

Cancer in children is not common; each year there are around 1,800 new cases of cancer in children under 16 years in the UK and over 80% of those diagnosed will survive for five years or more. Care for children with cancer can be complex given the number of different tumour types, the wide variety of risk strata within each of these and the individual family and social circumstances of each child. Treatment and supportive care for children with cancer involves many different health and care professions and disciplines, all requiring specialist training and experience in this highly emotive and challenging field.

Care for children with cancer is currently delivered by specialised multidisciplinary teams at 17 CCLG designated centres in the UK. In England, paediatric oncology care, including conventional radiotherapy treatment, is currently delivered and co-ordinated by 13 principal treatment centres (PTCs). Care is frequently delivered in collaboration with staff at paediatric oncology shared care units closer to patients’ homes and in the community. While most PTCs treat a wide breadth of childhood malignancies, some provide supra-regional referral services, such as bone marrow transplant units.
The upper age for referrals to children’s cancer services varies across different PTCs with the majority ranging from the 16th to the 19th birthday. TYA services are linked with children’s provisions in PTCs through the TYA multidisciplinary team infrastructure, supporting patients at the upper end of the age range treated within paediatrics.

A revised impact analysis of predicted paediatric conventional radiotherapy activity has been undertaken by NHSE based on feedback from this meeting. Reworked calculations indicate an annual average of 529 cases currently treated with conventional radiotherapy in 13 PTCs in England. (Assumptions; all paediatric cases (0–16 years), 25% of 16–18 year old cases, inclusive of total body irradiation [TBI] activity.)

When children require radiotherapy they are typically referred to the radiotherapy department associated with the PTC for children and young people with cancer, which may not be the closest radiotherapy service to the child’s home.

Paediatric/TYA clinical oncologists are core members of paediatric and TYA oncology multidisciplinary teams, contributing radiotherapy expertise to patients’ management plans during multidisciplinary team meetings and whenever required. The radiotherapy arrangements for TYA patients differ across PTCs. TYA radiotherapy provision for older teenagers, up to 24 years of age, may be provided by paediatric/TYA clinical oncologists or appropriate adult site-specific clinical oncologists (for example, central nervous system, lymphoma and sarcoma) with relevant expertise and with additional holistic support from the TYA multidisciplinary team and the paediatric radiotherapy team. For a number of highly specialist treatments including brachytherapy, stereotactic radiotherapy and molecular radiotherapy this may be delivered at a centre in another city in the UK.

Since 2008, children who require proton beam therapy (PBT) have accessed this treatment through the NHSE proton overseas programme (NHSE POP). Cases approved by the clinical reference panel have been referred abroad; the current NHSE POP providers are in the USA, Germany and Switzerland. Two UK NHS PBT facilities are currently under construction, one at The Christie in Manchester, opening in summer 2018 to be followed by the University College London Hospitals (UCLH) centre in London, planning to start its clinical service in 2020. After an initial transitional ramp-up period, these PBT centres will become fully operational at maximum capacity in 2021/2022, when it is expected that there will be no further need for overseas referrals.

**Future developments in paediatric radiotherapy**

Anticipated NHSE conventional radiotherapy activity figures, calculated assuming 40% of the total paediatric radiotherapy caseload would be treated with PBT, were presented to the meeting. Attendees expressed concern that this was significantly underestimating the future PBT utilisation in paediatric cancer care, as the indications would be likely to expand over time. NHSE has reworked these calculations in response to this feedback. The up-to-date revised remodelling assumes 60% of all paediatric radiotherapy cases will be treated with PBT. This would yield a residual 314 cases per annum requiring treatment with conventional radiotherapy, (including TBI) in England. (Assumptions; all paediatrics [0–16 years] and 25% of 16–18 year olds requiring radiotherapy.)

As a greater proportion of children will be treated with PBT, there will inevitably be a reduction in the number of children requiring conventional (photon) radiotherapy as illustrated above. Some PTCs with low volumes of paediatric cases may find it impossible to sustain adequate clinical expertise within their paediatric radiotherapy teams and to justify the multidisciplinary resource and infrastructure investment to maintain the high standards required to deliver an optimal holistic service for these complex cases. Low patient numbers may also jeopardise the credibility of the PTC as a paediatric radiotherapy centre in terms of recruitment potential. This will mean that some centres which currently provide paediatric radiotherapy will likely cease this service and it will
instead be provided at a smaller number of higher volume specialised centres. In light of this, the provision of paediatric radiotherapy throughout England, and the UK, needs to be reviewed to ensure that we continue to provide the highest quality service, with true equity of access.

In order to do this, it is proposed that there will be three types of paediatric radiotherapy centres underpinned by a networked approach and links with TYA radiotherapy services in the future. These types are:

- Paediatric radiotherapy centres delivering conventional and proton beam therapy
- Paediatric radiotherapy centres continuing to deliver conventional radiotherapy only
- Paediatric radiotherapy centres no longer providing radiotherapy.

For patients requiring conventional radiotherapy, a paediatric radiotherapy network approach with a proposed outreach service model from the PTCs delivering photon treatments is the current favourable option to ensure optimal radiotherapy input into the patient pathway. Outreach clinic models and innovative collaborative networking to ensure all paediatric oncology multidisciplinary teams have radiotherapy input and support are being explored. Connectivity with the UK PBT centres for all potential referrers is important. Paediatric radiotherapy reconfiguration cannot occur in isolation given its critical interdependencies with other services. It will be imperative that future restructuring plans are undertaken in alignment with parallel ongoing service reviews/proposed service specifications and policies in NHSE working groups within radiotherapy, but also in other areas (for example the adult radiotherapy service specification, the children and young peoples’ cancer service review, the UK PBT policy, the paediatric critical care and specialised surgery service review, paediatric surgery and paediatric neurosurgery).\(^1,^2,^4,^5\)

Implications of changing service delivery

**Potential advantages**

- The majority of clinical oncologists currently treating children also have an adult radiotherapy practice, which may well be treating unrelated tumour types, and for many, paediatric radiotherapy forms only a small part of their job plan. A smaller number of specialised centres should lead to a greater number of clinical oncologists whose practice is focused largely, if not exclusively, on paediatric radiotherapy. The greater numbers of children being treated in each centre will lead to greater experience within the treating teams and has the potential to enable further subspecialisation within paediatric clinical oncology practice.

- The limited resource of staff with such expertise is currently spread too thinly across the country with vacancies and gaps in provision. A centralised model of care offers a greater likelihood of safe and sustainable services into the future.

- A consolidation of photon treatment centres should ensure more consistency and strengthen focus on clinical trials of radiotherapy in children’s cancer treatment.

- A consolidated, networked approach will allow the remaining photon therapy only centres to maintain high-quality services delivering state-of-the-art radiotherapy within an appropriately resourced, age-appropriate environment and service, including the routine provision of general anaesthesia and play specialist support.

- Centralisation of the care of these patients with complex needs will enable development of expertise of the whole team and investment of resource for staff and infrastructure. This will enable safer and more consistent care and assist in cross-cover arrangements.
**Potential disadvantages**

- A greater proportion of patients and their families than currently have to do so may need to travel further for treatment and will potentially have to stay away from home which is disruptive to family life.
- Special consideration needs to be made of the needs of children requiring palliative radiotherapy or TBI for haematopoetic stem cell transplantation, where travel may be more challenging or even disadvantageous.
- Clinical oncologists and the associated multidisciplinary teams working at those centres which no longer provide radiotherapy will become deskillled in this area of practice.
- There is likely to be a loss of training opportunities and the ability of some centres to attract local trainees in all professions interested in a career in paediatric radiotherapy, with these training opportunities limited to the new, larger centres and requiring trainees to travel to them to get this experience.
- The national tariff system of radiotherapy payment is not flexible enough to recognise the additional work required for referral, consent and preparation were this to be done at a local site that does not offer radiotherapy. This work, undertaken by a team involving clinical oncologists, therapeutic radiographers, play specialists and nurses, is often vital to the success of the treatment and has been effectively provided at the site local to the patients receiving PBT abroad.

**Key considerations in any reorganisation of paediatric radiotherapy services**

- Getting the right holistic support for patients and their families would be vital in any reorganisation process. This includes appropriate accommodation and transport, access to social care, key worker support, financial support, concurrent chemotherapy delivery and in-patient resources, given the additional cost burden. Those families that have travelled to the USA for PBT continue to receive a very high standard of care from a well resourced service; the NHS-funded care given to patients and their families travelling within the UK for photons or protons should be able to replicate or even improve upon this. It is possible that charities would be able to provide some additional support but they need to know what the NHS cannot provide.
- Families must be consulted and listened to as they will be the ones that make any reorganisation a success. The needs of vulnerable families must be built into any new model of service delivery.
- A decision needs to be taken regarding the cut off point for paediatric radiotherapy. Options include 16 years, but this feasibly could extend to become a children and young people’s service including TYA. There is a real risk that TYA patients will fall through the gap between paediatric and adult services if this group are not explicitly considered as part of any reorganisation.
- Communication will underpin the success of any reorganisation; communication must be seamless between local centres and specialist centres.
- Technology is also an important consideration if remote multidisciplinary team meetings are to take place. There must be significant improvement in the physical data connections between centres and innovative uptake of the virtual meeting software available.
- The needs of palliative patients must be considered, and larger, more distant centres must be able to provide a flexible, responsive and timely service, focused on these needs.
The key worker role is vital in a number of respects, including facilitation of smooth transfers of care between centres, communication between families and professionals at different sites and in preparation of children and their families for radiotherapy. The key worker could be a therapeutic radiographer or a clinical nurse specialist. Consideration must be given to how these roles are funded and where they are based; at a local centre or the specialist centre.

A clinical oncologist must remain a key member of all paediatric oncology multidisciplinary teams and there should be cross cover available to ensure continuity of care through periods of leave. Consideration must be given to outreach attendance from the treating centre.

Follow-up for late effects and clinical trial outcomes must be flexible and funded. Models providing non-treating centres with outreach by the treating team should be explored.

The new configuration of centres must be deliverable and should be forward thinking, sophisticated and adaptable. It needs to work for the long term, not just the next few years.

The speed of any reorganisation will also be key. Any centre that takes on more work should be given sufficient time to allow for this, and there must be support for all centres in the transition period.

The two NHS proton centres offer a world leading opportunity to bring together technical excellence with holistic provision to patients and their families, within a framework of clinical trials to improve paediatric proton therapy and define how best to use this technology. This aspirational message needs to be communicated to patients, their families and the wider community.

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References

1. www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b05/ (last accessed 27 March 2018)