

# Good practice guide for paediatric radiotherapy Second edition

The Royal College of Radiologists, Society and College of Radiographers, Institute of Physics and Engineering in Medicine, Children's Cancer and Leukaemia Group



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## Foreword

Around 1,800 children under the age of 16 develop cancer in the UK and over 80% of those diagnosed will survive five years or more.<sup>1</sup> Radiotherapy is a key part of treatment for many, but patient care for children and teenagers is often complex and involves a range of different healthcare professionals.

The Royal College of Radiologists (RCR) has worked with the Children's Cancer and Leukaemia Group (CCLG), the Society and College of Radiographers (SCoR) and the Institute of Physics and Engineering in Medicine (IPEM) to publish a second edition of *Good Practice Guide for Paediatric Radiotherapy* – a framework for all those who are involved, directly or indirectly, with the care of children and teenagers receiving radiotherapy.

The principles and recommendations remain unchanged from the first edition published in 2012, and the purpose of the guidance is the same: to support healthcare professionals to deliver the best clinical outcomes, and to provide a high-quality service for patients and their families. However, the guidance has been updated to reflect the changing practice in paediatric radiotherapy in recent years. It takes account of the more widespread adoption of intensity-modulated radiotherapy and image-guided radiotherapy, as well as the development of national proton beam radiotherapy services in the UK. Other drivers for the update include the introduction of the Ionising Radiation (Medical Exposure) Regulations (IRMER 2017), which came into force in February 2018, and the national recommendation for peer review of target volume delineation.<sup>2</sup>

This second edition also benefited from being reviewed by stakeholders who attended an RCR meeting in February 2018 on the future of UK paediatric radiotherapy services. This stakeholder group included clinical and paediatric/teenage and young adult (TYA) oncologists, allied healthcare professionals and organisations, and patient and family representatives, with every paediatric radiotherapy centre represented.

We would like to thank Dr Mark Gaze (chair) and all members of the working party – clinical oncologists, therapeutic radiographers, radiotherapy physicists and patient representatives – for all their hard work in revising the guidance. We would also like to extend our thanks to all those who helped by reviewing and commenting on this second edition.

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## Key themes



### 1. Top quality clinical outcomes

- a. Best treatment technique for each patient, even if it requires referral to another centre
- b. Treatment given in a clinical trial where appropriate or according to recognised guidelines
- c. Full documentation of treatment given, and deviations from the norm explained and justified.

### 2. Excellent patient safety

- a. Departmental practice underpinned by externally validated quality assurance systems
- b. Access to a specialist paediatric anaesthetic service and paediatric resuscitation and life support teams immediately available
- c. Access to review by paediatric medical and nursing teams during treatment, and clear pathways to a closely located paediatric oncology principal treatment centre for children who become unwell during radiotherapy.

### 3. Good patient experience

- a. An integrated approach for both children and teenagers with careful and age-appropriate preparation for radiotherapy, recognising the different needs of teenagers from younger children, utilising play specialists or activity co-ordinators as required, in conjunction with their parents and families
- b. Staff with appropriate interpersonal skills and experience to engage with children, young people and their families, and who have the required time and resources available
- c. All patients and families to have a designated and appropriate key worker in the run up to, during, and after radiotherapy.

#### 4. Information and communication with families

- a. New patient consultations primarily conducted in an outpatient environment with radiotherapy team and key worker
- b. Consistent and accurate information available in various formats from a range of sources given by different individuals
- c. Information paced over time depending on the needs and capacity of individual families.

#### 5. Communication and multiprofessional relationships

- a. Timely referral with accurate and complete information
- b. Full involvement of clinical oncologists, therapeutic radiographers and radiotherapy physicists as valued contributors to the paediatric multidisciplinary team meeting planning multi-modality treatment
- c. Regular liaison with the wider paediatric multiprofessional team including appropriate allied health professionals and healthcare scientists throughout the radiotherapy pathway.

#### 6. Child- and family-friendly environment

- a. Comfortable and pleasant waiting areas fully equipped with toys and activities which are age-appropriate for children of different ages and teenagers
- b. Treatment room equipped with child-friendly features
- c. Facilitation of easy access including transport, parking and hotel or hostel family accommodation as required.

#### 7. Radiotherapy equipment and techniques

- a. Access to a full range of modern and up-to-date treatment equipment and protocols
- b. Facilities for quality-assured accurate and reproducible immobilisation
- c. Quality assurance of the accuracy and reproducibility of daily treatment with on-set verification with 2D and 3D imaging techniques to ensure geometric accuracy and in vivo dosimetry as appropriate.

#### 8. Human and financial resources

- a. Adequate numbers of staff in all disciplines including anaesthesia, clinical oncology, dosimetry, physics, radiography and support staff
- b. Adequate time specified in job plans and available in practice to devote to the paediatric radiotherapy component of work
- c. Access to sufficient equipment and staff to enable timely radiotherapy without delays or uncompensated interruptions.

#### 9. Education and training

- a. Newly appointed staff appropriately trained in paediatric aspects of care and communication skills as well as technical aspects of radiotherapy
- b. Established staff facilitated to attend paediatric oncology and radiotherapy meetings and courses to maintain and improve their knowledge base and skills

- c. All members of the paediatric radiotherapy team have a collective responsibility to teach and train others.

## 10. Research and development

- a. New radiotherapy techniques to be critically evaluated before widespread introduction
- b. Clinical oncologists fully involved in national and international groups developing clinical trials of multi-modality treatment for children's cancers
- c. Careful systematic data collection to allow the beneficial and adverse effects of radiotherapy to be continually assessed, and the effect of changes in practice and interventions to modify outcomes evaluated.

## 1. Introduction

The NHS aspires to the highest standards of excellence and professionalism – in the provision of high-quality care that is safe, effective and focused on patient experience; in the planning and delivery of the clinical and other services it provides; in the people it employs and the education, training and development they receive; in the leadership and management of its organisations; and through its commitment to innovation and to the promotion and conduct of research to improve the current and future health and care of the population.<sup>3</sup>

### The care of children and teenagers with cancer

Cancer in children is rare. About 1,800 children under the age of 16 years develop cancer or leukaemia each year in the United Kingdom.<sup>1</sup> They have a wide variety of diseases, each of which comes with a range of risk factors. These govern treatment and outcome, and when coupled with differing family circumstances mean that each child is unique. Patient care is complex and involves the input of many different healthcare professionals. It is co-ordinated by specialised multidisciplinary teams at one of 19 principal treatment centres, and is often delivered in conjunction with staff at paediatric oncology shared-care units closer to home and in the community. The best type of radiotherapy for an individual patient may not be available at the closest paediatric radiotherapy centre, and referral to another city or even abroad may be required. The most common example of this is referral for proton beam therapy: currently patients usually receive this treatment in the USA or Germany, but two NHS facilities are under construction in England and will open between 2018 and 2020. The advantages of better long-term outcomes usually outweigh the inconvenience of travelling long distances from home for a significant period of time to receive this treatment.

Radiotherapy is a component of treatment for many children and teenagers with malignant disease. While this contributes to the likelihood of cure, it can also result in adverse effects. For best results, radiotherapy must be given by an experienced and well-trained team in a well-equipped department with appropriate specialist paediatric and adolescent support. The different needs of teenagers and younger children must be recognised. Excellent communication, both between colleagues and with patients and their families, is essential. Research to clarify the role and to improve the effectiveness of radiotherapy is also necessary.

## Who this guide is for

This guide is written for all healthcare professionals who are involved directly or indirectly with the care of children and teenagers receiving radiotherapy. It may also be useful for service managers and commissioners who have responsibility for radiotherapy and paediatric oncology. Safe and sustainable services are only achieved when commissioners have a detailed understanding of good practice.

## The aim of this guide

All those responsible for paediatric radiotherapy and treatment of teenagers wish to obtain the best clinical outcomes, to ensure patient safety, and to offer a high-quality patient and family experience. The primary intention of this guide is to provide a framework to assist those working in this field to achieve these goals.

Throughout this guide, unless explicitly stated, it should be understood that the term 'paediatric' relates to children and teenagers, and that recommendations refer to both children and teenagers. Clearly, different individuals may have different needs for reasons other than age. Recommendations should be interpreted sensibly so that services are both age- and developmentally appropriate, and also take into account any other factors relevant to the individual.

This work was originally compiled by a multiprofessional working party with patient representatives, and published in 2012. After five years it has been revised and updated by a panel representing The Royal College of Radiologists, the Society and College of Radiographers, the Institute of Physics and Engineering in Medicine and the Children's Cancer and Leukaemia Group. This included clinical oncologists, therapeutic radiographers, radiotherapy physicists and patient advocates. Some had been involved with the first edition; others were new to the project. A multiprofessional stakeholder meeting on the future of paediatric radiotherapy was held at The Royal College of Radiologists in February 2018, and delegates were asked to review and comment on a draft. This document now takes account of the views expressed.

The intention was to draw together best practice from existing authoritative guidelines, and supplement this with the collective experience of working group members to produce an easy-to-use guide for paediatric radiotherapy. This encompasses continuous improvement in all aspects of the patient pathway, together with education of the multiprofessional team and research aimed at improving current practice (see Figure 1 below).

**Figure 1. The cycle of patient- and family-focused quality improvement in paediatric radiotherapy**



## Sources of guidance

### Box 1. The duties of a doctor registered with the GMC<sup>4</sup>

Patients must be able to trust doctors with their lives and health. To justify that trust you must show respect for human life and make sure your practice meets the standards expected of you in four domains.

#### Knowledge, skills and performance

- Make the care of your patient your first concern
- Provide a good standard of practice and care
- Keep your professional knowledge and skills up to date
- Recognise and work within the limits of your competence.

#### Safety and quality

- Take prompt action if you think that patient safety, dignity or comfort is being compromised
- Protect and promote the health of patients and the public.

#### Communication, partnership and teamwork

- Treat patients as individuals and respect their dignity
- Treat patients politely and considerately
- Respect patients' right to confidentiality
- Work in partnership with patients
- Listen to, and respond to, their concerns and preferences
- Give patients the information they want or need in a way they can understand
- Respect patients' right to reach decisions with you about their treatment and care
- Support patients in caring for themselves to improve and maintain their health
- Work with colleagues in the ways that best serve patients' interests.

#### Maintaining trust

- Be honest and open and act with integrity
- Never discriminate unfairly against patients or colleagues
- Never abuse your patients' trust in you or the public's trust in the profession
- You are personally accountable for your professional practice and must always be prepared to justify your decisions and actions.

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The most authoritative guidance comes from the General Medical Council in its publication *Good Medical Practice*.<sup>4</sup> The 'Duties of a Doctor' it lists (see Box 1), although specifically relating to medical practitioners, are generic and could apply equally well to any other healthcare worker in the multiprofessional team. Specific points of good practice in *Good Medical Practice* are linked into the recommendations of this guide. Other sources used in the preparation of this guide come from other GMC publications, and publications from various organisations including the Department of Health and related bodies including the National Institute for Health and Clinical Excellence (NICE), The Royal

College of Radiologists, The Royal College of Physicians of London, The British Institute of Radiology, the Institute of Physics and Engineering in Medicine, the Society and College of Radiographers and the Children's Cancer and Leukaemia Group. All sources are listed in the references.

## 2. The multiprofessional team

### Box 2. Multidisciplinary team<sup>5</sup>

A group of people of different healthcare disciplines which meets to discuss a given patient, and who are able to contribute independently to the diagnostic and treatment decisions about a patient.

### The team for children and young people with cancer

Multidisciplinary team (MDT) working is an integral and essential part of modern cancer management. The primary function of an MDT is clinical management of the patient, and to function correctly should ensure that:

- All relevant information is available
- All the relevant treatment options are considered
- Options and decisions about patient care are documented.

This is particularly important for the optimum management of paediatric tumours because of their rarity and complexity of multi-modality treatment. The structure of MDT working has been formalised by NICE through its *Improving Outcomes Guidance for Children and Young People with Cancer* (see Box 2), and its importance reiterated in more recent NICE quality standards: young people (aged 16–24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.<sup>5,6</sup>

Membership will include paediatric and clinical oncologists, surgeons, radiologists, pathologists, and other relevant healthcare professionals. There will be a core membership and an extended membership, which brings other expertise as appropriate. Support from the clinical trials team, for example research nurses and data managers, is important to ensure that the potential for recruiting patients into relevant studies is optimised. It is essential that there is a designated MDT co-ordinator to ensure that all relevant information is made available, and that discussions and action points are carefully documented.

It is essential that clinical oncologists with responsibility for paediatric radiotherapy are fully integrated core members of the paediatric oncology MDT to ensure that patients for whom radiotherapy may be appropriate are not overlooked. Therapeutic radiographers and radiotherapy physicists and dosimetrists can also make a valuable contribution to these MDT meetings. While the recommendation for integral clinical oncology input may not be straightforward to implement in paediatric oncology principal treatment centres which no longer provide radiotherapy locally, it remains an important requirement, and satisfactory local solutions will need to be developed.

Consideration needs to be given to survivorship and living beyond cancer. There should be an agreed pathway for long-term follow-up with surveillance for late effects and the necessary personnel for their management. The paediatric clinical oncologist is often key to supporting a good late-effects service, in conjunction with endocrinologists, psychologists, reproductive medicine specialists and others.

The working of MDTs should be reviewed periodically to ensure that they are as functional as possible.<sup>7</sup>

### Box 3. Suggested composition of paediatric oncology multidisciplinary teams<sup>5</sup>

#### Diagnosis

- Oncologist/haematologist
- Radiologist
- Surgeon/neurosurgeon
- Pathologist/cytogeneticist
- Clinical oncologist

#### Treatment

- Treating oncologist
- Key worker
- Paediatric haematologist
- Specialist nurses
- Nurses from inpatient and day care units
- Specialist pharmacist
- Dietician and other appropriate allied health professionals
- Paediatric oncology or other speciality outreach nurse/key worker
- Therapeutic radiographer
- Radiotherapy physics staff

#### Psychosocial support

- Treating oncologist and haematologist
- Key worker
- Play specialist; activity co-ordinator/youth worker
- Psychological services professional
- Specialist outreach nurse
- Appropriate allied health professionals
- Teacher
- Social worker
- Nurses from inpatient and day care units
- Child protection expertise

#### Palliative care

- Lead clinician
- Key worker
- Palliative care specialist/oncologist/haematologist
- Social worker
- Specialist outreach nurse
- Specialist pharmacist
- Psychological services professional
- Appropriate allied health professional

There is now a series of national discussions for a variety of different tumour types, for example Ewing's sarcoma, ependymoma, hypothalamic-pituitary-axis tumours, neuroblastoma, Wilms' tumour, and soft tissue sarcoma. Some are facilitated by the CCLG; others work independently. These are not MDTs in the traditional sense, but are better regarded as national advisory panels. Any clinician can refer a patient for discussion, and a broad range of specialties (including radiology, pathology, clinical oncology, paediatric oncology and relevant surgeons) will consider the case, and comment on the options for treatment. It is then up to the patient's own local MDT to make a definitive clinical decision in the light of the discussion. It is considered good practice to be actively involved in such panels, and to use them to get access to a greater range of expertise than may be available locally.

## The paediatric radiotherapy team

The planning, delivery and aftercare of radiotherapy for children and young people is a complex multiprofessional activity. It requires clinical oncologists, therapeutic radiographers, mould room (or other pre-treatment) staff and play specialists, supported by nurses, anaesthetic staff, physicists and dosimetrists, and psychologists or psychotherapists (see Box 3). The members of this team must have regular meetings to communicate about the requirements of individual patients. Delivery of care to children has complexities which do not exist in adult practice, and so more time is often needed for consultation, preparation, planning and treatment. It is essential that all members of the team have training in, experience of, and continuing development in paediatric issues. 'Paediatric' practice ranges from babies and toddlers through primary-school-age children to teenagers up to the age of 18 years. It is important that these are not lumped together, but that all patients are treated in age- and developmentally appropriate ways in age-appropriate facilities.

## The role of the advanced paediatric therapeutic radiographer practitioner

### Box 4. The advanced paediatric therapeutic radiographer practitioner<sup>5</sup>

There should be integration of the therapeutic radiographer into the paediatric oncology multidisciplinary team. This radiographer must have specific training and take the lead and responsibility for children and young people.

The department should have a lead therapeutic radiographer for children, who has specified time for the role in their job plan or timetable and an agreed list of responsibilities for the role.

The following should be in the list of responsibilities of a specialist paediatric therapeutic radiographer, agreed by the radiotherapy service manager (see Box 4).

- Work in close partnership with paediatric clinical oncologists to aid a seamless journey for children requiring radiotherapy and their families.
- Liaise with paediatric medical oncologists, nurses and other healthcare professionals, regarding schedules for planning and delivery of radiotherapy.
- Liaise with the anaesthetic team, providing necessary information including any previous anaesthetic notes.
- Attend new patient and on treatment review radiotherapy clinics with the clinical oncologist.
- Attend MDT meetings as necessary.
- Be the key contact for the child and family for the duration of radiotherapy planning and treatment.
- Communicate with patients/parents regarding planned radiotherapy treatment schedules.
- Provide information to children and their families regarding radiotherapy treatment, associated care and late effects.
- Liaise with hospital play specialists to provide age-appropriate preparation and support to all children prior to and during planning and delivery of radiotherapy treatment.

- Have overall responsibility for advising age-appropriate facilities, patient/family information and ensuring working practices are developed and maintained in the radiotherapy department.
- Provide education and information to staff and students regarding radiotherapy for children.
- Maintain professional practice competencies as a therapeutic radiographer.
- Develop with colleagues and update paediatric treatment and imaging protocols.
- Ensure radiotherapy treatment summaries are appropriately distributed to referring and shared-care centres.
- Receive appropriate training and maintain regular updates for safeguarding children. There should be periodic training to Level 3, especially if the radiotherapy department is based in an adult hospital with no on-site paediatric safeguarding lead.
- Attend paediatric resuscitation training periodically.
- Enhance knowledge of paediatric malignancies and the current management by undertaking further study.
- Maintain an awareness of normal psychosocial child development and effective age-appropriate communication skills.
- It is suggested that the specialist paediatric therapeutic radiographer should be the key contact from end of radiotherapy treatment to first follow-up appointment following radiotherapy. This requires liaison with the existing local key worker and exchange of holistic needs assessment summary prior to a child entering radiotherapy treatment and on the return to local care.
- Be involved in paediatric clinical trials, including data collection.
- The specialist paediatric therapeutic radiographer should be a member of the Specialist Paediatric Radiotherapeutic Radiographer Interest Group (SPRRIG) through the Society and College of Radiographers and/or the CCLG to be part of a supportive professional network.

In addition, the advanced paediatric therapeutic radiographer practitioner may also be involved in treatment planning and delivery, but this is not an essential part of the role.

### Other therapeutic radiographers

While the advanced paediatric therapeutic radiographer practitioner is the lead in the radiotherapy department for the team treating children, many other therapeutic radiographers may be involved in the planning and delivery of treatment.

These, as indeed all healthcare professionals that come into contact with children, parents and their carers, should be aware of safeguarding responsibilities. All radiographers in a department treating children should receive appropriate training for safeguarding children.

All radiographers – indeed, all staff – working in departments where children are treated should be trained in both adult and paediatric basic life support in accordance with the Resuscitation Council guidelines.<sup>8,9</sup>

## The role of the radiotherapy play specialist

### Box 5. The play specialist in paediatric radiotherapy

Specified time for the role of play specialist for children's radiotherapy in the department should be included in the job description of a named play specialist or specialists.

The qualified and registered hospital play specialist plays a very important part in preparing children for radiotherapy acting as a facilitator of communication through play (see Box 5). Adequate play specialist time must be available to cover the local service needs. Each child scheduled to receive radiotherapy should have the opportunity to meet with a radiotherapy play specialist early on – ideally at the first consultation with the clinical oncologist to ensure that effective assessment and preparation of the child can take place. The play specialist may be required to support the child at single or multiple appointments which may include planning, treatment and clinics, and after treatment at follow-up appointments.

### Box 6. The value of play<sup>10,11</sup>

Play is an integral part of the child's healthcare experience and should empower the child, help the child understand the procedure and allow them to develop individualised coping strategies.

Effective input from a radiotherapy play specialist, allowing the child through play to understand what will happen is empowering (see Box 6), and can result in fewer young children requiring a general anaesthetic for their radiotherapy treatment.<sup>12,13</sup>

The radiotherapy play specialist can be involved in:

- Preparation: giving the child or young person appropriate information taking into account their age and development. Preparation can help reduce the anxiety and fear of the unknown and also reduce misconceptions that they may have.
- Distraction: is an effective way of supporting children through procedures. Developing distraction techniques and coping strategies with children enables them to cope more effectively with their treatment.
- Action plans: can help with enabling teenagers to make choices in what is happening.
- Emotional support: enables the child/young person to express their feelings in a safe way. Incentive charts can be built into their treatment. If a play specialist has concerns about the behaviour shown they must refer the child/young person on to a clinical psychologist.
- Advocacy: the play specialist can pass on information to the MDT on behalf of the child, young person and/or their family.
- Post-procedural support: gives the hospital play specialist the opportunity to assess how the child/young person has coped, address misconceptions and non-compliance and develop strategies that are required to support the child/young person.
- Sibling support: siblings can require support as they can be unfamiliar about what is happening to their younger/older brother/sister and sometimes they want to feel part of procedures/treatment. They too require preparation, emotional support and post-procedural support for these procedures. This will enable more continuity and consistency in support when the child is home.

While the play specialist has appropriate skills to support children and young people of any age, the very title 'play specialist' may be off-putting to teenagers. Alternative titles such as 'activity co-ordinator' or 'radiotherapy preparation specialist' may be considered better. The non-clinical needs of young people with cancer have been well defined by CLIC Sargent.<sup>14</sup>

### The anaesthetic team

Immobilisation is a prerequisite for accurate radiotherapy. Most children older than three to four years of age can be encouraged to lie still with good radiotherapy play specialist input. Anaesthesia is required for younger children, and some older patients with learning difficulties or behavioural problems, and is more likely to be needed if beam-directing shells or prone positioning are used.

#### Box 7. Anaesthetic staffing and facilities

- The department should have a recovery room with paediatric resuscitation equipment, the room being reserved exclusively for this use when children are receiving radiotherapy under anaesthetic. The room should be within or adjacent to the radiotherapy department.
- The responsibility for anaesthetising children for radiotherapy in the department should be included in the responsibilities for which direct clinical care (DCC) programmed activity (PA) time is specified in the job plan of a named consultant paediatric anaesthetist or anaesthetists.
- Specified time for the role of paediatric recovery nurse for children's radiotherapy in the department should be included in the job description of a named paediatric recovery nurse or nurses.
- Specified time for the role of paediatric operating department practitioner (ODP) for children's radiotherapy in the department should be included in the job description of a named paediatric ODP or ODPs.

Safe paediatric anaesthesia, which is conducted in an area remote from the normal environment of anaesthetists with immediately available support in the event of a problem, requires an experienced team (see Box 7). This should be led by a consultant paediatric anaesthetist supported by an operating department practitioner and nurse. There should be a full range of paediatric anaesthetic and resuscitation equipment available.

A paediatric anaesthetic service should be available as often as necessary. This is at least five times a week on a regular basis, and a weekend service may occasionally be required for emergencies or to compensate for gaps caused by machine breakdown or public holidays. Occasionally protocols may call for hyperfractionated treatments which require provision of a twice-a-day anaesthetic service.

### The paediatric clinical oncologist

Paediatric clinical oncologists are the physicians legally responsible under the Ionising Radiation (Medical Exposure) Regulations 2017 as referrer and practitioner for justifying, prescribing and overseeing radiation treatment, and the associated diagnostic exposures.<sup>15</sup>

**Box 8. Core components of radiotherapy centres treating children and young people with cancer<sup>5</sup>**

- More than one consultant clinical oncologist with appropriate subspecialisation in paediatric radiotherapy, including membership of the CCLG, and programmed activities for paediatric radiotherapy specified in the job plan, to enable consultant cross-cover arrangements.
- Integration of the consultant clinical oncologists as core members of the paediatric oncology MDTs (and therapeutic radiographers where appropriate).
- Availability of clinical oncologists with declared subspecialisation in the tumour types common in young people.

The training of clinical oncologists involves general internal medicine and the treatment of cancer with ionising radiation and systemic therapies, but it is rare for any clinical oncologist to have specific paediatric training, or experience in paediatric (medical) oncology. There is at least theoretical coverage of paediatric oncology during training, but many clinical oncologists will obtain their CCT without significant practical experience in paediatric radiotherapy. There is no recognised subspecialty accreditation or credentialing in paediatric clinical oncology. Some trainees, depending on their interests, may have gained appreciable experience of paediatric practice either in their own training centre or during out of programme experience at major children's cancer centres. Newly appointed consultants with a responsibility for paediatric radiotherapy without the necessary knowledge and skills in this highly specialist area should be supported in gaining additional relevant experience by attending courses and visiting other centres. More experienced consultants need to continue their professional development (CPD) in line with RCR guidance for revalidation.<sup>16</sup> This should include both paediatric oncology and more general radiotherapy elements in order to keep abreast of developments in the field. It is important that all paediatric clinical oncologists have some degree of familiarity with the principles of those treatments which they will not themselves be responsible for delivering, but for which referral to another centre may be required, including proton beam therapy, brachytherapy, stereotactic treatment and molecular radiotherapy.

Excellent communication skills are essential for all oncologists, and all should have been on an advanced communication skills course. Paediatric clinical oncologists need to develop expertise in talking to children and young people in an age-appropriate way, and also in communicating well with parents and other family members. Periodic supplementary training in communication skills as part of CPD is important in addition to one-off courses.

As children's cancer is rare, paediatric clinical oncologists should develop professional networks through membership of organisations like the Children's Cancer and Leukaemia Group and the Paediatric Radiation Oncology Society and by attending meetings and conferences. Membership of CCLG is mandatory for those practicing in the UK.

The job plan of paediatric clinical oncologists should be informed by advice from The Royal College of Radiologists.<sup>17</sup> Specifically, it is important to ensure that there is enough time to fulfil the role in the following ways:

- **Attending MDT meetings**

Most paediatric oncology services will include several specialised MDTs including solid tumours and neuro-oncology where the paediatric clinical oncologist will be a core

member (see Box 8), and haematology and transplant and late effects where attendance may be required. It may also be necessary from time to time to attend various predominantly adult site-specialised MDTs to discuss specific patients.

#### ▪ **New and follow-up outpatient clinics**

It is recommended that a clinic slot of 60 minutes should be allowed for each new patient consultation – longer may be necessary for complex cases. Good practice suggests that consent for radiotherapy should not normally be undertaken at the first consultation – a second shorter consultation (30 minutes) is required after an interval to allow families to read information and to think through the issues. For subsequent consultations, 30 minutes should be allowed.

#### ▪ **Radiotherapy planning**

When a decision to treat with radiotherapy has been made, the consultant clinical oncologist should discuss the proposed treatment with radiographic and other colleagues and ensure that all relevant imaging, operation notes, pathology results, the treatment protocol and other data are available. These are essential to assign risk stratification which may affect radiotherapy dose prescription; and to determine patient positioning, immobilisation and treatment techniques and scanning parameters (levels and contrast, for example). Target volume definition following image fusion, if appropriate, and outlining of organs at risk is a complex and time-consuming process, but it is essential for optimal outcomes and patient safety that this is done carefully and accurately. Skill mix with treatment planning technologists/dosimetrists can aid efficient organs at risk (OAR) delineation. Peer review of target volumes with a colleague is now regarded as the standard of care, especially when individualised volumes are required, as is most often the case in paediatric radiotherapy.<sup>2</sup> Dose prescription is now more individualised, based on risk grouping, than it used to be. Time is required to inspect plans and select the best. Modification of plans and dose prescriptions should be carried out in close communication with the treatment planner, particularly when advanced techniques are being used, to ensure appropriate dose optimisation.

#### ▪ **Treatment delivery**

While the administration of radiotherapy is essentially a radiographer's responsibility, some input from the consultant clinical oncologist and medical physicist may be required to check various images for geometric accuracy and review results of in vivo dosimetry.

#### ▪ **On treatment review**

Patients and their families need to be seen regularly through treatment – usually at weekly intervals. This is the opportunity for monitoring of toxicity, and to answer questions which often arise after the initial consultations.

#### ▪ **Supporting professional activities**

Time should be specifically designated in the job plan for attending meetings and educational events as part of the CPD requirement for revalidation.<sup>16</sup> Research activities, such as acting as a principal investigator for a clinical trial, should also be recognised in job plans.<sup>17</sup> The importance of research is recognised in NICE quality standard 2: Children and young people with cancer (aged 0–24 years) should be offered the opportunity to take part in clinical trials if they are eligible.<sup>6</sup>

If things go wrong, as sometimes they will, it is the responsibility of the paediatric clinical oncologist to ensure that they are dealt with swiftly, and to minimise any harm to the patient.

Problems or complaints should be discussed sensitively and honestly with the family, in line with GMC and RCR guidance, as well as Duty of Candour legislation.<sup>5,18</sup>

### Radiotherapy physicists, technologists and dosimetrists

Radiotherapy physicists, technologists and dosimetrists are key participants in the MDT supporting safe and effective radiotherapy.<sup>18</sup> Specialist knowledge in advanced patient immobilisation and planning techniques are very helpful for paediatric radiotherapy. Some of the most specialised techniques, for example craniospinal radiotherapy, total body irradiation and IMRT are often used, and require special competence and training.

It is valuable for those involved in the planning of paediatric radiotherapy to have an understanding of children's growth and development, normal organ dose constraints and radiobiology, particularly with respect to understanding changes in dose fractionation. As with clinical oncologists, it is important for physicists to have knowledge of alternative treatments, for example proton beam radiotherapy, which may not be part of their own department's practice, so that they can recognise when other treatments might offer advantages.

Radiotherapy physicists can often have direct patient contact, advising on patient set-up variations particularly if there is a need to modify or adapt a treatment plan. Techniques such as total body irradiation (TBI) may be guided and/or planned based on in vivo dose measurements carried out by physicists.

As with all radiotherapeutic applications, a suitable medical physics expert (MPE) must be appointed and be closely involved with all treatments. They should be involved as appropriate for consultation on optimisation and be able to give advice on dosimetry, quality assurance, equipment and in vivo dosimetry. In addition, they must also contribute to the optimisation of the radiation protection of patients as well as the training of practitioners and other staff.

### Paediatric oncologists and other paediatricians

It is essential that children and teenagers undergoing radiotherapy or chemo-radiotherapy have rapid access to expert paediatric supportive care to manage complications of their disease, toxicity of treatment and co-morbidity. This will often be the referring paediatric oncology team, or may be shared-care paediatricians in local hospitals closer to that patient's home. Common problems include myelosuppression with the need for blood product support, neutropenic sepsis, fluid and electrolyte disturbances if there is severe vomiting or diarrhea, and the need for neurosurgical investigation or intervention if obstructive hydrocephalus develops. Paediatric support is also needed in the radiotherapy department for resuscitation, and paediatricians should be immediately available during the administration of intravenous contrast media in case of an adverse reaction. This may be difficult to arrange, especially when the radiotherapy department is located in a hospital with no paediatrics on site, but does not lessen its importance. Good radiotherapy depends on precision in planning, for which contrast is sometimes essential, although image registration may lessen the need. Close liaison is essential between the main players in the paediatric radiotherapy team, and paediatricians/paediatric oncologists providing supportive care or concomitant chemotherapy.

### 3. The patient pathway

#### Presentation, diagnosis and risk stratification

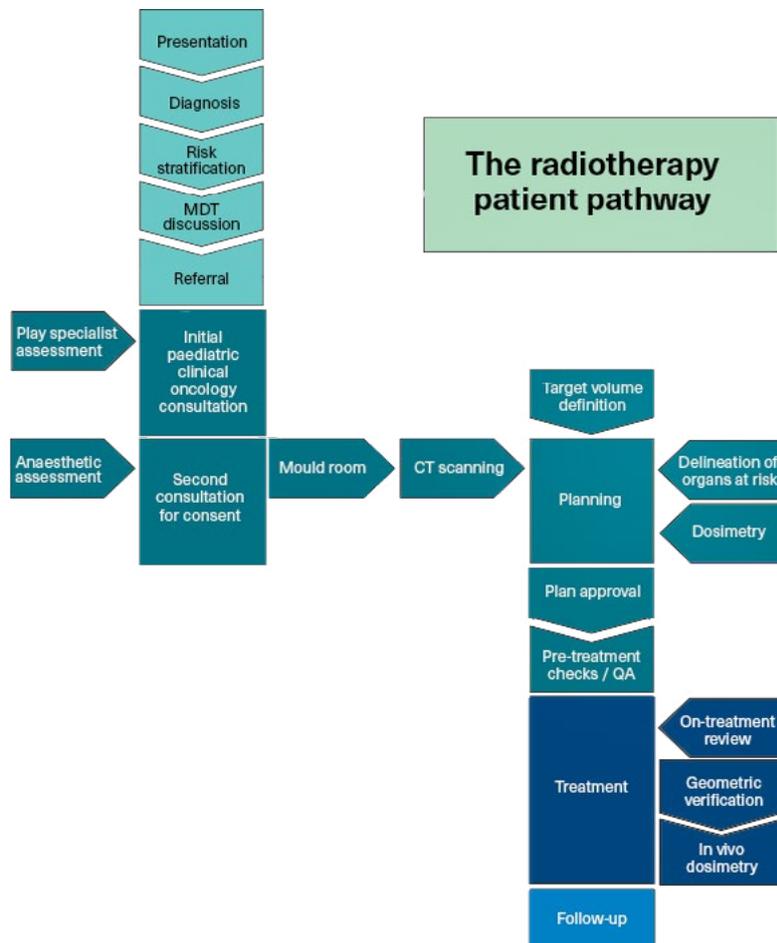
Children with cancer usually present to their general practitioner, and sometimes to accident and emergency departments. When cancer is suspected either on the basis of history or examination findings, or sometimes because of investigation results, the child is usually referred to a paediatrician. Patients in whom there is no initial suspicion of malignant disease may also be seen for assessment by a paediatrician. When further investigation confirms the presence of a tumour, or leukaemia, or raises suspicions that there is malignant disease, the paediatrician will refer the child to a tertiary centre: to a paediatric oncologist or haematologist, or possibly directly to a neurosurgeon if there is a brain tumour. Although at this stage management of the patient passes from the local hospital, continuing links are invaluable as, if cancer is confirmed, the paediatric oncology shared-care unit (POSCU) will be an essential component of future care, and close co-operation will be essential to facilitate timely and appropriate treatment.

At the tertiary centre, the patient will be assessed clinically, and will undergo additional investigations. Following this there will be a discussion in an appropriate MDT meeting. The paediatric clinical oncologists at a centre are core members of the MDT. This is usually the first point when a paediatric clinical oncologist is aware of the child, and can contribute to the discussion about clinical management, especially about whether or not radiotherapy may play a part. The patient may well be discussed on more than one occasion, for example at presentation, following initial biopsy to confirm the tissue diagnosis, or definitive surgery if this is undertaken early, and after all the investigation results necessary to assign a risk group are available (see Figure 2). Additional discussion about treatment options may take place in one of the national advisory panels, if considered appropriate.

#### Referral to meet the paediatric clinical oncology team

It is strongly recommended that if a patient is likely to require radiotherapy at some point, a referral to the clinical oncology team should be made early on. This approach ensures that patients and their families receive accurate and appropriate information about radiotherapy from the start. In addition, some treatment schedules require a short timeframe between decision to treat and actual delivery of radiotherapy, which can be more effectively facilitated if the clinical oncologist has been involved at an early stage of the patient journey. This will result in a number of patients being seen who may not eventually require radiotherapy, for example those with Wilms' tumours and Hodgkin's lymphoma. Nonetheless, early clinical oncology involvement should allay myths and prevent the notion that radiotherapy has been suggested as an afterthought or because something has gone very wrong.

Figure 2. The radiotherapy patient pathway



A documented discussion with a clinical oncologist of a patient at the MDT, although essential, is not of itself a referral. The discussion should be followed up with a formal written referral containing all relevant information to enable good communication and appropriate treatment in the light of the family circumstances (see Box 9).

**Box 9. Information required for referral to the paediatric clinical oncology team**

## Patient demographics, contact details and family situation

- Full name
- Date of birth and age
- Address
- Telephone numbers – home and parents' mobiles
- Email addresses
- Hospital number
- Names of parents and their relationship (for example, married/divorced, living together/apart)
- Languages spoken
- Names and relationships of other carers (for example, grandparents, step-parents)
- Names/ages of siblings
- Social/psychosocial history and any complicating factors
- Educational status

## Medical contacts

- Referring paediatric oncologist/haematologist
- Surgeon
- Key worker/paediatric oncology nurse
- General paediatrician
- Shared-care paediatrician
- General practitioner
- Other healthcare professionals essential to the child's care (for example, endocrinologist, other clinicians or social worker)

## Disease information

- Date of (age at) initial presentation
- Date of diagnosis
- Diagnosis
- Grade
- Stage
- Biology
- Risk stratification
- Clinical trial, randomisation outcome, and registration number
- Treatment protocol
  - Including surgery and chemotherapy dates especially if there is critical timing
  - Cytotoxic regimens used

- Date commenced chemotherapy
- Date of surgery
- Imaging (both initial and follow-up/reports attached/films available) for example, on PACS/disc
- Histology (report attached)
- Operation notes
- Response to treatment/toxicity
- Drug history and allergies (especially steroids, anti-convulsants)
- Past medical and anaesthetic history and co-morbidity.

## Initial consultation with the patient and family

### Location

The initial consultation with the clinical oncologist introduces a new phase in the treatment pathway and a new team of people that will care for the child. The clinical oncologist (normally the consultant) should arrange to see the patient and family at an appropriate time and place. This may be the referring hospital or the radiotherapy centre, and should be in an age-appropriate environment for younger and older children and teenagers, as relevant, which focuses on the patient's needs.

Pre-requisites for a successful initial consultation include access to all of the relevant clinical information (see section on [Referral to meet the paediatric clinical oncology team, page 18](#)) and a quiet and private environment with interruptions kept to a minimum. This means that a discussion with the patient and family on the open ward is rarely appropriate.

Although initial appointment arrangements may be made informally by telephone, these should be followed up with a formal appointment letter as well as the appointment being recorded on the hospital patient administration system.

### Participants

Attendance at the initial consultation will vary dependent on the age of the child:

- Parents and carers may wish another adult to join them to provide further support, either for the child or their siblings if present.
- Teenagers may wish to be accompanied by a sibling or friend.
- Although parents may wish to attend initially without the child, the child should be present at the introductory meeting – even if for only part of the consultation – so that an impression of their ability to co-operate with radiotherapy may be formed.
- The play specialist, specialist nurse or advanced paediatric therapeutic radiographer practitioner should also be in attendance.
- Where there are complex family arrangements or needs, or social care needs, impacting on radiotherapy decision-making consider including a specialist cancer social worker in the planning meeting. This can provide support for both the family and health professionals.
- The referring paediatric oncologist or neurosurgeon may also be present.

It is useful to include these options in the initial appointment letter, which should also give some indication of the structure of the meeting and who the family will meet.

A sufficient amount of time (at least 60 minutes) should be available for the studying of notes, including surgical and histopathology reports and images, and an unhurried discussion with the patient and family and dictation of correspondence relating to this meeting.

### **What is discussed**

As well as history and examination, the purpose of this initial meeting should be an assessment of the child's performance status and ability to cope with radiotherapy, and an introduction to the patient and family of the rationale for radiotherapy.

It may also be necessary to assess the current health and support needs of the child and family, depending on their individual circumstances. Consider involvement of other agencies, for example to assist with the financial burden of attending for treatment.

The consultation should introduce the patient and family to the reasons why radiotherapy is indicated. The family may have a range of information needs at this point and may wish to go over aspects such as tumour size and stage. Some families may be interested in viewing the tumour images.

The process of radiotherapy planning and the timeframe this involves should be discussed. Practical considerations may also be discussed to include:

- The number and duration of planning and treatment sessions
- The need for immobilisation devices
- Managing school attendance during treatment
- Whether the child be coming from home on a daily basis or if hostel facilities are available
- Review processes during treatment.

Potential side-effects and their mitigation may be introduced at this initial interview. Appropriate information sheets or booklets may be given to the family. Examples are the CCLG information sheets, which may be adapted to local circumstances, and should meet recognised quality standards. Contact details for the specialist paediatric radiographer and consultant's secretary should be offered to the family.

If at this stage it is not certain that radiotherapy will definitely be required, it is reasonable to give less detailed information and instead focus on introducing the team, and discussing the concept of radiotherapy as one part of multi-modality therapy which may be required depending on the response to other treatments.

It is not normally possible or appropriate to cover all the information in this first visit; indeed, an attempt to do so may result in 'information overload', and so a follow-up visit to recap and to cover aspects not discussed at the initial meeting should be arranged.

### **Subsequent consultation with the patient and family**

Given the inherent complexity of the discussions at the initial consultation it is usually appropriate to offer the patient and family a second appointment for further discussion. The timing may vary depending on whether radiotherapy is imminent or some time in the future.

It may also be dependent on the family's information needs at the time. The purposes include:

- More detailed discussion of the practicalities of treatment
- A discussion of short-term and late effects – discussed further below
- To obtain consent – discussed further below.

### Late effects

This is often the most difficult part of the radiotherapy interview and this should only be done either by, or under the supervision of an experienced clinician. It may not always be appropriate for the child to be present at the discussion of late effects. This judgement should be made by the clinician and guided by the wishes of the parents. It is highly dependent on the age and maturity of the individual child. Generally, discussion of late effects should be done in stages, responding at all times to the needs of the individual child and family. It should be backed up with written information (for example, CCLG radiotherapy information sheets or other locally produced leaflets).

It is important to mention, on a case-by-case basis, the possibility of the effect of radiotherapy (over and above that of chemotherapy) on reproductive integrity. The possibility of pre-radiotherapy interventions to maintain fertility options including semen cryopreservation, gonadal transposition, ovarian tissue storage or egg harvesting, as appropriate to the age and sex of the patient and the intended radiotherapy, should be considered.<sup>19</sup> NICE quality standard 7 is: Children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.<sup>6</sup>

Not all late effects of cancer treatment are caused by radiotherapy – surgery and chemotherapy can also result in permanent functional or cosmetic impairment. Some late effects are more likely in some individuals because of a genetic predisposition. Late effects should be discussed in the wider context, not just in relation to radiotherapy (see Box 10). It may be necessary to point out that late effects only become a problem in survivors, so the risks of late effects have to be balanced against the risks of failure to cure through under-treatment. As treatment schedules have evolved over time, survivors of current treatment may well have fewer or different late effects than those seen in patients with similar diseases treated years previously.

It should be mentioned that care will be lifelong, even when the risk of the original cancer returning has receded, in order to ensure that these potential long-term complications will be managed proactively and systematically in a late-effects follow-up clinic.<sup>20</sup> NICE quality standard 6 is: Children and young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.<sup>5</sup>

**Box 10. Key areas in discussing late effects**

- Effects on sexual and reproductive function
  - Ways to mitigate these<sup>19</sup>
- Neuro-cognitive deficits
- Hormonal deficiencies and the need for hormone replacement therapy
- Effects on bone and soft tissue growth
- Effects on vision and hearing
- Risk of second malignancies
- Risk of vascular complications such as stroke and heart disease.

**Consent****Box 11. Consent<sup>4</sup>**

You must be satisfied that you have consent or other valid authority before you carry out any examination or investigation, provide treatment, or involve patients or volunteers in teaching or research.

Authoritative guidance on good practice in relation to consent comes from the GMC in Consent: patients and doctors making decisions together and 0–18 years: guidance for doctors.<sup>21,22</sup>

**Box 12. Consent<sup>21</sup>**

Whatever the context in which medical decisions are made, you must work in partnership with your patients to ensure good care. In doing so you must:

- Listen to patients and respect their views about health
- Discuss with patients what their diagnosis, prognosis, treatment and care involve
- Share with patients the information they want or need in order to make decisions
- Maximise patients' opportunities, and their ability, to make decisions for themselves
- Respect patients' decisions.

In reality, consent is a multi-stage process, rather than just a signature on a form. It requires information about a proposed intervention and the associated risks to be given over time in ways which can be easily understood.

Risks include common minor side-effects, as well as possibly rare but severe or permanent adverse events, and the chance that the intervention might fail to have its intended outcome – failure of disease control in the case of radiotherapy.

Alternative treatment strategies, and the effects of not giving the treatment, need to be explained and understood.

In paediatric radiotherapy it can sometimes be hard to predict the effects on normal tissues until after the planning is finalised and doses to organs at risk are known accurately.

Children may or may not have the capacity to consent. This depends not just on age but more importantly on their level of development and understanding. At 16 years of age a young person can be presumed to have the capacity to consent. Under 16, a young person

may have capacity, depending on their maturity and ability to understand what is involved. Children with capacity should be encouraged to involve their parents in decision-making.

### **Box 13. Assessing the capacity to consent<sup>22</sup>**

You must decide whether a young person is able to understand the nature, purpose and possible consequences of investigations or treatments you propose, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others, can they consent to that investigation or treatment. That means you must make sure all relevant information has been provided and thoroughly discussed before deciding whether or not a child or young person has the capacity to consent.

If children lack the capacity to consent, you should ask for their parent's consent (see Boxes 11–13). It is usually sufficient to have consent from one parent. If parents cannot agree, and if disputes cannot be resolved informally, you should seek legal advice. Remember that not all parents legally have parental responsibility, depending on family circumstances.

The legal framework for the treatment of 16- and 17-year-olds who lack capacity differs across the UK. For further guidance, refer to the GMC publication 0–18 years: guidance for all doctors (see Box 12).<sup>22</sup>

Consent for radiotherapy planning and treatment should always be documented on approved trust consent forms with the signatures of the person receiving consent, and the person/people giving consent. In addition, it is good practice to document key points of the discussion in the medical notes, especially where it has been a hard decision for parents or there has been any difference of opinion. Any written information given out should be listed.

## **Communication and documentation**

Following these consultations, appropriate summaries of the discussion should be sent, in a timely manner, to all involved with patient care, or according to local guidelines. Recipients should normally include the GP, the paediatric oncologist, the surgeon, the key worker, the ward if the child is an in-patient, the specialist radiographer, and so on.

The family should be offered the opportunity to receive an appropriately worded, written summary of the radiotherapy consultation. This should normally be a summary produced specifically for the family, and appropriate resources in terms of time and secretarial support should be made available to enable copying of letters to patients and/or their families.

It may be appropriate for the radiotherapy team to liaise with the child's school either directly or via the key worker.

There should be a local mechanism for keeping track of the progress of patients who may need radiotherapy at a later stage in their pathway which is robust and allows for the timely booking of radiotherapy.

## **Immobilisation**

### **Play specialist assessment**

It is clear from the section on **The role of the radiotherapy play specialist** that appropriately experienced hospital play specialists have an essential role in the support

of children and families undergoing radiotherapy. They should if possible be present at the initial (see section on **Initial consultation with the patient and family, page 21**) and subsequent (section section on **Subsequent consultation with the patient and family, page 22**) consultations. The play specialist will make an initial assessment as to whether radiotherapy without the need for anaesthesia is possible. If it is possible, or if there is uncertainty, additional play sessions may be scheduled to help to prepare the child.

### **Anaesthetic assessment**

If it is clear from the outset, or decided subsequently, that anaesthesia will be required for planning and treatment, then there needs to be an assessment of the child by the anaesthetic team. It is helpful if full information is made easily available to the anaesthetist, and this is part of the role of the advanced paediatric therapeutic radiographer practitioner (see section on **The role of the advanced paediatric therapeutic radiographer practitioner, page 11**). This should include a history of previous anaesthetics, including problems with them, a list of current medications and allergies including steroids and hormones, details of co-morbidities such as airway compromise, venous access, positioning requirement and any relevant social issues. Often a number of different anaesthetists will be involved over the weeks of a course of radiotherapy, so there needs to be an established system of effective handover of the basic facts and any subsequent developments which may affect the safety or efficacy of anaesthesia.

### **Mould room**

The mould room appointment may be on the day of the first visit to the radiotherapy department for the child and their family, so it can be very daunting.

The minimum requirements that should be in place are:

- Discussion to facilitate the selection of the desired treatment position and the most appropriate immobilisation technique should have taken place prior to the patient's attendance, typically as part of the pre-planning meeting.
- Plenty of time should be allocated for the child's appointment in the mould room to allow for clear, age-appropriate explanations of the procedure and any questions to be answered before the procedure begins.
- The child may need to experience the procedure in small sections so additional time may need to be allocated.
- Action plans may need to be negotiated with the child to ensure they understand the procedure and feel empowered and will therefore co-operate.
- Additional support from the hospital play specialist or paediatric radiographer may be necessary.
- The clinical room where the mould will be made should be a child-friendly and safe environment.
- The mould room should be spacious enough to accommodate the needs of a disabled child and carers.
- The mould room should have some age-appropriate distraction tools for use when dealing with children, such as light projectors or music.
- It is important that at this first appointment if the paediatric radiographer has not met the child and family beforehand that they introduce themselves as the point of contact.

- The child and family may benefit from a visit or several visits to the mould room and department prior to their appointment so they can visualise the environment and have time to prepare themselves.

These points are all important, as if the making of an immobilisation device is done in a hurry or with a restless or frightened child it may not fit well and have to be re-made. It is far better to take the time necessary and get it correct at the first attempt.

### Pre-treatment: scanning, planning and quality assurance (QA)

The CT scanner or simulator appointment may be on the same day as the first visit to the radiotherapy department for the child or teenager and their family, so can be very daunting.

The minimum requirements that should be in place are:

- There should be a pre-planning meeting/discussion to prevent any delay/decision-making or uncertainties being discussed in front of the child and family. The purpose is to ensure that all members of the team have a good understanding of the specific requirements for each patient, including patient positioning, immobilisation, scanning levels, whether advanced imaging techniques such as 4DCT are to be employed, and so on.
- The child and family should be fully informed about the procedure before it begins and action plans negotiated with the child. This includes the removal of clothes, the use of pens on their skin and also the sticking of radio opaque markers to the skin
- It is important at this first appointment that the paediatric radiographer introduce themselves as the point of contact to the child and family, if they have not met beforehand.
- The number of staff present should be kept to the minimum. This is often difficult if the play specialist and paediatric radiographer are both in attendance as well as the pre-treatment radiographers. It is important that each person has their role and responsibilities clearly defined so that communication and support for the child and family is not hindered.
- It is important to establish from the parents the best way of discussing permanent skin markers (tattoos) with the child before they are done, as this process can be stressful and traumatic if badly handled.
- The clinical room where the scan will be performed should be a child-friendly and safe environment. Children may have had diagnostic scans before, but these could have been under anaesthetic.
- The room should have some distraction tools for use when dealing with children such as music or light projectors.
- The child and family may benefit from a visit or viewing a photograph prior to their scan so they can visualise the environment and have time to prepare themselves.

Patients and families should be made aware of the standard time interval between the scan and the start of treatment. This can be some time, and families may be concerned that something has gone wrong if they perceive a delay.

If pre-treatment checks or QA visits are required, patients and families should be informed about the reasons for this. They should be reassured that the scans and imaging done in

the pre-treatment stage are routine to ensure accuracy of radiotherapy delivery, and that they are not diagnostic images being done as a check on possible growth of the tumour.

### Radiotherapy treatment

- The advanced paediatric therapeutic radiographer practitioner is the key contact for the child and family whilst they are receiving treatment and for the following weeks until the first follow-up appointment.
- The staff treating the child during the course of treatment should ideally be kept to a small cohort.
- The advanced paediatric therapeutic radiographer practitioner should keep the treatment team up to date with changes in care and other aspects of the holistic management as appropriate.
- The advanced paediatric therapeutic radiographer practitioner does not necessarily treat the child every day but should be available to support the child and family.
- Children may benefit from seeing the treatment machine beforehand so they can visualise the environment and have time to prepare themselves.
- The child and family should be fully informed and prepared for the procedure before it begins. If necessary an action plan may need to be negotiated with the child to aid co-operation and compliance.
- The number of staff in the treatment room should be kept to the minimum. This is often difficult if the play specialist and advanced paediatric therapeutic radiographer practitioner are both in attendance as well as the treatment radiographers. It is important that each person has their role and responsibilities clearly defined so that communication and support for the child and family is not hindered.
- Ideally the child should be treated on the same treatment unit each day. If this is not possible, for example for machine breakdown and service days, then the child should be treated by familiar staff.
- A suitable amount of time should be set aside for the appointments, as children often take longer than adults to treat.
- The treatment room should be a child-friendly and safe environment. Radiographers should ensure that any equipment that may be in the treatment room that could cause anxieties for the child, for example other patients' shells, should be out of sight.
- The room should have some distraction tools for use when dealing with children such as light boxes, music, light projectors and using the two-way intercom when the child is in the treatment room.

It is essential for best outcomes that the delivery of treatment is as accurate as possible. Systematic and random errors may arise during treatment delivery. Geometric verification and in vivo dosimetry should be undertaken in accordance with RCR guidelines or alternative local protocols to minimise the impact of any errors.<sup>23</sup> With the introduction of various IMRT techniques resulting in smaller, more conformal treatment volumes with steep dose gradients, image guidance, often with a combination of planar (2D) and volumetric (3D) techniques, has become increasingly necessary. Daily image guidance is becoming more commonly used, especially with more complex techniques. Cone beam CT is being increasingly used for verification, and may often be considered the standard of care. Although doses from image guidance are generally low, they may increase the total radiation burden. While this is often justified by the added accuracy of treatment delivery,

the risks and benefits must still be considered and balanced. An accurate knowledge of cone beam computed tomography (CBCT) dosimetry is essential as the use of this modality increases. A medical physics expert must contribute to optimisation of the radiation protection of patients, ensuring imaging quality and doses are appropriate for paediatric applications. There are three concerns: artefacts; image quality; and patient dose. Educating the team, and using tools to reduce imaging exposure, will improve the quality of care.

### Supportive care

Children receiving radiotherapy should be reviewed with their family at least weekly by the clinical oncologist and/or other members of the paediatric radiotherapy team as appropriate.

Children receiving radiotherapy may experience some toxicity during treatment from the radiotherapy itself, or from chemotherapy given previously or concomitantly. Children may also have co-morbidity or other complications of their cancer or its treatment, for example the development of raised intracranial pressure due to shunt blockage or infection of a central venous catheter.

It is therefore essential that children should have immediate access to appropriate paediatric medical and nursing care. Ideally this will be in the same hospital where the radiotherapy is being delivered, but alternative pathways should be in place for this to be made available as required at the paediatric oncology principal treatment centre, or at a shared-care hospital.

Many patients need input from a range of allied health professionals during radiotherapy, including dieticians, speech and language therapists, physiotherapists and occupational therapists. Some patient groups are more likely to have complex needs, for example children with neurodisability due to a brain tumour.

It has long been recognised that tumour hypoxia reduces the efficacy of radiotherapy, and there is evidence in some adult tumour types that treatment of hypoxia may improve outcomes. Evidence that this is true in children's cancers is lacking, but there is no reason to assume that it is not true. It is therefore good practice to maintain an adequate haemoglobin level during radiotherapy. As many children receiving chemotherapy are anaemic, they should be transfused with the aim of achieving a haemoglobin level of up to 120 g l<sup>-1</sup> if the level is below 100 g l<sup>-1</sup> before or during treatment.

Cancer treatment is stressful for children and their families. This can be worse if radiotherapy necessitates transfer to an unfamiliar hospital, especially if there is a perception that the need for radiotherapy is because other treatments have not worked, or if there is anxiety about the need for frequent anaesthesia or worries about late effects. Psychological supportive care should therefore be available for families. It is ideal if this can be within the radiotherapy department, but if that is not practicable, alternative local arrangements should be in place. At the simplest level, all healthcare professionals involved should be aware of the difficulties for families, and work to create a supportive, caring environment, but availability of psychologists or psychotherapists as part of standard care is very helpful. NICE quality standard 4 is: Children and young people with cancer, and their families and carers, have their psychological and social needs assessed at key points on their care pathway and receive support based on their identified needs.<sup>6</sup>

There can be added burdens including financial stresses, and the practical difficulties for parents of needing to take a lot of time off work or care for the patient's siblings. Again, all staff should be sensitive to these issues, and aware of the role of social workers and other agencies which can provide support.

The hospital key worker has the responsibility of communicating with the community team to ensure appropriate support at home in between treatments.

## Waiting areas and policies

### Box 14. Age-appropriate environments

Care will be provided in an appropriate location and in an environment that is safe and well suited to the age and stage of development of the child or young person. Older children and teenagers have separate and distinct needs from younger children.

The radiotherapy department should provide a waiting area exclusive to the use of children and young people attending for consultation, planning and treatment and their carers (see Boxes 14 and 15). It is ideal to have a play room for younger children and a separate appropriately equipped space for teenagers, away from the adult area (see Box 16).

### Box 15. The waiting area

- The waiting area should be a child-friendly and safe environment with suitable play and recreational equipment to help distract the child while in the department.
- The environment should be suitable and spacious enough to accommodate the equipment required, meeting the needs of a disabled child. Disabled children should also be able to access the play and recreational facilities
- There should be full accessibility for wheelchairs and buggies, baby changing facilities, accessible car parking, clear signposting and low reception counters.

There should be information available for additional support for patients of all ages such as appropriate posters with contact details/websites; support groups leaflets and the hospital trust's patient advice and liaison service (PALS). If waiting areas are due to be upgraded or new departments are being built the Guidance from NHS Estates, *Improving the patient experience – Friendly Healthcare Environments for Children and Young People*, may be utilised, or specialist design advice sought from good architects.<sup>24</sup>

A child should be reviewed in an appropriate environment. Reviewing the child in the waiting area/play area should not be encouraged, unless this is the child's request, as this is the child's 'safe' area.

Some radiotherapy departments operate a 'no-wait' policy for children and young people. If the waiting area for paediatric patients is separate to the adult waiting area then it is not obvious to adult patients if children are brought into the treatment room ahead of them if there is a delay. This policy may be useful in the absence of appropriate waiting facilities.

**Box 16. Elements that contribute to a good patient experience for teenagers**

- Approachable staff who are good communicators
- Age-specialised facilities on a 'young oncology' or 'teenage cancer' unit
- Designated and well-equipped teenage waiting space
- Age-appropriate information leaflets
- Guidance towards authoritative websites and resources designed for teenagers
- Greater use of modern teenage communication methods.

**Documentation of treatment**

It is important that there is a summary of radiotherapy treatment accessible to treating paediatric oncologists early after completion of treatment, and also available in long-term follow-up. A copy should also be made available to the patient and family. This should include adequate patient identifiers and sufficient details of the diagnosis and other principal treatments, that is, chemotherapy and surgery, to allow it to be read in context.

To help with management of long-term follow-up, the summary should also include what was mentioned to the family in terms of late side-effects at the time of gaining consent.

With specific regard to radiotherapy, it should include as a minimum the following:

- Institution where treatment given
- Responsible clinician
- Treatment intent
- Anaesthesia (yes/no)
- Patient position
- Immobilisation
- Date of start of treatment
- Date of completion of treatment
- Site treated
- Beam energy
- Beam quality
- Field set-up
- Beam shaping
- Use of intensity modulation
- Total dose administered
- Dose prescription point.
- Dose hot-spot.
- Minimum dose to planned target volume (PTV)
- Total number of fractions
- Fraction size
- Verification imaging used, to report typical doses of imaging procedures
- Overall treatment time

- If the treatment has been given in more than one phase, dose and volume to each
- Doses to principal organs at risk
- Medication prescribed during radiotherapy
- Any problems encountered during radiotherapy
- Reasons for any compromise or deviation from protocol.

The summary should also have at least the following images:

- Digitally reconstructed radiograph, portal image or other verification imaging to show principal field for each phase and beam shaping
- Plan, at least transverse centre slice, but ideally in axial, sagittal and coronal planes
- Dose volume histograms for target volume and organs at risk.

A complete DICOM RT image set including RT image, plan and dose objects should also be available for review if required.

### Follow-up

Often, following radiotherapy, patients will be returned to the care of the referring paediatric oncologist for further chemotherapy. It is important, however, that patients are reviewed by clinical oncologists after radiotherapy, usually within the first few weeks, to monitor and treat any acute toxicity. Imaging may be required to monitor response and for routine surveillance for relapse. This can be done by the clinical oncologist alone, or in collaboration with colleagues in other disciplines. Subsequently it can be valuable for follow-up visits to be undertaken, often no more frequently than annually, in the context of a long-term follow-up service to monitor and treat late effects according to CCLG guidance *Therapy Based Long Term Follow Up – Practice Statement*.<sup>20</sup> It is important that the clinical oncologist is a core member of the long-term follow-up team.

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## 4. Types of radiotherapy

### Conventional radiotherapy

Over time, radiotherapy evolves. What was considered conventional even ten years ago may now seem quaintly old-fashioned. What is novel or experimental now, and possibly not widely available, may soon be common practice everywhere. So here we define conventional radiotherapy as *the sort of radiotherapy which should be available in every paediatric radiotherapy centre at the present time*.

This includes both 3D conformal and image-guided and intensity modulated radiotherapy (see section on **Intensity-modulated, image-guided and adaptive radiotherapy, page 33**).

Although it is now being less commonly used, there is still an important place for 3D conformal megavoltage external photon radiotherapy, typically delivered with two to four static fields, to a CT planned target volume. To improve conformality of the treated volume to the target volume, and to reduce the dose to organs at risk, beams may be shaped with multileaf collimators, and wedges or field-in-field boosts may be used to improve dose homogeneity. The patient may be immobilised in a beam-directing shell. Treatment may be given under general anaesthesia if necessary to reduce movement. Sometimes a relatively

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large initial volume may be treated, followed by a second phase of treatment or boost to a smaller volume where the risk of recurrence may be higher.

Conventional radiotherapy also includes the various form of IMRT (see section on **Intensity-modulated, image-guided and adaptive radiotherapy, page 33**), which is increasingly being used in paediatric practice.

It is important to recognise and respect treatment intent. When radiotherapy is being used as part of combined modality therapy or, rarely, by itself, with the intent of curing the tumour, it is considered radical. High doses and prolonged fractionation schedules may be necessary, depending on the type of the tumour being treated. When treatment is aimed at reducing symptoms, or delaying their appearance, or possibly prolonging life but with no expectation of cure, then it is regarded as being palliative. Palliative treatments are generally kept as simple and as short as possible, although sometimes radical treatment schedules are used if they are judged to be the best way of achieving good palliation.

### Radiotherapy fractionation

Conventional radiotherapy fractionation is to treat all fields, once a day, five days per week, for several weeks. Sometimes twice daily fractionation is used.

#### Box 17. Examples of standard fractionation schedules

- 14.4 Gy in eight fractions of 1.8 Gy over four days treating twice daily for conditioning prior to allogeneic bone marrow transplant in acute lymphoblastic leukaemia
- 21 Gy in 14 fractions of 1.5 Gy over three weeks for neuroblastoma
- 54 Gy in 30 fractions of 1.8 Gy over six weeks for a glioma

Hyperfractionated accelerated radiotherapy (HART) is the use of a larger than standard number of smaller than standard fraction sizes in a shorter overall time than normal.

Fractionation should follow guidance given in the general RCR guidance, *Radiotherapy Dose-Fractionation*, unless otherwise mandated by clinical trial protocols or CCLG guidelines.<sup>25</sup>

### Intensity-modulated, image-guided and adaptive radiotherapy

Intensity modulated radiotherapy (IMRT) is a generic term which covers a number of advanced radiotherapy techniques designed to deliver ultra-conformal radiotherapy to a precisely delineated volume, and the plan has incorporated a series of dose constraints to limit dose to organs at risk. Accuracy may be enhanced by imaging (image-guided radiotherapy – IGRT), which may now be considered the standard of care, or respiratory gating to ensure that treatment is delivered to the target, which may move between or within fractions. Repeated imaging results in a higher radiation dose, which carries potential disadvantages. However, these are unlikely to be clinically significant, and will almost certainly be offset by improved accuracy of treatment delivery leading to better tumour control and reduced irradiation of adjacent normal tissues.

Adaptive radiotherapy implies that the plan may change throughout a course of treatment as needs alter, for example shrinkage of a tumour. The use of IGRT, in particular 3D imaging techniques such as CBCT for verification of patient set-up, means that over the course of treatment changes in patient contour – due, for example, to weight loss or

weight gain – can be monitored, as can changes in internal organ or tumour shape and size. Adaptive radiotherapy is when a modification is made to the initial radiotherapy plan during the treatment course to take into account such changes. It should be considered if anatomical changes have occurred which could compromise tumour coverage or cause an unacceptable increase in dose to critical organs.

IMRT may be delivered in several ways. For example, a greater than conventional number of static fields, each composed of a number of differently shaped beamlets may be used. Alternatively, a rotational technique, where there is simultaneous variation in three parameters during treatment delivery: in machine output (dose rate), field shape via movement of multileaf collimators, and gantry rotational speed throughout an arc, may be used. The whole treatment may be delivered in one or two arcs, although complex cases may require more. There are various manufacturers who make radiotherapy machines specifically to deliver high-precision IMRT, including robotic focusing of small beamlets with respiratory gating and image guidance, or helical rotation therapy. Other manufacturers make add-ons to conventional linear accelerators to enable intensity-modulated arc therapy in addition to conventional treatment.

IMRT has been widely introduced into adult radiotherapy practice. Initially this was based on the belief that it must be better than conventional treatment on the basis of dosimetric analysis. There are now a number of clinical trials showing improved outcomes in head and neck, and prostate cancer. There was initially some reluctance to implement IMRT in paediatric practice, as there is a low dose bath effect, which may possibly increase the risk of second malignancy. However, IMRT has been implemented in selected paediatric cases where its better conformality may allow adequate treatment of the target volume which would otherwise have been impossible without exceeding normal tissue tolerance. There has also been a growing realisation that most second cancers occur in the high-dose region outside the target volume, so it is possible that the risk of IMRT causing second cancers may not be as high as was once thought. In addition, improved dose distributions may reduce long-term toxicity particularly to the heart.

Children should have access to IMRT where a superior dose distribution, with the advantages of greater conformity and better sparing of organs at risk, can be demonstrated. As with all new radiotherapy techniques, ideally these techniques should be evaluated in clinical trials. If IMRT is used outside a trial setting, long-term follow-up is mandatory.

### Proton beam radiotherapy

Proton beam radiotherapy is an alternative form of radiotherapy which uses beams of protons rather than the more usual photons to treat tumours. Protons have different physical properties to photons, which alters the pattern of travel through the tissues. Carefully planned proton therapy may give a superior dose distribution in some circumstances. This does not usually increase chance of cure, but may offer the opportunity to reduce the exposure of organs at risk outside the high-dose volume. Consequently, survivors may have fewer late side-effects and a better quality of life in the long term. In some situations (for example, skull base chordomas) avoidance of adjacent normal tissues may allow dose escalation and an improved chance of cure.

Initially, proton beam radiotherapy was introduced into paediatric clinical practice on the basis of a presumed benefit extrapolated from dosimetric studies which indicate the potential for reduction in late effects by exclusion of normal tissues such as brain, bone,

heart and lungs from the low and intermediate dose volume. There is now a gradually increasing body of clinical data confirming the theoretical benefits of protons over photons in terms of late effects. This should also result in reduced risk of carcinogenesis and thus reduced morbidity and mortality from radiation-induced malignancies.

Previously, there have been no high-energy proton beam facilities open in the UK. Over the last decade, the English Department of Health (via NHS England Specialised Commissioning) and the devolved nations have funded treatments abroad (mainly in the USA) for a number of indications, and subject to certain conditions (see Box 18). These are predominantly in children, teenagers and young adults and include brain tumours in which focal radiotherapy is indicated such as low-grade gliomas, craniopharyngiomas and ependymomas. Two NHS proton beam therapy centres are currently under construction in England. These are scheduled to start treating patients in 2018 and 2020. The up-to-date indications list, guidance for referrers and patient information sheets are available at [www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt](http://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt)

#### Box 18. Conditions for proton beam therapy referral

- Treatment should be given with curative intent
- Patients will have good performance status either 0 or 1 (World Health Organization [WHO])
- No other coincident diagnoses that are likely to either limit five-year survival or make a prolonged period abroad difficult to manage from a practical point of view
- There should be no metastatic disease other than for successfully treated small volume lung metastases, for example in Ewing's sarcoma.

Referral for treatment abroad, even when the full costs of treatment and transport and accommodation for the child and two adults are covered, places huge strains on families. Even the most socially advantaged find this difficult and stressful; for more deprived families the upheaval may be too much to agree to. A lot of support from the paediatric clinical oncologist, specialist paediatric radiographer and social worker at the referring centre is needed to facilitate and smooth out the process. This is very time-consuming, but essential for the wellbeing of the patient. The provision of supportive care for families of a patient who is being treated abroad is of fundamental importance. It does, however, place extra strain on the paediatric radiotherapy team and must be properly resourced.

#### Stereotactic ablative radiotherapy

Treatment of small, well-defined volumes in the brain may be treated with single fraction (stereotactic radiosurgery [SRS]) or hypofractionated stereotactic radiotherapy (SRT). The indications are limited, but include small-volume brain metastases and localised recurrences after prior treatment. Similarly, these techniques can be used in the body for locally recurrent or oligometastatic disease using stereotactic ablative body radiotherapy (SABR). These require very reliable immobilisation and image guidance, as smaller margins are used. A minor displacement could therefore result in a geographical mis- or over-treatment of an adjacent critical normal structure. Dedicated equipment for this treatment is available, including GammaKnife™ for stereotactic brain radiosurgery and CyberKnife™ for single fraction or fractionated treatments in the brain or body. Alternatively, a high-specification linear accelerator with a micro-multileaf collimator and a six degrees of freedom couch may be used. The whole-body dose, and corresponding risk of second

malignancy resulting from treatment, should be considered when choosing the most appropriate technology for delivering treatment. The role of SABR in children has yet to be fully evaluated. These highly specialised treatments are nationally commissioned from limited centres.

### Brachytherapy

Brachytherapy – the placement of sealed radioactive sources into, or immediately adjacent to, tumours – has been practiced since the earliest days of radiotherapy, but practice has evolved over time to include remote afterloading, image guidance for catheter placement, dosimetry to a planned target volume and other technical advances which mean it is now a high-precision technique on a par with IMRT and IGRT (see Box 19).

The role of brachytherapy in paediatric practice is limited, as many paediatric cancers require wide field irradiation, and brachytherapy is best suited to small, well-defined target volumes. The major advantages of brachytherapy in the treatment of accessible tumours is that it may avoid the need for major surgery which would result in loss of normal organ function, and that it may spare organs more effectively than external beam radiotherapy. The principal indications are for treatment of soft tissue sarcomas, especially those of the pelvic organs or in the head and neck. Brachytherapy is sometimes the treatment of choice for re-irradiation of a localised recurrence. Paediatric brachytherapy may be delivered independently of other treatments. Sometimes, however, it is linked with a surgical resection, with catheter insertion as part of the same procedure. It is possible for this to be done in one hospital, with subsequent transfer of the patient to another hospital for afterloading

#### Box 19. Advantages of brachytherapy

- Effective treatment for a small, well-localised tumour
- May avoid the need for ablative surgery
- May reduce late effects on organs at risk
- Completed in a short overall time.

Safe and effective brachytherapy in children requires an experienced team for treatment delivery including as a minimum clinical oncologists with expertise in brachytherapy and paediatric radiotherapy, brachytherapy MPEs and physicists or technologists/dosimetrists, radiographers, paediatric anaesthetists and paediatric radiologists working together in a hospital with paediatric inpatient support (see Box 20). Paediatric surgeons may also be required for intra-operative brachytherapy. Because of the limited number of patients requiring this type of treatment, and the fact that not every paediatric radiotherapy centre can meet all these requirements, paediatric brachytherapy should be performed in only a small number of centres across the country. Centralisation helps to promote expertise where special skills are needed.

#### Box 20. Challenges of paediatric brachytherapy

- Requires a large, experienced team
- Requires co-located brachytherapy and paediatric facilities
- May require referral away from local principal treatment centre.

Decisions about brachytherapy should be made by an experienced paediatric oncology multi-disciplinary team, taking into account the patient's history, imaging and pathology. All treatment options including radical surgery and various types of external beam radiotherapy need to be taken into account. Not every patient considered for brachytherapy will be best treated with this technique.

### Molecular radiotherapy

Molecular radiotherapy is also referred to as unsealed source radiotherapy or radionuclide therapy.<sup>26</sup> It is the use of a radioactive drug given orally (as in the case of radioactive iodine for the treatment of thyroid cancer) or intravenously (as in the case of radiolabeled meta-iodobenzylguanidine (mIBG) for the treatment of neuroblastoma or neuroendocrine tumours).

As with all types of radiotherapy, safe and effective care requires a multiprofessional team including paediatric clinical oncologists, play specialists, therapeutic radiographers and experienced physicists including a therapeutic nuclear medicine MPE for radiation protection and support.

#### Box 21. Requirements for a centre to give molecular radiotherapy to children

- Experienced paediatric clinical oncologists
- Therapeutic radiographers with special expertise
- Play specialists
- Physicists including a therapeutic nuclear medicine MPE for radiation protection and dosimetry
- Facilities in an age-appropriate environment with paediatric cover
- Nuclear medicine facilities for scanning with general anaesthetic available.

While all paediatric radiotherapy centres are situated in hospitals that give molecular radiotherapy to adults, paediatric molecular radiotherapy should only be given in hospitals where there are suitable protected facilities for administration of the treatment and subsequent care in a paediatric environment with round-the-clock paediatric medical and nursing support. While doctors and nurses need to be available to provide the required medical and nursing care, general childcare including feeding, toileting, dressing and entertainment is delegated to adults (parents, grandparents, other relatives or family friends) who are recognised as comforters and carers under radiation protection legislation. These people, who must be non-pregnant adults, are required to give written informed consent to act in this capacity. They require space outside, but immediately adjacent to the protected room, to wait and sleep.

There also needs to be on-site nuclear medicine imaging for dosimetry, with the facilities to perform scans under general anaesthesia if required (see Box 21).

## 5. Recommendations

### Top quality clinical outcomes

#### Best treatment technique for each patient, even if it requires referral to another centre

- Not every type of radiotherapy treatment is available in every centre.
- Use should be made of national advisory panels to support decision-making, especially in complex or unusual cases.
- In some clinical situations a treatment not locally available may offer an improved chance of cure, or a reduced chance of complications.
- Examples include proton beam therapy (see section on [Proton beam radiotherapy, page 34](#)), stereotactic radiotherapy (see section on [Stereotactic ablative radiotherapy, page 35](#)), brachytherapy (see section on [Brachytherapy, page 36](#)) and molecular radiotherapy (see section on [Molecular radiotherapy, page 37](#)).
- Sometimes a service usually available locally, for example, radiotherapy under general anaesthesia, may be unavailable temporarily or not available within an acceptable timeframe.
- Clinicians should recommend the best treatment for each child.
- Clinicians should offer referral to other centres, either at home or abroad, if appropriate.
- Clearly, referral of patients between different paediatric radiotherapy centres for specialised treatments requires careful advanced planning, as there may be financial and workload considerations, as well as logistic challenges.

#### Treatment given in a clinical trial where appropriate or according to recognised guidelines

- Clinical trials offer a way to improve knowledge about the best treatment for children with cancer which will benefit future patients
- Clinical trials offer a standardisation of care, with quality control and outcome monitoring
- Clinical trials and guidelines are based on a review of best current evidence-based practice
- Enrolment into appropriate clinical trials should be offered as standard practice
- Outside clinical trials, treatment choice should be informed by recognised guidelines if possible
- Clinical oncologists working as principal investigators for clinical trials should have this responsibility recognised in their job plans.

#### Full documentation of treatment given, and deviations from the norm explained and justified

- Full information (see section on [Documentation of treatment, page 31](#)) on past treatment enables risk stratification for focused long-term follow-up
- Information on past treatment is essential for safe retreatment
- Non-standard treatment may be entirely justified, but the reasons for this may not be clear subsequently unless the justification is documented.

## Excellent patient safety

### Departmental practice underpinned by externally validated quality assurance systems

- Quality cannot be assumed, but should be assessed and documented
- Departments should comply with NICE Improving Outcomes Guidance and National Cancer Standards and be assessed by peer review for radiotherapy and paediatric oncology
- Practice should be in line with the recommendations of Towards Safer Radiotherapy
- Departments should have an externally validated and audited quality management system, for example ISO 9001.
- The accuracy of target volume delineation in radiotherapy should be checked by colleagues in a systematic process of peer review.

### Access to a specialist paediatric anaesthetic service and paediatric resuscitation and life support teams immediately available

- Good immobilisation (see section on [Immobilisation, page 25](#)) is essential for high-quality radiotherapy
- Very young children cannot keep still by themselves and need general anaesthesia for immobilisation – sedation alone is unreliable
- All departments treating children must have access to a paediatric anaesthetic service (see section on [The anaesthetic team, page 14](#)) as required
- To ensure patient safety, paediatric resuscitation (see section on [Supportive care, page 29](#)) and life support must be available.

### Access to review by paediatric medical and nursing teams during treatment

- Children may develop complications of their cancer or its treatment
- Children may have co-morbidities and complex needs
- Patients and their families should be reviewed at least weekly by the clinical oncologist and/or other members of the paediatric radiotherapy team as appropriate
- Paediatric medical, nursing and allied healthcare support (see section on [Supportive care, page 29](#)) must be available.

## Good patient experience

### An integrated children/young people approach with careful and age-appropriate preparation for radiotherapy with play specialists as required

- Children of different ages have different needs
- Careful preparation makes treatment easier to understand and comply with
- Play specialist (see sections on [The role of the radiotherapy play specialist, page 13](#) and [Play specialist assessment, page 25](#)) support in the radiotherapy department is essential
- Care should be delivered in an age appropriate environment (see section on [Waiting areas and policies, page 30](#)).

### Staff with interpersonal skills and experience to engage with children, teenagers and their families, and have the required time and resources available

- The reasons for, and practicalities of, treatment need to be understood by patients and their families
- Anxiety levels may be higher in parents of children undergoing radiotherapy than in other patient groups
- Careful explanation, and listening to and responding sympathetically to concerns, is essential to achieve understanding and reduce stress
- This process is time-consuming, but time must be made available
- All involved staff must have adequate training in communication skills.

#### **All patients and families to have a designated and appropriate key worker in the run up to, during, and after radiotherapy**

- All patients need to have a contact point for communication and queries
- In the period around radiotherapy it may be helpful for this to be someone from that department who understands the processes.

### Information and communication with families

#### **New patient consultations usually in an outpatient environment with radiotherapy team and key contact**

- The first meeting with the radiotherapy team is an important one for families
- It is helpful for this to be away from the distractions of the ward, in a contained environment with all necessary information available
- It smooths subsequent progress for the radiotherapy key worker to be part of the early discussions with the paediatric clinical oncologist.

#### **Consistent and accurate information available in a various formats from a range of sources given by different individuals**

- Radiotherapy is usually a completely new concept for families – one which can be bewildering and complex
- Sometimes there are pre-existing misperceptions which need to be addressed
- Different people take in new information better in various ways
- Information from different sources or media should be accurate and consistent
- CCLG information (see Appendix 2) is recommended.

#### **Information paced over time depending on the needs and appetite of individual families**

- All families need information, but there may be differences in their perception of need
- Families differ in the speed and reliability of assimilation of new information
- Over time, understanding needs to be checked to correct any misunderstandings
- Basic information can be supplemented with more detail.

### Communication and multiprofessional relationships

#### **Timely referral with accurate and complete information**

- Radiotherapy techniques are now more complex and take longer to schedule
- Treatment is more individualised through greater risk stratification

- Complete and accurate information at the time of referral is essential
- Early referral allows time for scheduling.

#### **Full involvement of clinical oncologists, radiotherapy physics staff and therapeutic radiographers as valued contributors to the MDT meeting planning multi-modality treatment**

- Decisions about radiotherapy in children's cancer are challenging
- Paediatric oncologists know a lot about the role of radiotherapy in children's cancers, but may not be aware of subtle nuances or all relevant factors
- Paediatric clinical oncologists need to contribute actively to MDT decision-making.

#### **Regular liaison with the wider paediatric multiprofessional team including appropriate allied health professionals throughout the radiotherapy pathway**

- Circumstances change over time, and initial plans for patients may need to be modified
- Concerns over aspects of care need to be shared
- Radiotherapy needs to be scheduled carefully into multi-modality treatment
- Active cancer treatment needs to be closely integrated with supportive care
- Close communication about individual patients between different professional groups needs to be maintained.

### **Child, teenager and family-friendly environment**

#### **Comfortable and pleasant waiting areas fully equipped with age- and developmentally appropriate toys and amusements**

- Boredom, stress and anxiety are reduced by suitable distractions in a friendly environment
- Some preparation can take place in waiting areas or play rooms reducing fear and improving compliance
- Children and young people of different ages have different needs and expectations
- Teenagers require special care as they are no longer children but not yet adults and can find a too child-centred approach patronising.

#### **Treatment room equipped with child-friendly features**

- The need for a treatment room to be functional and efficient does not mean it cannot at the same time be made relaxed and comforting with toys and distractions
- A good early experience in a treatment room will make subsequent visits easier.

#### **Facilitation of easy access including transport, parking and hotel or hostel family accommodation as required**

- Treatment facilities are often a long way from home
- Treatment facilities may be separate from the principal treatment centre
- Help with transport and accommodation will improve each family's experience
- These factors are even more important for families who have to travel outside their home region for specialist treatment.

## Radiotherapy equipment and techniques

### Access to a full range of modern and up-to-date treatment equipment and protocols

- Newer photon radiotherapy techniques with potential advantages, such as IMRT and IGRT, should be used
- Clinicians should be able to choose the best treatment for a patient according to their needs, not be constrained by available facilities
- Referral for to other centres for specialist techniques such as proton beam therapy, stereotactic radiotherapy, molecular radiotherapy and brachytherapy may be required.

### Facilities for quality-assured accurate and reproducible immobilisation

- Accurate immobilisation is essential for high-quality radiotherapy.
- Audits should be undertaken to ensure the accuracy and precision of immobilisation devices.
- These audits will inform planning parameters such as the PTV margin.

### QA of the accuracy and reproducibility of daily treatment with on set verification with 2D and 3D imaging techniques to ensure geometric accuracy and in vivo dosimetry as appropriate

- Day-to-day treatments can vary.
- Measures must be in place to ensure that treatment delivery is accurate as intended.

## Human and financial resources

### Adequate numbers of staff in all disciplines including anaesthesia, clinical oncology, dosimetry, physics, radiography and support staff

- Safe and effective paediatric radiotherapy requires a highly skilled multiprofessional workforce.
- High-quality treatment cannot be delivered with too few, or inadequately skilled, staff.

### Adequate time specified in job plans and available in practice to devote to the paediatric radiotherapy component of work

- Treatment of children can take longer in most of its stages than adult treatment.
- Care and safety should not be compromised by haste.
- Adequate time must be available in practice as well as in theory.

### Access to sufficient equipment and staff to enable timely radiotherapy without delays or uncompensated interruptions

- Delays in starting treatment and interruptions to treatment in progress may lead to suboptimal outcomes.
- Adequate staff numbers and access to equipment is essential to prevent delays and minimise interruptions, and compensate for unavoidable interruptions.

## Education and training

### **Newly appointed staff appropriately trained in paediatric aspects of care and communication skills as well as technical aspects of radiotherapy**

- Paediatric radiotherapy requires knowledge and skills which not every clinical oncologist or therapeutic radiographer acquires during training.
- The required abilities include confidence and competence in managing children in the context of their families, as well as in technical radiotherapy.
- Relevant induction, and extra training if required, must be provided to those taking on this responsibility for the first time.

### **Established staff facilitated to attend paediatric oncology and radiotherapy meetings and courses to maintain and improve their knowledge base and skills**

- Knowledge of and clinical practice in children's cancers evolve over time.
- All staff should have an appropriate programme of continuing professional development.

### **All members of the paediatric radiotherapy team have a collective responsibility to teach and train others**

- Not everyone in a department can go to all meetings or courses.
- Those attending should disseminate their new knowledge to their peer group.

## Research and development

### **New radiotherapy techniques to be critically evaluated before widespread introduction**

- Radiotherapy techniques continually evolve
- New technologies become available in clinical practice
- New approaches may seem better, but could have unforeseen adverse consequences
- New techniques should be introduced only if there is evidence of potential benefit, and ideally in a clinical trial
- Care must be taken to ensure that new processes are audited and patient outcomes are monitored.

### **Clinical oncologists fully involved in national and international groups developing clinical trials of multimodality treatment for children's cancers**

- Clinical progress in rare cancers is achieved through international collaboration because of small patient numbers
- Development of new multimodality treatment schedules requires input from paediatric clinical oncologists to ensure that the best radiotherapy techniques are used and quality assured
- New radiotherapy techniques can be evaluated within international trials
- Clinical oncologists should have time to support aspects of clinical trials such as prospective peer review of international clinical trials
- A nationally co-ordinated approach to the timely opening of clinical trials in radiotherapy at all appropriate centres is required to ensure equity of access.

**Careful systematic data collection to allow the beneficial and adverse effects of radiotherapy to be continually assessed, and the effect of changes in practice and interventions to modify outcomes evaluated**

- Patients should be followed up to assess response to treatment, disease control and long-term adverse effects
- These should be systematically recorded so that reliable conclusions regarding changes in practice can be drawn.

**6.  
Glossary**

**Accelerated treatment** – Delivery of radiotherapy in a shorter than usual overall time, most commonly in association with hyperfractionation.

**Adaptive radiotherapy** – A change in the treatment plan during a course of radiotherapy to take into account changes in the body contour, or size of normal organs or the tumour.

**Catheter** – Flexible tube that can be inserted into a part of the body.

**CBCT** – Cone beam computed tomography – a form of 3D imaging used during treatment for image guidance and treatment verification.

**CCT** – Certificate of completion of training – usually confirms competence to become a consultant.

**Clinical oncologist** – Specialist in the comprehensive non-surgical management of cancer to include chemotherapy, radiotherapy, or other drug therapy.

**CPD** – Continuing professional development – a systematic process of updating knowledge and developing new skills across the individual's whole range of practice to ensure fitness for practice in a changing environment is maintained.

**Cytogeneticist** – Specialist in identifying genetic abnormalities in tumour material which may aid diagnosis and/or treatment strategy.

**Dosimetry** – The calculation of intended, or measurement of actual, doses of radiation used to treat cancer.

**Fraction** – A portion of the overall radiation treatment dose, usually given in one session.

**Haematologist** – Specialist in the treatment of cancers of the blood such as leukaemia and lymphoma, to include chemotherapy and other drug treatments.

**Hyperfractionated treatment** – Delivery of radiotherapy in a larger number of fractions than usual, most commonly implying a smaller than average fraction size delivered more frequently than once a day.

**Hypofractionated treatment** – Delivery of radiotherapy in a smaller number of fractions than usual, most commonly implying a larger than average fraction size delivered less frequently than once a day.

**IGRT** – Image-guided radiotherapy – see text.

**Immobilisation devices** – Various pieces of equipment for example head rest or shell to prevent patient movement during treatment, and to ensure reproducibility of set-up from day to day, thus increasing the accuracy of treatment.

**IMRT** – Intensity-modulated radiotherapy – see text.

**In vivo dosimetry** – measuring the actual dose delivered to the patient during treatment.

**IRMER** – Ionising Radiation (Medical Exposure) Regulations.

**Medical oncologist** – A cancer specialist skilled in the use of chemotherapy and other drug therapies.

**Medical physics expert** – An individual or a group of individuals, having the knowledge, training and experience to act or give advice on matters relating to radiation physics applied to exposure (see IRMER).

**Mould room** – The place for development and customisation of immobilisation devices, and, by inference, the staff with the skills to make such devices.

**MLC** – Multileaf collimator – a device, integral to a linear accelerator, which enables complex and variable shaping of the radiotherapy beam.

**NICE** – National Institute for Clinical Excellence (1999–2005), National Institute for Health and Clinical Excellence (2005–13), National Institute for Health and Care Excellence (2013–date) – a statutory body with a frequently changing name but a continuing responsibility for producing authoritative guidance.

**Oncologist** – specialist in the treatment of cancer.

**Paediatric oncologist** – A paediatrician specialising in the management of childhood malignancies including treatment with chemotherapy and other drug therapies.

**Pathologist** – A specialist in the diagnosis of cancer by microscopic analysis of either a sample of or the whole tumour.

**Practitioner** – An individual trained to administer radiation to a patient (see IRMER).

**Prone** – Patient position, lying on front.

**Radiotherapy physicist** – An individual trained in the physics aspects of radiotherapy.

**Radiotherapy technologist** – An individual trained in technological aspects of radiotherapy, such as treatment planning.

**Referrer** – An individual who, under IRMER legislation is able to request and authorise the administration of radiation to a patient.

**Supine** – Patient position, lying on back.

**Systematic errors** – Reproducible and quantifiable change in position of a patient or tumour which requires correction to improve treatment accuracy.

**Tertiary centre** – Usually refers to ‘teaching hospital’ (specialist) care, of primary care (‘general practice’) and secondary care (‘district general hospital’).

**Therapeutic radiographer** – Individual qualified to deliver therapeutic radiation.

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Approved by the Council of the Society and College of Radiographers: June 2018.

Approved by the Institute of Physics and Engineering in Medicine: June 2018.

Approved by the Executive of the Children’s Cancer and Leukaemia Group: June 2018.

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## Appendix 1. Membership of working party and acknowledgements

The Royal College of Radiologists (RCR), the Society and College of Radiographers (SCoR), the Institute of Physics and Engineering in Medicine (IPEM) and the Children's Cancer and Leukaemia Group (CCLG) are grateful to all the working party members for their contribution to the second edition of the guidance – many of whom also contributed to the first edition:

- Dr Mark Gaze (chair, RCR and CCLG)
- Dr Vivian Cosgrove (IPEM)
- Mrs Susan Hay (patient advocate)
- Dr Gail Horan (RCR and CCLG)
- Dr Michelle Kwok-Williams (RCR and CCLG)
- Dr Henry Mandeville (RCR and CCLG)
- Ms Linda Mortimer (IPEM)
- Mr Curtis Parker-Milnes (patient advocate)
- Dr Dan Saunders (RCR and CCLG)
- Dr Nicky Thorp (RCR and CCLG)
- Ms Charlotte Smith (SCoR)
- Mr Gregory Smyth (IPEM)
- Mr Christopher Stacey (IPEM)
- Ms Sarah Stead (SCoR and CCLG)
- Mr Mark Williams (SCoR and CCLG)
- Ms Helen Woodman (SCoR and CCLG)

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## Appendix 2. Example of a CCLG radiotherapy information sheet

### Radiotherapy treatment of the whole central nervous system

Treatment of the brain and spine in continuity is used to treat germ cell tumours and some other types of brain tumour. In most cases the treatment is successful but unfortunately not in all. The total radiation dose has to be spread out over quite a long time to make the individual treatments safe. We give treatment every day for up to seven weeks (usually excluding weekends and bank holidays). At each session, the patient spends about 20 minutes in the treatment room but most of this time is spent getting him/her into exactly the right position.

Radiotherapy does not hurt; the machine does not touch the patient and it is rather like having an ordinary x-ray. We have to treat the whole brain and the spine. This means that patient must lie very still. To make this easier, we make a facemask for each patient and we sometimes surround their shoulders and chest with a bag of polystyrene beads. Lying still can be very difficult for some children, especially very young ones. Occasionally we have to use a general anaesthetic.

Occasionally when we are treating the brain, a blue light is seen and there might be a strange smell. Also a quiet tick can be heard, which is the machine working.

We treat the whole brain and spine in the first 16–20 sessions. After that, we give extra treatment to the place where the tumour was found originally. If a scan shows that the disease has spread to anywhere else in the brain or spine, we give extra treatment to those places as well.

#### Side-effects

- There are always side-effects. We can relieve most of them but sometimes not completely. Some of the side-effects happen immediately, some of them happen soon after we finish treatment, and some take a longer time to show.

#### Immediate side-effects

- Sometimes the treatment causes the brain to swell slightly (at its greatest about ten days into treatment). This is usually not noticeable because pressure on the brain has been eased by removing the tumour or by relieving it with a shunt (a pressure-relieving device). If swelling causes problems, we give a small dose of steroids.
- We cannot prevent patients losing their hair. It starts to fall out after about two weeks of treatment and is more or less all gone by the end. It usually starts to grow back about three months after treatment. Hair might not grow back in the areas that have had a high dose of radiation.
- A sore throat can be a problem, starting about three weeks after treatment begins.
- Some patients feel sick and vomit because part of the radiation on the back passes through their stomach. When this happens, we can control the problem with anti-sickness drugs.

#### Side-effects after treatment

- A long course of radiotherapy makes patients very tired. This is at its worst near the end of the treatment and just afterwards. There might be a particularly sleepy spell starting four to six weeks after treatment ends, and going on for two to six weeks, or even longer.

- There may be occasional headaches or bouts of sickness.
- These side effects can be very worrying at the time but usually they all settle down within 6–9 months.

### Long-term side-effects

- These are the hardest to predict and, unfortunately, when they do happen they are permanent
- Young children will not be as tall as they would have been. The radiation affects the gland that controls growth (the pituitary gland). Also, radiation affects the bones of the spine (the vertebrae) and they do not grow as they would have done. Growth hormone can improve things. However, a young child will be several inches shorter when grown-up than they would have been without the illness and the treatment.
- The pituitary gland also controls development. Radiotherapy for children may make puberty start earlier. Endocrinologists (doctors specialising in hormones) will help deal with any problems and they will also monitor the thyroid gland as this can also be affected by radiotherapy.
- Girls' fertility is occasionally affected because of radiation reaching their ovaries. Options for overcoming infertility can be discussed at the appropriate time. Boys are not affected because their testicles are well away from the treatment area.
- It is possible for radiotherapy to affect learning ability, especially when very young children's brains are treated. We are finding that by 3 or 4 years after treatment young children don't learn new information and skills quite as easily. We need to know exactly what the effects are and how we can support and help people who have been affected. When it is possible, one of our neuropsychologists will see the patient before treatment starts and as required afterwards.
- Development of cataracts. This may occur because of unavoidable radiation to the eye. Fortunately cataract surgery today is very straightforward and successful.
- The heart is also treated at the same time as the spine. The radiation dose is very small but some adults, treated as children, show a tendency to heart problems. These could be aggravated by hallucinogenic drugs and/or smoking. It is important that any doctor you visit knows the full medical history.
- Hair may not grow back at all or may be very thin and patchy in the areas that receive a high dose of radiation.
- After many years, it is possible for blood vessels in the area of treatment to become narrower leading to an increased risk of strokes. Cigarette smoking should be avoided as it will increase this risk further.
- We are finding that, very rarely, children who have had treatment for one tumour can develop another type of tumour some years later. Smoking should be avoided as it also increases the risk of many types of tumour.
- Sometimes, many years after treatment has finished, an unusual and unexpected side effect occurs which we were not anticipating.
- Doctors who treat children are always interested in hearing about any side effects of treatment. If you do see your GP or hospital doctor with a new problem, please tell them about your previous treatment and ask them to inform your oncologist just in case the problem may be a side effect of that treatment.

During follow-up we will be looking out for all these problems.

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