



THE COLLEGE OF
RADIOGRAPHERS



Clinical
Oncology

The Royal College of Radiologists

Good practice guide for paediatric radiotherapy

Children's Cancer and Leukaemia Group
Society and College of Radiographers
The Royal College of Radiologists



Good practice guide for paediatric radiotherapy: ten key themes



1 Top quality clinical outcomes

- a. Optimal 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

3 Good patient experience

- a. An integrated children/young people approach with careful and age-appropriate preparation for radiotherapy, recognising the different needs of teenagers from younger children, with play specialists or activity co-ordinators as required
- b. Staff with specialist education and training, interpersonal skills and experience to engage with children, teenagers and their families, and 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 usually in an outpatient environment with radiotherapy team and key worker
- b. Consistent, accurate and age-appropriate information available in various formats from a range of sources given by different individuals
- c. Information paced over time depending on the needs and appetite of individual families

5 Communication and multi-professional relationships

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

6 Child and family-friendly environment

- a. Comfortable and pleasant waiting areas for children and teenagers, fully equipped with age-appropriate toys and activities, away from adult waiting areas
- 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 portal and other 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. The beneficial and adverse effects of radiotherapy to be continually assessed, and the effect of changes in practice and interventions to modify outcomes evaluated

Contents

Preface	7
1 Introduction	8
1.1 The care of children and teenagers with cancer	8
1.2 Who this guide is for	8
1.3 The aim of this guide	8
1.4 Sources of guidance	10
2 The multi-professional team	11
2.1 The team for children and young people with cancer	11
2.2 The paediatric radiotherapy team	11
2.3 The role of the advanced paediatric therapeutic radiographer practitioner	12
2.4 Other therapeutic radiographers	13
2.5 The role of the radiotherapy play specialist	14
2.6 The anaesthetic team	15
2.7 The paediatric clinical oncologist	16
2.8 Radiotherapy physicists and dosimetrists	18
2.9 Paediatric oncologists and other paediatricians	18
3 The patient pathway	19
3.1 Presentation, diagnosis and risk stratification	19
3.2 Referral to meet the paediatric clinical oncology team	19
3.3 Initial consultation with the patient and family	22
3.3.1 Location	22
3.3.2 Participants	22
3.3.3 What is discussed	22
3.4 Subsequent consultation with the patient and family	23
3.5 Late effects	23
3.6 Consent	24
3.7 Communication and documentation	25
3.8 Immobilisation	26
3.8.1 Play specialist assessment	26
3.8.2 Anaesthetic assessment	26
3.8.3 Mould room	26
3.9 Pre-treatment: scanning, planning and quality assurance (QA)	27
3.10 Radiotherapy treatment	28
3.11 Supportive care	29
3.12 Waiting areas and policies	30
3.13 Documentation of treatment	31
3.14 Follow-up	32
4 Types of radiotherapy	33
4.1 Conventional radiotherapy	33
4.2 Radiotherapy fractionation	33

4.3	Intensity-modulated radiotherapy	33
4.4	Proton beam radiotherapy	34
4.5	Brachytherapy	36
4.6	Molecular radiotherapy	37
5	Recommendations	38
5.1	Top quality clinical outcomes	38
5.2	Excellent patient safety	38
5.3	Good patient experience	39
5.4	Information and communication with families	39
5.5	Communication and multi-professional relationships	40
5.6	Child and family-friendly environment	40
5.7	Radiotherapy equipment and techniques	41
5.8	Human and financial resources	41
5.9	Education and training	42
5.10	Research and development	42
6	Glossary	44
7	References	46
	Appendix 1. Membership of the working party	48
	Appendix 2. Example of a CCLG information sheet	49

Preface

Between 1,500 and 1,700 children under the age of 16 years develop cancer or leukaemia each year in the United Kingdom.¹ Radiotherapy is a key part of treatment for many, but patient care for children and teenagers is complex and involves a range of different healthcare professionals.

This guide will provide a framework for all those who are involved, directly or indirectly, with the care of children and teenagers receiving radiotherapy. It will assist them to deliver the best clinical outcomes, to ensure patient safety, and to provide a high-quality patient and family experience. It will also be useful for service managers and commissioners who have responsibility for radiotherapy and paediatric oncology.

On behalf of the Children's Cancer and Leukaemia Group, the Society and College of Radiographers and The Royal College of Radiologists, we would like to thank Dr Mark Gaze (Chair) and all members of the Working Party – clinical oncologists, therapeutic radiographers and patient advocates – for their hard work in producing this document. We would also like to thank the many individuals who contributed their opinions and views on the guide.

Professor Sue Ablett
Executive Director
Children's Cancer and
Leukaemia Group

Mrs Jackie Hughes
President
Society and College of
Radiographers

Dr Adrian Crellin
Dean, Faculty of Clinical
Oncology
The Royal College of
Radiologists

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.²

1.1 The care of children and teenagers with cancer

Cancer in children is rare. Between 1,500 and 1,700 children under the age of 16 years develop cancer or leukaemia each year in the United Kingdom.¹ 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. Rarely, 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.

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 compared with 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.

1.2 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.

1.3 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.

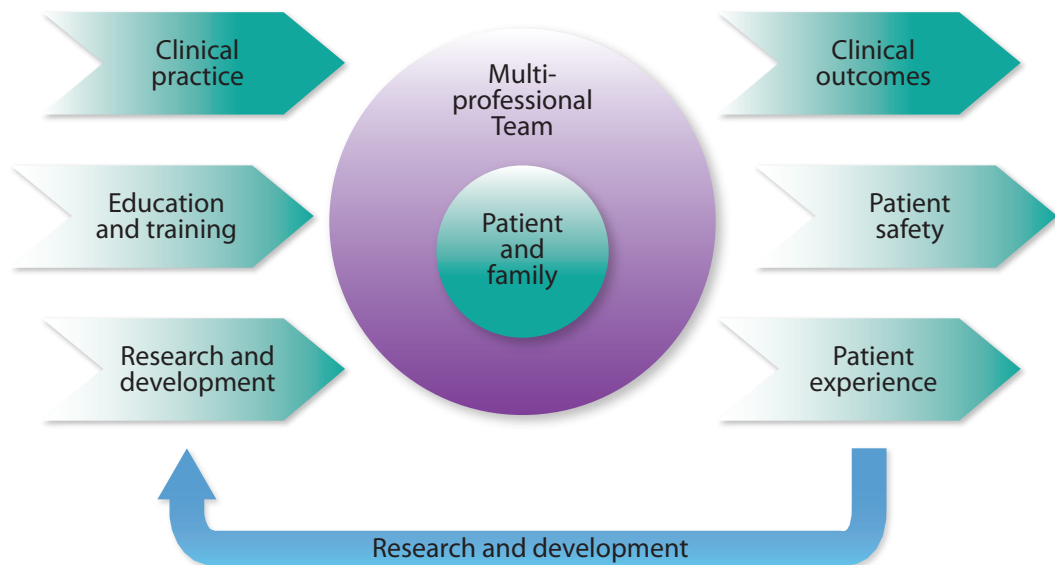
Throughout this guide, unless explicitly stated, it should be understood that the term 'paediatric' relates to children and teenagers, and that recommendations refer to both children and teenagers. Young adults have distinct care needs, which are not covered in this document. Clearly different individuals may have different needs for reasons other than age.

Recommendations should be interpreted sensibly so that services are both age-appropriate and also take into account any other factors relevant to the individual.

It has been compiled by a working party of representatives from The Royal College of Radiologists, the Society and College of Radiographers and the Children's Cancer and Leukaemia Group. These included clinical oncologists, therapeutic radiographers and patient advocates.

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 multi-professional team and research aimed at improving current practice (see Figure 1).

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



1.4 Sources of guidance

Box 1. The duties of a doctor registered with the General Medical Council³

Patients must be able to trust doctors with their lives and health. To justify that trust you must show respect for human life and you must:

- Make the care of your patient your first concern
- Protect and promote the health of patients and the public
- 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
 - Work with colleagues in the ways that best serve patients' interests
- 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 patients 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
- Be honest and open and act with integrity
 - Act without delay if you have good reason to believe that you or a colleague may be putting patients at risk
 - 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.

Reproduced with kind permission of the General Medical Council

The most authoritative guidance comes from the General Medical Council in its publication *Good Medical Practice*.³ 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 multi-professional 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) and the National Patient Safety Agency (NPSA; now the NHS Commissioning Board Special Health Authority), 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.

2. The multi-professional team

Box 2. The multidisciplinary team⁴

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

2.1 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 to ensure that:

- All relevant information is available
- All the relevant treatment options are considered
- Options and decisions about patient care are documented.⁴

This is particularly important for the optimum management of paediatric tumours because of their rarity and the 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).⁴

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. There should also be 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 can also make a valuable contribution to these MDT meetings.

The working practices of MDTs should be reviewed periodically to ensure that they are as functional as possible.⁵

2.2 The paediatric radiotherapy team

The planning, delivery and aftercare of radiotherapy for children and young people is a complex multi-professional activity. It requires clinical oncologists, therapeutic radiographers, mould room staff and play specialists supported by nurses, anaesthetic staff, physicists and dosimetrists, and psychologists or psychotherapists (see Box 3⁴). 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 younger teenagers. It is important that these are not lumped together, but that patients are treated in age-appropriate ways in age-appropriate facilities.

Box 3. Suggested composition of paediatric oncology multidisciplinary teams⁴

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

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

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

2.3 The role of the advanced paediatric therapeutic radiographer practitioner

The following should be in the list of responsibilities of an advanced paediatric therapeutic radiographer practitioner, 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
- 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 before 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, in liaison with other key members of the team, 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
- Receive training and maintain regular updates to the minimum of Level 2 for safeguarding children
- Attend paediatric resuscitation training annually
- 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 advanced paediatric therapeutic radiographer practitioner should be the key contact from the end of radiotherapy treatment to the first follow-up appointment following radiotherapy
- The advanced paediatric therapeutic radiographer practitioner 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.

Box 4. The advanced paediatric therapeutic radiographer practitioner

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.⁴

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.⁶

2.4 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 Level 1 training for safeguarding children.

All radiographers 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.⁷

2.5 The role of the radiotherapy play specialist

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).^{6,8,9} 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 5. The role of the radiotherapy play specialist

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.⁶

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.^{8,9}

Effective input from a radiotherapy play specialist can result in fewer young children requiring a general anaesthetic for their radiotherapy treatment.^{10,11}

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 the 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, youth worker, youth support 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.¹²

2.6 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 6. Anaesthetic staffing and facilities⁶

- 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 sedation or anaesthetic, in the department. 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) professional activity (PA) time is specified in the job plan of a named consultant paediatric anaesthetist or anaesthetists.
- Specified time for the role of the 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 6).⁶ 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. As some current treatment protocols call for hyperfractionated, accelerated treatment, a twice a day service may be needed on occasions.

Patient safety under anaesthesia is facilitated by the use of the World Health Organization (WHO) Surgical Safety Checklist endorsed by the NPSA (see Figure 2).¹³

Figure 2. WHO surgical safety checklist¹³

WHO Surgical Safety Checklist
(adapted for England and Wales)

National Patient Safety Agency
National Reporting and Learning Service

SIGN IN (To be read out loud)
Before induction of anaesthesia

Has the patient confirmed his/her identity, site, procedure and consent?
 Yes

Is the surgical site marked?
 Yes/not applicable

Is the anaesthesia machine and medication check complete?
 Yes

Does the patient have a:
Known allergy?
 No
 Yes

Difficult airway/aspiration risk?
 No
 Yes, and equipment/assistance available

Risk of >500ml blood loss (7ml/kg in children)?
 No
 Yes, and adequate IV access/fluids planned

Name: _____
Signature of Registered Practitioner: _____

PATIENT DETAILS

Last name: _____
First name: _____
Date of birth: _____
NHS Number: _____
Procedure: _____

*If the NHS Number is not immediately available, a temporary number should be used until it is.

TIME OUT (To be read out loud)
Before start of surgical intervention for example, skin incision

Have all team members introduced themselves by name and role?
 Yes

Surgeon, Anaesthetist and Registered Practitioner verbally confirm:
 What is the patient's name?
 What procedure, site and position are planned?

Anticipated critical events

Surgeon:
 How much blood loss is anticipated?
 Are there any specific equipment requirements or special investigations?
 Are there any critical or unexpected steps you want the team to know about?

Anaesthetist:
 Are there any patient specific concerns?
 What is the patient's ASA grade?
 What monitoring equipment and other specific levels of support are required, for example blood?

Nurse/ODP:
 Has the sterility of the instrumentation been confirmed (including indicator results)?
 Are there any equipment issues or concerns?

Has the surgical site infection (SSI) bundle been undertaken?
 Yes/not applicable
• Antibiotic prophylaxis within the last 60 minutes
• Patient warming
• Hair removal
• Glycaemic control

Has VTE prophylaxis been undertaken?
 Yes/not applicable

Is essential imaging displayed?
 Yes/not applicable

Name: _____
Signature of Registered Practitioner: _____

SIGN OUT (To be read out loud)
Before any member of the team leaves the operating room

Registered Practitioner verbally confirms with the team:
 Has the name of the procedure been recorded?
 Has it been confirmed that instruments, swabs and sharps counts are complete (or not applicable)?
 Have the specimens been labelled (including patient name)?
 Have any equipment problems been identified that need to be addressed?

Surgeon, Anaesthetist and Registered Practitioner:
 What are the key concerns for recovery and management of this patient?

Name: _____
Signature of Registered Practitioner: _____

This checklist contains the core content for England and Wales

www.npsa.nhs.uk/nrls

©BPS January 2008

16

2.7 The paediatric clinical oncologist

Box 7. Core components of radiotherapy centres treating children and young people with cancer⁴

- 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 multidisciplinary teams (and therapeutic radiographers where appropriate)
- Availability of clinical oncologists with declared subspecialisation in the tumour types common in young people

Paediatric clinical oncologists are the physicians legally responsible under the *Ionising Radiation (Medical Exposure) Regulations 2000*¹⁴ as referrer and practitioner for justifying, prescribing and overseeing radiation treatment, and the associated diagnostic exposures.¹⁵

The training of clinical oncologists involves general internal medicine and the treatment of cancer with ionising radiation and systemic therapies,¹⁶ 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 certification of completion of training (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 (see Box 7).⁴ More experienced consultants need to continue their professional development in line with RCR guidance for revalidation.¹⁷ This should include both paediatric oncology and more general radiotherapy elements in order to keep abreast of developments in the field.

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.

As children's cancer is rare, paediatric clinical oncologists should develop professional networks through membership of organisations like the CCLG and the Paediatric Radiation Oncology Society and by attending meetings and conferences.

The job plan of paediatric clinical oncologists should be informed by advice from the RCR.¹⁸ 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 involving solid tumours and neuro-oncology where the paediatric clinical oncologist will be a core member, 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. Dose prescription is more individualised now, based on risk grouping, than it used to be. Time is required to inspect plans and select the best.

- Treatment delivery
While the administration of radiotherapy is essentially a radiographer's responsibility, some input from the consultant clinical oncologist may be required to check various images for geometric accuracy and review results of *in vivo* dosimetry.¹⁹
- 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.

If things go wrong, as sometimes they will, it is the responsibility of the paediatric clinical oncologists to ensure that they are dealt with swiftly, to minimise any harm to the patient.²⁰ Problems or complaints should be discussed sensitively and honestly with the family, in line with RCR and NPSA guidance.^{16,21}

2.8 Radiotherapy physicists and dosimetrists

While radiotherapy physicists and dosimetrists seldom have direct patient contact, a degree of specialisation in paediatric radiotherapy planning is very helpful, as some of the most specialised techniques (for example, craniospinal radiotherapy and total body irradiation) are often used and require special competence. It is valuable for those involved in the planning of paediatric radiotherapy to have an understanding of children's growth and development and normal organ dose constraints.

2.9 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 diarrhoea, and the need for neurosurgical investigation or intervention if obstructive hydrocephalus develops. Some of these complications can be life-threatening.²² Paediatric support is also needed in the radiotherapy department for resuscitation, and paediatricians should be immediately available during the administration of IV contrast 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. 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

3.1 Presentation, diagnosis and risk stratification

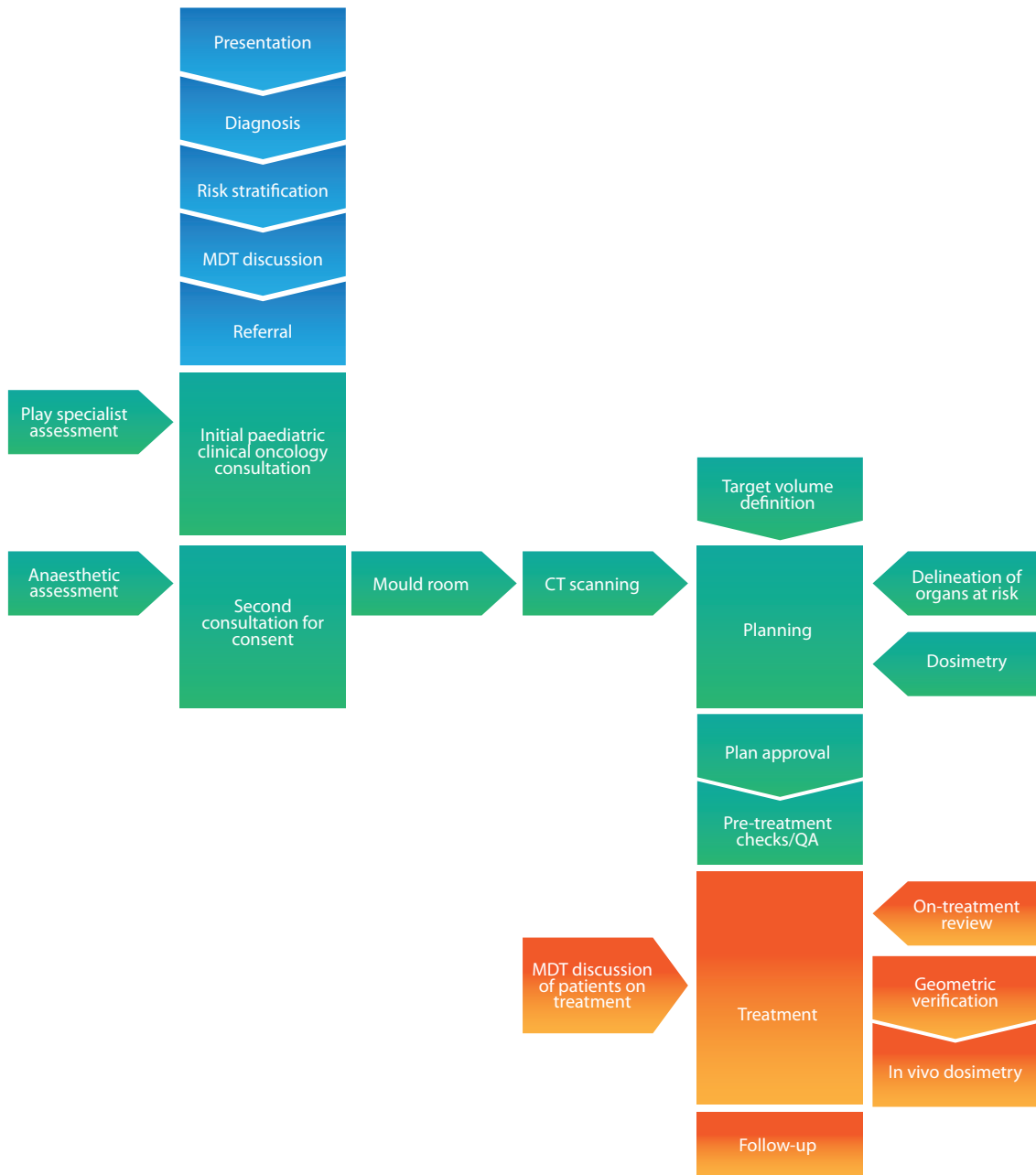
Children with cancer usually present to their general practitioner, and sometimes to accident and emergency departments. When cancer is suspected – either on the basis of history or examination findings, or sometimes because of investigation results – the child is usually referred to a paediatrician. 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 (see Figure 3, overleaf).

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 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.

3.2 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 time frame between the 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 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 3. 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 8).

Box 8. 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 (eg, married/divorced, living together/apart)
- Languages spoken
- Names and relationships of other carers (eg, 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
- Others healthcare professionals essential to the child's care (eg, 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) eg, 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

3.3 Initial consultation with the patient and family

3.3.1 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 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 3.2) 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, and the discussion should take place in a private area.

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.

3.3.2 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 initial 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, Macmillan nurse or advanced paediatric therapeutic radiographer practitioner should also be in attendance
- 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.

Sufficient amount of time, at least 60 minutes, should be available for 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.

3.3.3 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, 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, and 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 time frame 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
- Will the child be coming from home on a daily basis or are there hostel facilities 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 advanced paediatric therapeutic radiographer practitioner 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 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 and give less detailed information.

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.

3.4 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 sometime 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.

3.5 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 very 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 (such as CCLG radiotherapy information sheets or other locally produced leaflets).

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 9). 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 undertreatment. 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.

Box 9. Key areas in discussing late effects

- Effects on sexual and reproductive function
 - Ways to mitigate these²³
- 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

3.6 Consent

Box 10. Consent

You must be satisfied that you have consent or other valid authority before you undertake any examination or investigation, provide treatment or involve patients in teaching or research. Usually this will involve providing information to patients in a way they can understand, before asking their consent.³

Authoritative guidance on good practice in relation to consent comes from the GMC in *Consent: patients and doctors making decisions together*²⁴ and *0–18 years: guidance for doctors*²⁵ (see Boxes 10 and 11).

Box 11. Guidance on consent from the GMC²⁴

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 12. Assessing the capacity to consent²⁵

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.

25

If children lack the capacity to consent, you should ask for their parent's consent. 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).²⁵

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.

3.7 Communication and documentation

Following these consultations, appropriate summaries of the discussion should be sent, in a timely manner, to all those involved with the patient's 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 inpatient, the advanced paediatric therapeutic radiographer practitioner and so on.

The family should be offered the opportunity to receive a 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.

3.8 Immobilisation

3.8.1 Play specialist assessment

It is clear from Section 2.5 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 (Section 3.3) and subsequent (Section 3.4) 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.

3.8.2 Anaesthetic assessment

If it is clear from the outset, or decided subsequently, that anaesthesia will be required for planning and treatment, 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. 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.

3.8.3 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:

- 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 therefore will co-operate and comply
- Additional support from the hospital play specialist or advanced paediatric therapeutic radiographer practitioner 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. Far better to take the time necessary and get it correct at the first attempt.

3.9 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 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 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 number of staff present 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 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 with the child before they are done
- 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 before 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 that standard time for planning and so on as 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.

3.10 Radiotherapy treatment

- The advanced paediatric therapeutic radiographer practitioner is the key contact for the child and family while 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 paediatric radiographer should keep the treatment team up to date with changes in care and other aspects of the holistic management as appropriate.
- The paediatric radiographer does not necessarily treat the child everyday 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 (such as for machine breakdown, service days), 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 to minimise the impact of any errors (see Box 13).^{26,27}

Box 13. Suggested protocol for paediatric verification^{26,27}	
Fraction 1 (images acquired & actioned before treatment delivery)	<ul style="list-style-type: none"> • Acquire orthogonal images set, minimising dose to critical structures (where possible) • If field edge verification is needed, where possible image all treatment fields • Assess for and correct gross errors immediately
Fractions 2 & 3	<ul style="list-style-type: none"> • Image orthogonal set • Assess each image and correct gross errors for each fraction where necessary
Action before Fraction 4	<ul style="list-style-type: none"> • Calculate the overall systematic error (average of the isocentric set-up error) in each orthogonal direction • Apply the systematic set-up error correction
Fractions 4 & 5	<ul style="list-style-type: none"> • If the set-up has been corrected, confirm by repeat imaging (typically two or more fractions) • If practical, calculate the new overall systematic set-up error and correct
Weekly & first day of each phase of treatment plan	<ul style="list-style-type: none"> • Image orthogonal set each week • Assess each image and correct gross errors for each fraction where necessary • If set-up error is greater than the tolerance value, check by repeat imaging (typically two or more fractions) • Apply any systematic set-up error correction
<ul style="list-style-type: none"> • Daily verification may be required for treating tumours planned with very small margins or hypofractionated techniques 	
<ul style="list-style-type: none"> • Patient immobilisation devices to help maintain treatment position is essential 	
<ul style="list-style-type: none"> • Anaesthesia may be necessary for adequate immobilisation 	
<ul style="list-style-type: none"> • Concomitant exposures should be especially considered in children and adolescents 	
<ul style="list-style-type: none"> • Tolerances and action levels to use will vary, particularly with the immobilisation and treatment technique used as well as compliance of the patient and should be chosen accordingly 	

3.11 Supportive care

Children receiving radiotherapy should be reviewed with their family at least weekly by the clinical oncologist and 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 alternatively 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 such as 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 around 12 gdl^{-1} if the level is below 11 gdl^{-1} 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 within the radiotherapy department. 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.

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.

3.12 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.²⁸

The radiotherapy department should provide a waiting area exclusively for the use of children and young people attending for consultation, planning and treatment and their carers. 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 Boxes 14–16).^{28,29}

Box 15. The waiting area²⁹

- The waiting area should be a child-friendly and safe environment, with suitable play and recreational equipment to help distract the time spent 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 sign posting 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 Services (PALS). If waiting areas are due to be upgraded or new departments are being built the *Improving the patient experience – Friendly Healthcare Environments for Children and Young People*³⁰ may be utilised, or specialist design advice sought from good architects.

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

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, 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

3.13 Documentation of treatment

It is important that there is a summary of radiotherapy treatment, which is accessible to treating paediatric oncologists, and is 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 (such as 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

- 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
- Total dose administered
- Total number of fractions
- Fraction size
- 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
- Reasons for any compromise or deviation from protocol.

The summary should also have at least the following images:

- Planning film, digitally reconstructed radiograph or portal image 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.

3.14 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*.³¹ It is important that the clinical oncologist is a core member of the long-term follow-up team.

4 Types of radiotherapy

4.1 Conventional radiotherapy

Over time, radiotherapy has evolved. 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 is 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 multi-leaf 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 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.

4.2 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 (see Box 17 for examples).

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. This treatment is now recommended in guidelines for the treatment of some high-risk malignant brain tumours, such as metastatic medulloblastoma.

Fractionation should follow guidance given in the general RCR guidance *Radiotherapy Dose-Fractionation*,³² unless otherwise mandated by clinical trial protocols or CCLG guidelines.

4.3 Intensity-modulated 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) 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 diagnostic 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 change, for example shrinkage of a tumour.

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 are dynamic changes in machine output, field shape and rotational speed throughout an arc, may be used. 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. A national training programme has been developed to expand access to the 30% of patients who should benefit. There has been 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. 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. More recently, there has 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 previously 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 can be obtained. Ideally the technique should be evaluated in clinical trials. If IMRT is used outside a trial setting, long-term follow-up is mandatory.

4.4 Proton beam radiotherapy

High-energy proton beam radiotherapy is not presently available in the UK, although there are plans for this. There are an increasing number of centres abroad which deliver proton beam radiotherapy. Protons have different dose characteristics from conventional photon treatment, in that there is no exit dose. Carefully planned proton radiotherapy may have a superior dose distribution in some circumstances to conventional radiotherapy. Usually this does not offer an increased chance of cure, but exposure of organs at risk may be less, so survivors may have fewer late effects and a better quality of life. In some circumstances, avoidance of adjacent normal tissues may allow dose escalation and an improved chance of cure.

Box 18. Paediatric indications for referral abroad for proton beam therapy³³

Base of skull & spinal chordoma
 Base of skull chondrosarcoma
 Spinal and paraspinal 'adult type' bone and soft tissue sarcomas
 Rhabdomyosarcoma

- Orbit
- Parameningeal & head & neck
- Pelvis

 Ependymoma
 Ewing's sarcoma
 Retinoblastoma
 Pelvic sarcoma
 Optic pathway and other selected low grade glioma
 Craniopharyngioma
 Pineal parenchymal tumours (not pineoblastoma)
 Esthesioneuroblastoma

There is very little Level I evidence of proton superiority over photon radiotherapy. Most of the benefit is extrapolated from dosimetric studies. These indicate a reduced risk of late effects due to a better ability for exclusion of normal tissues; for example, brain, bone and soft tissues among others, from the intermediate to high-dose volume. Dosimetry indicates a reduced risk of carcinogenesis with high-energy proton beam therapy, and therefore fewer lives lost to second malignant neoplasms. While not randomised trial evidence, the dosimetric basis for the benefit of protons is enough for the English Department of Health to commit to the development of proton treatment facilities in this country, and in the interim to fund referral abroad for selected patients (see Box 18).³³

The NHS National Specialised Commissioning Team (NSCT) has devised a list of indications where there is sufficient evidence of benefit to warrant the additional cost of referral abroad.³³ In the first instance, application has to be made to the NSCT Proton Panel on an individual patient basis (see Box 19).³³ The Panel will consider if proton therapy is clinically justified, and if so will approve funding. The approval has to be granted by the Panel prior to referral to the treating centre. Details of the process – which is liable to change over time – are available on the NSCT website [<http://www.specialisedservices.nhs.uk/info/proton-beam-therapy>]. The locally agreed pathway for referral should be clear to team members.

Box 19. Conditions for proton beam therapy referral³³

- Treatment should be given with curative intent
- Patients will have good performance status either 0 or 1 (World Health Organization [WHO] see Appendix 2)
- 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
- Re-treatment cases will not be accepted

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, advanced paediatric therapeutic radiographer practitioner and social worker at the referring centre is needed to facilitate and smooth 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.

4.5 Brachytherapy

Brachytherapy – the placement of sealed radioactive sources into, or immediately adjacent to, tumours – has been practised 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.³⁴

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 enable greater sparing of organs at risk than external beam radiotherapy (see Box 20). 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 20. 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, radiographers, paediatric anaesthetists and paediatric radiologists working together in a hospital with paediatric inpatient support. Paediatric surgeons may also be required for intraoperative brachytherapy. Due to the limited number of patients requiring this type of treatment, and the fact that not every paediatric radiotherapy centre has all these requirements, paediatric brachytherapy should be performed in only a small number of centres across the country (see Box 21). Centralisation helps to promote expertise where special skills are needed.

Box 21. 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 MDT, 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.

4.6 Molecular radiotherapy

Molecular radiotherapy³⁵ is also referred to as unsealed source radiotherapy or radionuclide therapy. 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 radiolabelled meta-iodobenzylguanidine [mIBG] for the treatment of neuroblastoma or neuroendocrine tumours).

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

Box 22. Requirements for a centre to give molecular radiotherapy to children

- Experienced paediatric clinical oncologists
- Therapeutic radiographers with special expertise
- Play specialists
- Physicists 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 22).

5 Recommendations

5.1 Top quality clinical outcomes

5.1.a Optimal treatment technique for each patient, even if this requires referral to another centre

- Not every type of radiotherapy treatment is available in every centre.
- 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 (4.4), brachytherapy (4.5) and molecular radiotherapy (4.6).
- Sometimes a service usually available locally, such as radiotherapy under general anaesthesia, may be unavailable or not available within an acceptable time frame.
- 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.

5.1.b 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.

5.1.c Full documentation of treatment given, and deviations from the norm explained and justified

- Full information (3.13) on past treatment enables risk stratification for focused long-term follow-up.
- Information on past treatment is essential for safe re-treatment.
- Non-standard treatment may be entirely justified, but may not be clear subsequently unless the justification is documented.

5.2 Excellent patient safety

5.2.a 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*⁴ 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*.²⁰
- Departments should have an externally validated and audited quality management system; for example, ISO 9001.

5.2.b Access to a specialist paediatric anaesthetic service, and paediatric resuscitation and life support teams immediately available

- Good immobilisation (3.8) 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 (2.6) as required.
- To ensure patient safety, paediatric resuscitation (3.11) and life support must be available.

5.2.c *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 other members of the paediatric radiotherapy team as appropriate.
- Paediatric medical nursing and allied healthcare support (3.11) must be available.

5.3 Good patient experience

5.3.a *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 (2.5, 3.8.1) support in the radiotherapy department is essential.
- Care should be delivered in an age-appropriate environment (3.12).

5.3.b *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.

5.3.c *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.

5.4 Information and communication with families

5.4.a *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 smoothes subsequent progress for the radiotherapy key worker to be part of the early discussions with the paediatric clinical oncologist.

5.4.b *Consistent and accurate information available in 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.

5.4.c *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.

5.5 Communication and multi-professional relationships

5.5.a *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.

5.5.b *Full involvement of clinical oncologists and therapeutic radiographers as valued contributors to the multidisciplinary team 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 all relevant factors.
- Paediatric clinical oncologists need to contribute actively to MDT decision-making.

5.5.c *Regular liaison with the wider paediatric multi-professional 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 multimodality 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.

5.6 Child, teenager and family-friendly environment

5.6.a *Comfortable and pleasant waiting areas fully equipped with age-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.

5.6.b *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 relaxing and comforting with toys and distractions.
- A good early experience in a treatment room will make subsequent visits easier.

5.6.c *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.

5.7 **Radiotherapy equipment and techniques**

5.7.a *Access to a full range of modern and up-to-date treatment equipment and protocols*

- New photon radiotherapy techniques with potential advantages such as IMRT and IGRT are becoming available.
- Clinicians should be able to choose the best treatment for a patient according to their needs, not be constrained by available facilities.

5.7.b *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 planning target volume (PTV) margin.

5.7.c *Quality assurance of the accuracy and reproducibility of daily treatment with on-set verification with portal and other 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.

5.8 **Human and financial resources**

5.8.a *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 multi-professional workforce.
- High-quality treatment cannot be delivered with too few, or inadequately skilled, staff.

5.8.b *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 should not be compromised by haste.
- Adequate time must be available in practice as well as in theory.

5.8.c *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.

5.9 Education and training

5.9.a *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.

5.9.b *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.

5.9.c *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.

5.10 Research and development

5.10.a *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 if there is evidence of potential benefit.
- Care must be taken to ensure that new processes are audited and patient outcomes are monitored.

5.10.b *Clinical oncologists fully involved in national and international groups developing clinical trials of multi-modality treatment for children's cancers*

- Clinical progress in rare cancers is achieved through international collaboration because of small patient numbers.
- Development of new multi-modality 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.

5.10.c 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.

Approved by the Executive of the Children's Cancer and Leukaemia Group: 3 October 2011

Approved by the Council of the Society and College of Radiographers: 9 November 2011

Approved by the Board of the Faculty of Clinical Oncology of The Royal College of Radiologists: 28 October 2011

6 Glossary

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

Catheter – Flexible tube which can be inserted into part of the body

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, other drug therapy

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

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

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

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

IR(ME)R – Ionising Radiation (Medical Exposure) Regulations

Key worker – The person who takes a key role in co-ordinating the patient's care and promoting continuity, ensuring the patient (or carers of children) knows who to access for information and advice. This role may be undertaken by appropriately trained individuals from a variety of backgrounds including nursing and therapeutic radiography.

Medical oncologist – A cancer specialist skilled in the use of chemotherapy and other drug therapy

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

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

Oncologist – Specialist in the treatment of cancer

Paediatric oncologist – A paediatrician specialising in the management of childhood malignancies including chemotherapy and other drug therapy

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 IR(ME)R)

Prone – Patient position, lying on front

Referrer – An individual who, under IR(ME)R 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, c.f. primary care (general practice) and secondary care (‘district general hospital’)

Therapeutic radiographer – Individual qualified to deliver therapeutic radiation

7 References

1. Cancer Research UK. *CancerStats: Childhood Cancer – Great Britain & UK*. <http://publications.cancerresearchuk.org/downloads/product/CSCHILD10childhood.pdf> (last accessed 20/08/12)
2. Department of Health. *The NHS Constitution: The NHS belongs to us all*. London: DH Publications, 2010.
3. General Medical Council. *Good Medical Practice*. London: General Medical Council 2006.
4. National Institute for Health and Clinical Excellence. *Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer. The Manual*. London: National Institute for Health and Clinical Excellence, 2005.
5. Intercollegiate Cancer Committee. *Educational Initiatives to Improve the Effectiveness of Cancer Multidisciplinary Teams*. London: Academy of Medical Royal Colleges, 2009.
6. National Cancer Peer Review, National Cancer Action Team. *Manual for Cancer Services 2008: Children Cancer Measures*. London: National Cancer Action Team, 2009.
7. Resuscitation Council (UK). *Resuscitation Guidelines*. London: Resuscitation Council (UK), 2010.
8. Webster A. The facilitating role of the Play Specialist. *Paediatric Nursing* 2000; **12**: 24–27.
9. Wilmot M. The Specialised Play Specialist. *Paediatric Nursing* 2007; **19**: 33.
10. Evans P, Chisholm D. Anaesthesia and Paediatric Oncology. *Current Anaesthesia & Critical Care* 2008; **19**: 50–58.
11. Scott L, Langton F, O'Donoghue J. Minimising the use of sedation/anaesthesia in young children receiving radiotherapy through an effective play preparation programme. *European Journal of Oncology Nursing* 2002; **6**: 15–22.
12. CLIC Sargent. *More Than My Illness: Delivering quality care for young people with cancer*. London: CLIC Sargent, 2010.
13. National Patient Safety Agency. *WHO Surgical Safety Checklist*. London: NPSA, 2009.
14. *The Ionising Radiation (Medical Exposure) Regulations 2000*. London: Stationery Office, 2000, SI 2000/1059.
15. The Royal College of Radiologists, Society and College of Radiographers, Institute of Physics and Engineering in Medicine. *A Guide to Understanding the Implications of the Ionising Radiation (Medical Exposure) Regulations in Radiotherapy*. London: The Royal College of Radiologists, 2008.
16. www.rcr.ac.uk/CO/curriculum
17. www.rcr.ac.uk/revalidation
18. The Royal College of Radiologists. *Guide to job planning in clinical oncology, 2nd edn*. London: The Royal College of Radiologists, 2012.
19. The Royal College of Radiologists, Society and College of Radiographers, Institute of Physics and Engineering in Medicine, British Institute of Radiology. *Implementing in vivo dosimetry*. London: The Royal College of Radiologists, 2008.

20. The Royal College of Radiologists, Society and College of Radiographers, Institute of Physics and Engineering in Medicine, National Patient Safety Agency, British Institute of Radiology. *Towards Safer Radiotherapy*. London: The Royal College of Radiologists, 2008.
21. National Patient Safety Agency, National Reporting and Learning Service. *Being Open: Communicating patient safety incidents with patients, their families and carers*. London: National Reporting and Learning Service, 2009.
22. National Confidential Enquiry into Patient Outcome and Death. *For better, for worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy*. London: National Confidential Enquiry into Patient Outcome and Death, 2008.
23. Royal College of Physicians, The Royal College of Radiologists, Royal College of Obstetricians and Gynaecologists. *The effects of cancer treatment on reproductive functions: Guidance on management. Report of a working party*. London: Royal College of Physicians, 2007.
24. General Medical Council. *Consent: patients and doctors making decisions together*. London: General Medical Council, 2008.
25. General Medical Council. *0–18 years: guidance for all doctors*. London: General Medical Council, 2007.
26. The Royal College of Radiologists, Society and College of Radiographers, Institute of Physics and Engineering in Medicine. *On target: ensuring geometric accuracy in radiotherapy*. London: The Royal College of Radiologists, 2008.
27. National Radiotherapy Implementation Group. *Image Guided Radiotherapy (IGRT) Guidance for implementation and use*. (In press).
28. Department of Health. Getting the right start: National Service Framework for Children. Standard for Hospital Services. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006182 (last accessed 30 July 2011)
29. Department of Health. *National Service Framework for Children, Young People and Maternity Services: Core Standards*. London: DH Publications, 2004.
30. NHS Estates. *Improving the patient experience: Friendly healthcare environments for children and young people*. London: The Stationery Office, 2004.
31. United Kingdom Children's Cancer Study Group Late Effects Group. *Therapy Based Long Term Follow Up: Practice Statement*. Leicester: United Kingdom Children's Cancer Study Group, (2nd Edition) 2005.
32. The Royal College of Radiologists. *Radiotherapy Dose-Fractionation*. London: The Royal College of Radiologists, 2006.
33. National Specialised Commissioning Team. *Guidance for the Referral of Patients Abroad for NHS Proton Treatment*. London: NHS Specialised Services, 2011.
34. The Royal College of Radiologists. *The role and development of afterloading brachytherapy services in the United Kingdom*. London: The Royal College of Radiologists, 2012.
35. The British Institute of Radiology Molecular Radiotherapy Working Party. *Molecular Radiotherapy in the UK: Current Status and Recommendations for Further Investigation*. London: The British Institute of Radiology, 2011.

Appendix 1. Membership of Working Party

Dr Mark Gaze (Chairman, The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Dr Fiona Cowie (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Mrs Dawn-Marie Davies (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

Dr Daniel Ford (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Mrs Susan Hay (Children's Cancer and Leukaemia Group, Patient Advocate)

Dr Michelle Kwok-Williams (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Mrs Lesley McGuffie (The Royal College of Radiologists, Patient Advocate)

Mrs Liz Murphy (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

Mrs Di Readman (Society and College of Radiographers, Patient Advocate)

Dr Daniel Saunders (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Dr Ed Smith (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Dr Elaine Sugden (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Mr Kevin Sullivan (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

Ms Lesley Taylor (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

Dr Nicky Thorp (The Royal College of Radiologists and Children's Cancer and Leukaemia Group)

Mr Mark Williams (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

Ms Helen Woodman (Society and College of Radiographers and Children's Cancer and Leukaemia Group)

We would like to acknowledge the help and support of many individuals we consulted who gave their opinions on draft versions of this guide in part or in whole.

Appendix 2. Example of a CCLG 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 twenty 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 on their front. To make this easier, we make a face mask for each patient and we often 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 on 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 4 to 6 weeks after treatment ends and going on for 2 to 6 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 6–12 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 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 yearly 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 treated 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.

The Royal College of Radiologists 38 Portland Place London W1B 1JQ

Tel +44 (0)20 7636 4432 | Fax +44 (0)20 7323 3100 | Email enquiries@rcr.ac.uk | www.rcr.ac.uk |

A Charity registered with the Charity Commission No. 211540

Citation details:

The Royal College of Radiologists, Society and College of Radiographers, Children's Cancer and Leukaemia Group. *Good practice guide for paediatric radiotherapy*. London: The Royal College of Radiologists, 2012.

On publication this document will be made available on all the organisations' websites.

ISBN 978-1-905034-59-8. RCR Ref No. BFCO(12)5. © The Royal College of Radiologists, December 2012.

For permission to reproduce any of the content contained herein, please email: permissions@rcr.ac.uk

This booklet was prepared and published on behalf of The Royal College of Radiologists, the Society and College of Radiographers and the Children's Cancer and Leukaemia Group. While every attempt has been made to provide accurate and useful information, neither the RCR, the SCoR nor CCLG nor other persons contributing to the formation of the booklet make any warranty, express or implied, with regard to accuracy, omissions and usefulness of the information contained herein. Furthermore, the same parties do not assume any liability with respect to the use, or subsequent damages resulting from the use of the information contained in the booklet.

Design by innov8 graphic design: www.innov8gd.com. Printed by Acorn Print Media.



members £20
non-members £25