



# Quality Standards

## Children and Young People's Palliative Care

Version 2.4

November 2020

**These Quality Standards were developed in accordance with the International Standard ISO/IEC 17020:2012 - Conformity assessment – Requirements for the operation of various types of bodies performing inspection in line with our accreditation with UKAS as an Inspection Body (No 8831).**

**The Quality Review Service closed on 31st July 2021, UKAS have asked that the accreditation symbol now be removed.**

**The standards can be used until they reach their expiry date – April 2022.**

© November 2020 Quality Review Service (QRS)

These Quality Standards may be reproduced and used freely by NHS and social care organisations for the purpose of improving health services. No part of the Quality Standards may be reproduced by other organisations or individuals or for other purposes without the permission of the Quality Review Service. Organisations and individuals wishing to reproduce any part of the Quality Standards should email the Quality Review Service on: [grs@nhs.net](mailto:grs@nhs.net)

Whilst the Quality Review Service has taken reasonable steps to ensure that these Quality Standards are fit for the purpose of reviewing the quality of services, this is not warranted, and the Quality Review Service will not have any liability to the service provider, service commissioner or any other person in the event that the Quality Standards are not fit for this purpose. The provision of services in accordance with these Standards does not guarantee that the service provider will comply with its legal obligations to any third party, including the proper discharge of any duty of care, in providing these services.

Review by: April 2022 at the latest

Version No	Date	Change from previous version
V2	April 2019	Revised version.
V2.1	November 2019	Figure 1: Amended flow chart to show missing text QS PN- 601 'f': Amended to show missing QS reference number Appendix 6; Added resuscitation equipment checked in accordance with local policy
V2.2	April 2020	Rebranded from WMQRS to QRS
V2.3	April 2020	Final amendments following rebranding
V2.4	November 2020	<ul style="list-style-type: none"><li>• QRS Contact details amended.</li><li>• Added in addition to CQC that other regulatory frameworks are in use in the devolved nations.</li><li>• QS PN-499 and PN- 601 amended to include use of systems and governance arrangements for virtual consultations</li></ul>
V2.5	July 2021	<ul style="list-style-type: none"><li>• UKAS Symbol removed</li></ul>

## Contents

Foreword .....	4
Introduction.....	5
Scope of the Quality Standards .....	5
Structure of the Quality Standards .....	7
Excel and PDF Versions .....	8
Comments on the Quality Standards .....	8
Together for Short Lives Pathway Standards .....	9
Quality Standards .....	10
Services Providing Palliative Care for Children and Young People .....	10
Information and Support for Children, Young People and their Families .....	10
Staffing .....	15
Support Services.....	20
Facilities and Equipment .....	21
Guidelines and Protocols .....	22
Service Organisation and Liaison with Other Services .....	26
Governance .....	28
Commissioning .....	30
Service Organisation and Liaison with Other Services .....	30
Governance .....	30
Appendix 1 Reference Sources .....	31
Appendix 2 Cross-References to British Standards Institution PAS16:16 and Care Quality Commission Key Lines of enquiry.....	34
Appendix 3 Glossary of Terms and Abbreviations .....	37
Appendix 4 Presentation of Evidence for Peer Review Visits .....	39
Appendix 5 Key Working.....	41
Appendix 6 Equipment List.....	42

## Foreword

The Quality Standards for Children and Young People's Palliative care were produced with care and dedication back in 2012 by Dr Angela Thompson the then Chair Clinical Subgroup West Midlands Paediatric Palliative Care Network. As a network we are delighted and filled with anticipation that these Quality Standards can be used to push forward equitable, quality paediatric palliative care services across the region and beyond.

The vision for the Quality Standards grew out of the development of the West Midlands Paediatric Palliative Care Toolkit. This in turn had grown out of the recognition that common resources, tools and documentation around children's palliative care would support best practice, safe, effective and responsive care across the region. The aim was to improve the experience of care for all those families who find themselves in the difficult position of requiring access to children's palliative care services. The Quality Standards build upon this by considering what a service 'should look like and feel like' to a family to meet those needs, and therefore, what needs to be in place, as a minimum, to provide that experience of best practice care.

Children and their families are central to the whole Toolkit. They are what hold it all together. It is in itself a reflection of all that the families and their children so generously shared with us over the years as we listened to families' needs and planned and delivered care together with them, for each of their unique journeys. As one Mum said, '*My little boy deserved the very best*'. Thankfully, she felt that was her experience. The Toolkit aims to help this to be families' experience in all settings, at all times, so that they can live their lives as fully and well as possible, and with special memories of their time with their child, even though that time is always too short. It is important that we reflect upon these aims as we remind ourselves of *why* these Standards are required. With the launch of the National Institute for Health and Care Excellence (NICE) guideline: End of life Care for Infants, Children and Young People with Life-limiting Conditions: Planning and Management (NG61) at the end of 2016 this, has offered further impetus for a push towards the goal of equitable and quality paediatric palliative care for all. Even more recently Together for Short Lives Steering Group released their updated "Guide to Children's Palliative Care" to provide further guidance for services. Focusing back upon our families, we are aware that these Quality Standards will be relevant to some families who have trudged a long, winding and difficult path. They will be relevant to others who are 'shell shocked' following a short and aggressive period of deterioration. All will be at a place they never wished to reach. It is therefore hoped that these revised and reformed Quality Standards will provide the catalyst to further improve care for our families as best practice becomes embedded into practice and delivers improvement in families' experiences throughout each day of their unique journeys.

Dr Sarah Thompson, Consultant Paediatrician, University Hospital of North Midlands. Hospice Doctor, The Donna Louise Hospice, Stoke on Trent. Co-chair West Midlands Paediatric Palliative Care Network

Marie Clancy, Children's Nurse, Lecturer, PhD student exploring children's palliative care for refugee and asylum seeker families and Co-Chair West Midlands Paediatric Palliative Care Network

Dr Angela Thompson Associate Specialist, Palliative Care Lead Paediatrician Coventry & Warwickshire  
Chair Clinical Subgroup West Midlands Paediatric Palliative Care Network

## Introduction

These Quality Standards aim to improve the quality of children and young people's palliative care. They help to answer the question: "For each service, how will I know that national guidance and evidence of best practice have been implemented?" The Quality Standards are suitable for use in service-specifications, self-assessment and peer review visits. They describe what services should be aiming to provide and all services should be working towards meeting all applicable Quality Standards within the next two years.

The Standards were initially developed by a Sub-Group of the West Midlands Paediatric Palliative Care Network in 2012. This revised version are based on and support implementation of the Together for Short Lives (TSL) care pathway standards and goals, the West Midlands Children and Young People's Palliative Care Toolkit and national strategies and guidance, including NICE guidance and Quality Standards. Appendix 1 lists relevant national guidance and links it to each of the Quality Standards. Appendix 2 cross-references each of the Quality Standards to the British Standards Institution PAS16:16 and the Care Quality Commission Key Lines of Enquiry.

We hope that through the Quality Standards and, at some future date, a peer review programme, the quality of services providing palliative care for children and young people will improve and in particular:

- 1 Children and young people who need palliative care, and their families, will know more about the services they can expect.
- 2 Commissioners will be supported in assessing and meeting the needs of their population, reducing inequity of access to good care and, will have better service specifications.
- 3 Service providers and commissioners will work together to improve service quality.
- 4 Service providers and commissioners will have external assurance of the quality of local services.
- 5 Reviewers will learn from taking part in review visits.
- 6 Good practice will be shared.
- 7 Service providers and commissioners will have better information to give to the Care Quality Commission, NHS England and NHS Improvement. The devolved nations may have different regulatory frameworks in place but these QS can still be used with these frameworks to provide additional assurance to commissioners of services.

## Scope of the Quality Standards

The Quality Standards refer to the care of babies, children and young people. For ease, the term 'child' is used throughout to refer to babies, children and young people unless there is a specific reason for using baby or young person. The Quality Standards apply to the care of children and young people who are on long-term ventilation as well as to others needing paediatric palliative care. (Specific Quality Standards for services providing Long-Term Ventilation for Children and Young People are available from the QRS [grs@nhs.net](mailto:grs@nhs.net) )

A glossary of terms and abbreviations used in the Quality Standards is given in Appendix 3.

### Local and tertiary services

The Quality Standards apply to all services providing paediatric palliative care at a local level, including community teams, hospices and acute hospitals. These services should work together, and with primary care, social care, education and other local agencies, to provide integrated care for children and their families. The 'local area' is defined as the population for which paediatric palliative care services are collaboratively commissioned and provided. It is expected that a population of at least one million (children and adults) will be needed to support an appropriate, sustainable range of community, acute and hospice services (Craft A and Killen S; *Palliative Care Services for Children and Young People in England: An Independent Review*; DH 2007). Some services, especially hospices, may be involved in more than one 'local area'.

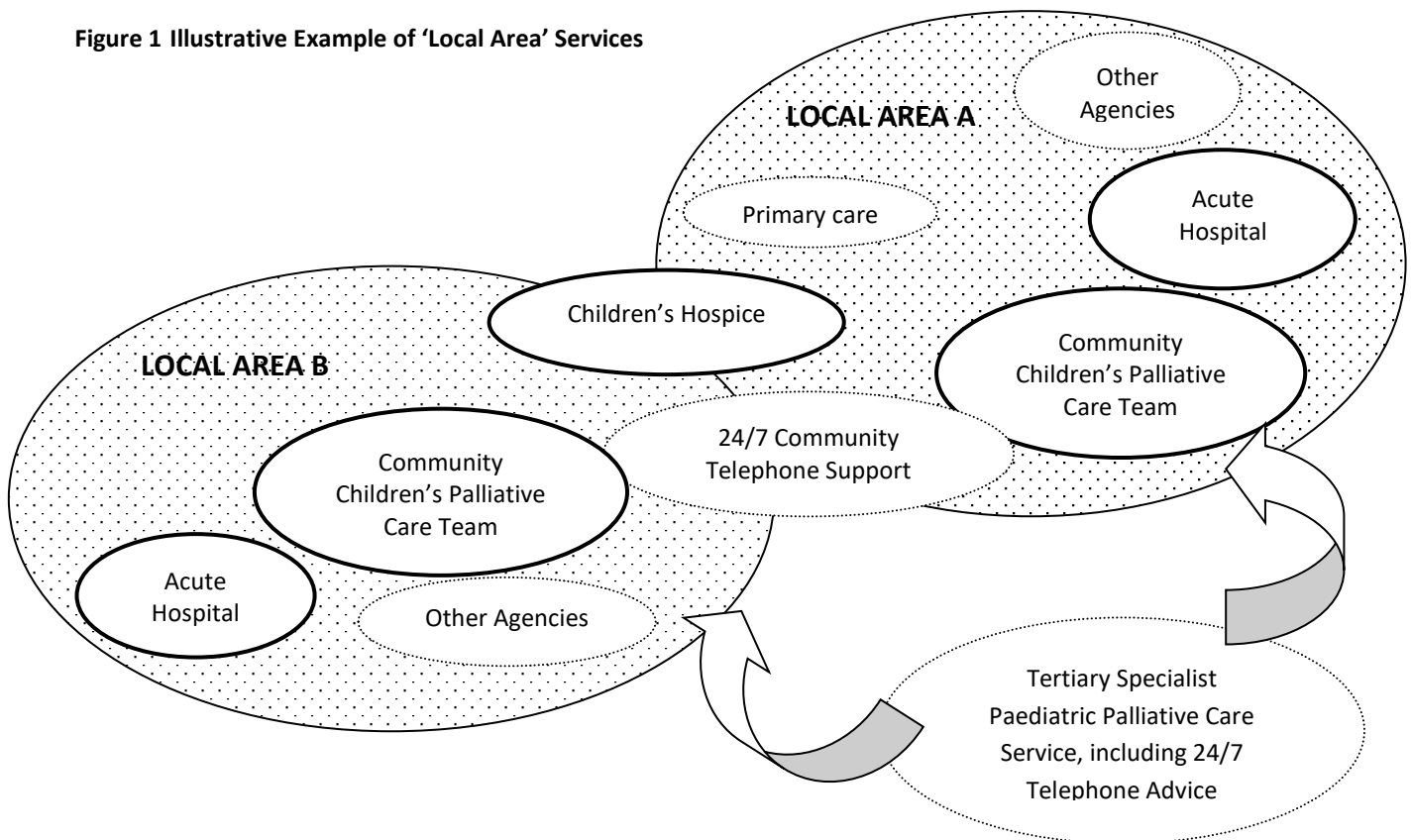
Quality Standards for tertiary, specialist palliative care services are included in this updated version. The Quality Standards are consistent with the *Service Specification E03/S/h Paediatric Medicine: Palliative Care* (NHS England, 2013) and provide a tool for demonstrating compliance with the national service specification. These services will be serving a population of over one million and, in some cases, up to four million (NHS England, 2013).

These arrangements are illustrated diagrammatically in Figure 1. The actual model in individual local areas may, of course, be different from this illustrative example.

Each paediatric palliative care service will need to meet the relevant Quality Standards. Standards for commissioners of local paediatric palliative care services are also defined.

Quality Standards for NHS-funded respite care provided by non-NHS facilities have not specifically been developed. The Steering Group considers, however, that non-NHS providers of respite care should aspire to meeting the Quality Standards and, in due course, commissioners may require this of all providers.

**Figure 1 Illustrative Example of ‘Local Area’ Services**

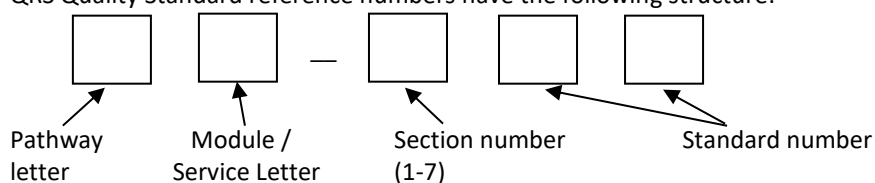


The Children and Young People's Palliative Care Quality Standards should sit within organisations' overall clinical governance arrangements. The QRS Clinical Governance Quality Standards describe the clinical governance arrangements which should be in place. Compliance in NHS provider organisations will usually be assured through other external mechanisms including internal and external audit, royal college reviews and inspections from regulatory bodies. Non-NHS organisations may wish to use the QRS Clinical Governance Quality Standards to assure themselves of the robustness of their overall clinical governance arrangements.

## Structure of the Quality Standards

### QRS Quality Standards Reference Structure

QRS Quality Standard reference numbers have the following structure:



Each Standard is structured as follows:

<b>Reference Number (Ref)</b>	<p>This column contains the reference number for each Standard, which is unique to these Standards and is used for all cross-referencing. Each reference number is composed of two letters and three digits (see above and below for more detail).</p> <p>The reference column also includes a guide to how the Standard will be reviewed:</p> <table border="1" data-bbox="612 770 1214 1189"> <tr> <td>BI</td> <td>Background information</td> </tr> <tr> <td>Visit</td> <td>Visiting facilities</td> </tr> <tr> <td>MP&amp;S</td> <td>Meeting service users (children, young people, adults) and staff</td> </tr> <tr> <td>CNR</td> <td>Case note review or clinical observation</td> </tr> <tr> <td>Doc</td> <td>Documentation should be available. Documentation may be written or be in the form of a website or other social media</td> </tr> </table> <p>The shaded area indicates the approach that will be used to reviewing the Quality Standard. Appendix 4 summarises the evidence needed for review visits.</p>	BI	Background information	Visit	Visiting facilities	MP&S	Meeting service users (children, young people, adults) and staff	CNR	Case note review or clinical observation	Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media
BI	Background information										
Visit	Visiting facilities										
MP&S	Meeting service users (children, young people, adults) and staff										
CNR	Case note review or clinical observation										
Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media										
<b>Quality Standard (QS)</b>	<p>This describes the quality that services are expected to provide.</p>										
<b>Notes</b>	<p><i>The notes give more detail about either the interpretation or the applicability of the Standard.</i></p>										

### Pathway and Service Letters:

The Quality Standards are in the following sections:

PN-	Paediatric Palliative Care Pathway	Service providing Paediatric Palliative Care
PZ-	Paediatric Palliative Care Pathway	Commissioning

### Topic Sections:

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

Within each section, each Standard has a unique two-digit number. These are not always sequential, to ensure that similar standards in different pathways have the same two-digit number.

The Quality Standards are cross-referenced to the British Standards Institution PAS16:16 and the Care Quality Commission Key Lines of enquiry in Appendix 2 .

#### **Policies, Protocols, Guidelines and Procedures:**

The Quality Standards use 'policy', 'protocol', 'guideline' and 'procedure' based on the following definitions:

<b>Policy</b>	A course or general plan adopted by an organisation, which sets out the overall aims and objectives in a particular area.
<b>Protocol</b>	A document laying down in precise detail the tests or steps that must be performed.
<b>Guidelines</b>	Principles which are set down to help determine a course of action. They assist the practitioner to decide on a course of action but do not need to be automatically applied. Clinical guidelines do not replace professional judgement and discretion.
<b>Procedure</b>	A procedure is a method of conducting business or performing a task, which sets out a series of actions or steps to be taken.

For simplicity, some standards use the term 'guidelines and protocols' which should be taken as referring to policies, protocols, guidelines and procedures. All clinical guidelines should be based on national guidance, including NICE guidance where available. Local guidelines and protocols should specify the way in which national guidance will be implemented locally and should show consideration of local circumstances.

## **Excel and PDF Versions**

The full text of the Quality Standards and all Appendices are available in a PDF version. A self-assessment form is available in Excel and it is recommended that this is used by services when considering their compliance with the Standards. The Excel version has the following advantages:

- The spreadsheet includes a 'CQC' tab. This updates automatically when a self-assessment is completed and allows services to see, and demonstrate, the extent to which they are achieving the CQC Key Lines of Enquiry. The devolved nations may have different regulatory frameworks in place but these QS can still be mapped to other frameworks to provide additional assurance to commissioners of services.
- Additional columns can be used for subsequent self-assessments, enabling progress to be seen without losing earlier information.

When using the Excel spread-sheet it is useful to know the following:

- If the tabs at the bottom of the spreadsheet do not appear, please minimise the spreadsheet and then maximise it again and the tabs should be there.
- 'Alt' and 'Enter' (together) allows you to put a new line within an Excel cell.

The PDF version includes appendices 1 to 5 which are not included in the Excel version.

## **Comments on the Quality Standards**

The Quality Standards will be revised as new national guidance becomes available and as a result of experience of their use in peer review. Comments on the Quality Standards are welcomed and will be taken into account when they are updated. Comments should be sent to [qrs@nhs.net](mailto:qrs@nhs.net)

More information about QRS and its Quality Standards and reviews is available at [www.qualityreview servicewm.nhs.uk](http://www.qualityreview servicewm.nhs.uk)



## Together for Short Lives Pathway Standards

These Quality Standards support implementation of the Together for Short Lives' care pathway standards and goals (2018)

### **The First Standard: Breaking News**

Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.

### **The Second Standard: Planning to Go Home**

Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

### **The Third Standard: Multi-agency Assessment of Family's Needs**

Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.

### **The Fourth Standard: Multi-agency Care Plan**

Every child and family should have a multidisciplinary, multiagency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multidisciplinary and multi-agency team should be identified in agreement with the family and use key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.

### **The Fifth Standard: End of Life Plan**

Every child and family should be helped to decide on an end of life care plan and should be provided with care and support to achieve this.

### **The Sixth Standard: Continuing Bereavement Support**

Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

## Quality Standards

### Services Providing Palliative Care for Children and Young People

These Quality Standards apply to all health services which provide palliative care for children and young people, including community-based services, acute hospital services and hospices.

Ref	Standard					
<b>Information and Support for Children, Young People and their Families</b>						
PN-101  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>General Support for Children, Young People and their Families</b></p> <p>Children, young people and their families should have easy access to the following services. Information about these services should be easily available:</p> <ol style="list-style-type: none"> <li>Interpreter services</li> <li>PALS and how to make a comment, compliment or complaint</li> <li>Social care</li> <li>Benefits advice</li> <li>Spiritual support</li> <li>HealthWatch or equivalent organisation</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Information should be written in clear, plain English and should also be available in formats and languages appropriate to the needs of the local population. This should include developmentally appropriate information for children and young people, including those with learning disabilities. Information for children and young people should meet the 'You're Welcome Quality Criteria' (DH, 2012).</li> <li>This QS is about 'signposting' to relevant services. The actual services available may be different in different areas.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-102  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Information</b></p> <p>Each service should offer children, young people and families information covering:</p> <ol style="list-style-type: none"> <li>What the service provides</li> <li>Organisation of the service, including times available (community services)</li> <li>Service routines such as meal times, visiting times and ward routines (if applicable)</li> <li>Staff and facilities available, including facilities that families may want to use such as multi-faith rooms, accommodation, shops, canteens or restaurants</li> <li>Transport facilities, car parking and arrangements for subsidised car parking costs (if available)</li> <li>How to contact the service for help and advice, including 'out of hours'</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>As PN-101 note 1.</li> <li>Information on service provision should also include additional support available for example therapies, respite provision, sibling support and access to psychology.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-103  <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Condition-Specific Information</b></p> <p>Children, young people and families should be offered discussion and access to written information about their condition including:</p> <ol style="list-style-type: none"> <li>Description of their condition and its impact</li> <li>Medication, including what it is for, when to take it, storage and possible side effects</li> <li>Management of acute and chronic changes in health</li> <li>Education, including planning together how to get help and support to continue education</li> <li>Lifestyle advice, including nutrition, exercise and travel</li> <li>Housing and housing adaptations</li> <li>Emotional, spiritual and psychological support for children and young people themselves and for their families, including siblings</li> <li>Benefits advice and how to access charitable funding, legal advice and other resources</li> <li>Transport and mobility</li> <li>Other local services available for children and young people with palliative and complex care needs and how to access them</li> <li>Advance Care Planning</li> <li>Pre- and post-bereavement support and care for children, young people and families</li> <li>Relevant voluntary organisations and support groups, including 'Together for Short Lives'</li> <li>Where to go for further information, including useful websites</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>As PN-101</li> <li>Information may be given at different stages in the patient pathway. 'Access to information' means that written information is either given to the child, young person and family or they are given something in writing which 'sign-posts' them to information of appropriate quality. Information may be given by other services involved in the care of the young person. If so, the paediatric palliative care service should document that the young person and their family has received the information from another service.</li> <li>Information should be consistent with that given by other services within the 'local area'. It is essential for services serving the same population to share the development and production of information for children, young people and families.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<p>PN-104</p> <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Personalised Care Planning</b></p> <p>Each child and young person and family should have the opportunity to discuss and agree their plan of care. This should be confirmed in a written Personal Care Record which is communicated to all services involved in their care, updated regularly and reviewed at least annually. The plan of care should cover:</p> <ol style="list-style-type: none"> <li>a. Agreed goals, including ‘parallel planning’ goals</li> <li>b. Therapeutic interventions (pharmacological and non-pharmacological)</li> <li>c. Equipment used</li> <li>d. Care provided for the child, young person and their family and any training needed</li> <li>e. Name of the person taking a ‘key working’ function and their contact details</li> <li>f. Named medical specialist</li> <li>g. Names and contact details of professionals and services involved in their care</li> <li>h. Education and education plan covering, at least, nursery, school or college attended and arrangements for liaison with them</li> <li>i. Choices and options for short breaks</li> <li>j. Housing and any housing adaptations needed</li> <li>k. Religious, spiritual and cultural needs</li> <li>l. Transport arrangements and transport needs</li> <li>m. Early warning signs of problems and what to do if these occur, including ‘just in case’ medication (if appropriate)</li> <li>n. How to access advice and support, including out of hours (QS PN-205)</li> <li>o. Planned review date and how to access a review more quickly, if necessary.</li> <li>p. Transition to adult services (if applicable)</li> </ol> <p>This QS should be met once for each child or young person (<b>not</b> once in each service).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>Personal Care Records, for example, ‘Passports’, may be in a variety of formats and levels of detail so long as these meet the requirements of the Quality Standard. Use of the WMPPCN Toolkit, Child and Young Person’s Advance Care Plan or use of a medical support plan/passport is sufficient for compliance with this Standard. The Personal Care Record may be combined with the Advance Care Plan (QS PN-106) or may be separate.</i></li> <li>2. <i>Responsibility for updating the care plan and ensuring that changes of care are communicated will usually be the main provider of care for the child and often the key worker. If required, clear arrangements should be in place for the transfer of responsibility for care planning between services (QS PN-105).</i></li> <li>3. <i>QS PN-602 covers arrangements for multi-disciplinary care planning.</i></li> <li>4. <i>‘Parallel planning’ is defined as ‘planning for the best but preparing for the worst’. ‘Key working’ is explained in more detail in Appendix 5.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<p>PN-105</p> <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>‘Key working’</b></p> <p>Each child and young person should have someone taking a ‘key working’ function who they and their family can contact for queries, advice and support. This person should have responsibility for:</p> <ol style="list-style-type: none"> <li>Maintaining regular contact with the child or young person and their family and providing information, support and advice covering all aspects of Qs PN-103 and PN-104</li> <li>Liaison with the child or young person’s named Community Children’s Nurse</li> <li>Informing other services involved with the child or young person about changes to their condition or plan of care (QS PN-104)</li> <li>Informing the child or young person’s nursery, school or college of changes to their condition, plan of care (QS PN-104) or Advance Care Plan (QS PN-106)</li> <li>Liaison with other services, including education and housing services, to advocate for needs of the child or young person and their family</li> <li>Initiating a multi-disciplinary care planning meeting in order to review the child or young person’s plan of care if this is needed before the next planned review date (QS PN-602)</li> <li>Initiating and / or participating in multi-disciplinary discharge planning (QS PN-507)</li> <li>Considering whether a ‘Child in Need Plan’ (or equivalent) should be opened to prevent or support periods of instability or crisis</li> <li>Consideration of and acting on safeguarding issues</li> <li>Handover to the next person taking a ‘key working’ function with the child or young person (if required)</li> </ol> <p>This QS should be met once for each child or young person (<b>not</b> once in each service).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Coordinating and maintaining an overview of the patient’s care pathway is central to the key working function. The individual will not be expected to answer all queries and will ‘signpost’ or support patients and carers in accessing other services or advice. The person taking a ‘key working’ function may or may not be the main provider of health care. They should be available on normal working days and cover for absences should be available. The ‘key working’ functions may be carried out by a small number of individuals rather than a single person, so long there is good coordination between them. The function is described in more detail in Appendix 5.</i></li> <li><i>QS PN-602 covers arrangements for allocation of the person taking the ‘key working’ function.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p>PN-106</p> <table border="1" data-bbox="209 1469 285 1615"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Advance Care Plan</b></p> <p>Each child or young person and their family should have an Advance Care Plan. The Advance Care Plan should be communicated to all relevant services involved in the care of the child or young person and should include a review date. If an Advance Care Plan is not yet appropriate, this should be documented in the child or young person’s medical record.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Use of the WMPPCN Toolkit, Child and Young Person’s Advance Care Plan or use of a medical support plan/passport is sufficient for compliance with this Standard.</i></li> <li><i>The Advance Care Plan may be combined with the Personal Care Record (QS PN-1064) or may be separate.</i></li> <li><i>The Advance Care plan may also include the child’s Recommended Summary Plan for Emergency Care and Treatment (ReSPECT).</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-107  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Family Involvement in Care</b></p> <p>Family members should have information, encouragement, support and training to enable them fully to participate in decisions about, and in the care of, their child.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>'Family members' also include siblings who may require information, support and training to participate in decisions and care of their sibling.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-108  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Facilities for Families</b></p> <p>Services providing overnight care should have the following facilities for families:</p> <ol style="list-style-type: none"> <li>a. A comfortable chair at the child's bedside</li> <li>b. Somewhere comfortable to sit away from the ward or child's bedroom</li> <li>c. A quiet room for relatives</li> <li>d. A toilet and washing area</li> <li>e. A kitchen or other facility for getting hot food</li> <li>f. Changing and play areas for other young children</li> <li>g. Overnight facilities including a foldaway bed or pull-out chair-bed next to the child and, ideally, accommodation on site but away from the ward or child's bedroom</li> <li>h. 'Personal care packs' for relatives who unexpectedly stay overnight</li> <li>i. Facilities for children with severe physical disability, including hoists and bath/shower equipment</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>This QS applies to in-patient hospital and hospice services but not to community services.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-109  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Play Support</b></p> <p>Children and young people should have access to support and opportunities for play and distraction during any painful or invasive procedures and to enable their development and well-being.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>NICE Guideline:61 (2016), section 1.1.9 states "Formats may include:</i> <ol style="list-style-type: none"> <li>a. <i>one to one discussion</i></li> <li>b. <i>Play, art and music activities</i></li> <li>c. <i>Written materials and picture</i></li> <li>d. <i>Digital media e.g. social media</i></li> </ol> </li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-110  <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Bereavement Support</b></p> <p>Families experiencing complex grief should have access to a service providing pre- and post-bereavement support for the family, including siblings.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>This QS is additional to the bereavement support provided by all staff working in paediatric palliative care.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-198  <table border="1" data-bbox="209 293 284 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Assessment of Carers' Needs</b></p> <p>Families should be offered information on:</p> <ol style="list-style-type: none"> <li>How to access an assessment of their own needs</li> <li>What to do in an emergency</li> <li>Access to a Carers' Programme (if appropriate)</li> <li>Services available to provide support</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Support for carers may include carer's breaks, emergency response, support for children in the family and cognitive and behavioural therapy, usually accessed through primary care-based psychological therapy services.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-199  <table border="1" data-bbox="209 707 284 853"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Involving Children, Young People and Families</b></p> <p>The service should have:</p> <ol style="list-style-type: none"> <li>Mechanisms for receiving feedback from children, young people and their families about the treatment and care they received.</li> <li>Mechanisms for involving children, young people and families in decisions about the organisation of the service.</li> <li>Examples of changes made as a result of feedback and involvement of children, young people and their families.</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The arrangements for receiving feedback from children, young people and families may involve surveys, including the national patient survey, focus groups and/or other arrangements.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p><b>Staffing</b></p>						
PN-201  <table border="1" data-bbox="209 1261 284 1406"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Named Lead Paediatrician</b></p> <p>A nominated lead paediatrician responsible for ensuring the service meets all applicable Quality Standards, and with the lead care professional, for liaison with leads of other paediatric palliative care services within the 'local area'. The lead paediatrician should have day to day involvement in paediatric palliative care.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Responsibility for meeting specific Quality Standards may be delegated.</li> <li>The lead paediatrician will normally be a consultant grade doctor. A GP or non-consultant grade doctor maybe appropriate in some circumstances but the individual should have at least level 3 competences in Paediatric Palliative Care Medicine.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-202  <table border="1" data-bbox="209 1675 284 1821"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Named Lead Care Professional</b></p> <p>A lead professional responsible for care should be responsible, with the lead paediatrician, for ensuring the service meets all applicable Quality Standards and for liaison with other paediatric palliative care services within the 'local area'. The lead professional should have day to day involvement in the provision of paediatric palliative care.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>As PN-201</li> <li>The lead professional responsible for care should be a registered health or social care professional</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-203  <table border="1" data-bbox="209 293 288 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Staffing Levels</b></p> <p>The service should have sufficient staff with appropriate competences for the usual number of children and young people cared for by the service, their dependency, the complexity of their needs and, for children thought to be in the final days of life, for undertaking visits and, if necessary, providing care in the preferred place of death. Staffing should include:</p> <p><b>All services:</b></p> <ol style="list-style-type: none"> <li>Access to appropriate medical staff able to attend a child at all times the service is operational</li> <li>At least one clinician with at least level 3 competences in Paediatric Palliative Medicine with some sessional time each week allocated for work with the service.</li> <li>Nursing staff and health care support workers (see note 2)</li> <li>Other staff providing support and care for children and young people needing palliative care (QS PN-301) who are part of the service's 'core team'.</li> </ol> <p><b>Tertiary Specialist Paediatric Palliative Care Services only:</b></p> <ol style="list-style-type: none"> <li>A consultant with Paediatric Palliative Care level 4 competences</li> <li>A senior nurse with Paediatric Palliative Care competences</li> <li>A multi-disciplinary team for in-patient care, outpatient care, 24/7 telephone advice to network providers and multidisciplinary care planning including:             <ol style="list-style-type: none"> <li>medical staff</li> <li>nursing staff</li> <li>pharmacy staff</li> <li>social workers</li> <li>psychologist/s</li> <li>play specialist/ youth worker</li> </ol> </li> </ol> <p>Cover for absences should be available so that the functions of the service can continue during times of annual leave, study leave and short-term sickness.</p> <p>Community services should have sufficient staffing to care for more than one child in the final days of life <b>or</b> should have a contingency plan covering this eventuality and which can also be used if staffing levels are reduced due to maternity leave or long-term sickness.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>Staffing may include volunteers with appropriate competences.</li> <li>RCN "Defining Staffing Levels for Children's and Young People's Services" (2013) gives advice on sufficiency of staffing. Many children with palliative care needs will require high dependency care and recommended staffing levels are: level 3 1.5:1; level 2 1:1; Level 1 1:2. Ward nursing establishments should be based on the level of clinical care each child / young person needs as determined by a patient dependency tool. The following provides an indicative baseline ration of registered nurses to children / young people taking into account the distinct care requirements linked to age and development: a) under 2 years 1:3; b) for other ages: during the day and night 1:4.</li> <li>Cover for absences may be achieved through agreed arrangements with another service.</li> <li>This QS can be met (except for Tertiary Specialist Paediatric Palliative Care Services) if services listed in QS PN-301 are not members of the core team.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						



Ref	Standard					
PN-204  <table border="1" data-bbox="209 293 288 454"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Competence Framework and Training Plan</b></p> <p>All staff should be working towards and, when achieved, should be maintaining competences appropriate to their role in:</p> <ol style="list-style-type: none"> <li>a. Philosophy of palliative care</li> <li>b. Symptom control, including:             <ol style="list-style-type: none"> <li>i. Pain evaluation</li> <li>ii. Pain management</li> <li>iii. Nausea, vomiting and reflux</li> <li>iv. Constipation, anorexia, cachexia and hiccough</li> <li>v. Mouth care, feeding and hydration</li> <li>vi. Dyspnoea</li> <li>vii. Seizures and other neurological and neuromuscular problems</li> <li>viii. Emotional and psychological symptoms</li> <li>ix. Skin symptoms</li> </ol> </li> <li>c. Management of clinical emergencies</li> <li>d. Ethics and Law</li> <li>e. Care immediately around the time of death</li> <li>f. Practicalities around death</li> <li>g. Advanced communication skills</li> <li>h. Use of palliative care equipment</li> <li>i. Psychosocial support</li> <li>j. Play support</li> <li>k. Working with children with emotional and behavioural difficulties</li> <li>l. Bereavement support</li> </ol> <p>A competence framework should show the competences expected for different roles within the service and a training plan should cover achievement and maintenance of these competences.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>This QS applies to all staff identified in QS PN-203 except doctors in training where expected competences are laid down by the relevant Royal College. Further guidance on competences needed is available from the Royal College of Nursing or Skills for Health <a href="http://www.skillsforhealth.org.uk">www.skillsforhealth.org.uk</a>. The Coventry and Warwickshire Children and Young Peoples Interactive Competency Framework may be helpful in achieving this QS and can be found at <a href="http://www.covandwarkschildcomps.org.uk">www.covandwarkschildcomps.org.uk</a></i></li> <li>2. <i>Where volunteers are providing care for children and young people, the competences they are expected to achieve should also be specified.</i></li> <li>3. <i>At least one play specialist should have a Play Specialist qualification or equivalent. In-patient services are expected to have play staff available daily. (QRS Standards for the Care of Critically Ill and Critically Injured Children). This also applies to hospice care.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-205 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>24/7 Community Support</b></p> <p>24/7 support and advice from a registered health care professional with competences in paediatric palliative care should be available through a single telephone number. Staff providing this service should:</p> <ol style="list-style-type: none"> <li>Be aware of the children and young people who may contact them</li> <li>For children thought to be in the last days of life, be able to mobilise staff to undertake home visits or to provide care</li> <li>Have access to more specialist advice on complex symptom management (QS PN-302)</li> <li>Have access to specialist advice on the child or young person's condition.</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>This service may be provided by the service itself or may be separately commissioned (QS PZ-601). This QS may be achieved through collaboration with other services within or outside the local area.</li> <li>The single telephone number may change from day to day but should be a single number at any one time.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-206 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Specialist Advice on Complex Symptom Management (Tertiary Specialist Paediatric Palliative Care Services only)</b></p> <p>24/7 specialist telephone advice on complex symptom management in children and young people should be available to all 'local area' providers within the network.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>This QS applies only to Tertiary Specialist Paediatric Palliative Care Services.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-207 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Nominated Lead for Transition</b></p> <p>The service should have a nominated lead for transition to adult care of young people with complex and palliative care needs.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The nominated lead for transition may be the lead paediatrician or lead nurse (Qs PN-201, PN-202) or may be different.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-208 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Emotional Support for Staff</b></p> <p>All staff should have direct access to emotional and psychological support or counselling.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>This QS also applies to administrative and clerical staff (QS PN-299).</li> <li>Access to psychological support through occupational health services should also be available but is not sufficient for compliance with this QS.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-209 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical and Social Care Supervision</b></p> <p>All registered healthcare and social care professionals should be offered regular clinical, safeguarding and professional supervision appropriate to their role.</p>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-298  <table border="1" data-bbox="209 304 288 483"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Competences – All Health and Social Care Staff</b></p> <p>All health and social care professionals working in the service should have competences appropriate to their role in:</p> <ol style="list-style-type: none"> <li>Safeguarding children and/or vulnerable adults</li> <li>Recognising and meeting the needs of vulnerable children and/or adults</li> <li>Dealing with challenging behaviour, violence and aggression</li> <li>Professional boundaries for caring for children with disabilities</li> <li>Consent, Mental Capacity Act and Deprivation of Liberty Safeguards</li> <li>Resuscitation</li> <li>Information Governance</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Safeguarding training should comply with the requirements of the Local Safeguarding Boards for Children and Adults.</i></li> <li><i>Where volunteers are providing care for children and young people, the competences they are expected to achieve should also be specified.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-299  <table border="1" data-bbox="209 904 288 1048"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Administrative and Clerical Support</b></p> <p>Administrative, clerical and data collection support should be appropriate for the number of children and young people cared for by the service.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>The amount of administrative, clerical and data collection support is not defined. Clinical staff should not, however, be spending unreasonable amounts of time which could be used for clinical work on administrative tasks and data entry.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<b>Support Services</b>						
<p>PN-301</p> <table border="1" data-bbox="209 394 285 539"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Support Services</b></p> <p>The following services should be available to support children and young people with palliative care needs in the location where care is delivered:</p> <ol style="list-style-type: none"> <li>Chaplain or multi-faith representative (24/7)</li> <li>Pharmacy advice (daily by telephone)</li> <li>Physiotherapy (daily)</li> <li>Occupational therapy (Monday to Friday)</li> <li>Dietetics (Monday to Friday)</li> <li>Speech and language therapy (Monday to Friday)</li> <li>Psychological support (Monday to Friday)</li> <li>Play support (for painful and invasive procedures and daily for in-patient and hospice services)</li> <li>Home Oxygen Assessment and Review Service (daily)</li> <li>Youth workers (Monday to Friday)</li> <li>Transport services for children with complex needs (Monday to Friday)</li> <li>Wheelchair assessment, supply and maintenance service (Monday to Friday)</li> <li>Assessments for housing adaptations (Monday to Friday)</li> <li>Social work (Monday to Friday) and Emergency Duty Team</li> <li>Bereavement support service (QS PN-110)</li> </ol> <p>These services should be able to respond urgently to acute deterioration as well as to planned changes in care.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>'Daily' means seven days a week.</li> <li>Access to medicines outside normal working hours is covered in QS PN-601.</li> <li>If support services are part of the 'core team' (PN-203 and PN-204) then that particular aspect of this QS is not applicable.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p>PN-302</p> <table border="1" data-bbox="209 1368 285 1514"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Links with Other Specialist Children's Services (Tertiary Specialist Paediatric Palliative Care Services only)</b></p> <p>The service should have appropriate links with other specialist children's services including:</p> <ol style="list-style-type: none"> <li>Specialised paediatric cancer services (paediatric oncology, malignant haematology and cancer surgery services)</li> <li>Specialised paediatric cardiology and cardiac surgery services</li> <li>Specialised paediatric gastroenterology, hepatology and nutritional support services</li> <li>Specialised paediatric intensive care services</li> <li>Specialised neonatal care services</li> <li>Specialised paediatric neurosciences services</li> <li>Specialised paediatric renal services</li> <li>Specialised paediatric respiratory services</li> <li>Specialised paediatric anaesthetic service that is able to offer nerve blocks when required</li> <li>Specialised paediatric surgery services</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Access to more specialist advice may be directly to a specialist service where staff have level 4 competences in Paediatric Palliative Medicine or may be through a variety of arrangements including the paediatrician on call locally, the 'local area' lead palliative care paediatrician or lead nurse or the local hospice.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<b>Facilities and Equipment</b>						
PN-401 <table border="1" data-bbox="209 394 285 535"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Equipment</b> Timely access to equipment (Appendix 6) should be available.
BI						
Visit						
MP&S						
CNR						
Doc						
PN-402 <table border="1" data-bbox="209 600 285 741"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Facilities</b> Facilities should be appropriate for the usual number of children and young people cared for by the service, their dependency and the complexity of their and their family's needs. <b>Tertiary Specialist Palliative Care Services only:</b> Appropriate facilities for in-patient and out-patient care should be available.
BI						
Visit						
MP&S						
CNR						
Doc						
PN-499 <table border="1" data-bbox="209 840 285 1016"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>IT System</b> IT systems should: <ol style="list-style-type: none"> <li>a. Store, retrieve and transmit patient information for patient administration, clinical records and outcome information</li> <li>b. Provide mechanisms for the collection of other data to support service improvement, audit and revalidation</li> <li>c. if used to deliver online consultations, assessments and therapeutic interventions, meet audit and governance requirements.</li> </ol> <p><i>Notes:</i></p> <p><i>IT and records systems should be integrated to avoid duplicate entry of patient data.</i></p>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<b>Guidelines and Protocols</b>						
PN-501  <table border="1" data-bbox="209 394 284 539"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Guidelines – Symptom Control</b></p> <p>Clinical guidelines should be in use covering common symptoms and problems in palliative care, including:</p> <ol style="list-style-type: none"> <li>Pain assessment and management, including use of syringe pumps</li> <li>Management of hydration and nutrition</li> <li>Management of nausea and vomiting</li> <li>Management of seizures</li> <li>Management of dyspnoea</li> <li>Management of agitation</li> <li>Management of secretions</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Use of the West Midlands Children and Young People’s Palliative Care Toolkit guidelines and formulary is sufficient for compliance with this QS.</i></li> <li><i>Guidelines should ideally be specific about the indications for seeking advice from the ‘local area’ lead palliative care paediatrician and lead professional.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-502  <table border="1" data-bbox="209 999 284 1144"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Guidelines – Tracheostomies and Long-Term Ventilation</b></p> <p>If the service is caring for a child or young person with a tracheostomy or on long-term ventilation, then clinical guidelines on the management of tracheostomies and long-term ventilation should be in use.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>QRS Quality Standards for Services providing Long-Term Ventilation for Children and Young People V4 2018, provide more detail in relation to long- term ventilation</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-503  <table border="1" data-bbox="209 1301 284 1447"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Pathway Guidelines</b></p> <p>Guidelines should be in use covering at least:</p> <ol style="list-style-type: none"> <li>High dependency care</li> <li>Advance Care Planning, including wishes for life and end of life</li> <li>Religious, spiritual and cultural care</li> <li>Antenatal and neonatal care</li> <li>‘Ceilings of care’ and alteration of management including compassionate extubation</li> <li>Bereavement, including indications for referral to more specialist bereavement services</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Note: Use of the West Midlands Children and Young People’s Palliative Care Toolkit guidelines is sufficient for compliance with this QS so long as this has been approved for use in the local service. For Advance Care Planning this will include ensuring that Toolkit guidelines are embedded into the local resuscitation policy. Transition and integrated palliative care pathways are not included in this QS because their implementation is covered elsewhere. Audit of these pathways is, however, included in QS PN-702.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-504  <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Communication of New Diagnosis or Changed Prognosis</b></p> <p>Guidelines should be in use on communication of a new diagnosis or change in prognosis covering:</p> <ol style="list-style-type: none"> <li>a. Importance of face to face discussions in privacy</li> <li>b. Use of interpreter services (QS PN-101)</li> <li>c. Involvement of the child or young person and their family</li> <li>d. Provision of information for the child or young person and their family (QS PN-103)</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-505  <table border="1" data-bbox="209 584 285 730"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Care Around the Time of Death</b></p> <p>Guidelines on care around the time of death should be in use covering, at least, arrangements for:</p> <ol style="list-style-type: none"> <li>a. Rapid discharge, including:             <ol style="list-style-type: none"> <li>i. Agreement with receiving services that care can be provided by them</li> <li>ii. Communication with the general practitioner</li> <li>iii. Communication with all services involved in the child or young person's care</li> </ol> </li> <li>b. If necessary, review of the choice of preferred place of death and transfer to an alternative setting</li> <li>c. Clinical review and assessment, including liaison with the general practitioner and 'local area' lead palliative care paediatrician</li> <li>d. Support for the family, including in the period immediately after the death</li> <li>e. Supply and disposal of medication and oxygen</li> <li>f. Supply and removal of equipment</li> <li>g. Verifying, certifying and registering the death</li> <li>h. Care and, if applicable, transfer of the child's body</li> <li>i. Ensuring compliance with the Child Death Review Panel</li> </ol> <p>Guidelines should ensure appropriate recognition of families' spiritual and cultural needs.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Use of the West Midlands Children and Young People's Palliative Care Toolkit guidelines on 'Rapid discharge for care at end of life' is sufficient for compliance with (a).</li> <li>2. Services should be aware that 'continuing care assessments' should not be required for children and young people thought to be in the final days of life.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-506  <table border="1" data-bbox="209 1444 285 1590"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>'Just in Case' Medication</b></p> <p>A policy on 'just in case' medication should be in use which ensures:</p> <ol style="list-style-type: none"> <li>a. Anticipatory drugs are 'written up'</li> <li>b. Where applicable, a Drug Administration Document is completed in advance of the discharge by a prescriber from the discharging team who is familiar with the child</li> <li>c. Anticipatory drugs are supplied to the family</li> <li>d. Appropriate advice on storage and administration is given verbally and in writing</li> <li>e. Communication about 'just in case' medication with the child or young person's general practitioner and all services involved in their care</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. This policy may be combined with the Service Operational Procedure (QS PN-601) or may be separate.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
<p>PN-507</p> <table border="1" data-bbox="209 293 288 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Communication with Ambulance Service</b></p> <p>Guidelines on communication with the ambulance service should be in use covering:</p> <ol style="list-style-type: none"> <li>Informing the ambulance service of a child or young person needing palliative care at home and any special arrangements, including Advance Care Plan (if applicable)</li> <li>Informing the ambulance service when the child of young person is no longer at a residential address.</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The ambulance service does not need to be informed of short-term absences from the child's usual address, for example, for respite care or hospital admission.</li> <li>These guidelines may be combined with the Service Organisational Procedure (QS PN-601) or may be separate.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p>PN-595</p> <table border="1" data-bbox="209 745 288 891"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Transition to Adult Care</b></p> <p>Guidelines on transition to adult care should be in use, covering:</p> <ol style="list-style-type: none"> <li>Age guidelines for timing of transition</li> <li>Involvement of the young person and their family in the decision about transition</li> <li>Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services</li> <li>Joint meetings with the young person, their family and children's and adult services prior to transition</li> <li>Responsibility for key working functions during the transition period</li> <li>A preparation period and education programme relating to transition to adult care</li> <li>Arrangements for monitoring during the time immediately after transition to adult care</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The Together for Short Lives 'Stepping Up' framework for Transition to Adult Services provide resources for the development and assessment of local guidelines.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						



Ref	Standard					
PN-597  <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Planning to Go Home</b></p> <p>Discharge planning guidelines should be in use covering arrangements for:</p> <ol style="list-style-type: none"> <li>a. Early multi-disciplinary discussion and planning of discharge covering all aspects of Qs PN-104 and PN-106 and involving, at least:             <ol style="list-style-type: none"> <li>i. The child or young person and their family</li> <li>ii. The child or young person's general practitioner</li> <li>iii. The person taking the 'key working' function (QS PN-105)</li> <li>iv. Local community service staff, local acute hospital staff and 24/7 community support service (QS PN-205)</li> <li>v. Education service</li> <li>vi. Other statutory and voluntary agencies involved in the care of the child or young person</li> </ol> </li> <li>b. Community staff to visit the child or young person in the acute hospital or hospice prior to discharge.</li> <li>c. Supply of equipment (QS PN-401)</li> <li>d. Seven-day supply of medicines and enteral feeding</li> <li>e. Supply of 'just in case' medication (QS PN-506)</li> <li>f. Handover to the service taking over responsibility for the care of the child or young person</li> <li>g. Medical review</li> <li>h. Support, advice and review during the 24 hours after discharge</li> <li>i. Discharge summary to be given to the child or young person or their family and to be sent at the time of discharge by fax or email to their GP, to the lead paediatrician and lead nurse of all services involved in their care.</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>For discharges from hospitals remote from the 'local area' where the child or young person lives, the local community and acute services should be involved in addition to staff of the discharging hospital.</i></li> <li>2. <i>This QS is not applicable to community-based services.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard
	Service Organisation and Liaison with Other Services

Ref	Standard					
PN-601  <table border="1" data-bbox="209 293 284 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Organisation</b></p> <p>The service should have an operational procedure describing the organisation of the service including, at least:</p> <ol style="list-style-type: none"> <li>a. Criteria and arrangements for referral into the service</li> <li>b. Communication between:             <ol style="list-style-type: none"> <li>i. All services involved in the care of the child or young person, including two-way communication with 24/7 community support service (QS PN-205)</li> <li>ii. Named medical specialist</li> <li>iii. All consultants involved (when more than one)</li> <li>iv. The child or young person’s nursery, school or college</li> <li>v. Social care</li> <li>vi. Any other statutory and voluntary agencies involved in their care</li> </ol> </li> <li>c. Arrangements for supply of equipment</li> <li>d. Arrangements for access to medicines outside normal working hours, including controlled drugs</li> <li>e. Access to short breaks, including respite in the child or young person’s home</li> <li>f. Involvement of family carers in providing care</li> <li>g. Arrangements for professional carers to work in the hospital or hospice             <ol style="list-style-type: none"> <li>i. For training</li> <li>ii. To provide care for the child or young person during a hospital or hospice stay</li> </ol> </li> <li>h. Arrangements for support visits as well as clinical visits, including arrangements for visiting at home after the child or young person is first identified as on the palliative pathway</li> <li>i. Arrangements for assessment for direct payments</li> <li>j. Arrangements, when necessary, for referral to social care for a carers’ needs assessment.</li> <li>k. For children thought to be in the final days of life, arrangements for undertaking visits and, if necessary, providing care in the preferred place of death</li> <li>l. System for support for staff (QS PN-208), including triggers for pre- and post- bereavement debriefs</li> <li>m. Arrangements for accessing specialist advice on complex symptom management (QS PN-302) and documenting advice given.</li> <li>n. Discharge to the care of general children’s services or specialist disability services</li> <li>o. Organs and tissue donation</li> <li>p. Governance arrangements for providing consultations, assessments and therapeutic interventions, virtually, in the home or in informal locations. (QS PN-499)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>The following may be part of the Operational Procedure or may be separate:</i> <ol style="list-style-type: none"> <li>i. <i>Pathway guidelines for high dependency care, Advance Care Planning and Bereavement (QS PN-503)</i></li> <li>ii. <i>Multi-disciplinary Care Planning and Key Working Agreement (QS PN-602)</i></li> <li>iii. <i>Planning to Go Home (QS PN-507)</i></li> <li>iv. <i>‘Just in case’ Medication (QS PN-506)</i></li> <li>v. <i>Transition to Adult Care (QS PN-595)</i></li> <li>vi. <i>Care around the time of death (QS 505)</i></li> </ol> </li> <li>2. <i>Criteria and arrangements for referral into and discharge from the service should be consistent with those commissioned (QS PZ-601).</i></li> <li>3. <i>For small teams; arrangements for caring for more than one child in the final days of life may involve cooperation with another service or other contingency plans.</i></li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-602  <table border="1" data-bbox="209 293 285 439"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Multi-disciplinary Care Planning and ‘Key Working’</b></p> <p>The service should have agreed, written arrangements covering all aspects of QS PN-104:</p> <ol style="list-style-type: none"> <li>a. Arrangements for multi-disciplinary care planning involving:               <ol style="list-style-type: none"> <li>i. The child or young person themselves and their family</li> <li>ii. The child or young person’s general practitioner</li> <li>iii. All relevant staff from the service (QS PN-203)</li> <li>iv. Representatives of other services involved in the care of the child or young person</li> <li>v. Social work, education and voluntary service representatives</li> </ol> </li> <li>b. Documentation of agreed plan of care in the Personal Care Record (QS PN-104)</li> <li>c. Allocation of person taking a ‘key working’ function (QS PN-105)</li> <li>d. Allocation of a named Community Children’s Nurse</li> <li>e. Communication of any changes to the plan of care to all services involved</li> <li>f. Consideration of whether a Common Assessment Framework (or equivalent) should be opened to prevent or support periods of instability or crisis</li> <li>g. Consideration of and acting on safeguarding issues</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Multi-disciplinary care planning should cover all aspects of QS PN-104.</li> <li>2. These arrangements may be part of the service organisational procedure (QS PN-601) or may be separate.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-603  <table border="1" data-bbox="209 1043 285 1189"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Liaison with Support Services</b></p> <p>Meetings should be held at least annually to review arrangements for liaison and address any problems identified with:</p> <ol style="list-style-type: none"> <li>a. Special Educational Needs services</li> <li>b. Transport services</li> <li>c. Equipment supply services</li> <li>d. Service providing social care for children with disabilities</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. This QS is additional to day-to-day liaison arrangements and should involve staff with management responsibility for the service. This QS does not require a face to face meeting - a planned telephone or video-conference is sufficient for compliance with this QS. The meetings may cover all local services and do not need to be separate for each service.) so long as review of operational issues with each service was specifically identified on the agenda and discussed.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p><b>Governance</b></p>						
PN-701  <table border="1" data-bbox="209 1671 285 1816"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Data Collection</b></p> <p>There should be regular collection of data and monitoring of:</p> <ol style="list-style-type: none"> <li>a. Number of children cared for by the service</li> <li>b. Key performance indicators agreed by the ‘local area’ paediatric palliative care planning group</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Key performance indicators may include, for example, time from referral to completion of a plan of care, delivery of agreed plan of care, achievement of choice of preferred place of care, preferred place of death and delays in discharge. Key performance indicators may be those agreed with commissioners, Trust Boards, Trustees or other ‘local area’ or regional network.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						

Ref	Standard					
PN-702 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Audit</b></p> <p>The services should have a rolling programme of audit of:</p> <ol style="list-style-type: none"> <li>Completeness of the Personal Care Record (QS PN-104), including whether reviewed at least annually</li> <li>Self-assessment against the:             <ol style="list-style-type: none"> <li>TSL Core Care Pathway</li> <li>TSL Transition Care Pathway</li> <li>TSL Extubation Care Pathway</li> </ol> </li> <li>Compliance with clinical guidelines (QS PN-501)</li> <li>Supply of equipment within expected timescales (QS PN-401)</li> <li>Calls to the 24/7 community support service (QS PN-205) outside normal working hours</li> <li>Compliance with NICE Quality Statement</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>The rolling programme should ensure that action plans are developed following audits and that implementation is monitored.</li> <li>Audit may be undertaken jointly with other services in the 'local area'.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-797 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Local Area Review and Learning</b></p> <p>Representatives of the service should meet with representatives of other services in the 'local area' and the tertiary Specialist Paediatric Palliative Care Service to review and learn from positive feedback, complaints, audits outcomes, incidents and 'near misses' involving more than one service providing palliative care for children and young people in the 'local area'.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>This QS is about clinical coordination of services for each 'local area', including community, acute hospital and hospice services (if applicable). These meetings are expected, for example, to review the care of children and young people which is proving more complex than expected, review any issues of clinical communication and liaison, review any incidents and 'near misses' which have involved more than one service and agree any actions which should be taken to improve clinical care.</li> <li>This QS is additional to QS PN-798 which should also be met for each service.</li> <li>The frequency of these meetings is not defined. This QS may be met through participation in network review and learning meetings covering more than one 'local area'.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-798 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Review and Learning</b></p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>This QS is additional to QS 797 and cannot be met by compliance with QS-797</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
PN-799 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Document Control</b></p> <p>All policies, procedures and guidelines should comply with Trust (or employing organisation's) document control procedures.</p>
BI						
Visit						
MP&S						
CNR						
Doc						

Return to [Index](#)

## Commissioning

Ref	Standard					
<b>Service Organisation and Liaison with Other Services</b>						
PZ-601  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Commissioning: Paediatric Palliative Care</b>  Services to meet the needs of children and young people requiring palliative care should be commissioned for an agreed 'local area', including: <ol style="list-style-type: none"> <li>a. 24/7 Community telephone support (QS PN-205) and Community-based services</li> <li>b. Acute hospital services</li> <li>c. Breaks at home and away from home</li> <li>d. Tertiary Specialist Paediatric Palliative Care Services including 24/7 specialist advice on complex symptom management</li> <li>e. End of life care</li> <li>f. Bereavement support</li> </ol> <p>The model of services commissioned should take into account sustainability of service quality and, in particular:</p> <ol style="list-style-type: none"> <li>g. Arrangements for providing care in the preferred place of death for children thought to be in the final days of life</li> <li>h. Ability of services to respond more than one child needs end of life care at the same time.</li> </ol> <p>Criteria and arrangements for referral to and discharge from each service should be specified.</p> <p><i>Note:</i></p> <ol style="list-style-type: none"> <li>1. The 'local area' is the population for which paediatric palliative care services are collaboratively commissioned and provided. It is expected that a population of at least one million (children and adults) will be needed to support an appropriate, sustainable range of community, acute and hospice services. (Craft A and Killen S; Palliative Care Services for Children and Young People in England: An Independent Review; DH 2007 also cited in NHSE NHS contract for paediatric Medicine: Palliative Care E03/S/h).</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<b>Governance</b>						
PZ-701  <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Quality Monitoring: Paediatric Palliative Care Services</b>  Commissioners should regularly review the quality of services provided by paediatric palliative care services (QS PN-701). Appropriate action should be taken to tackle any issues identified through quality monitoring.
BI						
Visit						
MP&S						
CNR						
Doc						

## Appendix 1 Reference Sources

Year	Publisher	Title	Number
2019	Department of Health and Social Care	NHS Long Term Plan	1.
2018	All Party Parliamentary Group, Together for Short Lives	End of Life Care: Strengthening Choice: An inquiry report by the All Party Parliamentary Group (APPG) for Children Who Need Palliative Care	2.
2018	Together for Short Lives	A Guide to Children's Palliative Care Services (4 <sup>th</sup> Edition)	3.
2018	Royal College of Nursing	RCN Competencies: Caring for Infants, Children and Young People Requiring Palliative Care. (2 <sup>nd</sup> Edition)	4.
2018	HM Government	Child Death Review Statutory and Operational Guidance (England).	5.
Accessed 12.11.2018	NHS Leadership Academy	Healthcare Leadership Model: The nine dimensions of leadership behaviour. Version 1.0 <a href="http://www.leadershipacademy.nhs.uk/">www.leadershipacademy.nhs.uk/</a>	6.
2017	National Institute for Health and care	End of Life Care for Infants, Children and Young People QS:160	7.
2017	Together for Short Lives	Commissioning children's palliative care in England: 2017 edition	8.
2016	National Institute for Health and Care	End of Life Care for Infants, Children and Young People with Life-limiting Conditions: Planning and Management NG:61	9.
2010 (revised 2016)	Royal College of Paediatrics and Child Health	Curriculum for Paediatric Training Paediatric Palliative Medicine	10.
2016	National Institute for Health and Care Excellence	Transition from Children's to Adults' Services NG:43	11.
2016	Department of Health	National Framework for Children and Young People's Continuing Care	12.
2016	Department of Health	Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care	13.
2015	Paediatric Intensive Care Society & WMQRS	Standards for the Care of Critically Ill Children (5 <sup>th</sup> Edition)	14.
2015	Together for Short Lives	Standards Framework for Children's Palliative Care ( 3 <sup>rd</sup> edition)	15.

Year	Publisher	Title	Number
2015	Together for Short Lives	'Stepping Up' A guide to developing a good transition to adulthood for young people with life-limiting and life-threatening conditions	16.
2014	West Midlands Paediatric Palliative Care Network	The West Midlands Children and Young People's Palliative Care Toolkit	17.
2014	Together for Short Lives	A Family Companion to the to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (3 <sup>rd</sup> Edition)	18.
2014	Royal College of Nursing	Health Care Service Standards in Caring for Neonates, Children and Young People.	19.
2014	National Institute for Health and Care Excellence	Cancer Services for Children and Young People QS55	20.
2013	Together for Short Lives	A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions (3 <sup>rd</sup> Edition)	21.
2013	NHS England	Service Specification E03/S/h Paediatric Medicine: Palliative Care	22.
2013	Royal College of Nursing	Defining Staffing Levels for Children's and Young People's Services (2 <sup>nd</sup> Edition)	23.
2012	Together for Short Lives, Early Support and CLIC Sargent	Promoting Key Working and Improving Outcomes for All: Summary Briefing	24.
2011	Together for Short Lives	A Care Pathway to Support Extubation within a Children's Palliative Care Framework (3 <sup>rd</sup> Edition)	25.
2011	Department of Health	You're Welcome - Quality Criteria for Young People Friendly Health Services	26.
2007	Department of Health- valid	Palliative Care Services for Children and Young People in England: An Independent Review, Alan Craft and Sue Killen, DH (2007)	27.



The table below shows the links between the Quality Standards and generic guidance documents. Quality Standards without a reference source are based on other QRS Quality Standards, taking into account comments received.

QS reference	Guidance documents	QS reference	Guidance documents	QS reference	Guidance documents
PN-101	15,17,21,22,26	PN-205	2,3, 4,7,9,15, 21,22	PN-505	3,5,7,9,12,15 18, 21,22,24
PN-102	1,15,21,22,26	PN-206	4, 5,7,8,9,15, 20,21,22	PN-506	7,9,15,17,22
PN-103	1,2,3,7,9,12,15,18, 20,21,22,26	PN-207	1,3,4,7,8,9, 10,11, 16	PN-507	15,17
PN-104	1,2,3,7,9,10,12,15 17,18,20,21,22,26	PN-208	1,5,7,8,20	PN-595	1,3,7,8,9,11
PN-105	3,5,7,9,12,13,16, 18, 20,21,22,24, 26	PN-209	4,7,9,19,23	PN-597	7,9,15,17,22
PN-106	3,7,9,15,17,18, 20,21,22,25,26	PN-298	1,3,4,19,21,23	PN-601	1,2,7,9,15, 19,22,24,27
PN-107	3,7,9,15,17,18,20, 21,22,26	PN-299		PN-602	3,7,8,9,15, 22,24,27
PN-108	3,7,9,26	PN-301	1,3,7,9,15,20, 21,22	PN-603	3,5,7,9,22
PN-109	15	PN-302	3,7,9,15,17,20, 21,22	PN-701	3,5,7,22
PN-110	3,7,9,15,18,22,25	PN-401	3,7,8,9,22,26	PN-702	7,9,22
PN-198	1,2,3,7,9,15,18 21,26	PN-402	15,22,26	PN-797	7,9,15,22
PN-199	18,22,26	PN-499		PN-798	3,5,7,9,22
PN-201	6,22	PN-501	3,15,17,21,22	PN-799	
PN-202	1,6,19, 22,23	PN-502	15,21,22	PZ-601	1,7,8,9,22,27
PN-203	1,2,3,4,6,7,8,9, 10,19,21,23	PN-503	1,3,7,9,11,14, 15, 17,19, 21, 22,25	PZ-701	7,9,22
PN-204	1,4,5,6,10,11,14, 16,19,22,23, 24,26	PN-504	3,9,15, 18,20,22,23		

## Appendix 2 Cross-References to British Standards Institution PAS16:16 and Care Quality Commission Key Lines of enquiry

The tables below show with an 'x' where a QRS Quality Standard addresses one of the following:

### 1. British Standards Institution PAS1616:2016 Healthcare – Provision of Clinical Services Specification

Ref	Requirements for the provision of clinical services
3	Leadership, strategy and management
4	Operational delivery of the clinical service
5	Systems to support clinical service delivery
6	Person-centred treatment and/or care
7	Risk and safety
8	Clinical effectiveness
9	Clinical service users with complex needs
10	Staffing a clinical service
11	Improvement, innovation and transformation
12	Educating the future workforce

### 2. Care Quality Commission's:-

- a. Key lines of enquiry, prompts and ratings characteristics for healthcare services (June 2017)
- b. Key lines of enquiry, sector-specific guidance: hospices for children V1 (July 2018)

Ref	CQC Five Key Line of Enquiry
S	Are they safe?
E	Are they effective?
C	Are they caring?
R	Are they responsive?
W	Are they well-led?

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																										
		Safe						Effective						Caring			Responsive				Well-Led							
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8
PN-101	6	x		x				x						x			x			x								
PN-102	6	x		x	x			x				x	x		x				x	x								
PN-103	6	x	x	x	x			x				x	x	x	x													
PN-104	6,8,9	x	x	x				x			x	x	x	x			x	x										
PN-105	6,9	x	x					x						x			x											
PN-106	6,8,9	x		x				x				x	x	x	x		x	x										
PN-107	6,9		x					x				x		x	x													
PN-108	6, 4, 10,	x						x						x	x		x											
PN-109	6													x			x											
PN-110	6							x						x				x										
PN-198	6							x				x		x	x		x	x										
PN-199	3, 4, 7, 6	x					x							x			x		x	x						x		
PN-201	3, 4, 10,12		x					x		x					x						x	X	x	X	x	x	X	X
PN-202	3, 4, 10,12										x				x	x					x	x	x	X	X	X	X	X
PN-203	4, 10, 12	x	x					x		x					x						x	x	x	X	x	x		
PN-204	4, 10, 12	x	x					x		x					x						x	x	x	X	x	x		
PN-205	4, 10, 12	x	x					x		x					x						x		X	X				
PN-206	3,10,12	x	x					x							x													
PN-207	3,4,10,12	x									x				x	x					x		X	X	X	X	X	X
PN-208	3,		x								x				x								X					
PN-209	10	x	x					x		x					x													
PN-298	3,4,10	x						x		x			x		x						x		X					
PN-299	4, 10,12		x					x		x					x							x	x					
PN-301	4, 5, 6, 8		x		x			x		x	x							x	x									
PN-302	4, 6,8,10,		x								x																	
PN -401	5,7	x		x				x											x									
PN-402	5,7	x																										
PN 499	5, 7			x				x											x							X		

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																										
		Safe						Effective						Caring			Responsive				Well-Led							
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8
PN-501	6,8,9		x					x					x	x	x	x												
PN-502	6,8,9							x																				
PN-503	6,8,9		x					x										x										
PN-504	6,8,9		x					x										x										
PN-505	6,7,8,9							x										x										
PN-506	6,8,9							x											x									
PN-507	6,8,9							x			x			x					x									
PN- 595	6,8,9	x									x				x	x												
PN-597	6,8,9				x			x			x					x			x									
PN-601	3,6, 7, 8, 9, 10, 11, 12		x	x	x	x	x	x			x				x	x		x	x	x				x	x			
PN-602	6,9							x			x			x														
PN-603	6,8,9							x											x									
PN-701	3, 4, 7, 8,11					x	x	x	x											x			x	x	x	x	x	x
PN-702	3, 4, 7, 8,11					x	x	x	x										x				x	x	x	x	x	x
PN-797	3, 4, 6,7, 8,11				x	x	x	x	x		x							x		x		x	x	x	x	x	x	x
PN-798	3, 4, 6,7, 8,11				x	x	x	x	x		x							x		x		x	x	x	x	x	x	x
PN-799	5,8			x														x										
XZ-601	3,6,8,9,10,11																											
XZ-701	3, 4, 7, 8,11																											

## Appendix 3 Glossary of Terms and Abbreviations

Glossary of terms and abbreviations	
<b>Advance Care Plan</b>	Advance care planning is a process that enables individuals to make plans about their future health care
<b>BI</b>	Background information to review team
<b>Carer</b>	Throughout the Quality Standards the term 'carer' applies to both family carers and paid carers or support workers
<b>Child</b>	Throughout the Quality Standards the term 'child' is used to refer to babies, children and young people with life-limiting conditions
<b>CNR</b>	Case note review or clinical observation
<b>Community Children's Palliative Care Service</b>	A community children's service providing paediatric palliative care within a local area as documented in Figure 1
<b>Commissioner</b>	A commissioner decides how NHS and / or social care resources are spent, with the aim of improving health, reducing inequalities, and enhancing patient experience
<b>CQC</b>	The Care Quality Commission is the independent regulator of health and social care in England
<b>DH</b>	Department of Health
<b>Doc</b>	Documentation should be available
<b>Family</b>	Family includes parents, siblings, grandparents, extended family members or others with carer responsibility
<b>GP</b>	A GP is a medical doctor, sometimes called a family doctor. They are usually the first person patients see for their health care, and they help patients to access other services.
<b>HDU</b>	High Dependency Unit
<b>Key working</b>	See Appendix 5
<b>Local Area</b>	The 'local area' is the population for which paediatric palliative care services are collaboratively commissioned and provided. It is expected that a population of at least one million (children and adults) will be needed to support an appropriate, sustainable range of community, acute and hospice services (Craft A and Killen S; <i>Palliative Care Services for Children and Young People in England: An Independent Review</i> ; DH 2007).
<b>MP&amp;S</b>	Meeting patients, carers and staff
<b>NICE</b>	National Institute for Health and Clinical Excellence
<b>PALS</b>	Patient advice and liaison service
<b>Parallel planning</b>	Planning for the best but preparing for the worst
<b>Provider</b>	A health or social care organisation which provides services to patients and service users
<b>QRS</b>	Quality Review Service
<b>RCN</b>	Royal College of Nursing
<b>ReSPECT Plan</b>	ReSPECT plan summarises a person's clinical care in a future emergency in which they are unable to make or express choices and can be complementary to a wider process of advance/anticipatory care planning
<b>Service provider</b>	See 'Provider'

Glossary of terms and abbreviations	
<b>Service commissioner</b>	<i>See 'Commissioner'</i>
<b>Tertiary Specialist Paediatric Palliative Care Service</b>	A service providing specialist paediatric palliative care for a population of 1-2 million. See Figure 1
<b>Together for Short Lives</b>	Charity who support children living with life-limiting conditions, and their families. The charity also provide a range of resources and support professionals caring for seriously ill children, young people and families
<b>TSL</b>	Together for Short Lives
<b>Trust</b>	A NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service
<b>WMPPCN</b>	West Midlands Paediatric Palliative Care Network

## Appendix 4 Presentation of Evidence for Peer Review Visits

Each Quality Standard reference column includes a box which illustrates how compliance will be reviewed.

Quality Standard reference column	
<b>Background information</b>	This means that the information should be included in the background report or self-assessment.
<b>Visiting facilities</b>	Reviewers will look for the information while they are visiting the service.
<b>Meeting patients, carers and staff</b>	These Standards will be discussed with patient, carers and /or staff as appropriate.
<b>Case note review or clinical observation</b>	A few Quality Standards require reviewers to look at case notes or other clinical information.
<b>Documentation</b>	These are policies, guidelines and other documentation that reviewers will need to see. Documentation may be in the form of a website or other social media.

The following table summarises the evidence needed for each Quality Standard.

QS	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
	BI	Visit	MP&S	CNR	DOC	
PN-101		X	X			
PN-102		X	X		X	Patient Information about the service
PN-103		X	X		X	Patient information about specific conditions
PN-104			X	X		
PN-105			X	X		
PN-106			X	X		
PN-107			X			
PN-108		X	X			
PN-109	X	X	X			
PN-110	X		X			
PN-198			X			
PN-199			X		X	Examples of changes made as a result of feedback
PN-201	X					
PN-202	X					
PN-203	X		X		X	Examples of staff rotas
PN-204			X		X	<b>Competence Framework and Training Plan:</b> <ul style="list-style-type: none"> <li>Competence framework describing the competences expected for roles within the service.</li> <li>Training and development plan to show how staff will achieve and maintain competences</li> </ul>

QS	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
	BI	Visit	MP&S	CNR	DOC	
PN-205	X		X			
PN-206	X		X			
PN-207	X					
PN-208			X			
PN -209			X			
PN-298	X		X		X	Overall service records showing compliance
PN-299	X		X			
PN-301	X		X			
PN-302	X		X			
PN-401		X	X			
PN-402		X	X			
PN-499		X				
PN-501			X		X	<b>Guidelines:</b> Symptom Control
PN-502			X		X	<b>Guidelines:</b> Tracheostomies and Long- Term Ventilation
PN-503			X		X	<b>Guidelines:</b> Pathway
PN-504			X		X	<b>Guidelines:</b> Communication of New Diagnosis or Changed Prognosis
PN-505			X		X	<b>Guidelines:</b> Care around the time of death
PN-506			X	X	X	<b>Policy:</b> 'just in case' medication provision
PN-507			X		X	<b>Guidelines:</b> Communication with Ambulance Service
PN-595			X		X	<b>Guidelines:</b> Transition
PN-597			X		X	<b>Guidelines:</b> Discharge Planning
PN-601			X		X	Service Operational Procedure
PN-602			X	X	X	Agreed arrangements for MDT/Key Working
PN-603			X		X	Meeting notes with attendance
PN-701			X		X	Examples of data showing compliance with 'a-b' within the QS
PN-702			X		X	Audit programme or plan Examples of completed audits, action plans and monitoring
PN-797			X		X	Documentation depends on local arrangements, for example, minutes of network or local areas review and learning meetings.
PN-798			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the service.
PN-799					X	Compliance determined from other documentation presented
PZ-601	X				X	Service specification
PZ-701			X		X	Meeting notes with attendance



## Appendix 5 Key Working

Extract from 'Promoting key working and improving outcomes for all' - Summary Briefing (Together for Short Lives, Early Support and CLIC Sargent; April 2012):

- *Key working provides a navigator, an enabler, a coordinator. The overall aim of key working is to ensure the provision of holistic care and support to meet the individual needs of the child and their family.*
- *We feel that much of the confusion and lack of clarity is created by referring to key working as if it is always **defined** by a key worker role. We feel it is more useful to define key working by a set of functions rather than defining it as a key worker role. With this approach, the model can then be applied to meet the needs of specific groups.*
- *The function of key working should be defined as:*
  - *Being a single point of regular and consistent contact for the child, young person and family*
  - *Providing information and signposting where necessary*
  - *Identifying the strengths and needs of all family members*
  - *Advocating on the child's, young person's and/or family's behalf where appropriate*
  - *Providing emotional and practical support as required, as part of a trusting relationship*
  - *Coordinating services and practitioners around the child, young person and family*
  - *Facilitating multiagency meetings*
  - *Supporting a single planning and joint assessment process*
  - *Enabling and empowering the child, young person and their family to make decisions and use their personalised budgets in a way that is most effective for them*
  - *Facilitating clinical care seamlessly integrated with specialist and universal services, where appropriate.*

## Appendix 6 Equipment List

The following equipment should be available for home, in-patient or hospice care. Timescales for availability are shown as 'within 24 hours' (24 hrs) or 'as soon as possible' (asap).

Equipment	Timescale
<b>ESSENTIAL</b>	
Profiling bed	24 hrs
Side rails for profiling bed	24 hrs
Pressure relieving mattress	24 hrs
Pressure relieving aids (child friendly)	24 hrs
Electric hoist	24 hrs
Bed pan	24 hrs
Commode wheeled	24 hrs
Female urinal	24 hrs
Male urinal	24 hrs
Suction machine and disposables	24 hrs
Nebuliser and disposables	24 hrs
Coloured towels	24 hrs
Mouth care equipment	24 hrs
Lockable drug cases	24 hrs
Syringe pump and equipment for use	24 hrs
Electric fan	24 hrs
Torch	24 hrs
Apnoea alarm	24 hrs
Pillow lifter	24 hrs
Resuscitation equipment checked in accordance with local policy	
<b>DESIRABLE</b>	
Sheepskin/soft blankets	Asap
Baby mattress and baby blankets	
V pillows and covers	
Child friendly cushions	
Over bed table	
Bed raisers	
Moveable doorbell	
Visual/musical sensory equipment	
Video monitors	
Memory box (or equivalent) and equipment for taking hand and foot prints	
Answering machine	
Hydraulic bath lift, including 'swivel and slide'	
Fax machine	