

# End of life care for infants, children and young people

Quality standard

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# Contents

Quality statements .....	4
Quality statement 1: Advance care plan.....	5
Quality statement.....	5
Rationale .....	5
Quality measures.....	5
What the quality statement means for different audiences.....	7
Source guidance.....	8
Definitions of terms used in this quality statement .....	8
Equality and diversity considerations .....	8
Quality statement 2: Named medical specialist .....	9
Quality statement.....	9
Rationale .....	9
Quality measures.....	9
What the quality statement means for different audiences.....	10
Source guidance.....	11
Definitions of terms used in this quality statement .....	11
Quality statement 3: Emotional and psychological support.....	12
Quality statement.....	12
Rationale .....	12
Quality measures.....	12
What the quality statement means for different audiences.....	13
Source guidance.....	14
Definitions of terms used in this quality statement .....	14
Equality and diversity considerations .....	14
Quality statement 4: Specialist paediatric palliative care team.....	16
Quality statement.....	16
Rationale .....	16

Quality measures.....	16
What the quality statement means for different audiences.....	17
Source guidance.....	18
Definitions of terms used in this quality statement .....	18
Quality statement 5: Support for grief and loss for parents or carers .....	19
Quality statement.....	19
Rationale .....	19
Quality measures.....	19
What the quality statement means for different audiences.....	20
Source guidance.....	21
Definitions of terms used in this quality statement .....	21
Equality and diversity considerations .....	21
Quality statement 6: Care at home.....	23
Quality statement.....	23
Rationale .....	23
Quality measures.....	23
What the quality statement means for different audiences.....	25
Source guidance.....	25
Definitions of terms used in this quality statement .....	25
About this quality standard .....	26
Diversity, equality and language.....	26

This standard is based on NG61.

This standard should be read in conjunction with QS168 and QS193.

## Quality statements

Statement 1 Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2 Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

Statement 3 Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

Statement 4 Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

Statement 5 Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Statement 6 Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

# Quality statement 1: Advance care plan

## Quality statement

Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

## Rationale

Advance care plans can help people with a life-limiting condition plan for and receive care at the end of their life that is in line with their wishes. Talking with the child or young person, and their parents or carers, at appropriate stages allows them to influence the care that they receive and improves their experience of care. This includes involving parents and carers when a potentially life-limiting condition is diagnosed in a baby during pregnancy. Advance care plans should be appropriate to the circumstances and continuously updated throughout the delivery of care and support.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

a) Evidence of local arrangements to ensure that parents of babies diagnosed with a life-limiting condition during pregnancy are involved in developing an advance care plan before the birth.

**Data source:** Local data collection, for example, service protocol.

b) Evidence of local arrangements to ensure that the parents or carers of infants with a life-limiting condition are involved in developing an advance care plan.

**Data source:** Local data collection, for example, service protocol.

c) Evidence of local arrangements to ensure that children and young people with life-limiting conditions and their parents or carers are involved in developing an advance care plan.

**Data source:** Local data collection, for example, service protocol.

## Process

a) Proportion of pregnancies with a diagnosis of a life-limiting condition in the baby in which the parents are involved in developing an advance care plan before birth.

Numerator – the number in the denominator in which parents are involved in developing an advance care plan before birth.

Denominator – the number of pregnancies with a diagnosis of a life-limiting condition in the baby.

**Data source:** Local data collection based on audits of patient care records.

b) Proportion of parents or carers of infants with a life-limiting condition who are involved in developing an advance care plan.

Numerator – the number in the denominator who are involved in developing an advance care plan.

Denominator – the number of parents or carers of infants with a life-limiting condition.

**Data source:** Local data collection based on audits of patient care records.

c) Proportion of children and young people with a life-limiting condition who are involved in developing their advance care plan.

Numerator – the number in the denominator who are involved in developing their advance care plan.

Denominator – the number of children and young people with a life-limiting condition.

**Data source:** Local data collection based on audits of patient care records.

## Outcome

Level of satisfaction with care in infants, children and young people with a life-limiting condition and their parents and carers.

**Data source:** Local data collection based on feedback from children and young people with a life-limiting condition and their parents and carers, and parents or carers of infants with a life-limiting condition.

## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices and GP practices) ensure that systems are in place for children and young people with a life-limiting condition and their parents or carers to be involved in developing an advance care plan (for example, using the [Child and Young Person's Advance Care Plan Collaborative](#) resource). Parents and carers of infants with life-limiting conditions should be involved in developing a plan and parents of babies diagnosed with a life-limiting condition during pregnancy should be involved in developing a plan before the birth.

**Health and social care practitioners** (such as secondary care doctors, nurses, GPs, community nurses and care workers) involve children and young people with a life-limiting condition and their parents or carers in developing an advance care plan. They involve parents and carers of infants in developing an advance care plan and ensure that parents of babies with a life-limiting condition diagnosed during pregnancy are involved in developing a plan before the birth.

**Commissioners** ensure they commission services that support children and young people with life-limiting conditions and their parents or carers to be involved in developing advance care plans. Services should also support parents or carers of infants with life-limiting conditions to be involved. They should support parents of babies diagnosed with a life-limiting condition during pregnancy to be involved in developing care plans before the birth.

**Babies, children and young people with a condition that may shorten their life** have an advance care plan that they and their parents or carers have helped develop. This involves talking about how they wish to be cared for at the end of their life. This may sometimes be

done before a baby is born if the condition is diagnosed during pregnancy.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendations 1.2.5, 1.2.6 and 1.2.10

## Definitions of terms used in this quality statement

### Advance care plan

A formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers (for example, about managing symptoms), and their wishes and ambitions. This plan is a core element of their palliative care. [NICE's guideline on end of life care for infants, children and young people with life-limiting conditions]

### Parents or carers

Parents or carers refers to the people with parental responsibility for a child or young person. [NICE's guideline on end of life care for infants, children and young people with life-limiting conditions]

## Equality and diversity considerations

Children and young people with life-limiting conditions who have a learning disability may have difficulties understanding information provided to them. Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the person has a learning disability and tailor any information accordingly. All support provided should be accessible, as far as possible, to people with learning disabilities.



# Quality statement 2: Named medical specialist

## Quality statement

Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

## Rationale

Assigning a named medical specialist to an infant, child or young person with a life-limiting condition can improve care. A named medical specialist can coordinate care and provide information and support, be a consistent contact to ensure that the infant's, child's or young person's needs are taken into account. The named medical specialist may change if the care that is needed or the care setting changes.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that named medical specialists are assigned to infants, children and young people with a life-limiting condition to lead and coordinate their care.

**Data source:** Local data collection.

## Process

Proportion of infants, children and young people with a life-limiting condition who have a named medical specialist.

**Numerator** – the number in the denominator who have a named medical specialist.

**Denominator** – the number of infants, children and young people with a life-limiting condition.

**Data source:** Local data collection based on audits of patient care records.

## Outcome

Level of satisfaction with end of life care in children and young people with a life-limiting condition.

**Data source:** Local data collection based on feedback from children and young people with a life-limiting condition and their parents and carers and other people important to them.

## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices, GP practices and community nursing services) ensure that a named medical specialist is available to lead and coordinate the care of infants, children and young people with a life-limiting condition.

**Health and social care practitioners** (such as secondary care doctors, nurses, GPs, community nurses and care workers) are aware of care pathways to ensure that infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

**Commissioners** ensure that they commission services in which infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

**Babies, children and young people with a condition that may shorten their life** have a healthcare professional who is their main contact. This person leads and coordinates their care as well as providing ongoing information and support.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendation 1.2.2

## Definitions of terms used in this quality statement

### Named medical specialist

Named medical specialists may include:

- specialists in the child's underlying condition
- consultants and community paediatricians
- palliative care consultants
- hospice medical leads.

[Expert opinion]

# Quality statement 3: Emotional and psychological support

## Quality statement

Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

## Rationale

Infants, children and young people with life-limiting conditions can face a wide range of stressful and distressing circumstances, particularly when they become aware that their life will be shortened. Emotional support for children and young people can help them cope with their distress and build resilience. This can help reduce the risk of developing psychological problems and enhance quality of life. Information should also be provided to parents and carers, especially those with infants and children who are too young to understand the information.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that information about emotional and psychological support for infants, children and young people, including how to access it, is available for infants, children and young people with a life-limiting condition and their parents or carers.

**Data source:** Local data collection.

## Process

Proportion of children and young people with a life-limiting condition and their parents or carers who are given information about emotional and psychological support, including how to access it.

Numerator – the number in the denominator who are given information about emotional and psychological support, including how to access it.

Denominator – the number of children and young people with a life-limiting condition and their parents or carers.

**Data source:** Local data collection based on audits of patient care records. Receipt of information can be measured at key points, for example, at diagnosis, during regular reviews, and at discharge from hospital.

## Outcome

Level of satisfaction of infants, children and young people with a life-limiting condition, and their parents or carers, with information they are given about emotional and psychological support.

**Data source:** Local data collection based on feedback from children and young people with a life-limiting condition and their parents and carers.

## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices, GP practices and community nursing services) ensure that information about emotional and psychological support for children and young people, including how to access it, is available for infants, children and young people with a life-limiting condition and their parents or carers. They also consider how support can be provided to siblings.

**Health and social care practitioners** (such as secondary care doctors, nurses, GPs, community nurses and care workers) give children and young people with a life-limiting condition, and their parents or carers, information about emotional and psychological

support for children and young people, including how to access it. They also consider how support can be provided to siblings.

**Commissioners** ensure that the services they commission include psychological support for children and young people with life-limiting conditions. They also consider how the services they commission can support siblings.

**Babies, children and young people with a condition that may shorten their life** are given information that they and their parents can use to let them know what emotional and psychological support is available and how to get it. Brothers and sisters are also considered for support.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendation 1.2.26

## Definitions of terms used in this quality statement

### Emotional and psychological support

The provision of psychological and psychotherapeutic interventions and therapies delivered or directly supervised by qualified psychological practitioners or psychotherapists with professional accreditation and registration. Practitioners providing interventions for families affected by childhood life-limiting conditions need to be skilled in both the evidence-based therapeutic approach and in adapting therapies to themes of medical decision-making, loss, death, dying, bereavement and early intervention to develop resilience and supportive family relationships. [[NICE's guideline on end of life care for infants, children and young people with life-limiting conditions](#)]

## Equality and diversity considerations

Children and young people with life-limiting conditions who have a learning disability may have difficulties understanding information provided to them. Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the person has a learning disability and tailor any information accordingly. All support provided

should be accessible, as far as possible, to people with learning disabilities.

# Quality statement 4: Specialist paediatric palliative care team

## Quality statement

Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

## Rationale

It is important to manage distressing symptoms, in particular pain and agitation, to ensure that infants, children and young people approaching the end of life have the best quality of life possible. Being cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team ensures necessary assessments are carried out and treatment can be provided to resolve any distressing symptoms as quickly as possible.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure multidisciplinary teams involved in the care of infants, children and young people with life-limiting conditions include input from the specialist paediatric palliative care team.

**Data source:** Local data collection.



## Process

Proportion of infants, children and young people with life-limiting conditions cared for by a multidisciplinary team that includes input from a specialist paediatric palliative care team.

Numerator – the number in the denominator cared for by a multidisciplinary team that includes input from a specialist paediatric palliative care team.

Denominator – the number of infants, children and young people with life-limiting conditions.

**Data source:** Local data collection.

## Outcome

Level of satisfaction with end of life care in infants, children and young people with life-limiting conditions, and their parents or carers.

**Data source:** Local data collection based on feedback from children and young people with a life-limiting condition and their parents or carers and other people important to them.

## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices, GP practices and community nursing services) ensure that protocols are in place for multidisciplinary teams caring for infants, children and young people with life-limiting conditions to include members of the specialist paediatric palliative care team.

**Health and social care practitioners** (members of the multidisciplinary team such as secondary care doctors, nurses, GPs and care workers) involve the specialist paediatric palliative care team when infants, children and young people are approaching the end of life and have unresolved distressing symptoms.

**Commissioners** ensure that the services they commission have arrangements in place for infants, children and young people with life-limiting conditions to be cared for by a

multidisciplinary team that includes members of the specialist paediatric palliative care team.

**Babies, children and young people with a condition that may shorten their life** are cared for by a team that includes specialists in caring for children and young people at the end of life. The team can provide treatment quickly to help with the symptoms and make sure the infant, child or young person is as comfortable as possible.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendation 1.3.20, 1.5.2 and 1.5.3

## Definitions of terms used in this quality statement

### Specialist paediatric palliative care team

The specialist paediatric palliative care team should include as a minimum:

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example, in providing social, practical, emotional, psychological and spiritual support).

[NICE's guideline on end of life care for infants, children and young people with life-limiting conditions, recommendation 1.5.4]

# Quality statement 5: Support for grief and loss for parents or carers

## Quality statement

Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

## Rationale

Support for grief and loss can help parents or carers as well as siblings to cope before and after the death of their child. It can help with emotional and anxiety and depression, and relationship issues, and provide information on how to talk to other family members and tell them what has happened. Support for grief and loss can also provide advice on care following death, including information about post-mortems.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to provide support for grief and loss to parents or carers when infants, children and young people are approaching the end of life and after their death.

**Data source:** Local data collection.

## Process

a) Proportion of parents or carers of infants, children and young people with a life-limiting

condition, who had a plan for support with grief and loss before the death of the infant, child or young person.

Numerator – the number in the denominator whose parents and carers had a plan for support with grief and loss before the death of the infant, child or young person.

Denominator – the number of infants, children and young people with a life-limiting condition who have died.

**Data source:** Local data collection based on audits of patient care records.

b) Proportion of parents or carers of infants, children and young people with a life-limiting condition who have a plan for support with grief and loss after the death of the infant, child or young person.

Numerator – the number in the denominator who have a plan for support with grief and loss after the death of the infant, child or young person.

Denominator – the number of parents or carers of infants, children and young people with a life-limiting condition who have died.

**Data source:** Local data collection based on audits of patient care records.

## Outcome

Level of satisfaction with grief and loss support in parents or carers of infants, children and young people receiving end of life care.

**Data source:** Local data collection based on feedback from the parents and carers of children and young people who have died following care for a life-limiting condition.

## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices, GP practices and community nursing services) ensure that systems are in place to offer grief and loss support to parents or carers of infants, children and young people when their child is approaching the end of life

and after their death. They also consider how support can be provided to siblings.

**Health and social care practitioners** (such as secondary care doctors, nurses, GPs and community nurses) are aware of referral pathways to services that offer grief and loss support to parents or carers of infants, children and young people when their child is approaching the end of life and after their death. They also consider the support needs of siblings.

**Commissioners** ensure that they commission services that include grief and loss support for parents or carers of infants, children and young people when their child is approaching the end of life and after their death. They also consider how the services they commission can support siblings.

**Parents or carers of babies, children and young people** are offered grief and loss support when their child is nearing the end of their life and after their death. The brothers and sisters of children nearing the end of life may also benefit from support for grief and loss.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendation 1.4.4

## Definitions of terms used in this quality statement

### Grief and loss support

Therapies aimed at supporting a person anticipating or experiencing the loss of a loved one. [Expert opinion]

### Equality and diversity considerations

Parents and carers of infants, children and young people with a life-limiting condition may have a learning disability that means they have difficulties understanding information given to them about grief and loss support. Healthcare practitioners caring for infants, children and young people with a life-limiting condition should establish if the child's parents or carers have any learning disabilities. All support provided should be accessible, as far as

possible, to people with learning disabilities.

# Quality statement 6: Care at home

## Quality statement

Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

## Rationale

Home-based care for infants, children and young people approaching the end of life can be preferable to hospital care and has been linked with improved patient experience. However, to ensure they receive the right care and have the highest quality of life possible, children's nursing care and advice from a consultant in paediatric palliative care should be available at all times, if needed. The advice from the consultant in paediatric palliative care could be provided in person or by phone.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

a) Evidence of local arrangements to ensure that children's nursing care is available 24 hours a day for infants, children and young people approaching the end of life who are being cared for at home.

**Data source:** Local data collection.

b) Evidence of local arrangements to ensure that advice from a consultant in paediatric palliative care is available 24 hours a day for infants, children and young people approaching the end of life who are being cared for at home.

**Data source:** Local data collection.

## Process

a) Proportion of infants, children and young people approaching the end of life and being cared for at home who have 24-hour access to children's nursing care.

Numerator – the number in the denominator who have 24-hour access to children's nursing care before their death.

Denominator – the number of infants, children and young people approaching the end of life and being cared for at home.

**Data source:** Local data collection based on audits of patient care records.

b) Proportion of infants, children and young people approaching the end of life and being cared for at home who have 24-hour access to advice from a consultant in paediatric palliative care.

Numerator – the number in the denominator who have 24-hour access to advice from a consultant in paediatric palliative care before their death.

Denominator – the number of infants, children and young people approaching the end of life and being cared for at home.

**Data source:** Local data collection based on audits of patient care records.

## Outcome

Proportion of infants, children and young people who had the option of being cared for at home when approaching the end of life.

**Data source:** Local data collection based on feedback from children and young people, and from the parents or carers of infants, in the last days of life.



## What the quality statement means for different audiences

**Service providers** (such as hospitals, hospices, GP practices and community nursing services) ensure that systems are in place for infants, children and young people approaching the end of life and being cared for at home to have 24-hour access to children's nursing care and advice from a consultant in paediatric palliative care.

**Health and social care practitioners** (such as secondary care doctors, nurses, GPs and community nurses) ensure that infants, children and young people approaching the end of life and being cared for at home are given contact details for children's nursing care and advice from a consultant in paediatric palliative care, available 24 hours a day.

**Commissioners** ensure that they commission services that provide 24-hour paediatric palliative care services at home for children and young people approaching the end of life, which include 24-hour access to children's nursing care and advice from a consultant in paediatric palliative care.

**Babies, children and young people who are nearing the end of their life and being cared for at home** can have nursing care or advice from a specialist at any time of day or night, if they need it.

## Source guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE guideline NG61 (2016, updated 2019), recommendation 1.5.9

## Definitions of terms used in this quality statement

### Children's nursing care

The children's nurse should be a nurse who holds a recognised qualification in caring for children and who has the right knowledge, skill and competency across the child/young person's care pathway. [Children and Young People's Health Outcomes Forum; and expert opinion]

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standards advisory committees](#) for details about our standing committees. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) are available. Any specific issues identified during development of the

quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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## Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of General Practitioners \(RCGP\)](#)
- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Physicians \(RCP\)](#)
- [CLIC Sargent](#)
- [Paediatric Chaplaincy Network](#)
- [Rainbow Trust Children's Charity](#)
- [Royal College of Anaesthetists](#)
- [Together for Short Lives](#)
- [Royal College of Paediatrics and Child Health](#)