

The role of the Lead Cancer Nurse for children and young people's (CYP) cancer services:

A position statement from the Royal College of Nursing (RCN) / Children's Cancer and Leukaemia Group (CCLG) Children and Young People's Cancer Nurses Community

The role of the Lead Cancer Nurse for children and young people's services has been enshrined in national guidance since the publication of guidance on 'Improving Outcomes in Cancer in Children and Young People' (NICE 2005). The most recent NHS England specification for a Children's Cancer Service makes little reference to the role, although it remains a requirement of the nursing service at the level of the Children's Cancer Network and within both the Principal Treatment Centre (PTC) and at the Paediatric Oncology Shared Care Unit (POSCU). This position paper aims to provide additional expert guidance on the requirements of these roles.

The focus of this paper is the role of the Lead Cancer Nurse within a PTC for Children's Cancer in England but will also advocate for the same approach in all four nations of the UK. It addresses the nursing leadership required within a Children's Cancer Network as set out in the NHS England/NHS Improvement (NHSE/I, 2020) service specification. It discusses the role of the Lead Nurse within a Paediatric Oncology Shared Care Unit (POSCU).

Since the introduction of the role of the Lead Cancer Nurse within a PTC (NICE 2005) there have been many changes within health service provision, and pressures on specialist services such as cancer. It has become apparent that the role of the Lead Cancer Nurse has in some centres been eroded; in others, combined with other responsibilities which have made it unsustainable. This position statement sets out the scope of the role; the key responsibilities which fall within its remit and the requirements of those taking it on. The aim of the position statement is to promote consistency in role definition, improving high quality care and excellent patient experience across the UK by clarifying expectations of the lead nurse role in service delivery.

The Children's Cancer Network

The current specification for a children's cancer service describes the purpose and requirements of the Children's Cancer Network which is to be hosted and run by a Principal Treatment Centre (PTC) and to work in collaboration with an associated Teenage and Young Adult (TYA) Cancer Network. In England, the model for implementation is that of an 'Operational Delivery Network.' Similar models exist or are being planned in Scotland (Managed Service Network), Wales (a Site in the Welsh Cancer Network), and Northern Ireland (draft cancer strategy).

It is recommended that such Networks will be 'hosted' by PTCs (Principal Treatment Centres) who will be responsible for ensuring the provision of high-quality care through the effective coordination of pathways across different providers, known collectively as the Children's Cancer Network. Within such a Network there would be the role of a Network Lead Nurse. There is likely to be no one single model that is applied across England with the Lead Nurse Network role potentially being incorporated with the Lead Nurse PTC role; being a stand-alone post or be combined with the role of Lead Nurse for an associated TYA Network. The actual configuration could be seen as less important than ensuring that the principles of the roles are adhered to, and adequate time is given for each of these critical roles to be undertaken effectively.

There are different service configurations and leadership arrangements in the devolved nations of the United Kingdom. In Scotland, there is a Lead Nurse for the TYA group but no Lead Nurse for Children's Cancer (although plans for this are in the CYP Cancer Strategy 2021-2026). In Wales, (which has a single PTC for children's services) there is a Lead Nurse for the TYA group but currently no Lead Nurse for Children's Cancer. In Northern Ireland, there is a Lead Nurse for Children's Cancer in the single treatment centre in Belfast.

Lead Nurse Network Role for Children and Young People's Cancer Service

As noted above network arrangements vary across all four countries of the UK. Our expectation is that as Children's Cancer Networks are formalised and developed, they will include a Lead Nurse role as is currently mentioned in the service specification for England.

Scope of the Network Lead Nurse role

The scope of the Lead Network Nurse role is to provide professional, strategic, and clinical nursing leadership in the delivery of CYP cancer services within the network. The Lead Nurse will work closely with the PTC, POSCUs (Paediatric Oncology Shared Care Units), Children's Community Nursing teams and third sector partners to ensure effective coordination of nursing services and the delivery of nursing quality measures.

The post holder will lead the nursing contribution to the strategic development of the whole cancer service in accordance with Network and relevant national targets and quality measures. The Lead Nurse will provide strategic and clinical leadership to all nurses within the Network. They will facilitate the development and practice of evidence-based cancer nursing in line with national recommendations and standards where these are available. The role ensures the advancement of patient focused cancer care and support through a collaborative approach with all members of the multidisciplinary team across the network and involving patients and their families through local participation initiatives and forums.

Core elements of the Network Lead Nurse role

The Network Lead Nurse:

- is a credible leader and exercises authority in decision making;
- is an expert in the care of children and young people with cancer with relevant accredited qualification and significant clinical practice experience in children's cancer nursing;
- advances the development and practice of evidence-based children and young people cancer nursing in accordance with service requirements and national recommendations;
- supports and advocates for relevant research and trials in children and young people cancer care;
- collaborates with members of the network lead team to enhance the holistic care and support of children and young people with cancer and their families, incorporating health promotion;
- ensures that the voice of the child and family is heard in the planning and implementation of children's cancer services across the network;

- develops effective communication arrangements with nurses and members of the multidisciplinary team across the Children's Cancer Network;
- works with individual Hospital Trusts to co-ordinate the nursing elements required by the Quality Surveillance Team, as outlined in the Quality Surveillance Information System (QSIS), and supports the preparation for peer review and Care Quality Commission (CQC) visits (administrative support will be required for this element of the role), including devolved nations equivalent bodies;
- collaborates regionally and nationally with PTC Lead Nurses, Networks and third sector partners to improve safe, high quality and cost-effective patient care.

Key Recommendations

The role should be implemented as set out in this document, incorporating the scope and the core elements of the role.

The role of Lead Nurse for the Children's Cancer Network will require a minimum of 0.5 WTE to fulfil the responsibilities required. Additional hours would be required if the post is combined with either the PTC Lead Nurse role or the Network Lead Nurse for TYA; both models are currently being considered or implemented.

The Network Lead Nurse role should be at Agenda for Change Band 8A or above in line with the responsibilities of the role and the high levels of autonomy and decision making required.

Lead Nurse for Children and Young People's Cancer Service at the Principal Treatment Centre

Scope of the PTC Lead Nurse role

The scope of the PTC Lead Nurse role is to provide professional, strategic, and clinical nursing leadership in the delivery of CYP cancer services within the PTC. The post holder will be responsible for all nursing elements of the CYP cancer services within the PTC and will be expected to contribute to the strategic development of the whole service in line with the individual hospital trust and relevant national targets and quality measures.

The PTC Lead Nurse will also take a leadership role within the Children's Cancer Network playing a key role in the development and co-ordination of cancer services either undertaking this role directly or working alongside the Lead Nurse Network role. They will facilitate the development and practice of evidenced based cancer nursing in line with national recommendations and standards where these are available. The role ensures the advancement of patient focused cancer care and support through a collaborative approach with all members of the multidisciplinary team across the network and advocating for the child and family.

Core elements of the PTC Lead Nurse role

The PTC Lead Nurse:

- is a credible leader and exercises authority in decision making;
- is an expert in the care of children and young people with cancer with relevant accredited qualification in the field and significant clinical practice experience in children's cancer nursing;
- advances the development and practice of evidence-based children and young people cancer nursing in accordance with service requirements and national recommendations;
- supports and advocates for relevant research and trials in children and young people cancer care;
- collaborates with members of the multidisciplinary team to enhance the holistic care and support of children and young people with cancer and their families, incorporating health promotion;
- ensures that the voice of the child and family is heard in the planning and implementation of children's cancer services within the PTC;
- develops effective communication arrangements with nurses and members of the multidisciplinary team both within the PTC and across the Children's Cancer Network;
- contributes clinically to maintain clinical expertise and professional competence;

- works with individual Hospital Trust and Network to co-ordinate the nursing elements required by the Quality Surveillance Team, as outlined in the Quality Surveillance Information System (QSIS), and supports the preparation for peer review and Care Quality Commission (CQC) visits (administrative support will be required for this element of the role), including devolved nations equivalent bodies;
- is responsible for the management and strategic planning of the nursing elements of Children and Young People's cancer services;
- collaborates regionally and nationally with other PTC Lead Nurses, Networks and third sector partners to improve cost-effective and safe patient care and sustain quality standards / benchmarks.

Key Recommendations

The role should be implemented as set out in this document, incorporating the scope and the core elements of the role.

The role of Lead Cancer Nurse for the PTC will require a minimum of 0.5 WTE to fulfil the responsibilities required. Any additional roles beyond that of Lead Cancer Nurse (e.g. Matron for the Children's Cancer service or Network Lead Nurse) will require additional dedicated hours and should be recognised in individual job plans.

The PTC Lead Nurse role should be at Agenda for Change Band 8a or above in line with the responsibilities of the role and the high levels of autonomy and decision making required.

Lead Nurse for Children and Young People's Cancer Service at the Paediatric Oncology Shared Care Unit (POSCU)

Scope of the POSCU Lead Nurse role

The scope of the POSCU Lead Nurse role is to provide professional, strategic, and clinical nursing leadership in the delivery of CYP cancer services within the POSCU. The post holder will be expected to contribute to the operational and strategic development of the whole service in line with the individual hospital trust and relevant national targets and quality measures. The POSCU Lead Nurse will work closely with the PTC, with other POSCUs, Children's Community Nursing teams and third sector partners to support coordination of nursing services and the delivery of nursing quality measures.

Core elements of the POSCU Lead Nurse role

The POSCU Lead Nurse:

- is an expert in the care of children and young people with cancer with relevant accredited qualification in the field;
- is a core member of the POSCU Multidisciplinary Team (MDT);
- participates in and leads educational activities which advance the development and practice of evidence-based children and young people cancer nursing in accordance with service requirements and national recommendations;
- supports relevant research and trials in children and young people cancer care;
- collaborates with members of the multidisciplinary team to enhance the holistic care and support of children and young people with cancer and their families, incorporating health promotion;
- develops effective communication arrangements with nurses and members of the multidisciplinary team both within the POSCU and across the Children's Cancer Network;
- contributes clinically in order to maintain clinical expertise and professional competence;
- works with their own Hospital Trust to co-ordinate the nursing elements required by the Quality Surveillance Team, as outlined in the Quality Surveillance Information System (QSIS), and supports the preparation for peer review and Care Quality Commission (CQC) visits, including devolved nations equivalent bodies;
- ensures that the voice of the child and family is heard in the planning and implementation of children's cancer services within the POSCU, and
- collaborates regionally and nationally with other PTC Lead Nurses, Networks and third sector partners to improve cost-effective and safe patient care and sustain quality standards / benchmarks.

Key Recommendations

There should be a single named Lead Nurse for the POSCU. The role should be implemented as set out in this document, incorporating the scope and the core elements of the role.

The scope of the role, and the time required to undertake it will depend on whether the POSCU provides a 'standard' or 'enhanced' level of Shared Care. This should be reflected in individual job plans which take account both the size of the service, and the level of Shared Care provided.

The POSCU Lead Nurse role should be at Agenda for Change Band 7 or above in line with the responsibilities of the role.

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Organisations supporting this position statement

