



Royal College
of Nursing



COMPETENCIES :

CARING FOR TEENAGERS AND YOUNG ADULTS WITH CANCER: A COMPETENCE AND CAREER FRAMEWORK FOR NURSING

**TEENAGE CANCER TRUST ENDORSED BY
THE ROYAL COLLEGE OF NURSING**

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Feedback and Review

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FOREWORD

Competence and career framework - teenage and young adult cancer nursing to support the national delivery of age appropriate care

It is almost twenty five years since the opening of the first Teenage Cancer Trust Unit in London. Our charity is recognised for having the vision and being the catalyst for the development of age appropriate cancer services. Teenage and Young Adult (TYA) cancer care has now gained recognition as a speciality within its own right and expertise has largely developed through experience and the sharing of professional knowledge of young people's specific needs and issues; specifically within nursing. The fact that the UK is seen as worldwide leaders in TYA cancer care is something everyone who has been involved in developing and supporting this specialism should feel incredibly proud of.

Despite this, young people will continue to receive treatment in a variety of settings, yet the TYA cancer specific nursing workforce is small and the knowledge and expertise has been largely attributed to a small number of nurses in the UK. TYA cancer care services are now rapidly evolving and it is therefore crucial that care and services are delivered by a skilled and appropriately trained nursing workforce. Competencies are the cornerstone for specialist age appropriate care delivery and Teenage Cancer Trust believes that nursing is fundamental to the delivery of high quality holistic care. We were delighted that Teenage Cancer Trust Head of Nursing and Quality; Sam Smith was awarded the Florence Nightingale Leadership scholarship that enabled her to lead the development of this competence framework and are proud to support this work. This national framework will help in working towards sustainability by embedding the principles of TYA care and its philosophy wherever young people with cancer are treated. Furthermore, the framework has scope to assist our international colleagues who are now looking to the UK for assistance in developing their own nurses to enable them to deliver best practice, and navigate the challenges of working with this unique patient group.

Siobhan Dunn,

Chief Executive Officer, Teenage Cancer Trust

The Florence Nightingale Foundation is delighted to have supported this work through its award of a Florence Nightingale Nursing Leadership Scholarship. The provision of Scholarships to senior nurses and healthcare workers particularly requires scholars to demonstrate that the skills they have developed led directly to improvements in patient care. We believe the work and ideas of Florence Nightingale should continue to be remembered, celebrated and implemented in our time through supporting leadership and development in nursing.

Whilst significant progress has been made in the advancement of nursing in the care of teenagers and young adults with cancer, there is much more to be done.

To embed high quality nursing care to young people with cancer will require a sustained effort to enhance the knowledge and skills of nurses who work with this patient group in all healthcare settings. The publication of this Competence and Career framework for nurses working with teenagers and young adults with cancer is welcomed. This is an important first step towards sharing nursing expertise and developing the future nursing workforce and leaders in this speciality to ensure that nursing continues to provide the best quality age appropriate care possible to all young people with cancer in years to come.

Professor Elizabeth Robb,

Chief Executive Officer, The Florence Nightingale Foundation

1 - INTRODUCTION TO THE FRAMEWORK

Teenagers and young adults are a unique group. Adolescence is marked by a rapid phase of development where a young person not only undergoes significant physical change, but also development in cognitive, psychological and social behaviours. This development varies between individuals and therefore, care should be individualized and flexible to recognise each young person's specific needs. The key value of TYA care is to allow the young person to mature through their illness developing coping strategies and a sense of self. Providing holistic care requires nurses who are highly trained, experienced and knowledgeable about this unique patient group.

Teenage Cancer Trust Nurses Group, 2012

This is the first competence and career framework for nurses who care for teenagers and young adults (aged 13-24 years inclusive - see footnote¹) with cancer across the broad spectrum of healthcare settings and describes the professional standards expected of them.

It is recognised that teenagers and young adults with cancer have distinct needs that are different to both children and adults. The Platt Report (1959) first drew attention to the specific needs of the adolescent patient and much later the Calman Hine Report (1995) acknowledged the particular issues faced by young people specifically with cancer. The charity Teenage Cancer Trust was launched in 1990 with a purpose to improve care and patient experience and over the past twenty four years have developed 27 specialist units within the NHS; together with a national network of specialist nursing and support staff.

The Improving Outcomes Guidance (IOG) for Children and Young People with Cancer (National Institute for Clinical Excellence 2005) recommended that all young people with cancer should benefit from expertise from both site specific teams and teenage and young adult specific teams. Young people should have unhindered access to an age appropriate environment and specialist nursing support. The Blueprint of Care (Teenage Cancer Trust 2012) describes and defines the core elements of the care needs of this patient group facing the challenge of cancer. This framework builds upon recommendations of the National Institute for Health and Clinical Excellence and the nursing skills described in the Blueprint of Care.

The best standard of care for teenage and young adult patients is undoubtedly provided by those who understand the complex developmental and psychosocial needs of this age group, and have the knowledge and skills required to meet those needs. With over twenty years in the development of nursing expertise in teenage and young adult cancer care we are now in a position to define the specific nursing competencies required in TYA cancer. This will enable care to be delivered by a skilled, competent and knowledgeable nursing workforce who will be equipped to deliver specialist age appropriate nursing to this unique client group.

This document does not replace previously published competence frameworks relevant to both cancer nursing and care of children and young people; but sets out to define the specific competencies required in teenage and young adult cancer care. This document is designed to be flexible, adaptable and complement existing Royal College of Nursing competency frameworks and wider frameworks such as those set by the Nursing and Midwifery Council and the Chief Nursing Officer. Nurses working with teenagers and young adults across all settings should utilise the competencies relevant to them individually in their role. The framework is designed as an aid and to develop nursing practice and does not replace local Trust policies and procedures. Whilst this framework will be used in England, it provides a transferable framework for nurses in the wider UK, Europe and beyond, and will assist in the international development of nursing competence in teenage and young adult cancer care.

¹ Teenagers and young adults refer to those aged 13-24 years inclusive throughout this document

2 - PURPOSE AND SCOPE OF THE COMPETENCE AND CAREER FRAMEWORK

DEFINING COMPETENCE:-

“The state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one’s professional responsibilities” Roach (1992)

COMPETENCE ASSESSMENT:-

“Competence assessment is an on-going process and supports the Nursing and Midwifery Council’s (NMC) requirements that nurses, must strive to learn to maintain competence and performance” (NMC 2008).

A competency framework is a structure that defines individual competencies and provides the building blocks to enable personal and professional growth, development and career progression in nursing practice. The purpose of this framework is to describe the knowledge, skills and performance levels required for nurses working specifically with teenage and young adult cancer patients and reflects what we know from the experience, views and contributions of the diverse group of nurses who have contributed to this work.

This framework should be used as a practical tool to assist nurses in developing their practice, assist assessors or managers to assess competence of their workforce and provide a route map for succession planning and role development. The framework should encompass the wide range of specific skills required for all nurses working with teenage and young adult patients in all healthcare settings.



3 - CONTEXT FOR DEVELOPING THE FRAMEWORK

Cancer in teenagers and young adults is rare; however it is the most common cause of disease related death in this age group in the UK (CRUK 2014) and therefore a major health problem. Cancer in this population incorporates the late onset of paediatric cancers and the early onset of adult tumours; including lymphoma, germ cell tumours, brain tumours, leukaemia, melanoma, bone tumours, soft tissue sarcomas, carcinomas and other rarer tumours. In addition, a number of 'true' TYA cancers have been classified which show a peak incidence between the ages of 15 and 24 years (Barr et al 2006).

Treatment for cancer occurring in this age group is often extremely complex and delivered over long periods of time from many months to years and has significant psychosocial and physical impact on wellbeing; often well beyond the end of active treatment. The National Cancer Survivorship Initiative (NCSI) was launched in 2010 in recognition that patients surviving cancer still needed support to maintain active and functional lives. In the case of teenagers and young adults; reintegration to normality beyond the cancer experience may require professional support several years after treatment (Teenage Cancer Trust 2012). Physical and psychosocial long term effects can impact on the quality of life (QoL); with 83% of 16-24 year olds reporting that their QoL is affected by cancer. Although overall 5 year survival rates for this patient group is on average 80-85% this can vary by cancer type from 46-92% (Fern 2013). Furthermore, the psychological and physical needs of young people facing end of life are particularly challenging and access to expert supportive care is crucial.

The normal challenges of adolescence and emerging adulthood still have to be faced by a young person with cancer and working in this field requires a detailed understanding of their development and behaviour. Care needs to be consistent; yet flexible and extend beyond the direct treatment focus assisting them to reach their full potential (Ritchie 2001). Cancer treatment is disruptive to school life, career and educational and vocational plans. In addition, many young people become socially isolated at a time when peer relationships are central to their world.

Treatment and care for cancer will be delivered in a range of healthcare settings including; Teenage Cancer Trust Units, children's cancer centres, adult cancer centres, community/home care, hospices and district general hospitals. This further adds to the complexity of this age group who fall between children's

and adult services. The drive for greater access to specialist care is due to poorer outcomes reported in young people compared to children (NICE 2005, Bleyer et al 2006) and young people reporting greater satisfaction with specialist care (Reynolds et al 2005).

Whilst teenage and young adult care as a specialty in its own right has gained increasing recognition; not all young people with cancer will receive care and support from nurses who have been specifically trained, educated or have experience in order to meet the needs of this group.

Evidence has been available for many years which shows that in clinical care higher level practitioner skills raise the quality of care. (National Cancer Action Team 2010). The Kennedy Report (2010) highlighted the lack of priority given to children and young people in the NHS and identified a need to improve workforce competence. The report of the Mid Staffordshire NHS Foundation trust Public Inquiry (2013, *known as the Francis Inquiry*) has been viewed as a watershed within NHS Care delivery and nursing as a profession has been particularly scrutinised in regard to failing standards of care. A key priority identified by the Children and Young People's Health Outcomes Forum (Department of Health 2014) is the need for a national approach to achieving a competent nursing workforce. Collectively these findings and recommendations have provided the platform for changes to nursing care and delivery. These changes are directed at the professional standards and development of nurses in order to create a competent workforce (Francis Inquiry 2013).

This Competence and Career Framework for nurses working with teenagers and young adults is underpinned by the overarching principles, vision and values of nursing outlined by the Chief Nursing Officer's (Department of Health 2012) *Compassion in Practice Nursing, Midwifery and Care Staff: Our Vision and Strategy*, *RCN Principles of Nursing Practice* (RCN, 2010) and professional regulations set by the Nursing and Midwifery Council (NMC 2008).

4 - HOW THIS COMPETENCY FRAMEWORK WAS DEVELOPED

This work specifically for teenage and young adult cancer nursing builds upon on previous work led by Professor Faith Gibson (Gibson et al 2003, 2012). Gibson et al (2003) defined a continuum of competencies from generalist to specialist in children’s nursing. Later, a preliminary scoping exercise undertaken by Gibson and colleagues (2012) reported on thirteen key core competencies across various health professions working in teenage and young adult cancer care (including nursing) and offered an early description of the knowledge and core skills required by these professionals.

Teenage Cancer Trust have carried out a 3 stage Delphi process to establish consensus amongst nurses working with TYA’s from across all levels, clinical and general settings, educators and researchers. The first phase engaged it’s funded nurses group (N=12) in order to define the core roles (Table 1) and skills they considered inherent within their work; the group reached consensus on a number of broad areas central to the role of a nurse working with teenagers and young adults. Patient views on nursing skills have been included from previous work carried out by Teenage Cancer Trust (FYSOT 2012 - see page 59 of this document)

The second phase involved the development of a structured questionnaire; administered via The Bristol Online Survey (<http://www.survey.bris.ac.uk/>) and was disseminated widely to nurses of all levels and across broad settings (Table 2) to capture views from specialist, generalist, adult, children’s and community nurses. 132 questionnaires were returned (Figures 1, 2 and 3)

**TABLE 1
CORE ROLES IDENTIFIED FROM
THE DELPHI PROCESS WITH
FUNDED NURSE**

Clinical and support
TYA Education and research
Patient involvement and advocacy
Patient pathways and MDT working
Leadership and professional development
Service development and policy

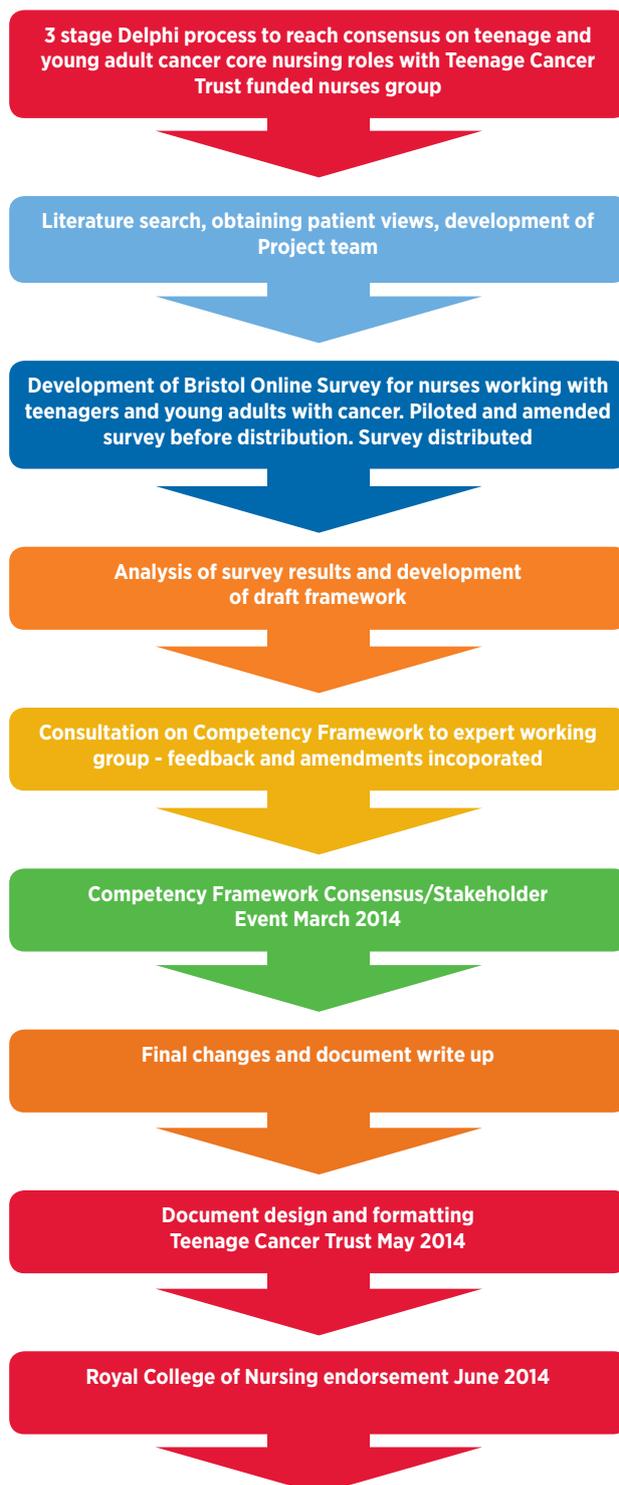


Table 2 - Questionnaire distribution

TYAC (Teenagers and young adults with cancer)
Teenage Cancer Trust funded nurses
Royal College of Nursing
Macmillan Cancer Care
Association of Young Peoples Health
Marie Curie

Returned questionnaires were analysed and the assimilated information used to develop the *draft* teenage and young adult cancer nursing competency and career framework. A consultation process with the expert advisory group provided opportunity for amendments and comments to the *draft* and the final phase of a consensus event was organised for wider consultation, comment and sign off. The consensus event was attended by 32 nurses; with the event consisting of small working groups to comment and amend the framework and achieve final consensus.

Figure 1 - Range of Nursing Qualifications

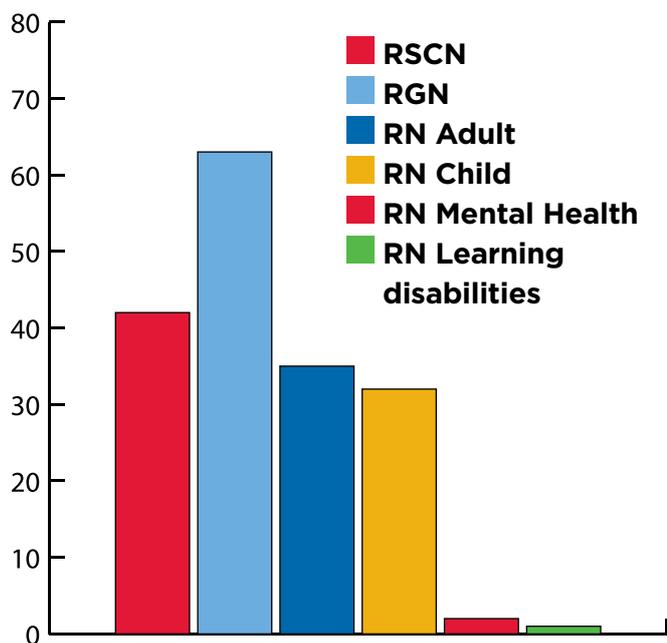
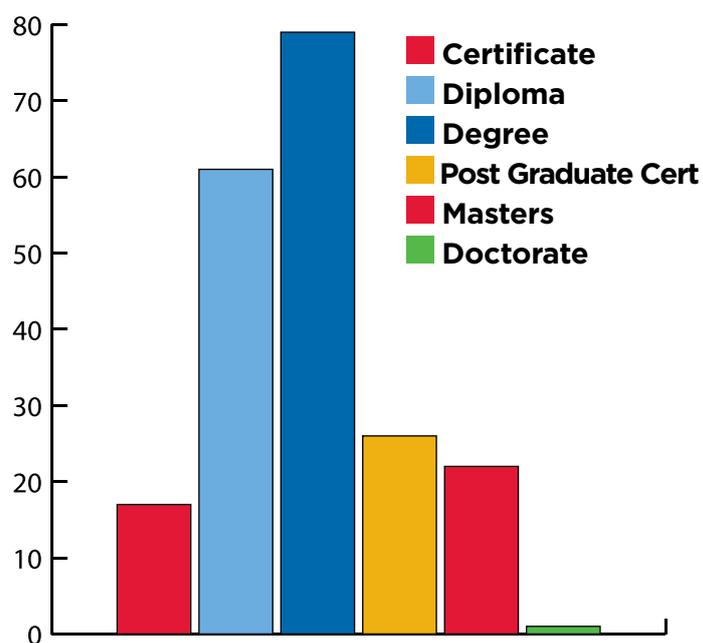


Figure 2 - Range of educational attainment



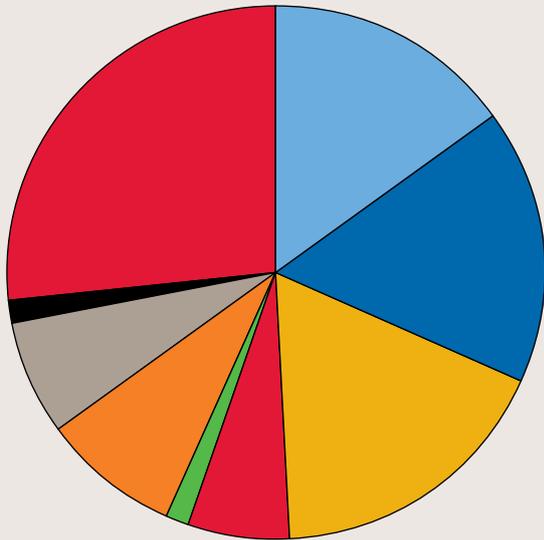


Figure 3 - 132 structured questionnaires returned from a range of of staff

Job Role

Clinical Nurse Specialist (TYA)	20
Clinical Nurse Specialist (site specific ie lymphoma, skin)	22
Staff Nurse.....	23
Ward manager	8
Nurse Consultant	2
Lead Nurse (TYA).....	11
Lead Nurse (other).....	9
Clinical Educator	2
Other**	35
Total.....	132

**Examples of other :- Advanced practitioner, deputy ward manager, charge nurse, bone marrow transplant nurse, community children's nurse



5 - LEVELS OF COMPETENCE

This framework sets out competencies required for qualified nurses; from staff nurse (Band 5) to Lead Nurse level (Band 8a) and Nurse Consultant (Band 8b/c).

The document does not set out to align grades of nursing roles to levels of competence as the variety of role types is determined locally. They may differ between organisations and may not necessarily correspond to university higher education levels.

Within the professional field of nursing a number of educational frameworks have been developed to underpin and enhance professional practice. Examples include, but are not limited to, Blooms Taxonomy of Learning (1956), the Dreyfus Model for Skill Acquisition (2004), Benner's: From Novice to Expert (1984) and Steinaker and Bell (1979). Given the limitations of validity and reliability testing of the aforementioned frameworks, this competency document is the product of a review of the literature, results of a stakeholder survey (n=132) and a consensus from lead nurses in the field of Teenage and Young Adult Cancer Care and Education. As such the levels of skills acquisition have therefore been identified for the purpose of this document as: - **Competent, Experienced/Proficient and Expert.**

Table 3
Definitions & Examples of nursing levels

Level	Competent	Experienced/Proficient	Expert
Definition	The competent nurse, plans and implements care based on conscious knowledge acquisition on a given issue.	The experienced/proficient nurse sees things as a whole rather than component parts, bases care on knowledge acquisition and experience and can set long term goals	The expert nurse has highly developed analytical evaluation and decision-making skills based on experience, academic achievement and dissemination.
Examples	Staff Nurse in various setting eg community, designated centre, specialist centre	Clinical Nurse Specialist in TYA Cancer or Site Specific Ward Manager TYA Cancer Unit Nurse Practitioner in Chemotherapy	Lead Nurse Nurse Consultant in TYA Cancer

It is important to remember that the competencies required for

a staff nurse working in the community may not be the same as those working in a specialist centre. Likewise, the competencies required of a site specific Clinical Nurse Specialist, e.g. Germ Cell, in a general hospital may not be the same as those required for a TYA cancer specific Clinical Nurse Specialist in a Principal Treatment Centre.

The level of competence is to be determined by the nurse and their manager/assessor so that education and development plans can be determined. This will enable the nurse to achieve core TYA cancer competencies required to work effectively and safely with TYA in their workplace.

Benefits of the Competence Framework

The beneficiaries of this framework include patients and families/ carers, nurses, managers and employers and society as a whole. Additionally it will assist in the identification of gaps in the service. Ultimately, TYA's with cancer should receive nursing care within a service where their age appropriate needs are foremost. This specialist nursing care is founded upon competent, knowledgeable practitioners and this document guides this practice.

The perceived benefits are that:

- It will assist in the delivery of consistently high standards of evidence based care.
- It contributes to the ongoing development of nursing practice.
- It contributes to the nurses' portfolio of continuing professional development to assist in their competence and ensure they continue work within their scope of their professional practice.
- The process of the development of this framework is transferable beyond the remit of TYA cancer nursing.
- The promotion of caring for self and others is integral to this work.
- Nurses will be guided along a structured education and career framework.
- This can support annual appraisals in associated organisations.
- In the spirit of the collaborative nature of TYA cancer care and service delivery, this framework will help to sustain and develop multi-professional working.
- This framework contributes to the recognition that the cancer nursing care of this group of patients is identifiable as a distinct nursing speciality.
- This framework provides a platform for further work and development beyond the scope of teenage and young adult cancer nursing care.

6 - USING THE COMPETENCE FRAMEWORK

There are multiple uses for this framework. It can be used by a nurse to determine the competencies for caring for a TYA with cancer in their area of practice. Agreement of the levels of care provided by the post holder and their care setting should be taken into account when using the framework in partnership with the assessor/manager. It can be used to identify gaps in an individual or team's knowledge for care provision for TYA's with cancer across a service. It also could be used to create new nursing roles specific to TYA cancer care by informing the development of a job descriptions and role specification.

The nurse is responsible for collating their own portfolio of evidence for each competence statement. This demonstrates that each level of competency is achieved, and where there are gaps which are identified by the nurse and/or the assessor/manager, an action plan for development can be implemented.

The framework is intended to be cumulative and nurses are expected to have achieved the criteria stated at lower levels in addition to the criteria for the current level of practice required of the role.

When reviewing the competencies and evidence required aligned to the role, it is important that the nurse considers the following:

- They are clear on the requirements that fulfil the competence statement
- The evidence they present is current and relevant
- Consideration is given to any work/projects they are currently involved with
- The same piece of evidence may be used several times, eg one

poster presentation may demonstrate multiple levels of knowledge and skills

Once the key competencies required for the assigned role are identified, the nurse can collate evidence that demonstrates they are working to that level, or seek to gain experience or learning related to that competency. Three examples of roles with associated competencies and development/action plans are included to demonstrate how the document could be used, (Appendix 1).

Assessment

There is no generally accepted 'gold standard' for the assessment of competence. Therefore a multi method approach to assessment of self and of others is recommended- eg direct observation, questioning, review of work practice, feedback from others and evaluation of the evidence that is presented. It is expected that this will form part of annual reviews of the post holder and that the competence requirements of the post may evolve over time.

Examples of evidence to meet competencies

A list of examples of evidence that could be used to demonstrate competence in conjunction with the framework is provided in Table 7 below. Many of these examples can be used across all three levels of competence. Please note that this is not an exhaustive list.

**TABLE 4
EXAMPLES OF EVIDENCE TO MEET COMPETENCIES**

Competent	Experienced/Proficient	Expert
<ul style="list-style-type: none"> • Certificate of attendance at TYA Cancer related study day/course where specific issues are discussed • Direct observation by senior colleague • Examples of referral documents made by nurse • Examples of care plans devised by the nurse • Reflective discussions/write ups • Attendance at MDT's • Academic essays • Collation of reference lists or bibliographies • Mandatory training records • Portfolio • Awards given • Personal development plans 	<ul style="list-style-type: none"> • Formal teaching sessions as a learner or as a teacher • Documentation, eg minutes or notes of meetings, letters • Poster or oral presentations at conferences • Examples of academic work or courses • 360 reviews • Audit Results • Patient satisfaction questionnaires • Patient engagement marketing materials • Patient Information production • Running focus groups 	<ul style="list-style-type: none"> • Documents that demonstrate attendance at advisory boards, • Published academic papers they authored • CV • Evidence of teaching, assessing or guiding/developing curricula at academic institutions • Research/Audit/Evaluation participation • International conference attendance • International conference presentation • Self assessment and reflection • Running focus groups • Chairing meetings • Conference organisation • Role as mentor/ supervisor • Leading on education initiatives

7 - KEY NURSING ROLES AND CAREER PATHWAY IN TEENAGE AND YOUNG ADULT CANCER CARE

TYA cancer care has developed over the past 25 years and alongside this service development nursing in this specialty has evolved and a number of defined TYA cancer specific nursing roles have emerged that work with, and alongside the broader nursing workforce in the delivery of care. More recently, TYA cancer nursing particularly, has largely advanced through strong partnership working between Teenage Cancer Trust and the NHS. This has led the way in the recognition of this field of nursing as a distinct specialty. We are now in a position to describe and define nursing roles in TYA cancer care that form part of the national approach to service delivery in the UK.

Whilst we recognise that nurses in a wide variety of settings may care for teenagers and young adults with cancer, **this section describes the specific roles and typical career pathway for nurses working exclusively in TYA cancer care.** The way in which these nurses work, is described according to the levels and banding within the current NHS Agenda for Change Framework in the UK(<http://www.nhsemployers.org/agendaforchange>). The wider context of other nursing roles that may work with TYA cancer patients/services and typical career/education pathways is shown in Table 8.

Typical roles and banding in TYA cancer care (these nursing roles work exclusively in TYA cancer care)

Expert Practitioners – Band 8b and 8c

Example:- Nurse Consultant - Teenage and Young Adult cancer

These posts conform to the common core of expectations of a consultant nurse role as defined by the NHS executive:

- Expert Practice
- Professional leadership and consultancy
- Education training and development
- Practice and service development, research and evaluation

These practitioners are experts in TYA cancer care work at a strategic level and lead the development of TYA cancer care locally, regionally and nationally/internationally - up to, and including working with national policy makers.

Nurse Consultants are expert communicators, advisors and educators. They typically may not carry their own patient caseload but will act as expert advisors to other healthcare professionals and junior nursing staff; particularly in complex cases. They will have advanced negotiating, facilitating and conflict management/resolution skills.

Other expert nursing posts in the career pathway for Teenagers and Young Adults with Cancer are emerging outside the NHS that contribute to, and complement this nursing workforce. Examples include posts such as Head of Nursing within Teenage Cancer Trust, TYA Nurse Educators and nurses working in research specific to TYA care and practice and service delivery. (Figure 4)

Expert Practitioners - Band 8a

Example:-

Lead Nurse Teenage and Young Adult Cancer Care

Lead nurses have advanced skills in leadership, management, strategy and influencing. Lead nurses work locally, regionally and nationally, working with multi professionals across all aspects of health care to develop and improve services for TYA with cancer. Lead nurses work autonomously and have strategic responsibility for the development of TYA cancer services within a defined geographical region. These nurses have developed their theoretical knowledge to a very high standard, are experts in TYA cancer care and will supervise less experienced staff. They are educators to all members of staff working with TYA.

Experienced/ proficient - Band 7 or Band 6

Example :-

TYA Clinical Nurse Specialist/ TYA Clinical Liaison Nurse Specialist- Band 6 and 7

Ward Manager/Charge Nurse- Teenage Cancer Trust Unit/ TYA Daycase Units

Ward Manager/Charge Nurse- TYA daycase Units, Ambulatory care

Band 7 These nursing roles work within a variety of settings according to local service need. E.g. TYA specialist units/wards, TYA outpatient departments, TYA Day case Units, TYA Community services. They will have extensive experience and develop in-depth knowledge of all aspects of TYA cancer care. Nurses at this level will be highly experienced in the care and treatment of patients and will work mainly in Principal Treatment Centres or in Designated Hospitals.

These roles will be able to work effectively with young people and their families using advanced interpersonal and communication skills and will typically have their own patient case load or manage a ward, unit or discrete service. They will supervise, advise and educate junior staff.

Band 6 These roles will have developed their TYA cancer care

knowledge to a high standard and will be able to demonstrate theoretical and practical knowledge of TYA cancer care. These roles will be able to work effectively with young people and their families using advanced interpersonal and communication skills.

They may have their own case load or manage a ward on a shift basis, and will work with the senior staff to develop the services offered locally to this group of patients. They will have an understanding of regional services and have input into the care of TYAs who may be cared for in Designated Hospitals. To achieve this they will be able to work effectively with multi professionals across all specialities. They will understand and recognise the needs of the TYA and their family through every aspect of their care i.e. from diagnosis to survivorship/end of life. They will use this knowledge to supervise, advise and educate junior staff.

Competent - Band 5

Example:-

Staff Nurses

Staff nurses working exclusively in TYA cancer care may have either adult or child registration (or both) and will be working in specific TYA dedicated environments. Staff nurses will be seeking to improve their knowledge and skills in this specialty. They will have a full understanding of the local service and beginning to understand about the regional services.

Staff nurses will be developing the expertise to assess and plan care for TYA patients on a daily basis and have a working knowledge of the cancers occurring in this age group and cancer treatment regimens in TYA cancer care. Staff nurses will be developing an understanding about the complex physical and psychosocial effects in TYA cancer and be developing an understanding of the impact of cancer on family and friends. With experience and supervision they will be beginning to develop the skills required in this specialty ,developing communication skills and multi-professional working.

Whilst typical nursing roles (and pay bandings) working with TYA's with Cancer in the UK NHS system have been outlined, it is acknowledge that nursing roles may well and do emerge that are different to those that are described above. This is particularly relevant outside of the NHS and beyond UK health systems. Additionally, within the UK, nurses will care for TYA's with cancer in non specific TYA cancer settings and as such, those wishing to understand more about the scope of TYA cancer specific nursing, can still draw elements from this framework that are relevant to their field of practice.

Figure 4:

Illustration of potential career pathways for nurses working with teenagers and young adults with cancer

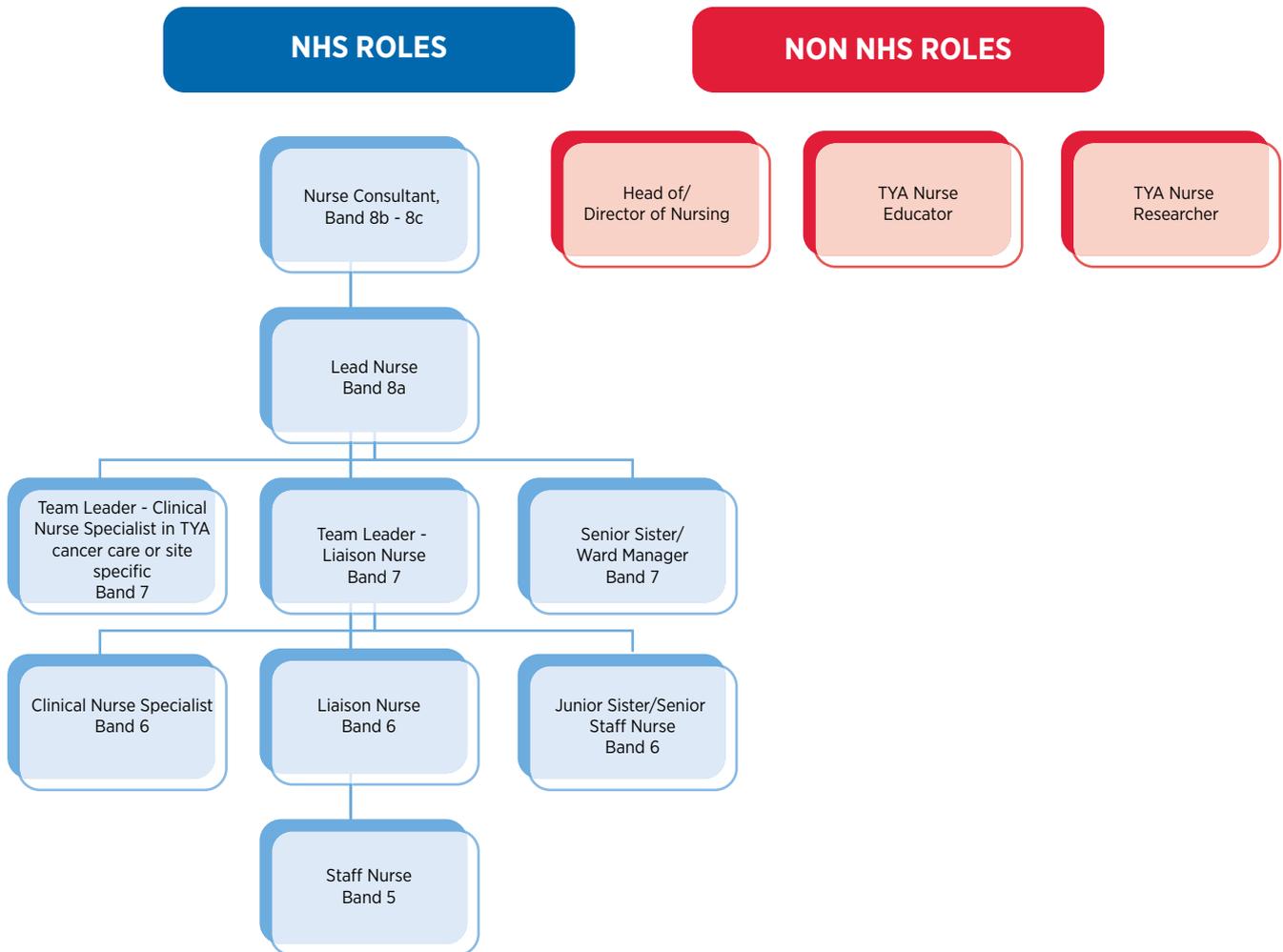


Figure 5
Education and Training needs of Nurses along the Career Framework

Expert	<ul style="list-style-type: none"> • TYA Cancer Study days plus 	<ul style="list-style-type: none"> • TYA Cancer specific accredited modules plus 	<ul style="list-style-type: none"> • Post Graduate specific TYA Cancer courses. • Post Graduate study in leadership, education, research, clinical care with a specific focus on TYA Cancer e.g. MSc, PhD 	<ul style="list-style-type: none"> • Accredited Post Graduate courses in Teenage and Young Adult Cancer Care at Coventry University • www.coventry.ac.uk/teenagecancercourses • GCP training • Masters in Nursing/leadership/education etc • PhD • Leadership programmes such as Florence Nightingale Scholarship • www.florence-nightingale-foundation.org.uk/ • Professional Leadership Programme NHS • www.leadershipacademy.nhs.uk/
Experienced / Proficient	<ul style="list-style-type: none"> • Children and Young People's Oncology Module • TYA Cancer Module • Study days plus 	<ul style="list-style-type: none"> • TYA Cancer specific accredited modules and/ or course plus • Own reading eg Blueprint of Care 	<ul style="list-style-type: none"> • Post Graduate specific TYA Cancer courses. 	<ul style="list-style-type: none"> • Accredited modules and courses in Teenage and Young Adult Cancer Care at Coventry University • www.coventry.ac.uk/teenagecancercourses
Competent	<ul style="list-style-type: none"> • TYA Cancer Study days • Online TYA cancer training plus • Own reading, eg Blueprint of Care 	<ul style="list-style-type: none"> • TYA Cancer Study days 	<ul style="list-style-type: none"> • TYA Cancer Study days 	<ul style="list-style-type: none"> • TYAC Study days • www.tyac.org.uk • Locally run Study days • E-training courses
Levels of Nursing	Education types	Examples and contact details		

8 - QUALITY ASSURANCE OF THE FRAMEWORK

Teenage and young adult (TYA) cancer care and nursing is evolving rapidly therefore, this framework will be periodically reviewed and updated. An annual risk assessment will be carried out in order to identify potential risks and the document will be reviewed in full every two years. This will ensure the framework remains relevant to nurses caring for teenagers and young adults with cancer in a changing and developing speciality. The risk assessment and reviews will be undertaken by the Teenage Cancer Trust national TYA nurses group with input from identified RCN nursing representatives.

CARING FOR TEENAGERS AND YOUNG ADULTS WITH CANCER: A COMPETENCE AND CAREER FRAMEWORK FOR NURSING



9 - OVERVIEW AND DEFINITION OF THE CORE COMPETENCIES FOR NURSES WORKING WITH TEENAGE AND YOUNG ADULT CANCER PATIENTS

The teenage and young adult cancer nursing competence and career framework is structured around 6 broad competencies. The competencies are independent and not in hierarchical order. All competencies are designed to start with an individualised patient approach.

Competence 1

Demonstrates and applies teenage and young adult (TYA) nursing specific knowledge and skills in order to support the complex needs of TYA patients with cancer; through individualised care planning to address physical, psychosocial and spiritual/cultural throughout the cancer trajectory.

This competence recognises that TYA Cancer Nursing requires additional knowledge, understanding and skills specific to the complexities of adolescence and the impact of cancer and its treatments for TYA's.

Competence 2

Demonstrates and applies the patient advocate role; working with and alongside Teenage and Young Adult patients, promoting patient empowerment to ensure patient views are central to all aspects of care, choice and decision making.

This competence recognises the importance of the nurse's role in supporting patient advocacy and choice in all aspects of TYA cancer care, particularly in complex and challenging situations.

Competence 3

Demonstrates and applies an evidence based approach to Teenage and Young Adult Cancer nursing practice and policy.

This competence supports advancement in TYA cancer nursing, research, service development at local and / or national level through collaborative working and the application of contemporary evidence. This determines how evidence and research shapes nursing practice and service development for Teenagers and Young Adults with cancer.

Competence 4

Contributes specific teenage and young adult cancer nursing knowledge and skills to the wider TYA Multidisciplinary Team (TYA MDT).

This competence recognises the diversity of services that treat TYA's with Cancer and is designed to encourage collaborative and partnership working to ensure individuals have patient centred care

Competence 5

Contributes to nursing leadership in Teenage and Young Adult Cancer Care.

This competence recognises the importance of nurse leadership in promoting quality of care for TYA with cancer and the contribution that nurses make to the development TYA cancer care

Competence 6

Demonstrates the need for professional development of self and others within teenage and young adult cancer care.

This competence recognises the need for nurses to maintain Continuous Professional Development that ensures competence to care for Teenagers and Young Adults with Cancer, whilst gaining knowledge, skills and practical experience. It also recognizes the variety of settings and roles where nurses are caring for TYA's with cancer.

1 Demonstrates and applies teenage and young adult (TYA) nursing specific knowledge and skills in order to support the complex needs of TYA patients with cancer; through individualised care planning to address physical, psychosocial and spiritual/cultural throughout the cancer trajectory

This competence recognises that TYA Cancer Nursing requires additional knowledge, understanding and skills specific to the complexities of adolescence and the impact of cancer and its treatments for TYA's

1a Applying knowledge and understanding of the ethos and principles of TYA cancer care

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes approaches and principles of TYA cancer nursing care. 2. Recognises and able to describe approaches and principles of TYA cancer nursing care 3. Applies this knowledge of TYA cancer nursing care in practice 	<ol style="list-style-type: none"> 4. Appraises approaches and principles of TYA cancer nursing care. 5. Contributes to the development of approaches and principles of TYA cancer nursing care 	<ol style="list-style-type: none"> 6. Critically evaluates approaches and principles associated with TYA care. 7. Building on the principles of TYA Cancer care, leads on developing local philosophy of care appropriate to the environment or service in which they work 8. Develops services and teams to deliver high quality TYA cancer care

1b Applying knowledge and understanding of adolescent development and behaviour

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes adolescent development theory 2. Describes normal adolescent behaviours 3. Demonstrates understanding of the impact of cancer and treatment on adolescent development and behaviour 4. Participates in the assessment of patients in the context of normal development processes. 5. Demonstrates communication skills that are age appropriate and specific to the needs of TYA with cancer 	<ol style="list-style-type: none"> 6. Analyses knowledge and understanding of adolescent development theories 7. Analyses knowledge and understanding of normal adolescent behaviour 8. Recognises deviations in expected adolescent development 9. Assesses patient in the context of normal development processes and incorporate individual patient needs into a plan of care to support normal adolescent development 10. Demonstrates advanced communication skills including interpretation of verbal and non-verbal cues when interacting with TYA with cancer 	<ol style="list-style-type: none"> 11. Critically evaluates adolescent development theories 12. Acts as expert advisor to other teams assessing patients and advising on individual care planning in particularly complex cases. 13. Advises across multi-professional agencies, teams and disciplines. 14. Leads and develops services and teams to deliver high quality TYA cancer care 15. Interprets verbal and non-verbal communication and use advanced skills to advise others in complex and challenging situations

1c Applying knowledge and understanding of the impact of cancer and implications for Teenagers and Young adults

Competent	Experienced/proficient	Expert Nurse
1. Describes knowledge and understanding of the impact of cancer on the TYA 's development and reports issues/ concerns to senior colleagues	9. Appraises the impact of cancer on the TYA 's development and incorporates into individualised care planning	17. Critically evaluates the impact of cancer on the TYA 's development and advises teams and colleagues in managing complex cases
2. Describes knowledge and understanding of the impact of cancer on the TYA and their behaviour	10. Appraises the impact of cancer on the TYA and their behaviour and plan individualised care to meet specific needs.	18. Leads and develops services and teams to deliver high quality TYA cancer care
3. Recognises the impact of a cancer diagnosis may have on risk taking behaviours and report concerns to appropriate senior colleagues	11. Recognises signs of increasing risk taking behaviours and supports the TYA to manage their behaviour	19. Acts as expert advisor and resource to other teams and colleagues , advising on individual care planning in particularly complex or challenging situations
4. Recognises the impact of cancer on the TYA's body image and offers support. Discusses concerns and issues with senior colleagues	12. Discuss with the patient the complex impact of cancer on the patients relationships with family, peer group and significant others and recognise changes to existing relationships	20. Advises and supports across multi-professional agencies, teams and disciplines (locally, regionally, nationally)
5. Recognises the complex impact of cancer on the TYA 's relationships with family, peer group and significant others and reports concerns to senior colleagues	13. Appraises the impact of cancer on education and employment plans	21. Develop services to meet the peer support needs of TYA with cancer
6. Describes and recognises the impact of cancer on education and employment plans	14. Comprehensive knowledge and understanding of the impact of cancer on an individual's sexuality	22. Act as expert advisor to teams and colleagues in complex situations
7. Recognises the potential impact of cancer and treatment on an individual's sexuality	15. Supports and advises less experienced colleagues , signposting where appropriate	
8. Recognises the impact of cancer on young people's peer group in the community and the importance of peer group support	16. Assess the impact on the TYA and identify individual needs with regard to peer support	

1d Applying knowledge and understanding of the impact of cancer treatment for Teenagers/Young Adults

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Discuss the impact of cancer treatment on the TYA and reports issues and concerns to senior colleagues 2. Plans individualised TYA Cancer care to meet needs 3. Describes appropriate referral pathways, and is able to signpost to other support services 4. Understands and recognises the potential impact of risk taking behaviours on cancer treatment and report concerns to appropriate senior colleagues 5. Recognises the impact of cancer treatment on body image and offers support. Discusses concerns and issues with senior colleagues 6. Recognises the complex impact of cancer treatments affecting the TYA 's relationships with family, peer group and significant others and reports concerns to senior colleagues 7. Describes and recognises the impact of cancer treatment on education and employment plans 8. Recognises the potential impact of cancer treatment on an individual's sexuality. 9. Demonstrates knowledge and understanding of how cancer and treatment may impact on short and long term fertility and its emotional implications 10. Can provide information to patients and their families in relation to fertility issues in TYA cancer 	<ol style="list-style-type: none"> 11. Assesses the impact of cancer treatment on the TYA using comprehensive knowledge 12. Plans individualised care needs using comprehensive knowledge 13. Recognises signs of increasing risk taking behaviours on cancer treatment and implements strategies to enable the TYA to manage their treatment 14. Discusses and supports the TYA to manage the impact of cancer treatment on relationships with family, peer group and significant others 15. Analyses the impact of cancer treatment on education and employment plans and can implement support accordingly 16. Evaluates the impact of cancer treatment on an individual's sexuality 17. Supports and advises less experienced colleagues, signposting where appropriate 18. Appraise the impact of cancer treatment on short and long term fertility issues : 19. Provides appropriate verbal and written information relating to fertility 20. Explains terminology and fertility preservation options to TYA and families 21. Refers patients directly to fertility preservation specialist teams 	<ol style="list-style-type: none"> 22. Advises teams and colleagues in managing the impact of cancer treatment on the TYA 's development, particularly in complex cases. 23. Acts as expert advisor and resource to other teams and colleagues, advising on managing treatment plans in particularly complex or challenging situations 24. Advises and supports across multi-professional agencies, teams and disciplines (locally, regionally, nationally) 25. Acts as an expert advisor to colleagues, teams and other healthcare professionals regarding fertility implications for TYA and preservation options within a defined service 26. Leads and develops services and teams to deliver high quality TYA cancer care

1e Applying knowledge and understanding of specific ethical and legal issues for teenagers and young adults with cancer

Competent	Experienced/proficient	Expert Nurse
<p>1. Understands and applies specific legal and ethical frameworks (see below) in relation to teenagers and young adults and refers to appropriate colleagues and agencies</p> <ul style="list-style-type: none"> • Informed consent • Confidentiality • Safeguarding Children and Vulnerable Adults • Refusal of Treatment • Mental Capacity Act 	<p>2. Critically appraises and responds to issues relating to legal and ethical frameworks</p> <p>3. Makes referrals to senior colleagues and other agencies in situations where a formal approach is needed to comply with legal frameworks</p> <p>4. Supports and advises less experienced colleagues, signposting where appropriate</p>	<p>5. Synthesises the complexities of legal and ethical frameworks</p> <p>6. Acts as expert advisor to clinical teams in relation to consent, confidentiality, safeguarding and refusal of treatment in TYA cancer care</p> <p>7. Assists and advises in situations where a formal approach is needed to comply with legal frameworks</p>

1f Applying knowledge and understanding of clinical trials and clinical research studies in Teenage and Young Adult cancer care

Competent	Experienced/proficient	Expert Nurse
<p>1. Demonstrates descriptive and procedural knowledge and understanding of clinical trials and terminology</p> <p>2. Identifies the principles of the importance of research in TYA cancer care</p>	<p>3. Applies knowledge and understanding of clinical trials, terminology and procedures as outlined in GCP training (Good Clinical Practice)</p> <p>4. Explains clinical trial options and research studies to TYAs and their families and signpost when necessary</p> <p>5. Participates in recruitment to clinical trials and studies where appropriate</p>	<p>6. Evaluates clinical trial availability, patient eligibility, trial procedures and terminology</p> <p>7. Undertakes GCP training in accordance with local and/or service requirements</p> <p>8. Advises other teams and colleagues in clinical trial and research study availability, options and procedures within a defined local service</p> <p>9. Evaluates clinical trial and research study availability and options beyond a local defined service and initiate discussion within MDTs.</p> <p>10. Supports teams to actively recruit TYA to appropriate trials and studies</p>

1g Applying knowledge and understanding of cancer treatment sequelae, late effects and survivorship

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes cancer treatments and potential long term effects 2. Discuss long term follow up in local services and procedures in TYA cancer care 3. Recognises survivorship/end of treatment issues for TYA patients who have completed treatment 4. Provides advice and information to TYA patients on End of Treatment initiatives and how to access appropriate services available 	<ol style="list-style-type: none"> 5. Assesses and evaluates treatment sequelae and late effects in TYA cancer care 6. Provides accurate information and assist others in developing care plans and treatment summaries with individual patients and families 7. Advises patients and families about common late effects and survivorship issues in TYA cancer and any future interventions and outcomes in relation to this. 	<ol style="list-style-type: none"> 8. Critically evaluates treatment sequelae and late effects for TYA with cancer 9. Promotes strategies and plans long term follow up to meet the needs of TYA patients likely to experience late effects and treatment sequelae 10. Advises and assists colleagues in the development and implementation of late effects services within a defined region 11. Acts as expert advisor to national groups involved in the development and implementation of survivorship initiatives 12. Acts as expert advisor to other colleagues and teams regarding survivorship needs of TYA

1h Applying knowledge of principles of grief and loss processes for TYA with cancer, their families and colleagues

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes grief and loss processes and principles 2. Discusses the effects of loss in its widest context, i.e., loss of peers, independence, body image 3. Identifies support services available for specific losses within a defined region 	<ol style="list-style-type: none"> 4. Applies processes and principles of grief and loss in the context of TYA cancer care 5. Refers appropriately, patients, carers and families to specialist services and signpost to other agencies 6. Supports young people, carers and colleagues regarding the effects of loss in its widest context, 	<ol style="list-style-type: none"> 7. Critically evaluates grief and loss processes and principles in the context of TYA cancer care 8. Develops and implements staff support strategies in TYA cancer care 9. Identifies services specific to dealing with losses within a defined locality or services (where current service is lacking) 10. Supports and advises young people, carers and colleagues where grief and loss is complex

1i Applying knowledge of principles of grief and bereavement processes for TYA with cancer, their families and colleagues

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes grief and bereavement processes and principles 2. Identifies bereavement services available within a defined region 3. Discusses the effects of bereavement in its widest context 	<ol style="list-style-type: none"> 4. Applies understanding grief and bereavement processes and principles in the context of TYA cancer care 5. Refers appropriately, families to specialist bereavement services and signpost to other agencies 6. Supports young people, carers and colleagues regarding the effects of bereavement in its widest context 	<ol style="list-style-type: none"> 7. Critically evaluates grief and bereavement processes and principles in the context of TYA cancer care 8. Develops and implements staff support strategies in TYA cancer care 9. Identifies gaps in bereavement services within a defined locality 10. Supports and advises young people, carers and colleagues where grief and bereavement is complex

1j Applying knowledge and understanding of professional boundaries/ issues arising in TYA Cancer Care

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Recognises and describes professional boundary issues that potentially can occur in TYA cancer care eg staff/patient / family relationships, social media. 2. Practices within professional frameworks in regard to respecting professional boundaries 	<ol style="list-style-type: none"> 3. Identifies issues and circumstances where professional boundary issues may have or have the potential of being breached or compromised. 4. Formulates a response/ action on actual breaches of professional boundaries. 	<ol style="list-style-type: none"> 5. Critically evaluates and takes actions in regard of breaches of professional boundary issues that occur in TYA cancer care 6. Advises and assists colleagues and teams to recognise and manage professional boundary issues 7. Acts as an expert advisor to colleagues and teams in circumstances where professional boundaries have been breached and escalate appropriately

2 Demonstrates and applies the patient advocate role; working with and alongside Teenage and Young Adult patients, promoting patient empowerment to ensure patient views are central to all aspects of care, choice and decision making.

This competence recognises the importance of the nurse's role in supporting patient advocacy and choice in all aspects of TYA cancer care, particularly in complex and challenging situations.

2a Engaging Teenagers/Young Adults and carers to obtain their views regarding service delivery and improvements

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes the importance of obtaining service user views of service delivery and improvement 2. Identifies different methods for obtaining patient views 	<ol style="list-style-type: none"> 3. Actively engages service users to obtain patient views of service delivery and improvement 	<ol style="list-style-type: none"> 4. Advises other professionals in methods appropriate for obtaining service user views 5. Develops tools to obtain and measure patient and user views to inform and improve service development

2b Acts as patient advocate in difficult or challenging situations to ensure the best interests of individual patients are met and the views of the TYA are central to decision making

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Recognises situations where a conflict exists between patient/ family/professional views and seeks assistance from senior staff supporting the TYA at all times 	<ol style="list-style-type: none"> 2. Provides unbiased information and realistic options for TYA to support informed patient choice and decision making 3. Facilitate discussions where a conflict of opinion exists 	<ol style="list-style-type: none"> 4. Acts as expert advisor to TYA's, carers, colleagues and teams in conflict resolution, complex decision making 5. Ensure patient choice is considered and advised in particularly complex/challenging situations 6. Implements support systems for colleagues and teams to ensure that the best interests of TYA are upheld

3 Demonstrates and applies an evidence based approach to Teenage and Young Adult Cancer nursing practice and policy

This competence supports advancement in TYA cancer nursing, research, service development at local and / or national level through collaborative working and the application of contemporary evidence. This determines how evidence and research shapes nursing practice and service development for Teenagers/Young Adults with cancer.

3a Understands the significance of evidence based approaches in TYA Cancer care and nursing practice

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Defines the purpose of research underpinning TYA cancer care. 2. Applies contemporary evidence to inform TYA cancer care to their nursing practice 	<ol style="list-style-type: none"> 3. Engages in appropriate research projects within TYA Cancer care 4. Individually or within a team, write for publication (paper or poster) on TYA cancer care and present posters/papers at conferences on TYA cancer care issues 5. Recognises how policy is applied in the context of current evidence and practice 6. Recognise the need for change to local policy and works collaboratively to instigate change 	<ol style="list-style-type: none"> 7. Identifies gaps in research in TYA cancer care/nursing 8. Acts in an advisory capacity in research projects in TYA cancer care 9. Leads in the design and completion of research projects/ audit/service research 10. Writes for publication on own research relating to TYA cancer care 11. Develops opportunities to create relationships with other agencies that promote TYA cancer research and nursing practice. 12. Develops and implements evidence based local policy for TYA cancer care and services 13. Contributes to national policy to represent the voice of TYA cancer nursing.

3b Contributes to Teenage and Young Adult cancer service development working in collaboration with other related services sharing best practice.

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Discusses how TYA cancer services fit within local and national policy frameworks/services 2. Understands the rationale for specific TYA cancer data collection 3. Records data required for service evaluation/Peer review within the TYA Cancer service 4. Contributes to the development of the TYA Cancer service engaging in evaluation processes 	<ol style="list-style-type: none"> 5. Engage in activities that promote service development 6. Contribute to the development of evidence-based policies and procedures for TYA Cancer care in line with local guidance 7. Conducts service evaluation of own practice within the TYA cancer service for example, patient satisfaction, local service standards/peer review 8. Contributes to the development and completion of service review in TYA Cancer services. 9. Promotes and communicates service development using a variety on methods 	<ol style="list-style-type: none"> 10. Leads on the development and delivery of local and national TYA Cancer services 11. Leads on the development and implementation of evidence-based protocols and guidelines specific to TYA Cancer care 12. Works strategically to elicit the views of service users on their opinions of service delivery and improvement 13. Represents TYA nursing within own and national organisations for the advancement of TYA nursing practice 14. Takes the professional nursing lead in completion of service reviews

3c Contributes to audits in Teenage and Young Adult Services

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes Clinical Audit, processes and quality monitoring within own service 2. Collects data required for audit within the TYA cancer nursing /care services 3. Contributes and actively engages in service improvement initiatives 	<ol style="list-style-type: none"> 4. Contributes to and implements service improvement initiatives and disseminates appropriately 5. Contributes to the development and completion of audit and local quality monitoring in TYA cancer care. 	<ol style="list-style-type: none"> 6. Contributes expertise in leading in the design and completion of audit projects of the TYA cancer service that ensures quality monitoring processes are complied with. 7. Manages TYA cancer care audits taking into account current evidence base

3d Contributes to the development and implementation of specific TYA Cancer and patient pathways

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Recognises that there are specific pathways for individual TYAs with cancer and how to access them 2. Recognises the specific phases of the transition process in TYA cancer care (e.g. children's services to TYA, TYA to adult services, TYA to survivorship, TYA to palliation) 3. Provides support and information to TYA and carers undergoing service transitions 4. Signpost to transition services 	<ol style="list-style-type: none"> 5. Participate in the development of TYA patient pathways 6. Supports TYA in navigating patient treatment/transitional pathways 7. Provides age appropriate information to TYA and carers undergoing transition between services 8. Assesses and supports the emotional and psychological readiness of the TYA to transition 	<ol style="list-style-type: none"> 9. Works within wider teams to develop and implement TYA patient pathways 10. Communicates changes in TYA patient pathways to teams 11. As an expert, reviews existing patient pathways and identifies gaps in services 12. Develops specific transition pathways and models in TYA cancer care 13. Advises other teams and colleagues on transition issues in TYA care

4 Contributes specific teenage and young adult cancer nursing knowledge and skills to the wider TYA Multidisciplinary Team (TYA MDT)

This competence recognises the diversity of services that treat TYA's with cancer and is designed to encourage collaborative and partnership working to ensure individuals have patient centred care

4a Role within TYAMDT including clinical and psychosocial meetings

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Describes own role and those of other professionals within the TYA MDT at the Principal Treatment Centre 2. Identifies the specific needs of patients and ensure needs are reported for discussion at the TYA MDT meeting 3. Participates and contributes to the TYA MDT meetings 4. Communicates the outcomes to the wider team from the TYA MDT meeting 	<ol style="list-style-type: none"> 5. Promote inter-professional working to ensure effective communication and collaborative MDT working 6. Supports junior staff in presenting patient information at TYA MDT meeting 7. Communicates outcomes from the TYA MDT meeting to the wider team and/or site specific or disease specific MDT teams, highlighting recommended actions 	<ol style="list-style-type: none"> 8. Lead/chair /Co Chair the TYAMDT meetings 9. Ensures referrals to the TYA MDT meeting are appropriate and presented accurately 10. Ensures outcomes are recorded accurately and action plans are in place and executed providing expert advice where needed 11. Manages difference of professional opinion using negotiating skills ensuring patients' interests are central to all decisions 12. Ensures that in his/her absence a nursing representative is in attendance at any TYA MDT meetings.

5 Contributes to nursing leadership in Teenage and Young Adult Cancer Care

This competence recognises the importance of nurse leadership in promoting quality of care for TYA with cancer and the contribution that nurses make to the development TYA cancer care

5a Demonstrates personal and professional leadership qualities, positively influencing at all levels.

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> 1. Understands own role and contributions to leadership within the nursing team 2. Seeks advice from senior TYA Cancer nurses on patient and nursing matters to aide professional development 	<ol style="list-style-type: none"> 3. Oversees the nursing teams approach to TYA nursing care by contributing comprehensive knowledge and expertise as required 4. Responds to less experienced colleagues, advising on TYA Cancer and nursing matters in a professional manner 5. Is proactive in instigating new initiatives that will improve the patient experience and nursing care 6. Networks with nurses in similar positions locally and nationally to learn with from and about each other's practice and care approaches. 7. Facilitates peer support of less experienced colleagues working with TYA with cancer 8. Deputises for senior nurses in their absence 9. Recognises own leadership development needs and seeks appropriate opportunities for personal and professional development 	<ol style="list-style-type: none"> 10. Takes an active role in Network groups and/or commissioning groups responsible for regional TYA cancer service implementation 11. Leads the nursing contribution and expertise that shapes TYA Cancer services locally and nationally 12. Acts as expert role model in TYA cancer care 13. Negotiates with and influences key stakeholders promoting excellence in TYA cancer care 14. Networks with other leading TYA Cancer Nurses nationally and internationally to foster the development of TYA Cancer nursing 15. Demonstrate active leadership personal and professional development 16. Seek to identify and develop nursing leaders of the future

6 Demonstrates the need for professional development of self and others within teenage and young adult cancer care

This competence recognises the need for nurses to maintain Continuous Professional Development that ensures competence to care for Teenagers and Young Adults with Cancer, whilst gaining knowledge, skills and practical experience. It also recognises the variety of settings and roles where nurses may care are caring for TYA's with cancer.

6a Demonstrates personal and professional development of self and others who may be providing care and support to TYAs with cancer in a variety of settings

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> Engages in professional development opportunities to enhance personal knowledge of TYA Cancer Acts as a role model actively engaging in the promotion of TYA cancer nursing practice 	<ol style="list-style-type: none"> Demonstrates personal and professional development in TYA cancer specific matters Demonstrates academic progression that supports the advancement of TYA cancer nursing/care/leadership/management/research Contributes to the education of other colleagues and professionals, locally and regionally , promoting TYA cancer nursing and practice 	<ol style="list-style-type: none"> Shares knowledge and expertise by participating in training/ education at post graduate level being undertaken on a variety of TYA cancer specific matters Demonstrates leadership development through participation in a recognised leadership programme Demonstrates training/ education at post registration/ post graduate level being undertaken on Nursing Research Demonstrate participation in national TYA cancer and TYA cancer nursing development

6b Demonstrates emotional resilience

Competent	Experienced/proficient	Expert Nurse
<ol style="list-style-type: none"> Knows when to seek help/ supervision when working within a TYA Cancer care setting 	<ol style="list-style-type: none"> Recognises when individuals or teams may be challenged emotionally and can implement strategies to support them Recognises own emotional needs and able to seek supervision when required Provides support and supervision to less experienced colleagues signposting to other resources where appropriate 	<ol style="list-style-type: none"> Recognises the need for own clinical supervision and support identifying mechanisms available Implements strategies to promote emotional resilience and wellbeing within teams Provides support and supervision for others who work with TYA's with cancer, signposting to other resources where appropriate

6c Professional development of others

Competent	Experienced/proficient	Expert Nurse
1. Considers and promotes the educational needs of staff in non specialist settings on the principles of TYA cancer care practice	2. Identifies the educational needs of less experienced staff in TYA Cancer issues 3. Educates students and colleagues from across the Multi-disciplinary team and wider geographical region on TYA Cancer issues 4. Understands the principles of teaching, learning and assessment of competence	5. Makes significant contribution to the development of training and accredited education packages 6. Critically appraises the principles of teaching, learning and assessment of competence and theory 7. Advises educators on TYA Cancer specific matters 8. Identifies the educational needs for a range of professionals and teams. 9. Delivers presentations and lectures to audiences to contribute to the appropriate education of multi-professionals in TYA care 10. Is academically and professionally credible and acts as a role model in striving to contribute to the education of others in academic and non-academic settings, nationally and internationally

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11 - GLOSSARY

360 appraisal	An appraisal system that gathers feedback on an individual from a number of sources. Sources may be colleagues, direct reports and patients/families. It is normally used as a learning and development aid and its main benefit is that it gives individuals better information about their skills, performance, and working relationships than more traditional appraisal arrangements based on line managers' assessment alone.
Adolescence	The developmental transition from childhood to adult hood.
Audit	Audit is defined as a systematic and independent examination of data, statements, records, operations and performances (financial or otherwise) of a recorded activity for a stated purpose
GCP Training	Good Clinical Practice (GCP) training is a key requirement for anyone involved in the conduct of clinical research. GCP is the standard and guidelines to which all health and social care research should be conducted.
HNA	Health Needs Assessment eg Distress Thermometer, HEADSS assessment.
Loss	Within this document 'loss' pertains to the many losses that TYA with cancer may face i.e. loss of hair, independence, a limb, a future, career, peers.
Multidisciplinary Team (MDT)	A team with many professionals working in it i.e. Doctors, nurses, psychologists, pathologists etc
Multi professional Agencies	Integrated, partnerships, 'joined up' working between health and social care teams. (Goodman et al 2011)
NCSI	National Cancer Survivorship Initiative
NMC	Nursing and Midwifery Council
TYA Philosophy of Care	The truths, basics and principles of care, knowledge and conduct used as guidance when caring for TYA with cancer.
PTC	Principal Treatment Centre
RCN	Royal College of Nursing
Site Specific	Site, in this instance, means place/type of cancer. For example, lung, breast, thyroid etc., In Cancer Centres, services are set up around the disease and not the age.
Stakeholders	A person, group or organisation that has an interest (stake) or concern in a Service. E.g. charities, commissioners, patients and staff.
Supervision	Clinical supervision allows a person to focus on a particular aspect of their clinical practice in a way that they would not normally do. This is through discussion, reflection gaining support, advice and constructive feedback. (Fowler 2011)
Survivorship	Patients living with and beyond cancer
Transition	Transition can be defined as a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems. TYA with cancer can have several transitions in their care e.g. Children's to TYA service; TYA services to adult services/long term follow up/palliative care. (DOH 2006)
TYA	Teenagers and Young Adults
TYA MDT	Teenage and Young Adult Multidisciplinary Team

12 - RESOURCES AND CONTACTS

Cancer Research UK	www.cancerresearchuk.org
CLIC Sargent	www.clicsargent.org.uk
Coventry University	www.coventry.ac.uk
European Oncology Nursing Society	www.cancernurse.eu
Florence Nightingale Foundation	http://www.florence-nightingale-foundation.org.uk
Macmillan Cancer Support	www.macmillan.org.uk
National Cancer Research Institute	www.ncri.org.uk
NHS Leadership Academy	www.leadershipacademy.nhs.uk
Nursing and Midwifery Council	www.nmc-uk.org
Royal College of Nursing	www.rcn.org.uk
Skills For Health	www.skillsforhealth.org.uk
Teenage Cancer Trust	www.teenagecancertrust.org
TYAC - A Group for Professionals	www.tyac.org.uk
United Kingdom Oncology Nurses Society	www.ukons.org

13 - APPENDIX 1 - COMPETENCE EVALUATION TOOL - EXAMPLE OF ROLES

Name	Job Title	Grade/Band	Place of Work
EXAMPLE 1 Mo Godson	Staff Nurse	Staff Nurse- Band 5	Cherry ward Adult Oncology

Demonstrates and applies teenage and young adult (TYA) nursing specific knowledge and skills in order to support the complex needs of TYA patients with cancer; through individualised care planning to address physical, psychosocial and spiritual/cultural throughout the cancer trajectory

Competence Number	Required for role Y/N	Self-Assessment Achieved Y/N	Assessor Assessment Y/N	Evidence of achievement
1a	Applying knowledge and understanding of the ethos and principles of TYA cancer care			
	1a.1	N	N	nil
	1a.2	N	N	nil
	1a.3	N	N	nil
Development/Action Plan incl Date to be Achieved				
<p><i>Read Blueprint of Care and identify key points- Download document from TYAC website by July 2014.</i> <i>Become a member of TYAC - Ward fund to pay for membership BY August 2014</i> <i>Attend a TYA Cancer study day - Attend TYAC study day Sept 2014 (seek funding from professional development team)</i></p>				
Comments				

Name	Job Title	Grade/Band	Place of Work
EXAMPLE 2 James West	Germ Cell Nurse Specialist	Staff Nurse- Band 7	Oaklands Hospitals NHS Trust

2. Demonstrates and applies the patient advocate role; working with and alongside Teenage and Young Adult patients , promoting patient empowerment to ensure patient views are central to all aspects of care, choice and decision making.

Competence Number	Required for role Y/N	Self-Assessment Achieved Y/N	Assessor Assessment Y/N	Evidence of achievement
1a	Applying knowledge and understanding of the ethos and principles of TYA cancer care			
2a.1	Y		Y	Observed through discussion, questions and answers June 2013 Only questionnaires used, need to consider alternatives as service is growing Results of questionnaire report from June 2013
2a.2	N		N	
2a.3	Y		N	
Development/Action Plan incl Date to be Achieved				
Given the development of the service and the growing number of young people being cared for, an alternative to the questionnaire as a means of engagement should be considered. Action Plan - James should engage with the local CAMHS service who have set up a patient forum for advice on setting up this type of group. Additionally seek support from TYA Cancer Lead Nurse and access expertise from Teenage Cancer Trust. Plan a TYAC Forum for 6 months time (Oct 2014) and engage with experts in the mean time for advice and guidance.				
Comments				

Name	Job Title	Grade/Band	Place of Work
EXAMPLE 3 Joanna Carlos	Ward Manager	Staff Nurse- Band 7	Teenage and Young Adult Inpatient Unit (16-24yrs)

5. Contributes to nursing leadership in Teenage and Young Adult Cancer Care

Competence Number	Required for role Y/N	Self-Assessment Achieved Y/N	Assessor Assessment Y/N	Evidence of achievement
5a	Demonstrates personal and professional leadership qualities, positively influencing at all levels.			
5a.1	Y	Y	Y	Minutes of TEAM MTGS
5a.2	Y	Y	Y	Feedback from Nurse Consultant or Head of Nursing TCT
5a.3	Y	Y	Y	Contributes in teaching programme for the department- see flyer
5a.4	Y	Y	Y	Observable in daily practice at handover, MDT Mtgs
5a.5	Y	Y	Y	Involved in business case for Youth Support Coordinator- minutes of mtgs
5a.6	Y	Y	N	
5a.7	Y	Y	Y	Sets up induction programmes for new starters and mentors them
5a.8	Y	Y	Y	See rota for department
5a.9	Y	Y	N	

Development/Action Plan incl Date to be Achieved

Jo's area for development centre upon the need for her to begin to externalise her profile and to network with other leaders in nursing both in TYA cancer care and beyond. Suggest Jo puts herself forward to national groups such as TYAC, UKONS, TCT nursing forums so that she is more proactive in this aspect of her work. Take action by Oct 2014

Jo should consider some leadership development opportunities that are offered by the hospital, consider studying a leadership module at university. She might like to explore initiatives such as Florence Nightingale Scholarship or NHS Leadership Programmes- Take action by Oct 2014.

Comments

14 - APPENDIX 2 - BLANK COMPETENCE EVALUATION TOOL

Please photocopy this sheet to document competences achieved or to be achieved. Each sheet can be used in conjunction with local policies and retained for the nurses professional portfolio.

Name	Job Title	Grade/Band	Place of Work

Competence Number	Required for role Y/N	Self-Assessment Achieved Y/N	Assessor Assessment Y/N	Evidence of achievement
Eg 1a				

Development and Action Plan

Comment

15 - LIST OF ADDITIONAL CONTRIBUTORS

Thanks are due to the following 32 nurse participants who engaged with the final consensus event to agree the competency framework. The event took place at Coventry University March 2014.

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QUALITY!



WHAT YOUNG PEOPLE WITH CANCER THINK QUALITY CARE IS

Over 300 young people from all over the UK and some other European countries, who have had or had cancer at the time, attended Teenage Cancer Trust's Find Your Sense of Tumour conference in February 2012. We asked them simply what quality care means to them and the main themes they expressed were:

EXPERT STAFF

Expert staff who have time and will listen, support, provide information and communicate effectively and appropriately for my age. Some comments from young people were:

- People that are there for you who can help and listen to you
- Treating patients as individuals, understanding that they all have different needs and don't necessarily understand what is happening in medical terms.
- Nurses have got to be nice and have a positive attitude to help the patient and give the patient confidence.
- A happy, helpful environment with people & staff who are easy to talk to.
- Support to suit the individual needs of each patient, as well as medical treatment.

'EXPERT'
'TIME' **'LISTEN'**
'INDIVIDUALS'
'POSITIVE ATTITUDE'
'CONFIDENCE'
'HAPPY' **'HELPFUL'**
'EASY TO TALK TO'
'SUPPORT'



'INTERNET ACCESS'
'OTHER YOUNG PEOPLE'
'TEENAGERS'
'ENVIRONMENT SPECIALISTS'

AGE-APPROPRIATE

An age appropriate environment, shared with other young people (not adults or children). Some comments from young people were:

- Access to the internet and flexible visiting hours.
- I think it is really important that young people are treated like teenagers and not like children or adults.
- Teenage Cancer Trust is great, it's a lot better than an adult ward.
- Being cared for in the right environment by specialist people.

SOCIALISE

Being able to meet other young people to socialise and for support. Some comments from young people were:

- Gives people who have suffered a chance to get their lives back by letting them meet new people and go to social events and activities in their local area.
- Young people on separate wards, together they can support each other, mind over matter - it really helps!
- Make sure they have a way to stay in touch with friends.

'MEET OTHERS'
'SOCIAL EVENTS'
'ACTIVITIES'
'SUPPORT'
'STAY IN TOUCH'



'SAFETY'
'COMFORT'
'LISTENING'
'INDEPENDENCE'
'SENSE OF IDENTITY'
'DIGNITY'

RESPECT

Feeling safe, comfortable, cared for and respected. Some comments from young people were:

- Trying to be interested and understand the patient's situation - care about them, take them seriously.
- People listening to you. Not treating you as invisible, but a person matters - NOT another Cancer Patient!
- Quality care is being supportive in a happy and jolly way, making everything as fun as possible and respecting everyone's needs.
- Quality care is when a person has opportunities to be independent, respected and able to keep their sense of identity.
- Having my dignity, thoughts, feeling and decisions respected.

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