Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Teenagers and Young Adults with Cancer

# **Career and Education Framework for** specialist nurses working in the field of long-term follow-up and late effects for children and young people after cancer V2.0

**This framework is supplementary to;**
The Career and Education Framework for Children and Young People Cancer Nursing V3.0 (RCN and CCLG, 2022)
www.cclg.org.uk/professionals/cyp-cancer-framework
**For those working in children's services**

Or

Health Education England (HEE) (2023) ACCEnD Career Pathway, Core Cancer Capabilities, and Education Framework
www.hee.nhs.uk/our-work/cancer-diagnostics-aspirant-cancer-career-education-development-programme/accend-framework
**For those working in adult services**

Royal College of Nursing
RCN ACCREDITED

ENDORSED BY
EUROPEAN ONCOLOGY NURSING SOCIETY
2023

YOUNG LIVES vs CANCER

| This Career and Education Framework belongs to: | |
|---|---|
| **Name of practitioner:** | |
| **Professional registration number:** | |
| **Unit/department & year:** | |
| **Job title & year:** | |

# Version Control

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[1] RCN Royal College of Nursing www.rcn.org.uk/

[2] CCLG Children's Cancer & Leukaemia Group www.cclg.org.uk/

[3] EONS European Oncology Nursing Society www.cancernurse.eu/

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# Summary

## Summary

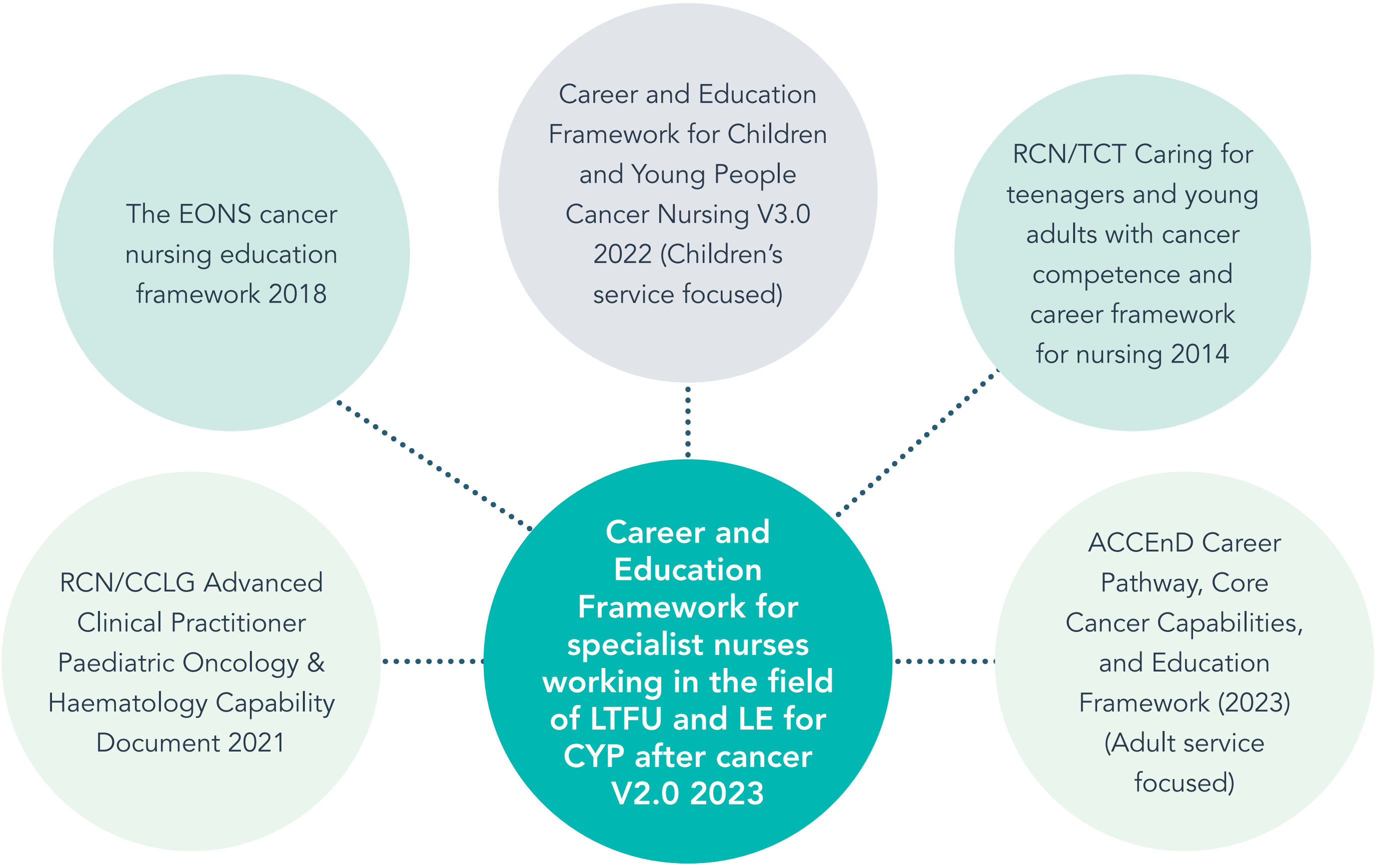
This updated career and education framework is intended for use by nurses employed in long-term follow-up (LTFU) roles for children, young people and adults after treatment for cancer during childhood, adolescence or young adulthood. Late effects (LE) services are provided across the developmental range including childhood, adolescence, and adulthood.

This framework encompasses supra-specialist[4] late effects nursing competencies which build on from other more generic career and education frameworks for cancer nurses. See Fig. 1.

Nurses working in the specialist area of LTFU for survivors of childhood and young adult cancer, may be based in children's services, adolescent, and young adult (AYA) services, or adult cancer services. LTFU nurses' core cancer nursing competencies therefore derive from their background nursing career; children, teenage and young adult (TYA) or adult field of practice.

This document represents a scheduled review of the 'RCN Competencies: an integrated career and competence framework for nurses working in the field of long-term follow-up and late-effects care of children and young people after cancer (2011)' and draws on content contained in the previous document. The document structure is informed by the 'RCN Group Education, Learning and Development Strategy 2021-2024: RCN Competency template guide'.

**Fig. 1 Relationship between Career and Education Frameworks for long-term follow-up nurses [5][6]**



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[4] The term 'supra'-specialist denotes that practitioners in long-term follow-up are likely to already be specialist in cancer, endocrinology or other specialty, and supra-specialise in late effects.

[5] Teenage Cancer Trust (TCT) www.teenagecancertrust.org/

[6] EONS European Oncology Nursing Society https://cancernurse.eu/

# Definitions

# Definitions

The term 'cancer' encompasses both malignant disease and non-malignant diseases, such as bone marrow failure disorders, managed within oncology and haematology settings.

The term 'children' refers to those diagnosed between the ages of 0 to 16th Birthday. The term 'teenage and young adult (TYA)' refers to those diagnosed between the ages of 13 to 25th birthday at diagnosis, however in Europe and globally the term AYA (adolescent and young adults is more common). The term 'children and young people (CYP)' is often used to encapsulate both the children and TYA age groups, and while it is nationally and internationally ambiguous, we have used CYP in this document to mean 0-25 years. The term 'adult' refers to those diagnosed from 25 years onwards. There is clearly overlap on the borders of each of these age groups, and variation with international criteria where AYA may also refer to those up to 39th birthday.

In the UK, regardless of age at diagnosis, long-term follow-up services are based in either a paediatric service or an adult service, requiring excellent transition planning to ensure patients do not get lost to appropriate follow-up (NICE, 2016, RCN, 2021c).

The Late Effects service consequently includes adults over 25 years who were treated for childhood, adolescent, or young adult cancer. To cover this group of service users we have used the term **"people affected by CYP (children and young people) cancer"** throughout the document. This may also include their family, partners, and carer givers.

The term 'care giver' has been used to describe those with significant caring responsibility such as a parent, guardian, or partner.

Within this framework the term 'nurse' refers to registered nurses on the UK Nursing & Midwifery Council Register (NMC, 2023b) working in LTFU. This competence framework describes the range of knowledge and skills required of the nursing workforce working in the supra-specialist field of LTFU and LE, building on from general and cancer nursing competencies.

# Background to long-term follow-up services after CYP cancer

# Background to long-term follow-up services after CYP cancer

Many of the cancer treatment regimens delivered to achieve excellent survival rates in children and young people include multi-agent cytotoxic, targeted, or biological therapies in combination with surgery and/or radiotherapy. There is an increasing recognition of the long-term consequences of cancer and its treatment, often referred to as 'late-effects'. The long-term consequences of cancer, or cancer treatment, may vary in their impact, with some being sub-clinical and others resulting in potentially life-threatening or debilitating conditions, and which include late psychological, emotional and social impacts. (Reulen & Winter et al, 2010, Hjorth et al, 2015, CCLG, 2022). Therapy related complications may affect multiple organ systems, with resultant impact on health status and quality of life, and many of these late effects can be potentially life altering (Frobisher et al, 2017, Landier et al, 2018). There are several factors that influence an individual's risk of developing late effects. These include the type of cancer, the cancer treatments received, age at diagnosis, gender, health status, time-lapse since treatment, healthy behaviours, individual psychosocial responses to diagnosis and treatment in addition to psychological, social and environmental influences (CCLG, 2019, CCLG, 2022).

Long-term follow-up care is designed to match a patient's personal journey through cancer; how they have coped with their treatment against a calculated risk stratification associated with their cancer treatments; (Frobisher et al. 2017, van Kalsbeek et al, 2021). The work by the National Cancer Survivorship Initiative (NCSI), written up by Frobisher et al., (2017), described stratified follow-up ranging from self-supported management at level one to consultant-led care at level three. However, these have not been tested in a research setting and remain theoretical. Anecdotal experience from practice suggests a 'needs' assessment, rather than a 'risk' assessment works best. The levels need to be flexible based on how stable a patient is, or what their needs are at a given time. This means that in practice patients can move up and down levels of follow-up and type of follow-up (postal, nurse led or medical) can be fluid based on their needs.

## Risk stratification of oncology patients (NCSI guidelines)

| LEVEL 1 | LEVEL 2 | LEVEL 3 |
|---|---|---|
| **Treatment groups:**<br>• low-risk chemotherapy (not received anthracyclines or alkylating agents)<br>• surgery alone<br><br>**Tumour groups;**<br>• stage I & II Wilms<br>• low-stage neuroblastoma<br>• germ cell tumours stage 1<br>• melanoma<br>• LCH | **Treatment groups;**<br>• multi agent chemotherapy with;<br>• cumulative anthracycline dose at 250mg/m2 or less<br>• cumulative alkylating dose less than 4g/m2<br>• low-dose cranial irradiation <24Gy<br><br>**Tumour groups;**<br>• standard & high-risk ALL<br>• standard risk oncology patients<br>• non-Hodgkin lymphoma group 1 & 2<br>• hodgkin's lymphoma group 1 & 2 | **Treatment groups;**<br>• multi agent chemotherapy;<br>• anthracyclines (dose >250mg/m2), alkylating agents (dose> 4g/m2) & platinum agents<br>• radiotherapy<br>• myeloablative high-dose chemotherapy with stem cell rescue<br>• bone marrow transplantation<br><br>**Tumour groups;**<br>• CNS tumours<br>• high-grade lymphoma/ relapsed leukaemia<br>• stage 4 oncology patients |

The risk assessment framework above is heavily focused on the medical model and doesn't account for human behaviours or individual and personalised needs. Nurses should work to support the holistic needs of patients through the biopsychosocial model. This approach is supported by the NHS England Long Term Plan 'Personalised Care and Support Model' (NHSE, 2018).

Late effects can occur at any time following treatment, and it is important to consider approaches to monitoring, supporting and clinically managing this group of patients. Evidence suggests that patients may require monitoring for many years and that specialist LTFU care should be available and accessible for survivors lifelong. In addition, patients should be provided with the support to enable them to self-manage and take responsibility for their own health needs where this is appropriate and possible. (Nicklin et al, 2021, Michel et al, 2019, National Health Service (NHS) England (2017).

Nurses play a vital role in LTFU services and are considered to have supra-specialised beyond the core specialist field of cancer. Thus, most nurses working in this field are enhanced, advanced or consultant nurse practitioners. They are frequently singleton nurse workers alongside medical colleagues in a small late-effects team, based in cancer centres (paediatric, or adult services).

Cancers that occur in children and young people present a unique set of challenges for the patient, their family and health care providers. The transition from childhood to adulthood is a time when self-identity, independence, new academic or employment roles, and social roles are being forged. Given the protracted time course spanning diagnosis, treatment and long-term survival, patients are at risk of psychosocial consequences such as the development of mental health problems and mental illness, failure to meet expected social milestones, reduced educational achievement and vocational attainment (Brinkman et al., 2018, Devine et al., 2022). This document will term all types of follow-up care after a cancer treatment as long-term follow-up care (LTFU); LTFU care encompasses patients who have had any treatment for any cancer that has, or may have, a physical or psychological impact on their health.

# Career pathways in late effects and long-term follow-up nursing

# Career pathways in late effects and long-term follow-up nursing

## Career pathways generally

Career pathways for nurses are far less clearly defined than for the medical profession. The authors continue to engage with and monitor the outputs of the Health Education England (HEE) led, UK wide Aspirant Cancer Career and Education Development Programme (HEE, 2021a, 2021b) which has now defined the levels of practice that are referred to in this framework. Currently career pathways in nursing are largely driven by opportunity, senior management priorities, strategy planning and external factors (national health policy, economic environment). ACCEnD aims to make potential career pathways more transparent and support education for achieving progression through levels of practice. CCLG and TYAC education aims to supplement NHS provision and assist career development through supporting resources like this, to providing lectures, seminars, educational events and eLearning.

Routes into supra-specialist late effects and long-term follow-up roles, for people affected by CYP cancer, may begin in paediatric, TYA, or adult cancer services, or from specialties unrelated to cancer but applicable to the types of late effects seen such as endocrinology.

## Career pathways from paediatric, TYA, and adult cancer care

Cancer nurses will develop their career guided by age specific career and education frameworks. (RCN and CCLG, 2022, HEE, 2023) Such frameworks help build the skills, knowledge and characteristics required for cancer nursing, alongside clinical experience, in-house learning, and academic study. This framework introduces cancer nurses to the long-term consequences of cancer and its treatments. Cancer nurses may develop a special interest in late effects from comprehending the consequences of systemic-anticancer therapies (SACT) during SACT training in wards, day care or chemotherapy units. Clinic nurses may also develop this interest after exposure to the patients attending for follow-up and seeing the long-term impact of treatment on individuals.

## Career pathways from other specialties

Often the consequences of cancer and its treatment affect systems and body function outside the remit of the cancer field, such as endocrinology, nephrology, hepatology, audiology, cardiology, psychology, fertility & reproductive health, physiotherapy, and rehabilitation. Nurses working in such specialities where they see and manage the long-term consequences of cancer or its treatment will need to develop their knowledge of cancer and cancer late effects, and may have the opportunity to be part of the extended LTFU multidisciplinary team.

All these pathways may present opportunities to apply for posts working within a CYP cancer LTFU service or closely connected with a LTFU service, at enhanced, advanced or consultant levels of practice. This framework offers competencies for nurses working in these supra-specialised roles. Nurses should explore country specific guidance on routes to enhanced, advanced and consultant levels of practice. (NLIAH Wales, 2010, Health Education England, 2017, Department of Health (DoH) Northern Ireland, 2018, Scottish Government, 2021).

[7] www.cclg.org.uk/professionals/cyp-cancer-framework

[8] www.rcn.org.uk/Professional-Development/publications/career-pathway-and-education-framework-for-cancer-nursing-uk-pub-010-076

## Research as a core function of the Registered Nurse’s role and clinical academic pathways

All nurses should be research aware, research engaged, and research active from reading, sharing and application to practice, to participating in research activity when possible. Clinical practice must be evidenced based, or evidence informed (where a directly applicable evidence base is absent.) All nurses should develop skills and knowledge in assessing the quality of research evidence and implementing research findings into practice where these are assessed as meeting rigour, validity, and statistically significant thresholds.

Some nurses will choose to follow clinical academic career pathways. They will usually be working at enhanced, advanced or consultant levels of practice and may have a research focus in late effects and LTFU care. CYP cancer survival rates have improved in recent decades, with emerging late consequences, and with that comes the imperative to study long-term outcomes for these patients (NIHR James Lind Alliance, 2018 and 2022). This framework has the potential to influence research and practice guidelines as well as informing future editions of this framework.

The framework will now move on to discuss the knowledge and skills required for late effects and long-term follow-up nursing roles, using a competency-based model.

# Purpose and rationale for the framework

# Purpose and rationale for the framework

Cancer care is complex, constantly developing, and requires person centred care in the context of family care (more strongly developed in paediatric practice, but no less important in adult cancer care and follow-up). The complexity places high demands on staff working in the field physically, emotionally, cognitively, technically, and educationally. **This framework has a broad range of scope to address this complexity but does not aim to replicate competencies that are core to all general and specialist nurses, rather focusing on LTFU specific care.**

Due to the supra-specialist nature of late effects services, this framework focuses on the professional development required for nurses at enhanced (Leary, 2021), advanced and consultant levels (HEE, 2021a, HEE 2021b), aspiring to build or maintain a career in long-term follow-up nursing. As a reminder, this builds on from core cancer nursing competencies previously mentioned, and focuses specifically on late effects and LTFU nursing, therefore some core competencies for enhanced, advanced and consultant nurse levels of practice such as workforce planning, and financial management have not been addressed here, but will underpin competencies addressed here.

The following definition of competence, proposed by Case Di Leonardi and Biel (2012, p. 350) which modified an original definition used by the Canadian Association of Schools of Nursing, is used because it encompasses continuing competence;

> *"Continuing competence is the ongoing commitment of a registered nurse to integrate and apply the knowledge, skills, and judgment with the attitudes, values, and beliefs required to practice safely, effectively, and ethically in a designated role and setting."*

Using an outcomes competency model, this framework focuses on the expectations of the nurse undertaking a role, addressing several issues, and initiatives, including:

- clinical practice
- leadership
- education
- research
- standards and guidelines
- lifelong learning with appropriate supervision
- service development for and with people affected by CYP cancer

Some of these reflect the pillars of practice described for advanced and enhanced nursing roles. (NHS Employers, 2022; Scottish Government, 2021; DoH Northern Ireland, 2018, NLIAH Wales, 2010).

## Topic areas covered within the framework

1. Assessment of actual and potential consequences of cancer or its treatments.
2. Developing individualised treatment summaries and long-term follow-up care plans.
3. Providing information, support and advice to children, young people, and adults, their families, carers, and partners (where applicable).
4. Encouraging self-care and support self-monitoring.
5. Liaison with members of the multidisciplinary team to optimise holistic care.
6. Demonstrating knowledge of the impact of cancer and its treatment on the psychosocial development of children and young people.
7. Supporting the smooth transition of care either from children to adult services, or from adolescent to adult services.
8. Creating services that can work in conjunction with, or link with, primary care.
9. Initiating or co-operating in research, audit and service evaluation.
10. Facilitating the development of evidence-based practice through service developments.
11. Participating in educational programmes in long-term follow-up care.

## Topic areas represented in four competency themes

1. Personalised pathway.
2. Psychosocial care.
3. Case management.
4. Quality improvement.

# How to use the framework

## How to use the framework

This 'Career and Education Framework' is intended to guide career development and enable assessment of an individual nurse's progress.

The framework can be used in two ways. Given that LTFU nurses mostly work in small teams, they may not have access to supervisors[9] who have the knowledge and skills in LTFU services to guide professional development, therefore as illustrated in Fig.2, the Framework can be used in a self-directed manner, using the knowledge and skills competencies to personally direct and record progress.

**Fig 2.**

**Example of how a nurse may use the framework for career planning**

Consider this role or future roles you are working towards.

Identify the competencies needed for that role (job descriptions/person specifications may help with this).

Discuss your plans with a colleague or peer if available, and only complete the self-assessment & evidence section of the WBRS.

Use the action plan to set yourself goals to work towards, taking opportunities to develop the competencies needed.

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[9] The term supervisor is used to encompass any position where a person may be offering career guidance and/or assessing competencies, for example, practice educator, mentor, preceptor, manager.

Where supervisors are available, then Fig 3. Illustrates how professional development can be guided by the Framework competencies and assessed by a supervisor (NMC, 2021a, 2021b). This includes options for other senior oncology nurses (not working in LTFU) or clinicians working in LTFU to provide the competency sign off. Alternatively, peer-to-peer sign off could occur across regional centres.

With your supervisor identify the competencies needed in your role at the current time. (A broad initial self-assessment will help inform this meeting).

Agree the level of achievement required and note N, AB, C, P or E (Benner's taxonomy level) in the level of achievement required column.

Agree a date for your competency review or series of dates for practical skills assessments.

Self Assess your current level of practice using Benner's taxonomy level in the 'self-assessment' column.

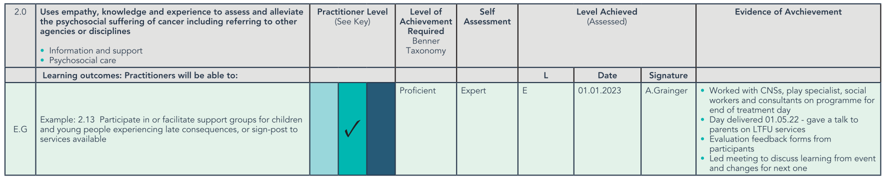
Between your initial meeting and your review date, build your evidence in the 'evidence of achievement' column (bullet points).

Hold your review meeting or practice-based assessment with your supervisor. (May be part of an appraisal or following a new skill acquisition e.g. completing the SACT Passport).

Supervisor notes level achieved. Discuss variations between assessors view and self assessment.

Complete the Work-based Record Sheet (WBRS) Action Plan for any areas where you need to further develop.

Fig 3: Example of how an organisation might integrate use of the framework in individual development



| 2.0 | Uses empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines<br>• Information and support<br>• Psychosocial care | Practitioner Level (See Key) | | | Level of Achievement Required Benner Taxonomy | Self Assessment | Level Achieved (Assessed) | | | Evidence of Avchievement |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | | | | | | L | Date | Signature | |
| E.G | Example: 2.13 Participate in or facilitate support groups for children and young people experiencing late consequences, or sign-post to services available | | ✓ | | Proficient | Expert | E | 01.01.2023 | A.Grainger | • Worked with CNSs, play specialist, social workers and consultants on programme for end of treatment day<br>• Day delivered 01.05.22 - gave a talk to parents on LTFU services<br>• Evaluation feedback forms from participants<br>• Led meeting to discuss learning from event and changes for next one |

## Step 1. Identifying the Nursing Level

The process begins by identifying which level the nurse is working at (or aspiring to if new in post). There are nine levels of practice recognised by the Nursing and Midwifery Council (NMC), the Royal College of Nursing (RCN), Health Education England (HEE), Skills for Health (2010) and NHS Education for Scotland (2020); although not all are 'registered' levels of practice. The full set of CYP cancer nursing levels can be found in Children's Cancer & Leukaemia Group (CCLG) and Royal College of Nursing (RCN) (2022) Career and Education Framework for Children and Young People (CYP) Cancer Nursing V3.0. Because this Framework covers supra-specialist levels of practice only Levels 6-8 (enhanced, advanced, and consultant) are addressed.

## Pre-requisite education, skills, knowledge

The pre-requisite for this framework is being a registered nurse who has knowledge and skills in CYP, TYA (Teenage and Young Adult), or adult cancer nursing and has achieved generic cancer nursing competencies to Registered Nurse Level. See Fig. 1., Page 7;

The Nurse Level Key [Table 1] provides a guide to levels of practice for individuals to consider their supra-specialist role in LTFU.

**Table 1. Nurse Level Key**

| | |
|---|---|
| ■ | **Enhanced level practice** with supra-specialist skills working in LTFU Services for people affected by CYP cancer.<br>This level includes, but is not limited to, Clinical Nurse Specialists, Specialist LE & LTFU Nurses, trainee ANPs **www.hee.nhs.uk/our-work/enhanced-practice-0** |
| ■ | **Advanced level practice** meeting the RCN (2018b) Royal College of Nursing Standards for Advanced Level Nursing Practice and working in LTFU Services for people affected by CYP cancer.<br>This level can include Advanced Nurse Practitioners and Clinical Nurse Specialists who meet the standards for advanced practice. |
| ■ | **Consultant level practice** in LTFU services working in LTFU Services for people affected by CYP cancer. |

## Step 2. Identifying which competencies apply to the nurse

Cancer care is a large and complex field with wide ranging knowledge and skills required. Completing all the competences within the framework may take many years to achieve and there may be competencies that are not applicable to every nurse within a level, due to variation in how services are delivered around the UK. The Framework is not intended to be used in a linear way starting at the beginning and working through. Nurses, ideally with their supervisor, should identify which competencies need to be attained (and then maintained), for example, during their first 6 months in a role, the first year, the first two years and so on at locally agreed timepoints for review. It is not specified how often progress and competence should be reviewed as this will be determined by individuals and their supervisors to fulfil local service requirements. **Even where the framework suggests that a competency is applicable to a level, this must be locally assessed**. However, assessment is expected to be an ongoing process throughout a nurse's career, to demonstrate continuing competence (Case Di Leonardi & Biel, 2012).

It must be made clear to individuals whether the framework is being used as a guide in a professional development discussion with optional competencies to be attained, or as part of a 'formal' assessment process (which may involve identifying mandatory and optional competencies to be attained and maintained). By 'formal', the working party means that the competency assessment is informing local monitoring of achievement of the knowledge and skills required to deliver an individual's job role, inform professional development planning and achievement, and support activities like appraisals and revalidation (NMC 2021a, 2021b, 2023a, 2023b). An 'informal' review may be a personal reflection, or a discussion with a colleague or supervisor, on possible career pathways.

To identify applicable competencies to be achieved a tick (✓) should be placed next to the competency, under the relevant level practice, in the Work-Based Record Sheet (WBRS). Nurses should prepare for this discussion by reading the framework document and self-assessing what they feel applies to their current role and what their current learning and development needs are. Recording level of taxonomy is further discussed in step 4. Recording Progress: Work-Based Record Sheets.

The competencies in each section are separated for;
**Learning outcomes:** This is the knowledge that nurses need and informs Higher Education Institutions (HEI) and course or study day leaders on theory content.

**Practice competencies:** These are the practical skills that nurses need to demonstrate in their clinical settings.

## Step 3. Identifying what level of competence is needed and in what timeframe

This framework uses Benner's (1984, p.21) stages of clinical competence as the taxonomy for assessment of achievement, see Table 2 below. The working party acknowledges that while there are benefits from using a stated taxonomy, to guide the assessment of levels of achievement, there may be variation in local interpretation and for some competences, it will be difficult to distinguish between taxonomy characteristics at higher levels of practice. There may be instances where an assessor simply needs to establish if a nurse is competent or not, rather than dwelling on nuances of levels above the competent classification. (Almalkawi, Jester & Terry, 2018).

The acronyms for each classification are explained in the competency table below (pg. 24).

**Table 2. Benner's (1984) Novice to Expert Classification**

| Classification | Description of behaviours to apply to job role and responsibilities |
|---|---|
| **Novice (N)** | The novice or beginner has no experience in the situations in which they are expected to perform. The novice lacks confidence to demonstrate safe practice and requires continual verbal and physical cues. Practice is slow and they are unable to use discretionary judgement. |
| **Advanced beginner (AB)** | Advanced beginners demonstrate marginally acceptable performance because the nurse has had prior experience in actual situations. They are efficient and skillful in parts of the practice area, requiring occasional supportive cues. May/may not be slow in practice. Knowledge is developing. Experience is needed before the nurse can apply guidelines to individual patients. Still need support in the clinical setting. |
| **Competent (C)** | The nurse can demonstrate efficiency, is coordinated, and has confidence in their actions. For the competent nurse, a plan establishes a perspective, and the plan is based on considerable conscious, abstract, analytic contemplation of the problem. The conscious, deliberate planning that is characteristic of this skill level helps achieve efficiency and organisation. Care is completed within a suitable timeframe without supporting cues. The competent nurse lacks the speed and flexibility of the proficient nurse but does have a feeling of mastery and the ability to cope with and manage the many contingencies in clinical nursing.<br>In what is now an all-graduate profession, and using the framework for higher levels of nursing, it is felt that competence can be achieved for some competencies in a short timeframe (rather than the two to three years first proposed by Benner), and others will take longer to master. This can be locally agreed and tailored to the specific competency. |
| **Proficient (P)** | The proficient nurse perceives situations as wholes rather than in terms of chopped up parts or aspects. Proficient nurses understand a situation as a whole because they perceive its meaning in terms of long-term goals. The proficient nurse learns from experience what typical events to expect in a given situation and how plans need to be modified in response to these events. The proficient nurse can now recognise when the expected normal picture does not materialise. This holistic understanding improves the proficient nurse's decision making; it becomes less laboured because the nurse now has a perspective on which many existing attributes and aspects in the present situation are the important ones. Maxims reflect nuances of a situation. |
| **Expert (E)** | The Expert nurse no longer relies on an analytic principle (rule, guidelines, maxim) to connect their understanding of the situation to an appropriate action. They have an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions. The Expert operates from a deep understanding of the total situation. His/her (their) performance becomes fluid and flexible and highly proficient. Highly skilled analytic ability is necessary for those situations with which the nurse has had no previous experience. |

**Who can assess competencies?**

Learning outcomes or knowledge-based competencies may be assessed in a variety of ways through clinical and practical experience, completing courses, study days, eLearning, and self-directed study. This may take the form of marked assignments, marking of completed workbooks, teacher evaluation from participating in debate during study days, completing eLearning quizzes and tests, writing reflective pieces that are discussed with supervisors, module assignments, reflective discussions with assessors, evidence from clinical practice assessments, or writing for publication.

Practice competencies can be assessed using locally agreed criteria for people who can assess clinical competencies, which may be based on in-house assessor courses or externally accessed courses, e.g. Anglia Ruskin University, 2021. Guidance on supervision and assessment of practice is also available via the Nursing and Midwifery Council, (NMC 2023a, 2023b). An assessor does not need to hold the competency themselves as long as they understand the competency statement, and any policies or procedures related to it (local, regional, or national) and have been approved by the Trust and/or service to be an assessor.

## Step 4. Recording Progress: Work-Based Record Sheets (WBRS)

Each competency section is followed immediately by a work-based record sheet (WBRS) for that section as recommended in the RCN Competency Template (RCN, 2021a).

The WRBS are designed to support all steps in the process to record plans and progress. These can be used towards the evidence for NMC revalidation (Nursing and Midwifery Council, 2021a) and local appraisals. They lend themselves to assessment of practice at a local level and may be completed as self-assessment or more formal assessment (described in Step 2) by supervisors, in partnership with members of the wider multi-disciplinary team. Local educators and/or managers should identify how the framework supports local practice relevant to the setting. Where nurses have access to support, including preceptorship, appraisal, or practice facilitation, the WBRS may be used to record assessment. Academic course leaders may also determine how the framework can support course development, learning outcomes, how learning could be assessed and recorded, and by whom. Where nurses do not have access to support and resources to enable competency assessment, the framework may be used to support self-directed learning and/or acquisition of skills, and NMC revalidation.

After Steps 1-3 have been completed (i.e. level of practice identified, applicable competencies identified, and Benner's taxonomy level required noted) the nurse should then self-assess what taxonomy level they feel they have achieved within the timeframe specified, using the WBRS. This process is illustrated in **Fig.3.** Bullet points of evidence of achievement are also noted on the WBRS, as described below in 'Evidence to demonstrate competence.' Progress should be reviewed with locally determined assessors, e.g., an educator or facilitator, who should then add their assessment of achievement.

Action plans at the bottom of each WBRS, can be used to guide future development through the taxonomies, or when a desired taxonomy level has not been met. **On each WBRS one of the competencies has been selected to show an example. Each WBRS example, in the four topics, uses a different nursing level to illustrate how the evidence may vary. In addition, Topic 4 (Quality Improvement) offers an example of how the Action Plan might be completed.**

Additional work-based record sheets can be used for repeat assessments during a career trajectory and will be available as individual pdfs at www.cclg.org.uk/professionals/late-effects-competencies

### Evidence to demonstrate competence

Individuals are responsible for producing evidence for each competence and ensuring it demonstrates competence at the agreed level. Supervisors should support individuals through identification of appropriate self-directed learning, study sessions and/or academic courses. In addition, adequate clinical opportunities and support should be made available.

When providing or reviewing evidence, consider the following points:
- ensure you understand what the competence statement requires
- consider pre-existing evidence, for example previous competencies/assessments, which may demonstrate knowledge and skills
- does the evidence demonstrate both knowledge and skill? e.g. attendance at a study day and supervised practice
- utilise a reflective model e.g. NMC Revalidation reflective accounts (NMC, 2021b)
- utilise evidence which encompasses several competencies e.g. a case study demonstrating application of knowledge and skills
- are there gaps in the evidence and, if so, is there an action plan in place?

### Examples of evidence

A wide variety of evidence may be provided to demonstrate attainment of knowledge and skills to fulfil competencies within the framework. These may include:
- 360° feedback
- assessments and appraisals
- audits
- case histories
- certificates of attendance for study sessions/days
- critical incidents
- evidence of completing higher education study, e.g. a university CYP cancer course
- evidence of group work
- evidence of membership of advisory groups
- evidence of qualification or verification of practice
- locally identified workbooks/e-learning
- policy and protocol development
- posters
- practice developments/changes in practice
- projects
- publications and presentations
- qualifications (Excellence, Achievement & Learning, 2015)
- reflective diaries, including self-appraisal
- research and evidence-based reviews
- service evaluation
- service user feedback e.g., ‘thank you’ cards
- signed evidence of supervised practice
- structured reflections e.g., NMC revalidation ‘reflective accounts’ (NMC, 2021b)
- witness statements

# Nursing competences for: long-term follow-up and late effects care of people affected by CYP cancer

# The competencies

# Section 1.

# Personalised cancer pathway, and information and support needs

| 1.0 | **Uses and applies experience and clinical knowledge of cancer and treatment to deliver and co-ordinate services, personalise the cancer pathway for individual patients, and meet the complex information and support needs of people affected by CYP cancer**<br>• knowledge of cancer and its treatment in relation to LTFU care for people affected by CYP cancer<br>• tests and investigations<br>• assessment<br>• care plans and treatment summaries – personalising the cancer pathway for individual patients<br>• medication | **Registered Nurses providing specialist CYP long-term follow-up and late effects cancer care** | | |
|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | **Enhanced** | **Advanced** | **Consultant** |
| 1.1 | Demonstrate a comprehensive knowledge of cancers affecting children and young people and its treatment. | ■ | ■ | ■ |
| 1.2 | Demonstrate a clear understanding of the potential physical, psychological and social long-term consequences of CYP cancer and its treatments. | ■ | ■ | ■ |
| 1.3 | Demonstrate a comprehensive understanding of treatment sequelae appropriate to own specialty area for example, endocrine, skeletal, developmental effects. | ■ | ■ | ■ |
| 1.4 | Recognise and describe potential interventions and outcomes in relation to **common** late consequences. | ■ | ■ | ■ |
| 1.5 | Recognise and describe potential interventions and outcomes in relation to **less common** consequences. | | | ■ |
| 1.6 | Demonstrate understanding of the normal physical developmental patterns of growth and puberty to be able to recognise delayed or precoscious puberty. | ■ | ■ | ■ |
| 1.7 | Demonstrate knowledge surrounding the impact of subfertility issues and hormone deficiencies to support and signpost appropriately to specialist services when needed. | ■ | ■ | ■ |
| 1.8 | Demonstrate knowledge of symptom management in relation to common long term consequences, including medicines and therapies, need for onward referral, lifestyle changes, activity and diet. | ■ | ■ | ■ |
| 1.9 | Demonstrate knowledge of the wide range of tests and investigations used within LTFU care as part of agreed guidelines and protocols, including rationale for use and normal ranges of results (Children's Oncology Group, 2010) (IGHG, PanCare Follow Up 2021). | ■ | ■ | ■ |
| 1.10 | Demonstrate a good working knowledge of the legal framework and guidelines relating to the consent process for children, young people and vulnerable adults. | ■ | ■ | ■ |
| 1.11 | Describe detailed understanding of the holistic needs assessment process, and its implications for practice. | ■ | ■ | ■ |
| 1.12 | Understand the principles of comprehensive history taking and clinical examination within the scope of own role. | | ■ | ■ |
| 1.13 | Demonstrate knowledge of medications commonly used in own area of practice in relation to late consequences including indication, mode of action, contraindications and adverse effects. | ■ | ■ | ■ |
| **Practice competencies: Practitioners will be able to:** | | **Enhanced** | **Advanced** | **Consultant** |
| **Apply knowledge of cancer and its treatment in relation to LTFU care for people affected by CYP cancer** | | | | |
| 1.14 | Apply knowledge of cancer and its treatment in relation to consequences of cancer and its treatments for people affected by CYPC to the clinical situation. | ■ | ■ | ■ |
| 1.15 | Use this knowledge to:<br>• create and promote innovative solutions to health problems<br>• develop services that meet the needs of patients requiring long-term-follow-up | | ■ | ■ |
| **Applying knowledge to tests and investigations** | | **Enhanced** | **Advanced** | **Consultant** |
| 1.16 | Independently initiate a wide range of investigations used within LTFU care as part of agreed guidelines and protocols (Children's Oncology Group, 2010) (IGHG, PanCare Follow Up, 2021). | ■ | ■ | ■ |

Section 1 continued ▼

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| 1.17 | Carry out observations and investigations appropriate to own area of practice appropriate to own area and scope of practice. | ■ | ■ | ■ |
| 1.18 | Organise tests and investigations requested by senior colleagues. | ■ | ■ | ■ |
| 1.19 | Use expertise to prescribe, initiate, interpret and monitor diagnostic tests and investigations utilised within late effects care independently and without supervision, according to the child or young person's clinical need. | | ■ | ■ |
| 1.20 | Make appropriate decisions in seeking help in relation to findings of tests and investigations. | ■ | ■ | ■ |
| 1.21 | Accurately interpret the findings of common and routine tests and investigations used within LTFU care. | ■ | ■ | ■ |
| 1.22 | Accurately interpret the findings of specialised tests and investigations within advanced scope of practice used within LTFU care. | | ■ | ■ |
| 1.23 | Provide simple descriptive and procedural information about tests and investigations to people affected by CYP cancer. | ■ | ■ | ■ |
| 1.24 | Provide detailed information to people affected by CYP cancer about tests and investigations; identify new support or information needs arising from findings of results. | ■ | ■ | ■ |
| 1.25 | Make appropriate changes to the plan of care or make appropriate referrals in the light of findings, in conjunction with clinicians or within protocols and guidelines. | ■ | ■ | ■ |
| 1.26 | Facilitate independent consultations with people affected by CYP cancer to discuss tests and investigations, offering time without parents or partners. | ■ | ■ | ■ |
| 1.27 | Use routine strategies to enable good practice with consent. | ■ | ■ | ■ |
| 1.28 | Act as an expert resource for other health care professionals (HCPs) when dealing with complex or challenging situations relating to consent. | | ■ | ■ |
| 1.29 | Use expertise to relay difficult news to people affected by CYP cancer at a level of their own understanding. | ■ | ■ | ■ |
| 1.30 | Participate in developing protocols and clinical guidelines relating to tests and investigations used within LTFU care. | ■ | ■ | ■ |
| 1.31 | Play a leading role in developing protocols and clinical guidelines relating to tests and investigations used within LTFU care. | | ■ | ■ |
| **Assessment** | | | | |
| 1.32 | Carry out a structured nursing assessment for people affected by CYP cancer with appropriate explanation and support to the child or young person undergoing clinical assessments in LTFU care. | ■ | ■ | ■ |
| 1.33 | Carry out a comprehensive health history. | | ■ | ■ |
| 1.34 | Carry out a physical examination. | | ■ | ■ |
| 1.35 | Assess the impact of cancer diagnosis and treatment on lifestyle and future education and employment needs. | ■ | ■ | ■ |
| 1.36 | Use specialist knowledge and skills to assess the psychosocial wellbeing of people affected by CYP cancer receiving LTFU care. | ■ | ■ | ■ |
| 1.37 | Consider the need for specialised assessments (such as neuropsychology) that may influence the process of formal statutory assessment. | ■ | ■ | ■ |
| 1.38 | Use clinical examination skills to develop LTFU plans of care independently. | | | ■ |

Section 1 continued ▼

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|---|---|---|---|---|
| 1.39 | Recognise actual and potential late consequences of treatment that might require attention, and report concerns to appropriate colleagues when required. | ■ | ■ | ■ |
| 1.40 | Recognise signs and symptoms of health problems associated with late effects requiring urgent review by senior colleagues. | ■ | ■ | ■ |
| 1.41 | Use specialist knowledge to recognise deviations in expected childhood and adolescent development. | ■ | ■ | ■ |
| 1.42 | Manage defined consequences of treatment within scope of practice, e.g. dietary advice, managing chronic fatigue. | | ■ | ■ |
| 1.43 | Use complex strategies to deal with challenging issues relating to consent. | | ■ | ■ |
| 1.44 | Act as an expert resource for other colleagues in relation to issues and concerns arising from outcomes of assessments. | | ■ | ■ |
| 1.45 | Contribute to the development of assessment tools and clinical guidelines for LTFU care. | ■ | ■ | ■ |
| 1.46 | Play a leading role in developing assessment tools and clinical guidelines for LTFU care. | | ■ | ■ |
| 1.47 | Communicate changes to national and international guidelines on assessment to colleagues locally. | ■ | ■ | ■ |
| 1.48 | Lead and make autonomous clinical decisions where appropriate in the assessment, care and treatment planning, transition support and referrals for CYP in Long Term Follow up. (See www.cclg.org.uk/ACP-capabilities for detailed breakdown). | | ■ | ■ |
| **Care plans and treatment summaries – personalising the cancer pathway for individual patients** | | | | |
| 1.49 | Document clear and accurate information about people affected by CYP cancer within the service. | ■ | ■ | ■ |
| 1.50 | Use specialist knowledge to create age appropriate care plans with people affected by CYP cancer according to agreed protocols and guidelines, using case notes and consultation information. | ■ | ■ | ■ |
| 1.51 | Provide accurate and appropriate information when assisting others to develop care plans and treatment summaries for people affected by CYP cancer. | ■ | ■ | ■ |
| 1.52 | Use expert knowledge to independently assess, evaluate, select and implement appropriate and holistic late effects care plans. | | ■ | ■ |
| 1.53 | Provide information and explanation to patients and carers in relation to their treatment summary and holistic care plan, and assist thinking about where to store care plan digitally or paper. | ■ | ■ | ■ |
| 1.54 | Demonstrate awareness of confidentiality issues relating to the age and self-responsibility of people affected by CYP cancer. | ■ | ■ | ■ |
| 1.55 | Use a range of clinical data to facilitate timely and effective interventions for people affected by CYP cancer. | ■ | ■ | ■ |
| 1.56 | Identify and prioritise people affected by CYP cancer requiring urgent intervention and referral. | ■ | ■ | ■ |
| 1.57 | Use specialist knowledge to recognise and report deviations from the expected progress of an individual child, young person or adult. | ■ | ■ | ■ |
| 1.58 | Co-ordinate LTFU care where appropriate to ensure prompt and appropriate referral to specialist services. | ■ | ■ | ■ |
| 1.59 | Act as an expert resource for other HCPs when dealing with challenging situations arising from the late effects care plan, for example, different perspectives on treatment decisions between people affected by CYP cancer and their family or care givers. | | ■ | ■ |
| 1.60 | Contribute to the design, develop and implement care pathways to guide practice within the LTFU service. | ■ | ■ | ■ |

Section 1 continued ▼

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|---|---|---|---|---|
| 1.61 | Lead and make autonomous decisions where appropriate, using generic clinical decision making and associated skills.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). |  | ■ | ■ |
| 1.62 | Lead and make autonomous decisions where appropriate, in assessing the need for radiological investigations and using findings to inform management plans.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). |  | ■ | ■ |
| **Medication** |  |  |  |  |
| 1.63 | Administer appropriate medication as prescribed in accordance with professional and organisational standards. | ■ | ■ | ■ |
| 1.64 | Provide advice and explanation to patients on medication used within LTFU care. | ■ | ■ | ■ |
| 1.65 | Provide medication for people affected by CYP cancer according to protocol and guidelines (for example, patient group directions (PGDs). | ■ | ■ | ■ |
| 1.66 | Lead and make autonomous clinical decisions where appropriate in the assessment, prescribing for late effects, managing late effects and monitoring of SACT.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). |  | ■ | ■ |
| 1.67 | Evaluate effectiveness and outcomes of medication, and consult with clinician/ANP regarding changes. | ■ | ■ | ■ |
| 1.68 | Use specialist knowledge to provide individualised information about medication used within LTFU care to enable informed consent and self- management. | ■ | ■ | ■ |
| 1.69 | Work with the multidisciplinary team (MDT) to develop protocols and guidelines for medications for use within the LTFU service. | ■ | ■ | ■ |

## Work Based Record Sheet

| 1.0 | **Uses and applies experience and clinical knowledge of cancer and treatment to deliver and co-ordinate services, personalise the cancer pathway for individual patients, and meet the complex information and support needs of people affected by CYP cancer**<br>• knowledge of cancer and its treatment in relation to LTFU care for people affected by CYP cancer<br>• tests and investigations<br>• assessment<br>• care plans and treatment summaries – personalising the cancer pathway for individual patients<br>• medication | **Practitioner level** (See key) | | | **Level of achievement required** Benner Taxonomy | **Self assessment** | **Level achieved** (Assessed) | | | **Evidence of achievement** |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | | | | | | **L** | **Date** | **Signature** | |
| E.G | Example: 1.8 Demonstrate knowledge of symptom management in relation to common long term consequences, including medicines and therapies, need for onward referral, lifestyle changes, activity and diet. | ▨ | ▨ | ✓ | Proficient | Expert | E | 01.01.2023 | A.Grainger | • Created course content on late consequences for Uni CYP cancer course.<br>• Delivers teaching on topic - positive delegate evaluation.<br>• CPD Journal article published. |
| 1.1 | Demonstrate a comprehensive knowledge of cancers affecting children and young people and its treatment. | ▨ | ▨ | ▨ | | | | | | |
| 1.2 | Demonstrate a clear understanding of the potential physical, psychological and social long-term consequences of CYP cancer and its treatment. | ▨ | ▨ | ▨ | | | | | | |
| 1.3 | Demonstrate a comprehensive understanding of treatment sequelae appropriate to own specialty area for example, endocrine, skeletal, developmental effects. | ▨ | ▨ | ▨ | | | | | | |
| 1.4 | Recognise and describe potential interventions and outcomes in relation to **common** late consequences. | ▨ | ▨ | ▨ | | | | | | |
| 1.5 | Recognise and describe potential interventions and outcomes in relation to **less common** consequences. | | | ▨ | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|---|
| 1.6 | Demonstrate understanding of the normal physical developmental patterns of growth and puberty to be able to recognise delayed or precoscious puberty. | ■ | ■ | ■ | | | | | | | |
| 1.7 | Demonstrate knowledge surrounding the impact of subfertility issues and hormone deficiencies to support and signpost appropriately to specialist services when needed. | ■ | ■ | ■ | | | | | | | |
| 1.8 | Demonstrate knowledge of symptom management in relation to common long term consequences, including medicines and therapies, need for onward referral, lifestyle changes, activity and diet. | ■ | ■ | ■ | | | | | | | |
| 1.9 | Demonstrate knowledge of the wide range of tests and investigations used within LTFU care as part of agreed guidelines and protocols, including rationale for use and normal ranges of results (Children's Oncology Group, 2010) (IGHG, PanCare Follow Up 2021). | ■ | ■ | ■ | | | | | | | |
| 1.10 | Demonstrate a good working knowledge of the legal framework and guidelines relating to the consent process for children, young people and vulnerable adults. | ■ | ■ | ■ | | | | | | | |
| 1.11 | Describe detailed understanding of the holistic needs assessment process, and its implications for practice. | ■ | ■ | ■ | | | | | | | |
| 1.12 | Understand the principles of comprehensive history taking and clinical examination within the scope of own role. | | ■ | ■ | | | | | | | |
| 1.13 | Demonstrate knowledge of medications commonly used in own area of practice in relation to late consequences including indication, mode of action, contraindications and adverse effects. | ■ | ■ | ■ | | | | | | | |

Section 1b continued ▼

| **Practice competencies: Practitioners will be able to:** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Apply knowledge of cancer and its treatment in relation to LTFU care for people affected by CYP cancer** | | | | | | | | | | |
| 1.14 | Apply knowledge of cancer and its treatment in relation to consequences of cancer and its treatments for people affected by CYPC to the clinical situation. | ■ | ■ | ■ | | | | | | |
| 1.15 | Use this knowledge to:<br>• create and promote innovative solutions to health problems<br>• develop services that meet the needs of patients requiring long-term-follow-up. | | ■ | ■ | | | | | | |
| **Applying knowledge to tests and investigations** | | | | | | | | | | |
| 1.16 | Independently initiate a wide range of investigations used within LTFU care as part of agreed guidelines and protocols (Children’s Oncology Group, 2010) (IGHG, PanCare Follow Up, 2021). | ■ | ■ | ■ | | | | | | |
| 1.17 | Carry out observations and investigations appropriate to own area of practice appropriate to own area and scope of practice. | ■ | ■ | ■ | | | | | | |
| 1.18 | Organise tests and investigations requested by senior colleagues. | ■ | ■ | ■ | | | | | | |
| 1.19 | Use expertise to prescribe, initiate, interpret and monitor diagnostic tests and investigations utilised within late effects care independently and without supervision, according to the child or young person’s clinical need. | ■ | ■ | ■ | | | | | | |
| 1.20 | Make appropriate decisions in seeking help in relation to findings of tests and investigations. | ■ | ■ | ■ | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.21 | Accurately interpret the findings of common and routine tests and investigations used within LTFU care. | | | | | | | | | |
| 1.22 | Accurately interpret the findings of specialised tests and investigations within advanced scope of practice used within LTFU care. | | | | | | | | | |
| 1.23 | Provide simple descriptive and procedural information about tests and investigations to people affected by CYP cancer. | | | | | | | | | |
| 1.24 | Provide detailed information to people affected by CYP cancer about tests and investigations; identify new support or information needs arising from findings of results. | | | | | | | | | |
| 1.25 | Make appropriate changes to the plan of care or make appropriate referrals in the light of findings, in conjunction with clinicians or within protocols and guidelines. | | | | | | | | | |
| 1.26 | Facilitate independent consultations with people affected by CYP cancer to discuss tests and investigations, offering time without parents or partners. | | | | | | | | | |
| 1.27 | Use routine strategies to enable good practice with consent. | | | | | | | | | |
| 1.28 | Act as an expert resource for other health care professionals (HCPs) when dealing with complex or challenging situations relating to consent. | | | | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.29 | Use expertise to relay difficult news to people affected by CYP cancer at a level of their own understanding. | | | | | | | | | |
| 1.30 | Participate in developing protocols and clinical guidelines relating to tests and investigations used within LTFU care. | | | | | | | | | |
| 1.31 | Play a leading role in developing protocols and clinical guidelines relating to tests and investigations used within LTFU care. | | | | | | | | | |
| **Assessment** | | | | | | | | | | |
| 1.32 | Carry out a structured nursing assessment for people affected by CYP cancer with appropriate explanation and support to the child or young person undergoing clinical assessments in LTFU care. | | | | | | | | | |
| 1.33 | Carry out a comprehensive health history. | | | | | | | | | |
| 1.34 | Carry out a physical examination. | | | | | | | | | |
| 1.35 | Assess the impact of cancer diagnosis and treatment on lifestyle and future education and employment needs. | | | | | | | | | |
| 1.36 | Use specialist knowledge and skills to assess the psychosocial wellbeing of people affected by CYP cancer receiving LTFU care. | | | | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.37 | Consider the need for specialised assessments (such as neuropsychology) that may influence the process of formal statutory assessment. | | | | | | | | | |
| 1.38 | Use clinical examination skills to develop late effects plans of care independently. | | | | | | | | | |
| 1.39 | Recognise actual and potential late consequences of treatment that might require attention, and report concerns to appropriate colleagues when required. | | | | | | | | | |
| 1.40 | Recognise signs and symptoms of health problems associated with late effects requiring urgent review by senior colleagues. | | | | | | | | | |
| 1.41 | Use specialist knowledge to recognise deviations in expected childhood and adolescent development. | | | | | | | | | |
| 1.42 | Manage defined consequences of treatment within scope of practice, e.g. dietary advice, managing chronic fatigue. | | | | | | | | | |
| 1.43 | Use complex strategies to deal with challenging issues relating to consent. | | | | | | | | | |
| 1.44 | Act as an expert resource for other colleagues in relation to issues and concerns arising from outcomes of assessments. | | | | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.45 | Contribute to the development of assessment tools and clinical guidelines for LTFU care. | | | | | | | | | |
| 1.46 | Play a leading role in developing assessment tools and clinical guidelines for LTFU care. | | | | | | | | | |
| 1.47 | Communicate changes to national and international guidelines on assessment to colleagues locally. | | | | | | | | | |
| 1.48 | Lead and make autonomous clinical decisions where appropriate in the assessment, care and treatment planning, transition support and referrals for people affected by CYP cancer in Long Term Follow up. (See www.cclg.org.uk/ACP-capabilities for detailed breakdown) | | | | | | | | | |
| **Care plans and treatment summaries - personalising the cancer pathway for individual patients** | | | | | | | | | | |
| 1.49 | Document clear and accurate information about people affected by CYP cancer within the service. | | | | | | | | | |
| 1.50 | Use specialist knowledge to create age appropriate care plans with children and young people according to agreed protocols and guidelines, using case notes and consultation information. | | | | | | | | | |
| 1.51 | Provide accurate and appropriate information when assisting others to develop care plans and treatment summaries for people affected by CYP cancer. | | | | | | | | | |
| 1.52 | Use expert knowledge to independently assess, evaluate, select and implement appropriate and holistic late effects care plans. | | | | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.53 | Provide information and explanation to patients and carers in relation to their treatment summary and holistic care plan, and assist thinking about where to store care plan digitally or paper. | | | | | | | | | |
| 1.54 | Demonstrate awareness of confidentiality issues relating to the age and self-responsibility of people affected by CYP cancer. | | | | | | | | | |
| 1.55 | Use a range of clinical data to facilitate timely and effective interventions for people affected by CYP cancer. | | | | | | | | | |
| 1.56 | Identify and prioritise people affected by CYP cancer requiring urgent intervention and referral. | | | | | | | | | |
| 1.57 | Use specialist knowledge to recognise and report deviations from the expected progress of an individual child, young person or adult. | | | | | | | | | |
| 1.58 | Co-ordinate LTFU care where appropriate to ensure prompt and appropriate referral to specialist services. | | | | | | | | | |
| 1.59 | Act as an expert resource for other HCPs when dealing with challenging situations arising from the late effects care plan, for example, different perspectives on treatment decisions between people affected by CYP cancer and their family or care givers. | | | | | | | | | |
| 1.60 | Contribute to the design, develop and implement care pathways to guide practice within the LTFU service. | | | | | | | | | |

Section 1b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.61 | Lead and make autonomous decisions where appropriate, using generic clinical decision making and associated skills.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). | | | | | | | | | |
| 1.62 | Lead and make autonomous decisions where appropriate, in assessing the need for radiological investigations and using findings to inform management plans.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). | | | | | | | | | |
| **Medication** | | | | | | | | | | |
| 1.63 | Administer appropriate medication as prescribed in accordance with professional and organisational standards. | | | | | | | | | |
| 1.64 | Provide advice and explanation to patients on medication used within LTFU care. | | | | | | | | | |
| 1.65 | Provide medication for people affected by CYP cancer according to protocol and guidelines (for example, patient group directions (PGDs). | | | | | | | | | |
| 1.66 | Lead and make autonomous clinical decisions where appropriate in the assessment, prescribing for late effects, managing late effects and monitoring of SACT.<br>(See www.cclg.org.uk/ACP-capabilities for detailed breakdown). | | | | | | | | | |
| 1.67 | Evaluate effectiveness and outcomes of medication, and consult with clinician/ANP regarding changes. | | | | | | | | | |
| 1.68 | Use specialist knowledge to provide individualised information about medication used within LTFU care to enable informed consent and self-management. | | | | | | | | | |

Section 1b continued ▼

## Work Based Record Sheet

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|---|---|---|---|---|---|---|---|---|---|---|
| 1.69 | Work with the multidisciplinary team (MDT) to develop protocols and guidelines for medications for use within the LTFU service. | 🟦 | 🟦 | 🟦 | | | | | | |

**Action plan** to achieve required competency level:

| Reviewed by | |
|---|---|
| Signature and role: | |
| Signature and role: | |
| Signature and role: | |

# Section 2.
## PsychoSocial

| 2.0 | **Uses empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines.**<br>• information and support<br>• psychosocial care | **Registered Nurses providing specialist CYP long-term follow-up and late effects cancer care** | | |
|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | **Enhanced** | **Advanced** | **Consultant** |
| 2.1 | Demonstrate a comprehensive understanding of the potential social consequences of cancer and its treatment on people affected by CYP cancer. | ■ | ■ | ■ |
| 2.2 | Demonstrate knowledge of the psychological consequences of cancer and it's treatment on people affected by CYP cancer. | ■ | ■ | ■ |
| 2.3 | Demonstrate knowledge of the impact of cancer and its treatment on psychosocial development in children and young people and the transition to adulthood. | ■ | ■ | ■ |
| 2.4 | Discuss knowledge of support services and referral pathways available in region and nationally to support people affected by CYP cancer with LTFU and management of late consequences. | ■ | ■ | ■ |
| 2.5 | Understand critical thinking skills and apply them to psychosocial LTFU care. | ■ | ■ | ■ |
| 2.6 | Understand the principles of advanced communication and collaborative working with individuals, utilising the whole MDT service, colleagues and multiple agencies involved in the care of people affected by CYP cancer. | ■ | ■ | ■ |
| 2.7 | Understand the Levels of Psychological support described in the NICE 2004 Supportive and Palliative Care Guidelines and is able to operate at Level 2. | ■ | ■ | ■ |
| 2.8 | Demonstrate further education to supplement Level 2 psychological support, such as basic Cognitive Behavioural Therapy (CBT), Motivational Interviewing, basic Acceptance and Commitment Therapy (ACT). | | ■ | ■ |
| 2.9 | Demonstrate knowledge of assessing capacity, child protection considerations and the United Nations Convention on the Rights of the Child (1990) to manage or refer on requests from children for private conversations. | ■ | ■ | ■ |
| **Practice competencies: Practitioners will be able to:** | | | | |
| **Information and suppport** | | | | |
| 2.10 | Direct people affected by CYP cancer to appropriate agencies and information sources within the LTFU service. | ■ | ■ | ■ |
| 2.11 | Provide written, online and verbal information to people affected by CYP cancer about their condition and treatment | ■ | ■ | ■ |
| 2.12 | Explain complex medical terminology in lay terms. | ■ | ■ | ■ |
| 2.13 | Participate in or facilitate support groups for children and young people experiencing late consequences, or sign-post to services available. | ■ | ■ | ■ |
| 2.14 | Provide information about late psychosocial consequences to people affected by CYP cancer that requires advanced specialist knowledge. | | ■ | ■ |
| 2.15 | Lead on the development, audit and evaluation of patient information resources. | | ■ | ■ |
| 2.16 | Support people affected by CYP cancer in evaluating information in relation to their individual needs and preferences. | ■ | ■ | ■ |
| 2.17 | Access information from a range of resources and use it to meet the individual needs of people affected by CYP cancer. | ■ | ■ | ■ |
| 2.18 | Critically assess written information/websites prior to recommending these to people affected by CYP cancer. | ■ | ■ | ■ |
| 2.19 | Use specialist knowledge to provide telephone consultations autonomously to people affected by CYP cancer. | ■ | ■ | ■ |

Section 2 continued ▼

| | | | | |
|---|---|---|---|---|
| 2.20 | Provide advice and information relating to late consequences over the phone. | ■ | ■ | ■ |
| 2.21 | Develop strategies and guidelines for managing issues raised during telephone contact autonomously. | | ■ | ■ |
| 2.22 | Manage requests from children for private conversations, acknowledging their capacity, child protection considerations and the United Nations Convention on the Rights of the Child (1990). | ■ | ■ | ■ |
| 2.23 | Contribute to the development and evaluation of patient information resources within the LTFU service. | ■ | ■ | ■ |
| 2.24 | Use specialist knowledge to assess the supportive needs of people affected by CYP cancer. | ■ | ■ | ■ |
| 2.25 | Assist in the provision of planned education programmes for people affected by CYP cancer. | ■ | ■ | ■ |
| 2.26 | Work with agencies outside of the LTFU service to develop appropriate information and support. | | ■ | ■ |
| **Psychosocial care** | | | | |
| 2.27 | Communicate effectively and appropriately with people affected by CYP cancer along the developmental continuum. | ■ | ■ | ■ |
| 2.28 | Provide Psychology Level 2 information and support to people affected by CYP cancer on late consequences, management and treatment and services. | ■ | ■ | ■ |
| 2.29 | Provide advanced Psychology Level 2 information and support to people affected by CYP cancer on late consequences, management and treatment and services, utilising aspects of CBT, motivational interviewing and/or ACT. | | ■ | ■ |
| 2.30 | Use local pathways to refer people affected by CYP cancer with Level 3 or 4 psychosocial support needs to appropriate services. | ■ | ■ | ■ |
| 2.31 | Use specialist knowledge to foster the development of coping strategies that are effective for children and young people and their carers. | ■ | ■ | ■ |
| 2.32 | Provide advice and support to enable people affected by CYP cancer to manage consequences on their relationships with those important to them - carers, siblings, friends, partners. | ■ | ■ | ■ |
| 2.33 | Use complex strategies to deal with communication issues such as breaking bad news about relapse, secondary cancers or the development of new or worsening late consequences. | | ■ | ■ |
| 2.34 | Use knowledge and experience of the needs of people affected by CYP cancer to provide psychological support on a wide range of diverse issues. | ■ | ■ | ■ |
| 2.35 | Provide advice and support about work or new roles to ensure the people affected by CYP cancer are not inappropriately disadvantaged by the consequences of their diagnosis or treatment. | ■ | ■ | ■ |
| 2.36 | Use expert knowledge to effectively communicate with CYP and families in challenging situations. | | ■ | ■ |
| 2.37 | Work with families and other agencies to ensure the people affected by CYP cancer maximum individual potential is achieved. | | ■ | ■ |
| 2.38 | Act as an expert resource for other HCPs when dealing with complex and challenging communication issues. | | ■ | ■ |
| 2.39 | Work with other agencies to develop clear pathways for complex psychosocial support needs relating to LTFU care. | | ■ | ■ |

Section 2 continued ▼

## Work Based Record Sheet

| 2.0 | **Uses empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines.**<br>- information and support<br>- psychosocial care | **Practitioner level** (See key) | | | **Level of achievement required** Benner Taxonomy | **Self assessment** | **Level achieved** (Assessed) | | | **Evidence of achievement** |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | | | | | | **L** | **Date** | **Signature** | |
| E.G | Example: 2.13 Participate in or facilitate support groups for children and young people experiencing late consequences, or sign-post to services available. | | ✓ | | Proficient | Expert | E | 01.01.2023 | A.Grainger | - Worked with CNSs, play specialist, social workers and consultants on programme for end of treatment day<br>- Day delivered 01.05.22 - gave a talk to parents on LTFU services<br>- Evaluation feedback forms from participants<br>- Led meeting to discuss learning from event and changes for next one |
| 2.1 | Demonstrate a comprehensive understanding of the potential social consequences of cancer and its treatment on people affected by CYP cancer. | | | | | | | | | |
| 2.2 | Demonstrate knowledge of the psychological consequences of cancer and it's treatment on people affected by CYP cancer. | | | | | | | | | |
| 2.3 | Demonstrate knowledge of the impact of cancer and its treatment on psychosocial development in children and young people and the transition to adulthood. | | | | | | | | | |
| 2.4 | Discuss knowledge of support services and referral pathways available in region and nationally to support people affected by CYP cancer with LTFU and management of late consequences. | | | | | | | | | |
| 2.5 | Understand critical thinking skills and apply them to psychosocial LTFU care. | | | | | | | | | |

Section 2b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 2.6 | Understand the principles of advanced communication and collaborative working with individuals, utilising the whole MDT service, colleagues and multiple agencies involved in the care of people affected by CYP cancer. | ■ | ■ | ■ | | | | | | |
| 2.7 | Understand the Levels of Psychological support described in the NICE 2004 Supportive and Palliative Care Guidelines and is able to operate at Level 2. | ■ | ■ | ■ | | | | | | |
| 2.8 | Demonstrate further education to supplement Level 2 psychological support, such as basic Cognitive Behavioural Therapy (CBT), Motivational Interviewing, basic Acceptance and Commitment Therapy (ACT). | | ■ | ■ | | | | | | |
| 2.9 | Demonstrate knowledge of assessing capacity, child protection considerations and the United Nations Convention on the Rights of the Child (1990) to manage or refer on requests from children for private conversations. | ■ | ■ | ■ | | | | | | |
| **Practice competencies: Pracitioners will be able to:** | | | | | | | | | | |
| **Information and support** | | | | | | | | | | |
| 2.10 | Direct people affected by CYP cancer to appropriate agencies and information sources within the LTFU service. | ■ | ■ | ■ | | | | | | |
| 2.11 | Provide written, online and verbal information to people affected by CYP cancer about their condition and treatment. | ■ | ■ | ■ | | | | | | |
| 2.12 | Explain complex medical terminology in lay terms. | ■ | ■ | ■ | | | | | | |

Section 2b continued ▼

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 2.13 | Participate in or facilitate support groups for children and young people experiencing late consequences, or sign-post to services available. | ■ | ■ | ■ | | | | | | | |
| 2.14 | Provide information about late psychosocial consequences to people affected by CYP cancer that requires advanced specialist knowledge. | | ■ | ■ | | | | | | | |
| 2.15 | Lead on the development, audit and evaluation of patient information resources. | | ■ | ■ | | | | | | | |
| 2.16 | Support people affected by CYP cancer in evaluating information in relation to their individual needs and preferences. | ■ | ■ | ■ | | | | | | | |
| 2.17 | Access information from a range of resources and use it to meet the individual needs of people affected by CYP cancer. | ■ | ■ | ■ | | | | | | | |
| 2.18 | Critically assess written information/websites prior to recommending these to people affected by CYP cancer. | ■ | ■ | ■ | | | | | | | |
| 2.19 | Use specialist knowledge to provide telephone consultations autonomously to people affected by CYP cancer. | ■ | ■ | ■ | | | | | | | |
| 2.20 | Provide advice and information relating to late consequences over the phone. | ■ | ■ | ■ | | | | | | | |

Section 2b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 2.21 | Develop strategies and guidelines for managing issues raised during telephone contact autonomously. | | ■ | ■ | | | | | | |
| 2.22 | Manage requests from children for private conversations, acknowledging their capacity, child protection considerations and the United Nations Convention on the Rights of the Child (1990). | ■ | ■ | ■ | | | | | | |
| 2.23 | Contribute to the development and evaluation of patient information resources within the LTFU service. | ■ | ■ | ■ | | | | | | |
| 2.24 | Use specialist knowledge to assess the supportive needs of people affected by CYP cancer. | ■ | ■ | ■ | | | | | | |
| 2.25 | Assist in the provision of planned education programmes for people affected by CYP cancer. | ■ | ■ | ■ | | | | | | |
| 2.26 | Work with agencies outside of the LTFU service to develop appropriate information and support. | | ■ | ■ | | | | | | |
| **Psychosocial care** | | | | | | | | | | |
| 2.27 | Communicate effectively and appropriately with people affected by CYP cancer along the developmental continuum. | ■ | ■ | ■ | | | | | | |
| 2.28 | Provide Psychology Level 2 information and support to people affected by CYP cancer on late consequences, management and treatment and services. | ■ | ■ | ■ | | | | | | |

Section 2b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 2.29 | Provide advanced Psychology Level 2 information and support to people affected by CYP cancer on late consequences, management and treatment and services, utilising aspects of CBT, motivational interviewing and/or ACT. | | ▒ | ▓ | | | | | | |
| 2.30 | Use local pathways to refer people affected by CYP cancer with Level 3 or 4 psychosocial support needs to appropriate services. | ░ | ▒ | ▓ | | | | | | |
| 2.31 | Use specialist knowledge to foster the development of coping strategies that are effective for children and young people and their carers. | ░ | ▒ | ▓ | | | | | | |
| 2.32 | Provide advice and support to enable people affected by CYP cancer to manage late consequences on their relationships with those important to them – carers, siblings, friends, partners. | ░ | ▒ | ▓ | | | | | | |
| 2.33 | Use complex strategies to deal with communication issues such as breaking bad news about relapse, secondary cancers or the development of new or worsening late consequences. | | ▒ | ▓ | | | | | | |
| 2.34 | Use knowledge and experience of the needs of people affected by CYP cancer to provide psychological support on a wide range of diverse issues | ░ | ▒ | ▓ | | | | | | |
| 2.35 | Provide advice and support about work or new roles to ensure the people affected by CYP cancer are not inappropriately disadvantaged by the consequences of their diagnosis or treatment. | ░ | ▒ | ▓ | | | | | | |

Section 2b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 2.36 | Use expert knowledge to effectively communicate with CYP and families in challenging situations. | | | | | | | | | |
| 2.37 | Work with families and other agencies to ensure that children and young people's maximum individual potential is achieved. | | | | | | | | | |
| 2.38 | Act as an expert resource for other HCPs when dealing with complex and challenging communication issues. | | | | | | | | | |
| 2.39 | Work with other agencies to develop clear pathways for complex psychosocial support needs relating to LTFU care. | | | | | | | | | |

**Action plan** to achieve required competency level:

Reviewed by

| | |
|---|---|
| Signature and role: | |
| Signature and role: | |
| Signature and role: | |

# Section 3.

## Case management

| 3.0 | **Acts as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risks to patients from disease or treatment**<br>• self-management<br>• transitional care - supporting patients as they move from child/adolescent-centred to adult-orientated health care systems<br>• multi-Professional Team (MDT) working | **Registered Nurses providing specialist CYP Long-term follow-up and late effects cancer care** | | |
|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | **Enhanced** | **Advanced** | **Consultant** |
| 3.1 | Demonstrate awareness of key developments and milestones leading up to the age at transition, during transition, and into adulthood as young people learn self management, GP supported management or enter telephone or hospital based LTFU services. | ■ | ■ | ■ |
| 3.2 | Recognise the potential holistic care needs of people affected by CYP cancer and the contributions of other health and social care professionals in meeting these needs – for example youth support, educational and emotional support. | ■ | ■ | ■ |
| 3.3 | Identify the barriers and facilitators to achieving successful case management including promoting self-care, managing transitional care, and MDT working. | ■ | ■ | ■ |
| 3.4 | Recognise the importance of primary care services in providing local services for people affected by CYP cancer. | ■ | ■ | ■ |
| 3.5 | Understand when and how CYP affected by cancer may need rehabilitation services following treatment, including interventions for late effects. | ■ | ■ | ■ |
| 3.6 | Understand the phases of the transition process and ensure people affected by CYP cancer receive services appropriate to their age and individual needs | ■ | ■ | ■ |
| **Practice competencies: Practitioners will be able to:** | | **Enhanced** | **Advanced** | **Consultant** |
| **Self management** | | | | |
| 3.7 | Assess the ability and motivation of people affected by CYP cancer to manage self care. | ■ | ■ | ■ |
| 3.8 | Respond to changes in people's self care ability throughout their LTFU pathway (appropriate to their age, ability to understand as to their individual information needs). | ■ | ■ | ■ |
| 3.9 | Use communication skills to encourage people affected by CYP cancer to become more responsible for their own health. | ■ | ■ | ■ |
| 3.10 | Create care plans for people affected by CYP cancer to encourage self-care and self-reporting of any significant symptoms. | ■ | ■ | ■ |
| 3.11 | Teach children and young people to carry out self-monitoring and self-care and mentor them in the process. | | ■ | ■ |
| 3.12 | Identify risk and age-related behaviours in relation to adherence with care instructions or advice. | ■ | ■ | ■ |
| 3.13 | Support people affected by CYP cancer in healthy lifestyle choices and to reduce their risk factors given their consequences of cancer or treatment. | ■ | ■ | ■ |
| 3.14 | Respond to identified risk behaviours and take appropriate action to minimise their impact on adherence to care instructions and advice. | ■ | ■ | ■ |
| 3.15 | Assess individuals' progress, provide encouragement, and advise on difficulties with self- management. | ■ | ■ | ■ |
| 3.16 | Act as a resource to other staff in supporting children and young people with complex needs in relation to adherence with care instructions and advice. | | ■ | ■ |

Section 3 continued ▼

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|---|---|---|---|---|
| 3.17 | Work with other agencies to develop clear pathways for referral to support and information services within the long term follow-up service | | ■ | ■ |
| 3.18 | Proactively engage in promoting the self care principle at local, national and international forums. | | | ■ |
| 3.19 | Create services that can work in conjunction with, or link with primary care services. | | | ■ |
| **Transitional care** | | | | |
| 3.20 | Provide information to ensure people affected by CYP cancer have a good understanding of their diagnosis and associated late consequences, or risks for developing late consequences, to enable them to take an active role in their future care. | ■ | ■ | ■ |
| 3.21 | Provide support and information to enable people affected by CYP cancer to gradually take more responsibility for their own care ahead of transition and feel fully involved in the changes in care associated with the transition process. | | ■ | ■ |
| 3.22 | Guide people affected by CYP cancer in the use and updating of their care plan. | ■ | ■ | ■ |
| 3.23 | Provide practical and emotional support to encourage people affected by CYP cancer to develop their confidence in taking an active role in communicating with health professionals as appropriate. | ■ | ■ | ■ |
| 3.24 | Provide information to ensure people affected by CYP cancer are aware of the changes in care and service provision associated with the transition process. | ■ | ■ | ■ |
| 3.25 | Respect the privacy and confidentiality issues of people affected by CYP cancer as they move into adulthood and assume responsibility for their own health care. | ■ | ■ | ■ |
| 3.26 | Assess the emotional and psychological readiness of people affected by CYP cancer to take more responsibility for their own care, and develop appropriate individualised interventions to support them to do so. | | ■ | ■ |
| 3.27 | Support people affected by CYP cancer to develop the skills and confidence required to enable them to negotiate transition from parental responsibility to self-care and assisting parents/care givers with 'letting go.' | ■ | ■ | ■ |
| 3.28 | Develop treatment summaries and care plans to provide information to support the transfer of people affected by CYP cancer as they move from children's to young adult and adult health care services. | ■ | ■ | ■ |
| 3.29 | Participate in educational programmes including health education to support staff involved in transitional care. | ■ | ■ | ■ |
| 3.30 | Take a leading role in developing and implementing services to support transitional care from children's to young adult services and to adult health care in primary, secondary and tertiary care | | | ■ |
| 3.31 | Work with other agencies to develop clear pathways and guidelines for the transfer of LTFU care between services, including liaising with other agencies if periods of rehabilitation need are identified. | | | ■ |
| 3.32 | Develop educational programmes to enable young people to develop the knowledge, confidence and skills to take more responsibility for self-management and self-care and make healthy lifestyle choices. | | ■ | ■ |
| 3.33 | Develop approaches to monitoring transition arrangements and services to ensure they meet the needs of people affected by CYP cancer. | | | ■ |
| **Multi-Disciplinary Team Working** | | | | |
| 3.34 | Liaise between patients and family and members of the MDT involved in LTFU services to optimise care. | ■ | ■ | ■ |
| 3.35 | Make appropriate referrals to other members of the MDT involved in LTFU up services. | ■ | ■ | ■ |
| 3.36 | Communicate with the MDT coordinators and secretaries to ensure information is prepared for the MDT. | ■ | ■ | ■ |
| 3.37 | Attend MDT meetings in LTFU services. | ■ | ■ | ■ |

Section 3 continued ▼

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|---|---|---|---|---|
| 3.38 | Chair MDT meetings in the LTFU services. | | ■ | ■ |
| 3.39 | As a core member, present patients at LTFU MDT meetings. | ■ | ■ | ■ |
| 3.40 | Use communication and supportive skills to encourage people affected by CYP cancer to become more involved in consultations with the MDT. | ■ | ■ | ■ |
| 3.41 | Co-ordinate MDT interventions including complex discharge or treatment plans for people affected by CYP cancer. | ■ | ■ | ■ |
| 3.42 | Liaise with health care professionals in the community and sign-posts to other health care teams as appropriate. | ■ | ■ | ■ |
| 3.43 | Liaise with agencies outside the LTFU service in relation to current and anticipated future needs of individual patients for example, education and employment services. | ■ | ■ | ■ |
| 3.44 | Communicate effectively with the MDT using a wide range of strategies to promote patient experience and quality of care within the LTFU service. | ■ | ■ | ■ |
| 3.45 | Promote inter-professional working to ensure effective communication and develop the MDT approach to patient care delivery within the LTFU service. | | ■ | ■ |
| 3.46 | Work with the MDT to ensure people affected by CYP cancer pathways are robust, feasible, sustainable and promote quality care. | | ■ | ■ |
| 3.47 | Provide expert advice to other members of the MDT across the LTFU service. | | ■ | ■ |
| 3.48 | Play a leading role in developing LTFU service MDT operational policy and activities of the MDT meeting. | | ■ | ■ |

## Work Based Record Sheet

| 3.0 | **Acts as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risks to patients from disease or treatment**<br>• self-Management<br>• transitional care – supporting patients as they move from child/ adolescent-centred to adult-orientated health care systems<br>• multi-Professional Team (MDT) Working | **Practitioner level** (See key) | | | **Level of achievement required** Benner Taxonomy | **Self assessment** | **Level achieved** (Assessed) | | | **Evidence of achievement** |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | | | | | | **L** | **Date** | **Signature** | |
| E.G | Example: 3.27 Support people affected by CYP cancer to develop the skills and confidence required to enable them to negotiate transition from parental responsibility to self-care and assisting parents/care givers with 'letting go.' | ✓ | | | P | C | P | 01.01.2023 | A.Grainger | • Uses 'ready, steady, go' patient information with families regularly to inform them about transition process<br>• Provided case study of family who struggled with transition, discussing steps taken, and outcomes.<br>• Able to discuss content of NICE TYA Transition Guidance and how to apply in practice with supervisor. |
| 3.1 | Demonstrate awareness of key developments and milestones leading up to the age at transition, during transition, and into adulthood as young people learn self management, GP supported management or enter telephone or hospital based LTFU services. | | | | | | | | | |
| 3.2 | Recognise the potential holistic care needs of people affected by CYP cancer and the contributions of other health and social care professionals in meeting these needs – for example youth support, educational and emotional support. | | | | | | | | | |
| 3.3 | Identify the barriers and facilitators to achieving successful case management including promoting self-care, managing transitional care, and MDT working. | | | | | | | | | |
| 3.4 | Recognise the importance of primary care services in providing local services for people affected by CYP cancer. | | | | | | | | | |
| 3.5 | Understand when and how CYP affected by cancer may need rehabilitation services following treatment, including interventions for late effects. | | | | | | | | | |

Section 3b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 3.6 | Understand the phases of the transition process and ensures people affected by CYP cancer receive services appropriate to their age and individual needs. | ■ | ■ | ■ | | | | | | |
| **Practice competencies: Practitioners will be able to:** | | | | | | | | | | |
| **Self management** | | | | | | | | | | |
| 3.7 | Assess the ability and motivation of people affected by CYP cancer to manage self care. | ■ | ■ | ■ | | | | | | |
| 3.8 | Respond to changes in people's self care ability throughout their LTFU pathway (appropriate to their age, ability to understand as to their individual information needs). | ■ | ■ | ■ | | | | | | |
| 3.9 | Use communication skills to encourage people affected by CYP cancer to become more responsible for their own health. | ■ | ■ | ■ | | | | | | |
| 3.10 | Create care plans so that people affected by CYP cancer to encourage self-care and self-reporting of any significant symptoms. | ■ | ■ | ■ | | | | | | |
| 3.11 | Teach children and young people to carry out self-monitoring and self-care and mentor them in the process. | | ■ | ■ | | | | | | |
| 3.12 | Identify risk and age-related behaviours in relation to adherence with care instructions or advice. | ■ | ■ | ■ | | | | | | |

Section 3b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 3.13 | Support people affected by CYP cancer in healthy lifestyle choices and to reduce their risk factors given their consequences of cancer or treatment. | ■ | ■ | ■ | | | | | | |
| 3.14 | Respond to identified risk behaviours and take appropriate action to minimise their impact on adherence to care instructions and advice. | ■ | ■ | ■ | | | | | | |
| 3.15 | Assess individuals' progress, provide encouragement, and advise on difficulties with self- management. | ■ | ■ | ■ | | | | | | |
| 3.16 | Act as a resource to other staff in supporting children and young people with complex needs in relation to adherence with care instructions and advice. | | ■ | ■ | | | | | | |
| 3.17 | Work with other agencies to develop clear pathways for referral to support and information services within the long-term follow-up service. | | ■ | ■ | | | | | | |
| 3.18 | Proactively engage in promoting the self care principle at local, national and international forums. | | | ■ | | | | | | |
| 3.19 | Create services that can work in conjunction with, or link with primary care services. | | | ■ | | | | | | |
| **Transitional care** | | | | | | | | | | |
| 3.20 | Provide information to ensure people affected by CYP cancer have a good understanding of their diagnosis and associated late consequences, or risks for developing late consequences, to enable them to take an active role in their future care. | ■ | ■ | ■ | | | | | | |

Section 3b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 3.21 | Provide support and information to enable people affected by CYP cancer to gradually take more responsibility for their own care ahead of transition and feel fully involved in the changes in care associated with the transition process. | ▨ | ▨ | ▨ | | | | | | |
| 3.22 | Guide people affected by CYP cancer in the use and updating of their care plan. | ▨ | ▨ | ▨ | | | | | | |
| 3.23 | Provide practical and emotional support to encourage people affected by CYP cancer to develop their confidence in taking an active role in communicating with health professionals as appropriate. | ▨ | ▨ | ▨ | | | | | | |
| 3.24 | Provide information to ensure people affected by CYP cancer are aware of the changes in care and service provision associated with the transition process. | ▨ | ▨ | ▨ | | | | | | |
| 3.25 | Respect the privacy and confidentiality issues of people affected by CYP cancer as they move into adulthood and assume responsibility for their own health care. | ▨ | ▨ | ▨ | | | | | | |
| 3.26 | Assess the emotional and psychological readiness of people affected by CYP cancer to take more responsibility for their own care, and develop appropriate individualised interventions to support them to do so. | | ▨ | ▨ | | | | | | |
| 3.27 | Support people affected by CYP cancer to develop the skills and confidence required to enable them to negotiate transition from parental responsibility to self-care and assisting parents/care givers with 'letting go.' | ▨ | ▨ | ▨ | | | | | | |
| 3.28 | Develop treatment summaries and care plans to provide information to support the transfer of people affected by CYP cancer as they move from children's to young adult and adult health care services. | ▨ | ▨ | ▨ | | | | | | |

Section 3b continued ▼

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 3.29 | Participate in educational programmes including health education to support staff involved in transitional care. | ■ | ■ | ■ | | | | | | |
| 3.30 | Take a leading role in developing and implementing services to support transitional care from children's to young adult services and to adult health care in primary, secondary and tertiary care. | | | ■ | | | | | | |
| 3.31 | Work with other agencies to develop clear pathways and guidelines for the transfer of LTFU care between services, including liaising with other agencies if periods of rehabilitation need are identified. | | | ■ | | | | | | |
| 3.32 | Develop educational programmes to enable young people to develop the knowledge, confidence and skills to take more responsibility for self-management and self-care and make healthy lifestyle choices. | | ■ | ■ | | | | | | |
| 3.33 | Develop approaches to monitoring transition arrangements and services to ensure they meet the needs of people affected by CYP cancer. | | | ■ | | | | | | |
| **Multi-Disciplinary Team working** | | | | | | | | | | |
| 3.34 | Liaise between patients and family and members of the MDT involved in LTFU services to optimise care. | ■ | ■ | ■ | | | | | | |
| 3.35 | Make appropriate referrals to other members of the MDT involved in LTFU services. | ■ | ■ | ■ | | | | | | |
| 3.36 | Communicate with the MDT coordinators and secretaries to ensure information is prepared for the MDT. | ■ | ■ | ■ | | | | | | |

Section 3b continued ▼

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 3.37 | Attend MDT meetings in LTFU services. | ■ | ■ | ■ | | | | | | |
| 3.38 | Chair MDT meetings in the LTFU services. | | ■ | ■ | | | | | | |
| 3.39 | As a core member, present patients at LTFU MDT meetings. | ■ | ■ | ■ | | | | | | |
| 3.40 | Use communication and supportive skills to encourage people affected by CYP cancer to become more involved in consultations with the MDT. | ■ | ■ | ■ | | | | | | |
| 3.41 | Co-ordinate MDT interventions including complex discharge or treatment plans for people affected by CYP cancer. | ■ | ■ | ■ | | | | | | |
| 3.42 | Liaise with health care professionals in the community and sign-posts to other health care teams as appropriate. | ■ | ■ | ■ | | | | | | |
| 3.43 | Liaise with agencies outside the LTFU service in relation to current and anticipated future needs of individual patients for example, education and employment services. | ■ | ■ | ■ | | | | | | |
| 3.44 | Communicate effectively with the MDT using a wide range of strategies to promote patient experience and quality of care within the LTFU service. | ■ | ■ | ■ | | | | | | |

Section 3b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 3.45 | Promote inter-professional working to ensure effective communication and develop the MDT approach to patient care delivery within the LTFU service | | | | | | | | | |
| 3.46 | Work with the MDT to ensure people affected by CYP cancer pathways are robust, feasible, sustainable and promote quality care. | | | | | | | | | |
| 3.47 | Provide expert advice to other members of the MDT across the LTFU service. | | | | | | | | | |
| 3.48 | Play a leading role in developing LTFU service MDT operational policy and activities of the MDT meeting. | | | | | | | | | |

**Action plan** to achieve required competency level:

Reviewed by

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| Signature and role: | |
| Signature and role: | |
| Signature and role: | |

# Section 4.
# Quality improvement

| 4.0 | **Uses experience, clinical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make the service responsive to patient need.**<br>• research, audit and service evaluation<br>• service development<br>• education | **Registered Nurses providing specialist CYP long-term follow-up and late effects cancer care** | | |
|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | **Enhanced** | **Advanced** | **Consultant** |
| 4.1 | Understand quality improvement principles and how to relate these to research, audit, service evaluation, service development and education. | ■ | ■ | ■ |
| 4.2 | Discuss appropriate research and evaluation methodologies useful in improving understanding of late consequences of cancer treatment. | ■ | ■ | ■ |
| 4.3 | Understand workforce development for self and colleagues, contributing to sustainable LTFU service delivery. | ■ | ■ | ■ |
| 4.4 | Understand principles of budget monitoring and financial reporting for the LTFU service. | | ■ | ■ |
| 4.5 | Demonstrate a working knowledge of the late consequences of cancer treatment and LTFU delivery models, to a level that facilitates educating and supporting others in the basics. | ■ | ■ | ■ |
| 4.6 | Demonstrate an advanced (broad and deep) level of knowledge of the consequences of cancer treatments and LTFU service delivery models, to a level that facilitates educating more senior and/or specialist healthcare professionals. | | ■ | ■ |
| 4.7 | Evidence a specialist qualification at (Level 4 PGCert or 5 Diploma – England, N.Ireland & Wales) (Level 7 HNC/Cert HC or 8 HND/DipHE- Scotland). | ■ | | |
| 4.8 | Evidence a specialist qualification at (Level 6 Degree, England, N.Ireland & Wales) (Level 9 Graduate diploma/degree or 10 degree with honours- Scotland) | ■ | | |
| 4.9 | Evidence a specialist qualification at advanced level (Level 7 Masters or 8 Doctorate - England, N.Ireland & Wales) (Level 11 Masters or 12 Doctoral -Scotland). | | ■ | ■ |
| **Practice competencies: Practitioners will be able to:** | | **Enhanced** | **Advanced** | **Consultant** |
| **Research, audit and service evaluation** | | | | |
| 4.10 | Collect data required for service evaluation, audit or research within the LTFU service. | ■ | ■ | ■ |
| 4.11 | Play a leading role in local and network audits within the LTFU service MDT. | | ■ | ■ |
| 4.12 | Show awareness of and engagement in research and evidence based practice for LTFU. | ■ | ■ | ■ |
| 4.13 | Take a key or leading role in LTFU implementing research findings and establishing the evidence base for the LTFU service. | | ■ | ■ |
| 4.14 | Carry out service evaluation and audit of key aspects of own practice within the LTFU service for example, patient satisfaction, and local, national or international service standards. | ■ | ■ | ■ |
| 4.15 | Lead in the design and completion of service review and audit projects of the LTFU service. | | | ■ |
| 4.16 | Lead in the design and completion of research projects within the LTFU service. | | | ■ |
| 4.17 | Contribute to the development and completion of service review, audit and local research in LTFU services | ■ | ■ | ■ |
| 4.18 | Demonstrate an understanding of the principles of clinical research and explain to people affected by CYP cancer the meaning of common terms and concepts (for example, placebo, randomisation, qualitative research, patient reported outcomes, informed consent). | ■ | ■ | ■ |

Section 4 continued ▼

| | | | | |
|---|---|---|---|---|
| 4.19 | Present posters or papers at conferences on own specialty or service review. | ■ | ■ | ■ |
| 4.20 | Write for publication on own specialty e.g. Journal articles on specific aspect of late effects care or book chapters. | | ■ | ■ |
| 4.21 | Identify problems experienced by people affected by CYP cancer that can be the focus of research. | | ■ | ■ |
| 4.22 | Write for publication on own research relating to LTFU service and consequences of treatment. | | ■ | ■ |
| 4.23 | Develop relationships with other agencies to promote research and enterprise partnerships within LTFU service. | | | ■ |
| **Service development** | | | | |
| 4.24 | Use expert knowledge to inform the development and delivery of local LTFU services. | | ■ | ■ |
| 4.25 | Contribute to the development of the late effects service by identifying concerns or gaps in the service and sharing them with senior colleagues. | ■ | ■ | ■ |
| 4.26 | Respond to service deficits and develop strategic plans for LTFU service, including workforce development planning. | | ■ | ■ |
| 4.27 | Demonstrate awareness that the views of service users are important to influence change in practice. | ■ | ■ | ■ |
| 4.28 | Engage people affected by CYP cancer to obtain their views of service delivery and improvement. | ■ | ■ | ■ |
| 4.29 | Respond positively to change to improve clinical services. | ■ | ■ | ■ |
| 4.30 | Use specialist knowledge to contribute to the development of evidence-based policies and procedures for LTFU care. | ■ | ■ | ■ |
| 4.31 | Represent the long-term follow-up service or own discipline within the LTFU service at local strategic meetings. | ■ | ■ | ■ |
| 4.32 | Build partnerships with health, social, voluntary and independent sectors to develop the LTFU service. | | | ■ |
| 4.33 | Contribute to the development of service reports within the LTFU service. | ■ | ■ | ■ |
| 4.34 | Develop evidence-based protocols and guidelines for the LTFU service. | | ■ | ■ |
| 4.35 | Monitor and evaluate LTFU protocols and policies. | | ■ | ■ |
| 4.36 | Represent the long-term follow-up service or own discipline within the LTFU at regional and national meetings. | ■ | ■ | ■ |
| 4.37 | Play a leading role in the development of business cases and service reports within the LTFU service. | | ■ | ■ |
| 4.38 | Hold the budget for the LTFU, contribute to and lead financial planning for the LTFU service. | | | ■ |
| 4.39 | Influence LTFU care policy at local and national level. | | ■ | ■ |

Section 4 continued ▼

| **Education** | | | | |
|---|---|---|---|---|
| 4.40 | Teach and supervise staff in the late consequences of cancer and its treatments in a range of settings. | ■ | ■ | ■ |
| 4.41 | Support and educate multi-professional staff on the delivery of specialist LTFU care. | ■ | ■ | ■ |
| 4.42 | Provide formal taught sessions on late consequences of cancer and its treatments on local, regional and national study days. | ■ | ■ | ■ |
| 4.43 | Teach on externally run educational programmes on the late consequences of cancer and treatment, for example, on undergraduate and postgraduate training programmes. | ■ | ■ | ■ |
| 4.44 | Participate in creating and delivering local and national programmes of education on late consequences of care and treatment for example, study days and conferences. | ■ | ■ | ■ |
| 4.45 | Create local and network educational programmes for other Health Care Professionals in LTFU care. | | ■ | ■ |
| 4.46 | Create educational programmes on LTFU care for academic credit in liaison with university. | | | ■ |
| 4.47 | Advise on the workforce development needs to achieve or maintain a sustainable LTFU service. | | ■ | ■ |

## Work Based Record Sheet

| 4.0 | **Uses experience, clinical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make the service responsive to patient need**<br>• research, audit and service evaluation<br>• service development<br>• education | **Practitioner level** (See key) | | | **Level of achievement required** Benner Taxonomy | **Self assessment** | **Level achieved** (Assessed) | | | **Evidence of achievement** |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Learning outcomes: Practitioners will be able to:** | | | | | | **L** | **Date** | **Signature** | |
| E.G | Example 4.11 Play a leading roll in local and network audits within the LTFU service. | ░ | ✓ | ▓ | P | AB | C | 01.01.2023 | A.Grainger | • Attended audit meetings within the department.<br>• Conducted an audit looking at the transition process in the LTFU clinic against NICE guidance |
| 4.1 | Understand quality improvement principles and how to relate these to research, audit, service evaluation, service development and education. | ░ | ▒ | ▓ | | | | | | |
| 4.2 | Discuss appropriate research and evaluation methodologies useful in improving understanding of late consequences of cancer treatment. | ░ | ▒ | ▓ | | | | | | |
| 4.3 | Understand workforce development for self and colleagues, contributing to sustainable LTFU service delivery. | ░ | ▒ | ▓ | | | | | | |
| 4.4 | Understand principles of budget monitoring and financial reporting for the LTFU service. | | ▒ | ▓ | | | | | | |
| 4.5 | Demonstrate a working knowledge late consequences of cancer treatment and LTFU service delivery models, to a level that facilitates educating and supporting others in the basics. | ░ | ▒ | ▓ | | | | | | |
| 4.6 | Demonstrate an advanced (broad and deep) level of knowledge of the consequences of cancer treatments and LTFU service delivery models, to a level that facilitates educating more senior and/or specialist healthcare professionals. | | ▒ | ▓ | | | | | | |

Section 4b continued ▼

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 4.7 | Evidence a specialist qualification at (Level 4 PGCert or 5 Diploma - England, N.Ireland & Wales) (Level 7 HNC/Cert HC or 8 HND/ DipHE- Scotland). | ■ | | | | | | | | |
| 4.8 | Evidence a specialist qualification at (Level 6 Degree, England, N.Ireland & Wales) (Level 9 Graduate diploma/degree or 10 degree with honours- Scotland). | ■ | | | | | | | | |
| 4.9 | Evidence a specialist qualification at advanced level (Level 7 Masters or 8 Doctorate - England, N.Ireland & Wales) (Level 11 Masters or 12 Doctoral -Scotland). | | ■ | ■ | | | | | | |
| **Practice competencies: Practitioners will be able to:** | | | | | | | | | | |
| **Information and support** | | | | | | | | | | |
| 4.10 | Collect data required for service evaluation, audit or research within the LTFU service. | ■ | ■ | ■ | | | | | | |
| 4.11 | Play a leading role in local and network audits within the LTFU service MDT. | | ■ | ■ | | | | | | |
| 4.12 | Show awareness of and engagement in research and evidence based practice for LTFU. | ■ | ■ | ■ | | | | | | |
| 4.13 | Take a key or leading role in LTFU implementing research findings and establishing the evidence base for the LTFU service. | | ■ | ■ | | | | | | |
| 4.14 | Carry out service evaluation and audit of key aspects of own practice within the LTFU service for example, patient satisfaction, and local, national or international service standards. | ■ | ■ | ■ | | | | | | |

Section 4b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 4.15 | Lead in the design and completion of service review and audit projects of the LTFU service. | | | ■ | | | | | | |
| 4.16 | Lead in the design and completion of research projects within the LTFU service. | | | ■ | | | | | | |
| 4.17 | Contribute to the development and completion of service review, audit and local research in LTFU services. | ■ | ■ | ■ | | | | | | |
| 4.18 | Demonstrate an understanding of the principles of clinical research and explain to people affected by CYP cancer the meaning of common terms and concepts (for example, placebo, randomisation, qualitative research, patient reported outcomes, informed consent). | ■ | ■ | ■ | | | | | | |
| 4.19 | Present posters or papers at conferences on own specialty or service review. | ■ | ■ | ■ | | | | | | |
| 4.20 | Write for publication on own specialty e.g. Journal articles on specific aspect of late effects care or book chapters. | | ■ | ■ | | | | | | |
| 4.21 | Identify problems experienced by people affected by CYP cancer that can be the focus of research . | | ■ | ■ | | | | | | |
| 4.22 | Write for publication on own research relating to LTFU service and consequences of treatment. | | ■ | ■ | | | | | | |

Section 4b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 4.23 | Develop relationships with other agencies to promote research and enterprise partnerships within LTFU service. | | | ■ | | | | | | |
| **Service Development** | | | | | | | | | | |
| 4.24 | Use expert knowledge to inform the development and delivery of local LTFU services. | | ■ | ■ | | | | | | |
| 4.25 | Contribute to the development of the LTFU service by identifying concerns or gaps in the service and sharing them with senior colleagues. | ■ | ■ | ■ | | | | | | |
| 4.26 | Respond to service deficits and develop strategic plans for LTFU service, including workforce development planning. | | | ■ | | | | | | |
| 4.27 | Demonstrate awareness that the views of service users are important to influence change in practice. | ■ | ■ | ■ | | | | | | |
| 4.28 | Engage people affected by CYP cancer to obtain their views of service delivery and improvement. | ■ | ■ | ■ | | | | | | |
| 4.29 | Respond positively to change to improve clinical services. | ■ | ■ | ■ | | | | | | |
| 4.30 | Use specialist knowledge to contribute to the development of evidence-based policies and procedures for LTFU care. | ■ | ■ | ■ | | | | | | |

Section 4b continued ▼

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 4.31 | Represent the long-term follow-up service or own discipline within the long-term follow-up service at local strategic meetings. | ■ | ■ | ■ | | | | | | |
| 4.32 | Build partnerships with health, social, voluntary and independent sectors to develop the long-term follow-up service. | | | ■ | | | | | | |
| 4.33 | Contribute to the development of service reports within the long-term follow-up service. | ■ | ■ | ■ | | | | | | |
| 4.34 | Develop evidence-based protocols and guidelines for the long-term follow-up service. | | ■ | ■ | | | | | | |
| 4.35 | Monitor and evaluate LTFU protocols and policies. | | ■ | ■ | | | | | | |
| 4.36 | Represent the long-term follow-up service or own discipline within the LTFU service at regional and national meetings. | ■ | ■ | ■ | | | | | | |
| 4.37 | Play a leading role in the development of business cases and service reports within the LTFU service. | | ■ | ■ | | | | | | |
| 4.38 | Hold the budget for the LTFU, contribute to and lead financial planning for the LTFU service. | | | ■ | | | | | | |

Section 4b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 4.39 | Influence LTFU care policy at local and national level. | | ■ | ■ | | | | | | |
| **Education** | | | | | | | | | | |
| 4.40 | Teach and supervise staff in the late consequences of cancer and its treatments in a range of settings. | ■ | ■ | ■ | | | | | | |
| 4.41 | Support and educate multi-professional staff on the delivery of specialist LTFU care. | ■ | ■ | ■ | | | | | | |
| 4.42 | Provide formal taught sessions on late consequences of cancer and its treatments on local, regional and national study days. | ■ | ■ | ■ | | | | | | |
| 4.43 | Teach on externally run educational programmes on the late consequences of cancer and treatment, for example, on undergraduate and postgraduate training programmes. | ■ | ■ | ■ | | | | | | |
| 4.44 | Participate in creating and delivering local and national programmes of education on late consequences of care and treatment for example, study days and conferences. | ■ | ■ | ■ | | | | | | |
| 4.45 | Create educational programmes on LTFU care for academic credit in liaison with university. | | ■ | ■ | | | | | | |
| 4.46 | Create educational programmes on LTFU care for academic credit in liaison with university | | | ■ | | | | | | |

Section 4b continued ▼

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|---|---|---|---|---|---|---|---|---|---|---|
| 4.47 | Advise on the workforce development needs to achieve or maintain a sustainable LTFU service. | | 🟩 | 🟦 | | | | | | |

**EXAMPLE**
**Action plan:** Emily has worked on a local audit but wants a stretch objective to Proficient taxonomy. Discussed expanding the local audit, and comparing the transition process in the LTFU clinics in regional centres.
A. Grainger 28.03.21

**Action plan** to achieve required competency level:

Reviewed by

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| Signature and role: | |
| Signature and role: | |
| Signature and role: | |

# Acronyms and glossary

# Acronyms & glossary

| | |
|---|---|
| **AYA** | Adolescent and young adult (This is more global terminology but known as TYA in the UK – see below). |
| **ANP/ACP** | Advanced Nurse Practitioner or Advanced Clinical Practitioner. |
| **Cancer service** | Includes solid tumours, haematological malignancies, neuro-oncology, benign tumours, bone marrow failure disorders and cancer-like diseases. |
| **Care giver/carers** | A person with significant caring responsibility such as a parent, partner or legal guardian.<br>It can also relate to those with temporary responsibilities for the child or young person, such as Grandparents and other relatives, teachers, and other responsible adults such as friends and neighbours. |
| **CANUK** | Cancer Aftercure Nurses UK (a special interest group within CCLG/ TYAC). |
| **CCLG** | Children's Cancer and Leukaemia Group. |
| **CYP** | Children and young people. |
| **DH** | Designated Hospital for TYA cancer (as described in NHS England service specifications – terms used UK wide). |
| **GCP** | Good Clinical Practice. |
| **HNA** | Holistic Needs Assessment. |
| **HSCT** | Haematopoietic Stem Cell Transplant. |
| **IRMER** | Ionising Radiation (Medical Exposure) Regulations. |
| **MDT** | Multidisciplinary Team, also referred to as multi-professional team in practice. |
| **People affected by CYP cancer** | People affected by children and young people cancer<br>This terminology is used throughout the document to encompass many people; the list is not exhaustive: patients, parents, carers, partners, siblings, family, friends, teachers, club leaders, etc. This recognises that people who are survivors of childhood or young people's cancers may now be adults. |
| **POSCU** | Paediatric Oncology Shared Care Unit (as described in NHS England service specifications – terms used UK wide). |
| **PTC** | Principal Treatment Centre (as described in NHS England service specifications – terms used UK wide). |
| **SACT** | Systemic anti-cancer therapy. |
| **Supra-specialised** | Cancer is a highly specialised field employing professionals who are recognised as specialising in the field. Certain roles are further specialised again and usually need the cancer specialisation as a pre-requisite. Examples, CYP cancer research nurses, HSCT nurses, long-term follow-up & late effects nurses, palliative care nurses. |

# Acronyms & glossary

| | |
|---|---|
| **TBI** | Total Body Irradiation |
| **TYA** | Teenagers and Young Adults |
| **TYAC** | Teenagers and Young Adults with Cancer |
| **WBRS** | Work-Based Record Sheet. Form to sign off competencies in this framework |
| **YP** | Young person |

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# Appendix 1:
# How this update was conducted

# Appendix 1: How this update was conducted

The Royal College of Nursing identified that this framework was overdue a scheduled review, but as the Department of Health National Cancer Survivorship Initiative team who originated this work in 2011, were no longer a defined working group, they approached the RCN / CCLG Children and Young People Cancer Nurses Community to undertake this work. A working group was established to update this framework derived from members of the CCLG Cancer Aftercure Nurses UK group (CANUK). The working party has expertise in supra-specialist late-effects roles.

The working group updated this framework in line with similar frameworks (HEE, 2023). References were reviewed and updated, and known practice developments were updated, such as the expansion of targeted and biological therapies in cancer care. The update was then reviewed by the wider CANUK membership (no.48 ) and CCLG multi-professional Late Effects Group Chairs (No.2). This is described in Fig 4.

The resultant career and education framework provides a comprehensive set of skills and knowledge competency statements which illustrate the breadth and depth of specialist long-term follow-up cancer nursing. It is intended that the framework be used to support academic, theoretical and practical skill acquisition for post-registration nurses practicing at enhanced, advanced or consultant levels.

Figure 4. Outline of the iterative process undertaken to review and update this career and competency framework.

2021 RCN CYP Nursing Lead contacted chairs of the RCN/CCLG CYP cancer nurses group (CYPCN) to notify of scheduled review due for the document; "Competences: An integrated career and competence framework for nurses working in the field of long-term follow-up and late effects care of children and young people after cancer (2011)."

March 2021 CYPCN Chairs contacted 'Cancer AfterCure Nurses UK' (CANUK) to undertake this review. CANUK is the late effects nursing supra-specialist group within the CCLG.
Need for the framework assessed and confirmed by the wider CANUK group.

June 2021 Working party established to review the framework with project management support from CCLG Chief Nurse.

July 2021 - December 2022 Framework structure re-assessed against contemporary similar documents in the field of cancer nursing, and revised for parity.

- ownership of document evaluated since original authors and the National Cancer Survivorship Initiative (NCSI) team at NHS Improvement have moved on

2021 - 2022

- CAYA cancer survivorship literature review to update evidence base.
- documents updated and reviewed in successive rounds by the working party
- working party provided expert input regarding current clinical practice in UK, relating to the evidence base

Dec 2022 - Feb 2023 Penultimate drafts shared with stakeholders in the CANUK group, CCLG Late Effects multi-professional group, CYP cancer Nurses Group, International PanCare Meeting Hungary Oct 22

- iterative process enabled consensus to be reached

May 2023 Final draft shared with RCN Endorsement for approval prior to final design.

- document design by CCLG for both digital and booklet formats
- EONS Endorsements applied for May 2023

May 2023 Communication Plan developed plan and launch date advised November 2023.

# Appendix 2:
# Who benefits from standardised career and education frameworks?

# Appendix 2:
# Who benefits from standardised career and education frameworks?

The framework aims to benefit individual nurses, employers, education providers and organisations alongside people affected by CYP cancer (Stanford, 2016; CIPD, 2021). It may achieve this in any number of ways, including those identified below.

## Individual nurses

**A framework for personal and professional development, enabling:**

- consideration of the requirements for a career in CYP cancer
- self-assessment of knowledge and skills
- identification of continuous professional development requirements
- structured career development
- development of an individual portfolio which may support Revalidation (NMC, 2021b)
- opportunities to influence the direction of practice
- foster and improve professional relationships with medical colleagues and allied health professionals through a greater understanding of skills and responsibilities

## Trust/local educators, facilitators, and managers

**A framework:**

- to support individual nurses' development
- to support development of induction programmes for staff new to the role
- for formal appraisal, supporting assessment of competence
- for identification of individual and team training needs
- for planning and delivery of study sessions/days
- for planning and procurement/delivery of academic courses

## Employers/organisations

**A framework:**

- enabling identification of knowledge and competence requirements of late effects nurses
- to support risk management and workforce planning
- to guide consistently high standards of care
- giving clearer insight into the expertise and competence of nursing staff in this field

## Academic institutions/education providers

**A framework:**

- to map course content to support the needs of nurses providing long-term follow-up care
- to support planning and delivery of academic courses

## Patients, their families, and the public

**In addition to the above, which support patient care, the framework should inspire:**

- increased effectiveness to service provision
- improved access and choice for care provision
- facilitate early identification of late effects
- promote timely intervention for late effects
- assist patients with the transition from children to adult LTFU care as needed
- provide a model of follow-up care that supports the patient throughout their lifespan
- promote healthy lifestyles
- promote self-monitoring of health after cancer treatment

# Appendix 3: Alignment/mapping to national transferable standards

# Appendix 3:
# Alignment/mapping to national transferable standards

This competence framework has been developed to guide practice and provide a framework for training and development for nurses working within the field of CYP cancer care. It should be used in conjunction with other core and specialist standards and competence frameworks, as appropriate to the individual nurse and their working environment.

**The following documents informed development of this career and competence framework:**
Children's Cancer & Leukaemia Group (2021) Advanced Clinical Practitioner Paediatric Oncology & Haematology Capability Document

Children's Cancer & Leukaemia Group (CCLG) and Royal College of Nursing (RCN) (2022) Career and Education Framework for Children and Young People (CYP) Cancer Nursing V3.0: Guidance for; Pre-registration nursing child branch students, Registered nurses in general settings, Support workers, Nursing Associates, and Registered Nurses in specialist CYP cancer care

European Oncology Nursing Society (2018) The EONS cancer nursing education framework

Health Education England (2017) Multi-professional Framework for Advanced Clinical Practice in England

Royal College of Nursing (2021c) Nursing Workforce Standards

Teenage Cancer Trust & Royal College of Nursing (2014) Competencies: Caring for Teenagers and Young Adults with Cancer: A Competence and Career Framework for Nursing

ACCEnD Career Pathway, Core Cancer Capabilities, and Education Framework (2023)

Workforce Development Trust (2021) Skills for Health Competencies

# Appendix 4:
# Relationship to RCN core competencies and sustainability

# Appendix 4:
# Relationship to RCN core competencies and sustainability

These items aim to reflect how all RCN endorsed work has considered equality, diversity and sustainability.

## RCN core behavioural competencies and Equality & Diversity

This framework is aligned to, and expects demonstration of, the RCN core behaviours outlined in their values statement: (https://careers.rcn.org.uk/about-us/our-values)

The six core behavioural competencies are:
- stay one step ahead
- inspire others to greater heights
- build outstanding relationships
- get to the heart of the business
- show passion for our services
- value those around you

The RCN Dignity Charter (RCN 2010) and Respect Charter (RCN, 2017) embraces diversity and treating others with respect. This framework is strongly embedded in the principles of respect and diversity, equality, inclusion and belonging for both staff and the public we serve.

## United Nations Sustainable Development Goals

We know cancer 'costs' across many domains of a families' life (Young Lives vs Cancer 2018). We work holistically and across organisations and agencies to ensure CYP with cancer and their families do not end up disadvantaged because of their cancer diagnosis. The United Nations (UN) sustainable development goals encompass 17 goals that provide "a blueprint for peace and prosperity for people and the planet, now and into the future" (United Nations, 2015). This career and competency framework is broadly supportive of all 17 goals and would positively influence the 5 listed goals.
- Goal 3 Good Health and Wellbeing
- Goal 4 Quality Education
- Goal 5 Gender equality
- Goal 10 reduce inequalities
- Goal 16 Peace, justice, and strong institutions

# Appendix 5: Acknowledgements

# Appendix 5: Acknowledgements

We are most grateful to the authors of the original publication 'Competencies: An integrated career and competence framework for nurses working in the field of long-term follow-up and late effects care of children and young people after cancer,' (2011). The original project was commissioned as part of a programme of work undertaken by the National Cancer Survivorship Initiative's Children and Young People Work stream, funded by the Department of Health (DH) in partnership with NHS Improvement and Macmillan Cancer Support. NHS Improvement worked in partnership with the Department of Health and Macmillan UK to support the delivery of the National Cancer Survivorship Initiative (NCSI). That initiative was designed to test, develop, and recommend the provision of appropriate aftercare to each and every cancer patient 'living with and beyond cancer 'to meet their individual holistic needs.

**The original NCSI Children and Young People workstream was led by Diana Greenfield and Clare Warnock at Sheffield Teaching Hospitals NHS Foundation Trust, in partnership with Sheffield Children's Hospital NHS Foundation Trust and supported by the North Trent Cancer Network and the Yorkshire and the Humber Specialised Commissioning Group (SCG). (Warnock, C., Siddall, J., Freeman, J., & Greenfield, D., 2013)**
The foundation of that work built on efforts to implement the recommendations of the National Institute for Health and Clinical Excellence's guidance Improving out comes in children and young people with cancer: the manual (NICE, 2005).

We would like to thank members of the CCLG Cancer Aftercure Nurses United Kingdom (CANUK) for supporting the review of this career and education framework for nurses working in long-term follow-up and late-effects services for survivors of childhood cancer.

We are most grateful to the Royal College of Nursing who supported the original publication in 2011, and this review.

The document outputs would not have been possible without the resources and support of CCLG graphic designer, and project management support from the CCLG Chief Nurse funded by Young Lives vs Cancer. We give our heartfelt thanks to both organisations for their commitment to quality patient care through nursing education.

## Working group members: V.20 2022 Review

- Charlotte Granville-George: TYA Clinical Nurse Specialist in Late Effects, Cambridge University Hospital NHS Foundation Trust.
- Hannah Greene: Clinical Nurse Specialist in Late Effects (Working group Chair), Cambridge University Hospital NHS Foundation Trust.
- Jeanette Hawkins: Chief Nurse Children's Cancer & Leukaemia Group (CCLG) funded by Young Lives vs Cancer (Project Management only).
- Claire Strong: Clinical Nurse Specialist in Late Effects, Sheffield Children's NHS Foundation Trust.
- Nicky Webb: Macmillan Clinical Nurse Specialist, Long-term follow-up survivors of childhood cancer, Nottingham University Hospitals NHS Trust.

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Email: info@cclg.org.uk F.A.O. Chief Nurse
www.rcn.org.uk/Get-Involved/Forums/Children-and-Young-People-Specialist-Care-Forum/Communities/CYP-Cancer-Nurses Use the link to the current listed group chair named at the bottom of the page under "Members can get involved by contacting…."

Live Feedback and opportunity to ask questions via CCLG Nursing Members based in all UK Principal Treatment Centres on the CCLG Connect Platform in the Nursing Networks thread. connect.cclg.org.uk/c/nursing-networks/canuk/34

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Leicester LE1 7GB

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0333 050 7654
info@cclg.org.uk
www.cclg.org.uk

ChildrensCLG
CCLG_UK
CCLG_UK