Children's Health Ireland

National Cancer
Control Programme

National Model of Care for
Psycho-Oncology Services for Children, Adolescents and Young Adults with Cancer
and their families in Ireland

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Contents

Foreword

The National Cancer Control Programme is delighted to publish the National Model of Care (MoC) for Psycho-Oncology Services for Children, Adolescents and Young Adults (CAYA) with Cancer and their families in Ireland.

It is an ambitious undertaking, aiming to address the psychosocial needs of people who develop cancer in the substantial age range of 0 to 24 years. It is well recognised that this cohort of patients and their families have particular psychosocial needs. It is intended that this MoC will begin to address these needs over the lifetime of the current National Cancer Strategy and beyond.

Since the publication of the third National Cancer Strategy in 2017, there has been an added emphasis on the need for Psycho-Oncology services in both hospital and community settings, for all patients with cancer. This has been driven not only by professionals who deliver these services, but, importantly, by the children and young people who live with cancer, and their parents, who are only too acutely aware of the demands that a cancer diagnosis brings at a time of great developmental change in the lives of these children and young people and the lives of their siblings.

The MoC highlights the need for fair and equitable access to services. I am especially pleased that the document outlines a clear patient pathway for children, adolescents and young adults with cancer that aims to improve access to Psycho-Oncology services, no matter where people live.

This MoC, which is based on national and international best practice, will provide guidance for the delivery of an accessible, flexible and appropriately skilled response to Psycho-Oncology services, tailored to the needs of the individual person.

I would like to thank Dr. Helen Greally and Dr. Chiara Besani, co-chairs of the CAYA Psycho-Oncology Working Group, for all of their work on producing this document. The NCCP will continue to seek resources and work with our partners to deliver the important psychosocial needs of children and young people with cancer and their families.

Professor Risteárd Ó Laoide

National Director

National Cancer Control Programme

Preface

It gives me great pleasure to support the publication of the MoC for Psycho-Oncology services in Ireland for the CAYA cohort. Following on from the publication of the Framework for the Care and Support of Adolescents and Young Adults (AYA) with cancer in Ireland, in May 2022, it is a timely addition to support the psychosocial needs of CAYA. Children, adolescents and young adult cancer patients constitute a unique group that deserve special attention, particularly from the perspective of psychosocial and psychological needs. Cancer continues to be the leading disease related cause of death in this age cohort.

Psychosocial concerns include but are not limited to fertility considerations, transition to survivorship care, feelings of isolation, fear of recurrence, impact on education and other issues that sometimes only emerge once active treatment has finished.

The aim of this document is to both draw attention to the very unique challenges faced by this group and also outline a blueprint for how these needs can be addressed over the coming years.

I want to express my gratitude to everyone involved in the development of this MoC and I look forward to close co-operation with my colleagues to ensure that the recommendations outlined can come to fruition.

Professor Owen Smith

National Clinical Programme Lead for CAYA with cancer

National Cancer Control Programme

Acknowledgements

The development of the MoC for Psycho-Oncology services for CAYA represents a major milestone in the progress in the development of professional psychosocial and psychological support services for children, adolescents and young adults with cancer in Ireland, as well as their parents/carers and siblings. We would like to acknowledge the hard work, guidance and patience of the members of CAYA Psycho-Oncology Working Group and the subgroups whose expertise and experience was critical to the creation of this document.

We want to acknowledge the contribution of the following without whom this document would not have been possible:

- The members of the working group who came together to progress this document.
- Professor Risteárd Ó Laoide and the Executive Management Team of the NCCP who have encouraged this development.
- The patients and families whose experience, expertise and advice have shaped the development of the MoC.
- Cancer support charities who have contributed greatly to inform about the impact of a cancer diagnosis on this cohort of patients and their families.
- Staff at Children's Health Ireland (CHI) who have shared their expertise to progress this MoC.
- Ms Deirdre Love, Evidence Methodologist at the NCCP, who has coordinated this document with expertise, commitment and enthusiasm, and who has provided evidence and research that has contributed significantly to its structure and completion.
- Ms Niya Mateeva, Project Manager in Psycho-Oncology and Survivorship at the NCCP, who joined the team in October 2022 and who has contributed a significant amount of research evidence and coordination to the document.

Dr Helen Greally
National Clinical Programme Lead
for Psycho-Oncology
National Cancer Control Programme

Dr Chiara Besani
Principal Clinical Psychologist
Psycho-Oncology Clinical Lead
National Paediatric Psycho-Oncology Service
Children's Health Ireland (CHI) at Crumlin

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Abbreviations

ABI	Acquired Brain Injury
AYA	Adolescents and Young Adults
AYACSN	Adolescent and Young Adult Cancer Service Network
CAYA	Children, Adolescents and Young Adults
CHI	Children's Health Ireland
CNC	Children's Neurosurgery Centre
CNS	Central Nervous System
CNSp	Clinical Nurse Specialist
CUH	Cork University Hospital
GUH	Galway University Hospital
HSCP	Health and social care professionals
LTFU	Long-term follow-up
MDM	Multi-disciplinary meeting
MDT	Multi-disciplinary team
MoC	Model of Care
MSW	Medical Social Worker
MTSM	Medical Traumatic Stress Model
NCCP	National Cancer Control Programme
NCCS	National Children's Cancer Service
NCH	National Children's Hospital
NCIS	National Cancer Information System
NRH	National Rehabilitation Hospital
NPPO	National Paediatric Psycho-Oncology Service
OT	Occupational Therapist
PAT-HCT	Psychosocial Assessment Tool-Hematopoietic Cell Transplantation
PPPHM	Paediatric Psychosocial Preventative Health Model
s.i.	Special interest
SJH	St James's Hospital
SLRON	St Luke's Radiation Oncology Network
SLT	Speech and Language Therapy
SOP	Standard Operating Procedure

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Executive Summary

The current National Cancer Strategy (2017-2026) sets out a clear vision and blueprint for the development of optimum cancer services for Ireland. It is very clear in identifying the need for Psycho-Oncology services across the age range from childhood to old age.

This document describes the MoC of Psycho-Oncology services for CAYA and their families envisioned for Ireland, based on international best practice and aligned with national strategies and frameworks. It is divided into two main sections - the first covers services for children (0-15 years) and the second outlines the emerging services for the older cohort (16-24 years).

The Paediatric Psycho-Oncology section gives a brief overview of the current paediatric services in Ireland and details all the main psychosocial and psychological aspects of cancer in this cohort as well as describing the implementation structure. This part of the model is grounded in the work conducted over the last twenty years by the newly re-named National Paediatric Psycho-Oncology (NPPO) service in the National Children's Cancer Service (NCCS) and the international standards of care published in 2015 and subsequently updated.

The AYA Psycho-Oncology section describes the new AYA Cancer Service Network (AYACSN) recently developed following the launch of the Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland (NCCP, 2022). This framework outlines some principles of care and key targets for service developments in future years. The four centres involved in the new AYACSN were identified in 2022. This part of the MoC is evolving and will be reviewed and updated within 3 years.

One of the key priorities for both services is building an expert workforce, ensuring that all aspects of psychosocial and psychological care are addressed. It is proposed that the MoC will be delivered via a collaborative, integrated and shared care approach. It covers the full spectrum of psychosocial care provided for in the NPPO service within the NCCS in CHI at Crumlin, the Shared Care Centres and in the community, as well as within the newly developing AYACSN (CHI, Cork University Hospital, Galway University Hospital, and St James's Hospital).

Primary Goal

Recognition of the significant psychological impact of a cancer diagnosis, and that for CAYA who experience psychological distress due to their cancer diagnosis, there will be a comprehensive evaluation of their needs and development of a referral pathway to the appropriate type, setting and level of service they require in the hospital, primary care and community settings.

Secondary Goal

Acknowledgement of the psychological impact of a cancer diagnosis on the families of patients in the CAYA cohort. Every member of the family is part of the family network and as such when a cancer diagnosis occurs, the whole family system is impacted.

Introduction

The National Model of Care for Psycho-Oncology services for Children, Adolescents and Young Adults (CAYA) with Cancer and their families in Ireland was developed by the NCCP in collaboration with the NPPO service, in CHI at Crumlin and the developing AYACSN, in order to provide a framework to support the way that psychosocial care is delivered to this cohort and their families.

This document will serve as a blueprint for promoting psychological well-being, improving access to Psycho-Oncology services at acute hospital and community support level, and enhancing the quality of life for children and young people, and their families, who are faced with the challenge of a cancer diagnosis.

Receiving a diagnosis of cancer as a child, adolescent, or young adult (0-24 years) is a major life stressor, associated with a range of physical, psychological, emotional and social difficulties and understandable rates of distress for patients and their families (Katz et al., 2018). Evidence suggests that these patients feel that their psychological needs are undetected and unmet (Lewandowska, 2021; Lakavana, 2022). Psychosocial care, which should include screening, therapeutic assessment, and referral for psychosocial intervention, is recognised as both an essential and international standard of care (Wiener et al., 2015).

The MoC draws upon recommendations from a number of key publications such as the current National Cancer Strategy (2017 – 2026), the NCCP National Cancer Survivorship Needs Assessment (2019), the Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland (2022), the international Standards for the Psychosocial Care of Children with Cancer and their families (2015), and a recent review by the AYA Working Group of the European Society for Medical Oncology and the European Society for Paediatric Oncology (2021).

Similarly to the MoC for Psycho-Oncology services for adults (Greally et al., 2020), this MoC addresses the psychosocial needs of CAYA with cancer. By detailing pathways for the development of services nationally, this MoC will be an invaluable tool and reference point to spearhead the development of psychosocial support services over the next decade. This is an ambitious MoC in that it covers a wide age range, in particular highlighting the unique issues around transitioning from paediatric to adolescent and young adult services, the challenges associated with a cancer diagnosis occurring in late adolescence, and finally the transition to adult services.

Context

In terms of paediatric cancer in Ireland, there are approximately 200 new diagnoses per year from the ages of 0-15 years comprising patients who present with a paediatric-centric cancer or other haematological conditions that require cancer treatment. All of these children are currently and will remain under the care of the NCCS and its network of 16 Shared Care Centres located across the country. The service has approximately 800 children and adolescents attending for active and maintenance treatment (age range 0-18/19 years per year). Approximately 60 of these children newly diagnosed per year also attend the Paediatric Neurosurgery Service in Temple Street and approximately 40-45 will attend the Paediatric Radiotherapy Service in St Luke's Radiation Oncology Network.

At present there are approximately 69 adolescents between the ages of 16-19 years diagnosed with cancer every year. There is a growing realisation amongst patient advocacy groups and oncology services that this cohort of cancer patients experience significantly more challenges in accessing psychosocial/psychological services. At present these patients are seen medically in one of the eight designated cancer centres for adults. However, from a Psycho-Oncology point of view, only some have access to Psycho-Oncology services. It is envisaged that recommendations within this MoC will create the opportunity for this group of patients to come under the umbrella of the AYACSN with access to the best Psycho-Oncology care available within the network. With the move to the new National Children's Hospital (NCH), the NCCS will take approximately 40 of these 69 patients who present with a paediatric-centric cancer. This cohort of patients will be offered Psycho-Oncology support within the NPPO service in CHI. The remaining patients (approximately 29) within this cohort will be seen by Psycho-Oncology Service across the AYACSN.

In terms of young adults with cancer, there are approximately 111 newly diagnosed cases per year between the ages of 20-24 years. They are, at present, under the care of the adult cancer services. However, with the development of the AYACSN, these patients will also become part of this network.

Table 1 summarises the number of newly diagnosed patients according to age range, however it is important to acknowledge that the actual number of patients receiving treatment in these services is significantly higher.

Table 1 Estimated number of patients newly diagnosed with cancer each year in Ireland

Psycho-Oncology Service	Location of service	Age range	No. of new cancer diagnoses per year (estimated)
Paediatric	National Paediatric Psycho-Oncology Service within the NCCS (in conjunction with the Shared Care Centres)	0-15 years	200
AYA	AYA Cancer Service Network (AYACSN) at CHI, CUH, GUH & SJH	16-19 years	69 (including c.40 paediatric-centric cancers)
		20-24 years	111

Paediatric - 0-15 years (+364 days); Adolescents - 16-19 years (+364 days); Young Adults – 20-24 years (+364 days) (NCRI data 2017-2019 cited in NCCP, 2022)

The intention of the MoC is to ensure that patients are treated in the centre most appropriate to their needs and have access to high-quality age-appropriate psychosocial and supportive care services. A recent article by Darlington et al. (2022) identified the requirement for the recognition of the variation between paediatric and AYA cancer patients when assessing their psychosocial needs with a view to providing more targeted/appropriate support and care for all patients.

Rationale

A significant improvement in childhood cancer survival rates has been seen over the last 50 years. A report by the NCRI identified that 81% of children with cancer are now surviving 5 years or more post treatment (NCRI, 2017).

Despite this increase, receiving a potentially life-threatening cancer diagnosis has been found to be universally distressing and potentially traumatising for CAYA and their families (Liptak et al., 2015). Furthermore, treatments have become longer, more intense, with a higher rate of relapse and late effects, and these factors can significantly impact on quality of life. Although most patients and families adjust over time, a significant number exhibit long-term psychosocial difficulties (Bitsko et al., 2016). Assessment of the psychosocial needs of children/adolescents and their families, at diagnosis and at appropriate times during and after treatment, is necessary to determine how to best implement interventions addressing psychosocial needs (Kazak et al., 2015). Evidence suggests that cancer patients who have their psychological needs met during treatment have a better quality of life and improved health outcomes (Meyerson et al., 2011). Without appropriate support, there are significant psychosocial risks for patients and family members including anxiety, depression, adjustment problems, post- traumatic stress symptoms, family problems, social isolation (Steele et al., 2015).

Psycho-Oncology, while still a relatively new sub-specialty within oncology in Ireland, has facilitated the integration of the psychological domain into the disease-specific speciality of oncology/haemato-oncology (Castelli et al., 2015). The focus of Psycho-Oncology services in the CAYA cohort is concerned with:

1. The psychological responses of patients, families and carers to the diagnosis of cancer, and
2. The behavioural, social, medical and psychological factors that may affect the disease process.

The MoC was developed by a multidisciplinary working group comprising healthcare professionals from acute, primary and community settings, patient and family advocates from across the country, as well as representation from the NCCP and CHI (Appendix 1).

Aims & Objectives

Aim

To develop a MoC for Psycho-Oncology services to guide the optimal psychosocial management, care and support services for CAYA with cancer and their families and to ensure equitable access for all.

This model is flexible, outlining optimum psychosocial standards of care for CAYA with cancer and their families, identifying the multiple healthcare professionals that should be available in a range of healthcare settings, from pre-diagnosis across the entire life-long patient journey.

Objectives

- **To emphasise the psychosocial needs of cancer patients and their families thereby improving their quality of life**
- **To design an MoC that has the capacity to cross the voluntary, primary and acute hospital services, with the appropriate level of expertise and intervention at each level, relative to patients' needs**
- **To enable easy access to CAYA Psycho-Oncology services for patients and their families at any stage of the cancer journey**
- **To identify and support the development of Psycho-Oncology MDTs for CAYA services**
- **To identify gaps in current services in order to determine the resources needed to implement this MoC and to ensure an adequate workforce for the future**

Scope

This MoC is designed for an age range rather than specific cancer type, to provide a framework to raise awareness of the psychosocial issues of CAYA and their families and their broad range of needs. It will also act as a blueprint to ensure best practice. It is designed to guide healthcare professionals, managers and those that deliver services in the development of psychosocial services going forward.

Its recommendations offer clear guidelines on how these services should be delivered. The MoC also highlights the importance of collaborating with other healthcare providers, such as primary care and community cancer support centres, in order to deliver its aims and objectives.

Patients with cancer and their families, as well as patient advocates, may be interested in the MoC to understand how services are being provided, what they can expect from service providers and how services will be developed in the future.

The MoC will evolve in line with best practice evidence, the development of the new National Children’s Hospital and the new AYA service, and in response to the changing needs of patients and their families. It is proposed that the MoC will be reviewed within a maximum of 3 years to ensure service progress is captured (2026). Updates of the MoC will be undertaken through consultation with the original working group members and/or other key stakeholders. A review of the Psycho-Oncology service within the AYACSN will be carried out in Q2 2024.

Structure

The MoC is laid out in two ***distinct*** sections:

1. Paediatric Psycho-Oncology
2. AYA Psycho-Oncology

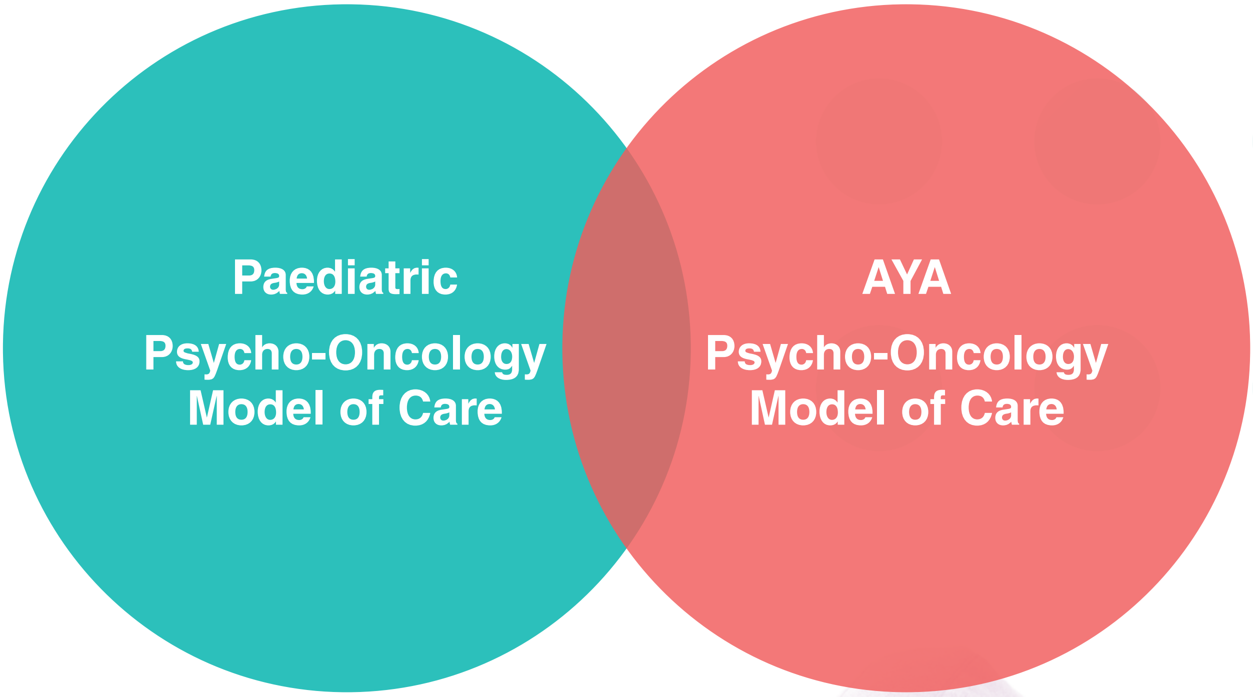
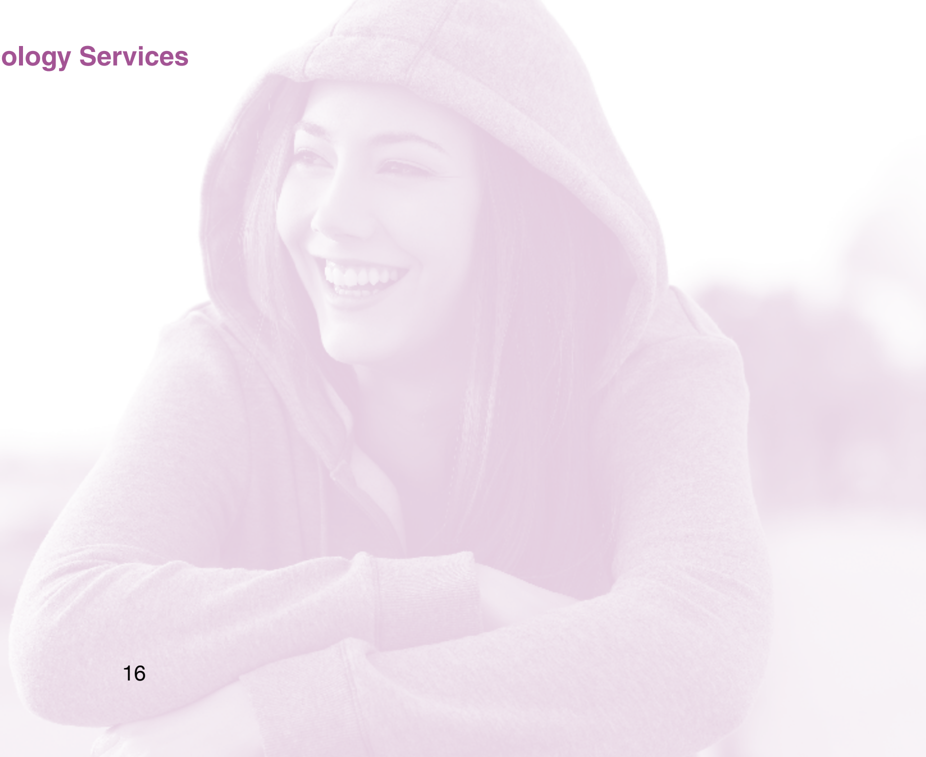


Figure 1 Paediatric & AYA Psycho-Oncology Services



Key Policies

National Cancer Strategy (2017-2026)

There are a number of recommendations in the current National Cancer Strategy in relation to developing Psycho-Oncology services in Ireland.

Recommendation 26 – The HSE will ensure that an age appropriate facility is designated for adolescents and young adults with cancer within the new children's hospital.

Recommendation 27 – The HSE will develop closer links, on a hub and spoke model, between the National Centre for Child and Adolescent Cancer and the other designated cancer centres to provide appropriate and flexible transition arrangements for adolescents/ young adults. This will include the joint appointment of adolescent/young adult oncologists and haemato-oncologists and the provision of age-appropriate psychosocial support for these patients.

Recommendation 29 – The NCCP will appoint a National Clinical Lead for Psycho-Oncology to drive the delivery of networked services.

Recommendation 30 – Each designated cancer centre will establish a dedicated service to address the psychological needs of patients with cancer and their families. This will operate through a hub and spoke model, utilising the MDT approach, to provide equitable patient access.

International Standards for Paediatric Psychosocial Care (2015)

The first evidence-based clinical standards for the psychosocial care of children and adolescents with cancer and their families were developed a number of years ago (Wiener et al., 2015) and are aimed at helping to ensure essential psychosocial care is received by all. These 15 standards (see Appendix 2) address a wide range of needs for patients and their families from diagnosis through survivorship and/or end-of-life. They were developed to identify and highlight key assessments that every patient and family should receive to optimise psychosocial care. It is important to note that the vast majority of international paediatric literature is based on age range of 0-18 years and for this reason this literature should also be considered when developing AYA services.

National Cancer Survivorship Needs Assessment (2019)

The NCCP Survivorship Needs Assessment provides an overview of the current situation for cancer survivors and services in Ireland and details a number of actions to develop cancer survivorship care (Mullen & Hanan, 2019). One of the priority areas for action identified was to address the needs of CAYA cancer survivors by:

- implementing the recommendations of the Survivorship After Childhood Cancer: Health Needs Assessment and National Cancer Strategy,
- improving the coordination of care,

- providing psychological support to all survivors including information relating to long-term treatment effects, and
- improving data intelligence for CAYA.

Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland (2021-2026)

The framework (NCCP, 2022) sets out the vision and aspirations for the care and support of AYA with cancer in Ireland. Key priorities include building a partnership of services across Ireland to ensure streamlined access, diagnosis and treatment for this patient group based around local services and a national MDT, building an expert workforce for the future, improving access to clinical trials for AYA patients, and collecting data in a systematic and streamlined way.

Challenges in relation to addressing the unique needs of this cohort, such as fertility considerations, survivorship issues, psychological support, adherence to treatment difficulties, symptom control, end-of-life care and other problems exclusive to this group of patients, and the need for a more consistent psychological and medical therapeutic approach, have been highlighted in the framework and one of its primary aims is to improve AYA cancer services and priorities to close the gap of unmet needs for those with AYA cancer.

AYA Oncology Psychosocial Care Manual (2021)

A guideline for health professionals, working with the AYA population, to support psychosocial coping during cancer treatment, including best practice in screening, assessment, and care plan development. It represents an important tool for the provision of age appropriate supportive care that every young person with cancer has the right to receive (Canteen, 2011; rev.ed.2021).

Hospital and Community-based Psychosocial Care for Patients with Cancer and their Families: A Model of Care for Psycho-Oncology (2020)

The Model of Care, for adult patients, details how psychosocial support will be developed in Ireland over the next number of years and may guide Psycho-Oncology services for young adults particularly as patients' transition to adult services (Greally et al., 2020; see Appendix 3).

Sláintecare Report

The Sláintecare Report was developed by the Government on the future of health services in Ireland over a ten-year period. The main aims were to provide a universal, single-tier health service with an emphasis on integrating primary and community care (Oireachtas Committee on the Future of Healthcare, 2017).

Childhood Cancer Survivorship Project: Assessment of the needs of childhood cancer survivors in Ireland (2022)

A needs assessment study that documented a population-based set of priority needs for Ireland's cohort of survivors of childhood cancer and their parents/guardians/carers. The top priority identified by the participants was the need for psychological support. The information gathered will inform the development of the Childhood Cancer Survivorship Service over the coming years (Gavin et al., 2022).

Paediatric Psycho-Oncology Model of Care

Principles underlying the Philosophy of Care for Paediatric Services in Ireland

The following philosophy has been at the heart of psychosocial work within the NCCS for the last 30 years (figure 2).

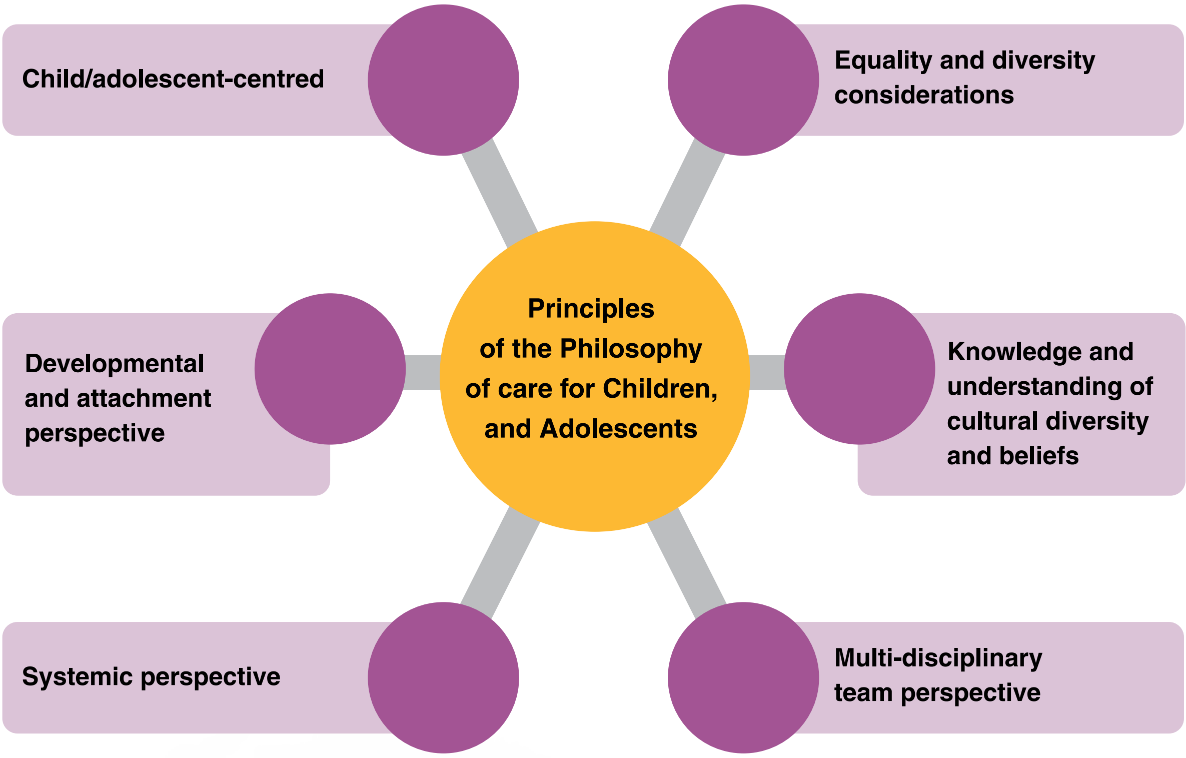


Figure 2 Principles of the philosophy of care for children and adolescents

Child/Adolescent-centred	Ensuring children, adolescents and their families are at the centre of care planning and delivery
Developmental & attachment perspective	Assessing and considering the stage of development of patients is essential - increases compliance to treatment and reduces distress
Systemic perspective	Assessing how the family system functions is important, with consideration given to relationships, health, communication styles, finances and extended support
Equality & diversity considerations	Working with children and adolescents with special needs to help them find ways to cope with the new challenges of diagnosis and treatment
Knowledge & understanding of cultural diversity & beliefs	Recognising and respecting different religions, cultures, beliefs, and orientations and acknowledging inequalities and barriers encountered by some children and adolescents when accessing services
MDT perspective	Acknowledging the wide range of healthcare professionals needed to provide comprehensive and holistic psychosocial care

Theoretical Framework for Paediatric Psycho-Oncology Services in Ireland

The development of paediatric Psycho-Oncology services in Ireland is informed by the international standards of care which are based on two models: The Paediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) and the Medical Traumatic Stress Model (MTSM; Kazak et al., 2006). These models were written for children and adolescents (0-18 years).

The PPPHM (figure 3) suggests that cancer in children and adolescents should be viewed as an abnormal life event that happens to competent families who adjust over time to cope with the stressful nature of this event. The expected pattern is intense distress initially, reducing over time, with peaks at times of acute events, such as recurrence or progression of disease.

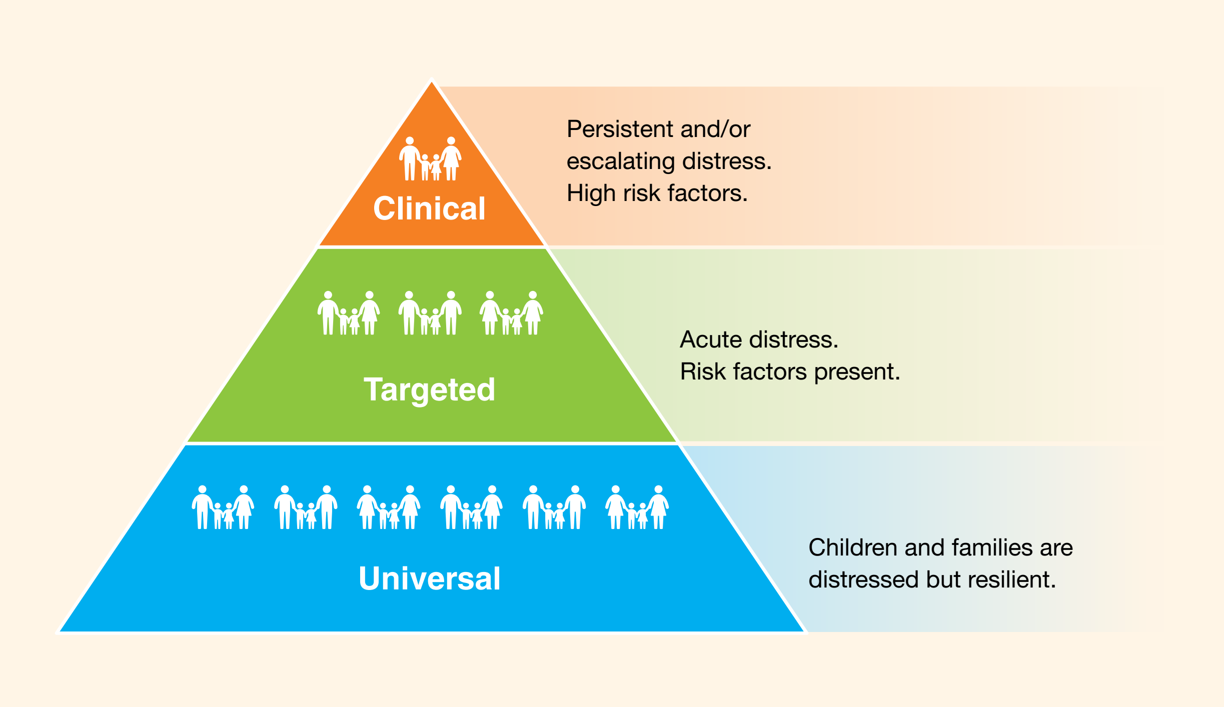


Figure 3 Paediatric Psychosocial Preventative Health Model

Kazak et al. (2018) identified three psychosocial outcomes to a diagnosis of childhood cancer: 62% of families are competent and able to cope; 27% have elevated or increasing distress and need more support; and 11% are clinically vulnerable and need more specialised interventions. Key to this model is thorough early psychosocial screening. Screening can change the course of psychosocial and medical outcomes - it is preventative and helps to provide the right intervention at the right time. It also promotes health equity, ensuring that all patients get care matched to their level of needs (Kazak et al. 2015). In addition, re-assessment at critical times is also essential as the need of the child and family may change.

Paediatric Psycho-Oncology also relies on the Medical Traumatic Stress Model (table 2) to conceptualise the potential trauma of being diagnosed with childhood cancer (Kazak et al., 2006) at various stages across the cancer trajectory, namely:

Table 2 Medical Traumatic Stress Model

Phase I	**Peritrauma** (e.g. initial diagnosis and waiting for treatment)
Phase II	**During treatment** (e.g. dealing with medical side-effects, worries about recurrence etc.)
Phase III	**Long-term sequelae** (e.g. medical, cognitive and psychosocial)

This model emphasises that the normative and understandable experience of a transient trauma reaction after childhood cancer is not always a pathological response or one with singularly negative implications.

Considered together, these two models, offer the opportunity to map out key events in the childhood cancer trajectory, by helping to identify the specific needs of each family and allowing for the development of interventions which are appropriate, necessary, and preventative.

Child and adolescent Psycho-Oncology embraces a resilient, preventative, competence/strengths and systemic-based model of care. In conclusion, there is a clear framework on how Psycho-Oncology services for this cohort should be developed.

Current Paediatric Psycho-Oncology services in Ireland

Paediatric Psycho-Oncology care in Ireland is provided by a network of acute, rehabilitation and community services. All of these services have an essential role in supporting children, adolescents and their families (parents, guardians, and siblings).

The three main hospital-based Psycho-Oncology services for children and adolescents in Ireland at present are:

- **National Paediatric Psycho-Oncology Service** based in the NCCS, CHI at Crumlin,
- **Radiotherapy Psycho-Oncology Service** based in the National Radiotherapy Oncology Service, St Luke's Radiation Oncology Network at St Luke's Hospital
- **Paediatric Neurosurgery Service** based in CHI at Temple Street.

The NCCS also has a network of 16 Shared Care Centres which will be introduced briefly below.

National Paediatric Psycho-Oncology (NPPO) Service

The NPPO service, within the NCCS, located in CHI at Crumlin, will be officially launched in 2023. This service has been working with children and adolescents and their families for over 20 years and currently sees approximately 200 new diagnoses per year (0-15 years) on both an inpatient and outpatient basis. The full patient cohort is circa 800 patients per year (0-18/19 years), including those who present with benign haematological conditions who receive chemotherapy, transplant and CAR-T cell as part of their medical treatment.

This service is based on international best practice, and has been clinically led by a Principal Psychologist for a number of years. At present, core MDT disciplines are psychology, neuropsychology, social work, complementary therapy clinical nurse specialist (CNSp), play specialists, music therapy and occupational therapy. The role of Psycho-Oncology CNSp may also be added to the MDT in the future to enrich the service provided.

Over the past 20 years, the Paediatric Psychiatric Liaison Service has provided consultation to the NCCS and the Oncology Neurosurgical service in Temple Street when needed as indicated by the standard of care (Standard 4). Review by the Psychiatric Liaison Team during the period 2019-2021 indicated that approximately 2% of patients in active treatment were referred. It should be noted that this included two pandemic years. In the future, psychiatry will become an integrated member of the Psycho-Oncology service, contributing to assessment and the formulation of recommendations for treatment and therapy for patients, when needed as indicated by the standards of care (Standard 6).

The recently published AYA framework of care stated that, once the NCCS moves to the new National Children's Hospital at St. James's Hospital, the service will increase its clinical remit to include older adolescents with paediatric-centric newly diagnosed tumours up to the age of 19 years. This will contribute to approximately an extra 40 new diagnoses per year, with an estimated total number of patients on active, maintenance and surveillance treatment approaching 1,000 per year. Adolescents diagnosed at 19 years will continue to be offered support, within the NPPO service, in their early twenties (young adulthood) while they are receiving treatment in the NCCS.

Genetic predisposition to cancer development

Recent studies indicate that at least 10% of children with cancer have a genetic predisposition to cancer development, with a significant risk of cancer development in early life and for some, a risk of multiple cancers over their lifetime (Gröbner et al., 2018; Zhang et al., 2015). In CAYAs with high-risk, relapsed or refractory cancers, this number may be as high as 20% (Langenberg et al., 2022; Wong et al., 2020). Within the NCCS, a Paediatric Cancer Genetics service has commenced development over the last 12 months to address the specific needs of CAYA. At present, children with cancer up to the age of 16 who attend the NCCS at CHI are eligible for genetic testing, where appropriate, through a collaboration between the NCCS and the Department of Clinical Genetics also based at CHI. When the NCCS moves to the NCH, the age limit will be extended up to the age of 19 will be eligible for consideration for genetic testing via this service. Over the age of 19, adolescents and young adults may still be eligible for genetic testing where appropriate through their primary teams wherever their care is based, but in consultation with centralised genetic services if appropriate. This service offers a monthly MDT that incorporates haematologists, oncologists, clinical geneticists, genetic counsellors. At present, due to gaps in staffing, the NPPO is not able to provide appropriate input into this new medical service. However, this will need to be prioritised in the future because this minority of children confirmed as having a genetic cancer predisposition have significant implications for cancer treatment, cancer surveillance and ongoing cancer risk, as well as having complex wider psychological needs for themselves and also extended family members (siblings/parents/extended relatives).

As the NCCS prepares to develop and launch a genetics and genomics programme that will offer genetic testing to all CAYAs with cancer, and on foot of the recent launch of the National Strategy for Genetics & Genomics in Ireland (HSE, 2022), funds need to be allocated to ensure that this cohort of CAYA with unique needs, challenges and psychosocial distress related to their genetic cancer diagnosis, are supported in the context of the NPPO and will receive appropriate Psycho-Oncology support.

Shared Care Services

During active treatment, patients receive medical treatment within the NCCS, which collaborates with a network of 16 Shared Care Centres via a hub and spoke model. These Shared Care Centres are located across the country and provide supportive care and treatment closer to the child's home. The aim of shared care is to provide high-quality, safe and effective care in an appropriate environment, as close to the child's home as possible. Available services differ across each of the shared care centres in terms of access to various healthcare professionals and vary depending on the needs of each child and adolescent. Psycho-Oncology services at NCCS and SLRON liaise with health care professionals in these centres.

The largest Shared Care Centre is located in the Mercy University Hospital, Cork, which is at present the only unit with a Psycho-Oncology service. Approximately 30 new diagnoses per year attend this service, which is clinically led by a Senior Psychologist.

The remaining Shared Care Centres do not have access to therapeutic Psycho-Oncology services from psychologists and/or social workers. Some children, adolescents and their families may have contact with an oncology CNSp within their Shared Care Centre who will be a link person throughout their treatment and will provide patients and families with emotional support and signpost them to other relevant services.

It is envisaged that a number of Shared Care Centres will need to be supported to develop Psycho-Oncology services, on a regional basis. This will be explored further when the MoC is reviewed in 3 years.

Radiotherapy Psycho-Oncology Service

St Luke's Radiation Oncology Network (SLRON) is the national radiation oncology centre in Ireland. Their Psycho-Oncology service provides psychological support across the lifespan. All children (circa 40-45 patients every year) requiring radiotherapy in Ireland are treated in SLRON. The medical care of this cohort is coordinated between the Medical Oncology and Haematology consultants in the NCCS and the Radiation Oncologists in SLRON. These patients will usually attend for a period of 6-8 weeks before returning to the NCCS. It is planned that Radiotherapy Psycho-Oncology services will remain in St Luke's Hospital. Psychological assessment, intervention and therapy are provided by the Psycho-Oncology team who provide a service to children, adolescents and their families (including siblings, parents, guardians) during treatment and in the post treatment period. The Psycho-Oncology team are supported by medical social workers, paediatric radiation oncology nurses, physiotherapy, dietitians, speech and language therapy and the wider medical team. This service is clinically led by a Principal Psychologist who is also manager of the service.

Paediatric Neurosurgery Service

The Children's Neurosurgery Centre (CNC) is based in CHI at Temple Street and is a national centre of excellence, providing care for patients from 0-16 years, who require neurosurgery in Ireland. There are approximately 550 paediatric neurosurgical procedures performed each year, which is among the highest activity levels across neurosurgical centres in Ireland and the UK. Brain tumours are the second most common cancer in children and the majority of children who present with central nervous system (CNS) tumours will receive their initial treatment, namely neurosurgical intervention, in CHI at Temple Street. There are approximately 50-60 new brain tumours diagnosed each year in patients under the age of 16 years. Not all patients will require surgery however it does generate circa 180 oncology-related neurosurgical procedures per year. There are also approximately 50 inpatient admissions per year for children with previously diagnosed tumours, for a variety of reasons from recurrence to blocked shunts to symptom progression. The early medical care of children with brain tumours is provided by the Consultant Paediatric Neurosurgeons in CHI at Temple Street and the Consultant Paediatric Oncologists in CHI at Crumlin. In CHI at Temple Street, the neurosurgeons are supported by a broad multidisciplinary team, which includes; clinical nurse specialists, social workers, physiotherapists, occupational therapists, speech and language therapists, dietitians, music therapists and play specialists. An inpatient paediatric psychology service is provided to children who may experience emotional distress, behavioural dysregulation or difficulties adjusting to their new diagnosis whilst in hospital. Two paediatric neuropsychologists serve the neurosurgical team. They provide consultation and a specialised outpatient assessment service for children who have experienced neurocognitive sequelae consequent to their neurosurgical intervention, which may include neuro-oncology cases under the medical care of the oncology team in CHI at Crumlin.

An Acute Paediatric Rehabilitation Service was established in May 2019, in CHI at Temple Street, for patients admitted to hospital with moderate-severe acquired-brain injury (ABI), for whom neurosurgical input was necessary. The purpose of this service is to provide rehabilitation to those with neurological injuries, including oncology patients, to optimise recovery, support improved functioning, prevent secondary disability and facilitate discharge home with transition to the care of local teams. Access to this service is currently limited to neurosurgical inpatients with ABI and spinal cord injuries. Children and adolescents undergoing treatment for brain tumours, who experience significant neurological complications following their neurosurgery, will receive acute inpatient rehabilitation in CHI at Temple Street. Further therapy input can be continued by a different team in CHI at Crumlin if the patient is transferred across sites to commence inpatient chemotherapy. Inpatient neurological rehabilitation for children on active treatment in CHI at Crumlin only exists at present for children with significant neurological impairment, which limits them from being safely discharged home.

National Rehabilitation Hospital

The National Rehabilitation Hospital (NRH) Paediatric Family-Centred Programme provides input to children and adolescents aged 0-18 years requiring complex specialist interdisciplinary rehabilitation services, including those with physical and/or cognitive rehabilitation needs arising from cancer, who comprise approximately 30% of the inpatient cohort based on most recent figures available. The paediatric psychology/neuropsychology service at NRH forms part of the wider network of psychologists the person with cancer and their family may encounter along their continuum of care. Liaison and close working relationships with others involved in the child or adolescent's care are core elements of the service to ensure that their psychological needs are met appropriately and in a timely manner. As part of the NRH interdisciplinary team, the NRH paediatric psychologists support the patient and their family as inpatients through the rehabilitation process and, where appropriate, with issues that might arise for the young person or their family rLiaison and close working relationships with others involved in the child or young person relating to their cancer diagnosis or treatment. The paediatric neuropsychologists at NRH, as part of a wider national network of neuropsychologists, carry out detailed assessments with those up to age 18 years to ascertain the cognitive impact of injury and help guide therapeutic and educational services. In some cases, the NRH neuropsychologist will remain the their primary neuropsychologist and, in line with best practice guidelines, review them as appropriate until they reach 18 years and link with their school and other services as required. If services are still required into adulthood, the person with cancer may be referred to the Transition to Adult service, which has a dedicated Rehabilitation Consultant overseeing the needs of young adults with acquired brain injury aged 18 to 24 years.

Community Cancer Support Centres

Cancer Support Centres are recognised as being an essential part of the cancer journey. They fill substantial gaps in patient services and have been recognised as a key stakeholder in the provision of psychosocial support to patients and their families during and after active treatment. An internal scoping study was conducted by the NCCP in 2021 to establish the availability of services for children and adolescents with a diagnosis of cancer and their families in Community Cancer Support Centres in Ireland. The findings highlight that there are a number of centres providing a range of services for this cohort. The most common services provided for children and adolescents with cancer, are counselling, play therapy and art therapy. There are also support services available for family members. Some services are delivered on a one-to-one basis and some are delivered in groups.

The Alliance of Community Cancer Support Centres & Services, a recently launched initiative by the NCCP to develop a collaborative framework for community-based cancer support centres and services, will highlight and promote the services that are available to children, adolescents and their families. A list of services offered in Cancer Support Centres across the country will be made available through the Alliance. This will assist healthcare professionals when signposting to services.

Many charities in Ireland also provide a wide variety of practical, social and psychosocial support for children and adolescents with cancer and their families. Please see Appendix 4 for further information.

National Paediatric Psycho-Oncology Service in the National Children Cancer Service

Introduction

The following section presents the model of Psycho-Oncology care which operates in the NCCS. In accordance with the medical model of care that is currently used in Ireland for children with cancer, the NCCS remains the main treatment service, and for this reason every child diagnosed with cancer in Ireland will be under the care of one of the medical consultants of the service. The key professional for each patient throughout treatment will be the medical consultant (in conjunction with the general practitioner) until the end of treatment, transfer to adult services or through end of life care. They will work collaboratively with other medical consultants and specialities based on the needs of their patients and families.

Every child/adolescent will also be under the care of a Haematology, Oncology or Transplant CNSp, who will follow the patient throughout treatment. Nursing staff have always been a very important point of psychosocial support for patients and families. They are often the first point-of-contact within the NCCS MDT and integrate with the team to provide optimal nursing care and psychosocial support to each family. In particular, CNSp's act as main link between the medical/nursing service and the Psycho-Oncology services.

In addition to medical and nursing healthcare professionals, every child/adolescent in the NCCS has access to an extensive MDT (figure 4). This is based on the principle that the best cancer care for children and adolescents is delivered by a variety of professionals working collaboratively. The diagram below shows the current composition of the NCCS MDT.

Figure 4 Full complement of disciplines within the NCCS

Function

The NPPO service has been developed in collaboration with the NCCS and the NCCP. Its main function is to assess and meet the psychological and psychosocial needs of every family diagnosed with cancer, under the care of the NCCS, in order to achieve optimal outcomes. It is important to highlight that the NPPO service is embedded in the NCCS and will continue to work within the NCCS MDT and collaborate with medical, nursing, health and social care professionals (HSCP's), Our Lady's Hospital school, volunteers and charities to provide holistic, integrated psychosocial care. The NPPO service is not a separate service with separate governance from the NCCS, all disciplines remain under the governance of their own professional body. This is a group of highly skilled professionals with vast and varied knowledge of the developmental and mental health needs of children and adolescents. The NPPO service has been clinically led for a number of years by a Principal Psychologist.

The NPPO service also has a role in providing consultation, education, training and support to staff working within the NCCS, as recommended by the international standards of care (standard 15).

Access to the NPPO service

With the launch of the NPPO service in 2023, it is envisaged that in the future, every family with a new diagnosis or a new relapse within the NCCS will be referred directly to the service. Traditionally, referrals were made to each individual discipline (psychology, social work, play therapy, complementary therapy, music therapy and occupational therapy) separately by consultants and nurses. With this new centralised referral pathway to the NPPO service, there is a commitment that every child and adolescent will receive the right level of coordinated support based on their needs and also the needs of their parents, guardians and siblings. All new and relapsed patients will be reviewed at weekly referral meetings, where at least one representative from each of the core Psycho-Oncology MDT disciplines will attend and a discussion will take place to decide the support the family should receive in the first weeks after diagnosis. Updates regarding therapeutic work, assessment and formulation will be shared with the full NCCS MDT, at weekly psychosocial meetings (separate meeting for oncology, malignant haematology and transplant) in order to coordinate and advance patients' care (standard 15).

Core Psycho-Oncology MDT members

Best practice in cancer care involves a multidisciplinary approach. The following section provides an overview of the core disciplines in the Paediatric Psycho-Oncology MDT and their role within the service, recognising that each discipline has specific skills to address the needs of the patient and their family. The line management for each discipline remains within their own profession. Clinically, these HSCP's collaborate together, with the support of the Clinical Lead for the NPPO service, to develop the best possible evidence based practice for children, adolescents and their families. The role of the Clinical Lead is to ensure that the service strives to develop and excellent standard of care that evolves in line with progress in medical cancer treatment, for example, joining clinical trials and international multi-centred studies that will improve outcomes for CAYA and their families.

The recommended core composition for the NPPO service is based on the international standards of care (figure 5). The MDT works collaboratively, meets regularly, and maintains strong links with the wider treating team and other professionals working within the NCCS. This model of care recognises the role of CNSp's, both in paediatric and in AYA services, as a specific role that acts as a link between the medical and nursing team and the Psycho-Oncology Service, while also providing psychosocial support at a universal level.

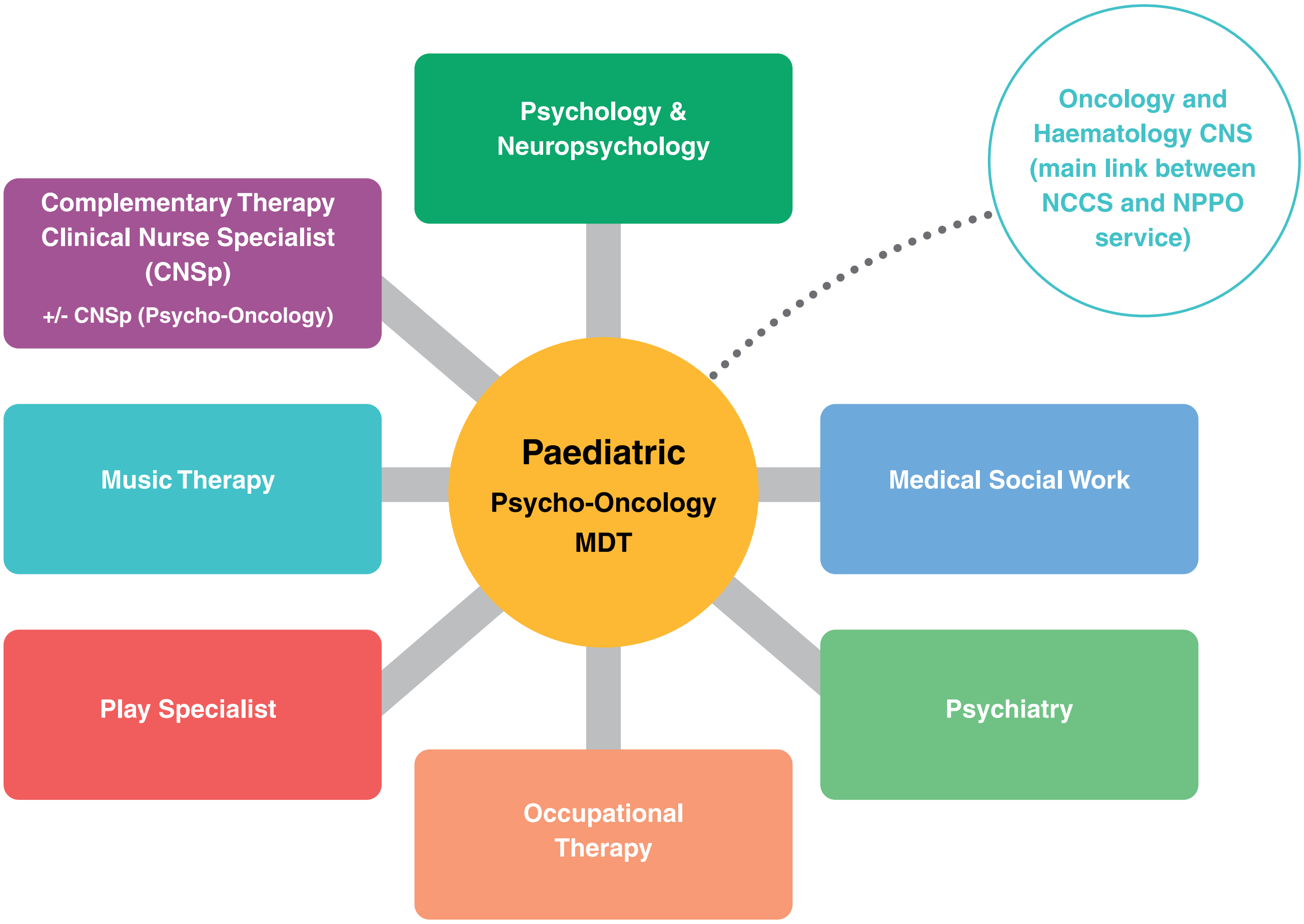


Figure 5 Paediatric Psycho-Oncology MDT - core team composition

Training and professional development for the core MDT

As paediatric services continue to grow over the next decade and expand the age range they serve, specialised training and education programmes should be developed as indicated in the international standards of care (standard 15). Within the NPPO service, pathways of training will be developed with the main universities in Ireland to provide teaching, placement and training opportunities for different disciplines who want to develop professional knowledge in Psycho-Oncology. The Clinical Lead of the NPPO service and senior members of the team will also provide Psycho-Oncology supervision and reflective practice within the NPPO service and also to CNSp's in their role as a link between the NPPO service and the NCCS.

It would also be important that the NPPO service, CHI at Crumlin and the NCCP explore the possibility of developing postgraduate specific training in CAYA Psycho-Oncology.

Extended Psycho-Oncology MDT team

While there is no specific reference within the international standards of care to other disciplines, within the NCCS, it is recognised that other professions offer a unique contribution to the wider and holistic psychosocial and physical care of children and adolescents with cancer. See figure 6 and Appendix 5 for further details. It is possible that in the future the international standards of care will be updated and these professions may be included in the core NPPO service.

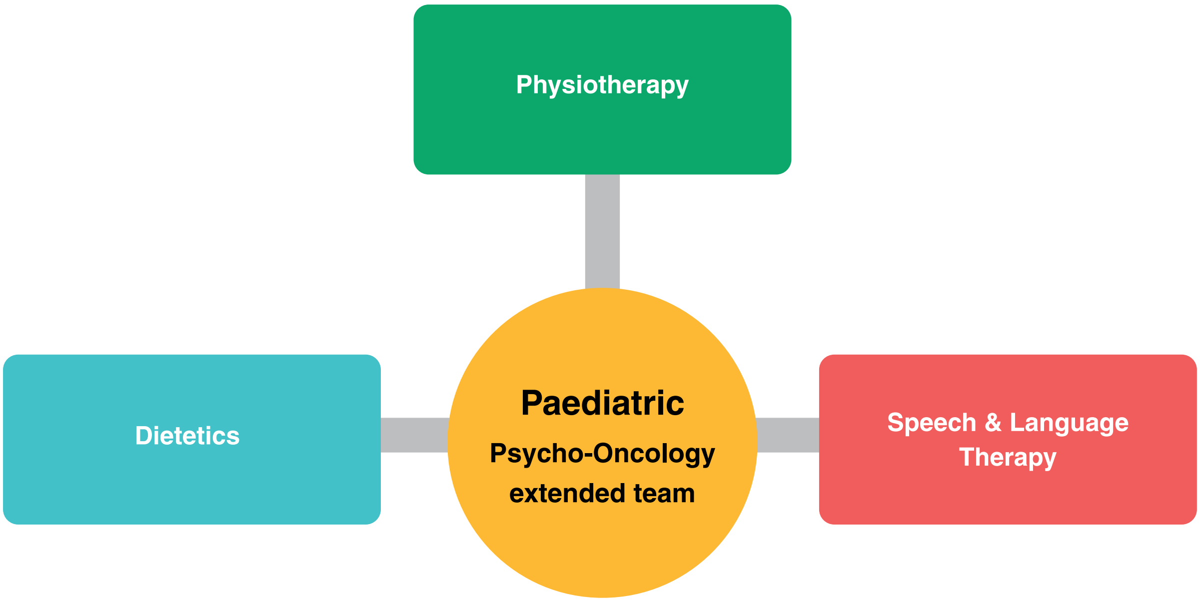
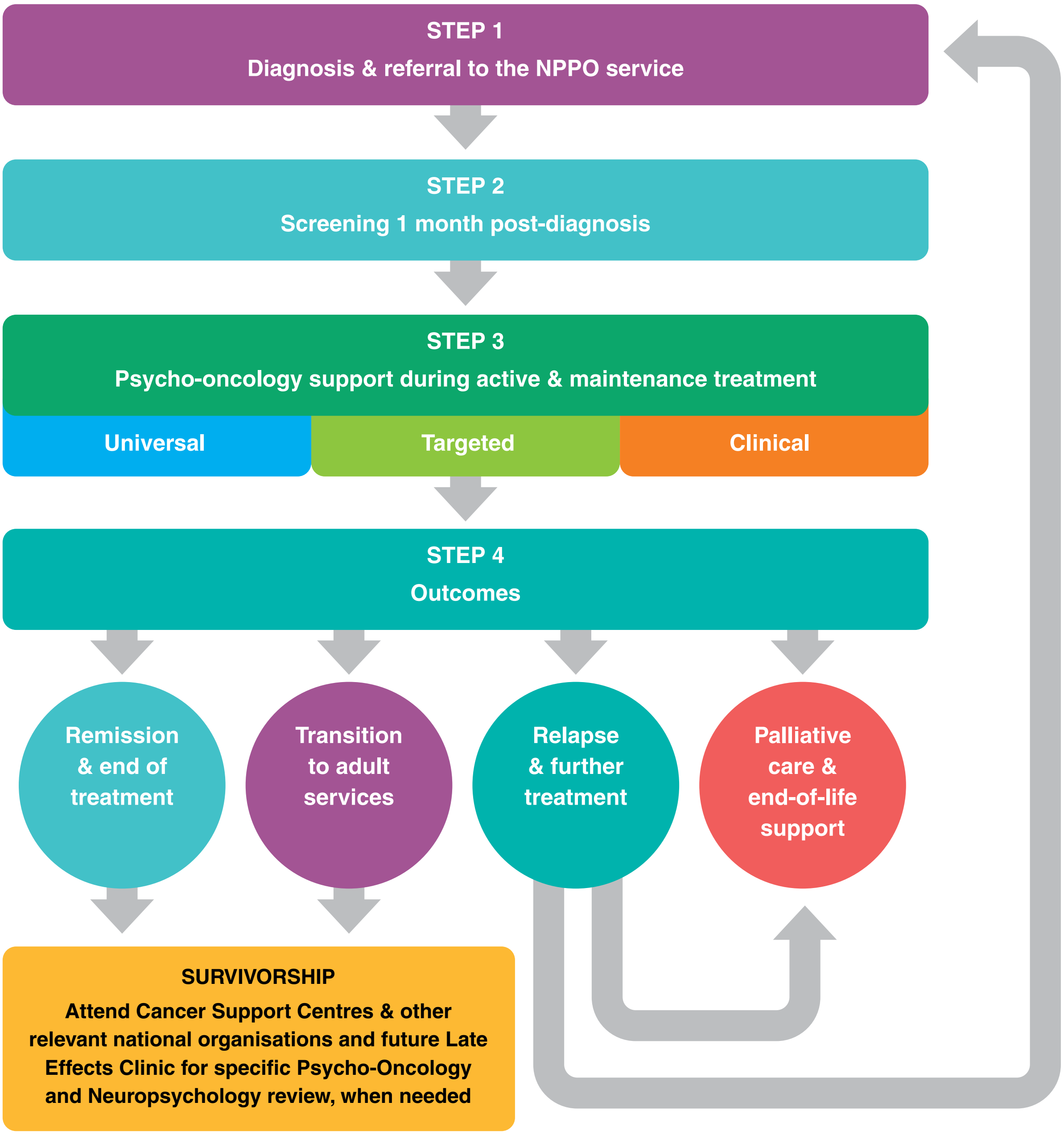


Figure 6 Paediatric Psycho-Oncology extended team

Patient Pathway

Every person with cancer who is seen within the NCCS, will automatically be referred to the NPPO service. Figure 7 describes the patient pathway that will be established within the NPPO service, over the next number of years, with obvious implications for workforce planning. The proposed layered care approach will enable patients to avail of a range of supports and services at the level of complexity that best meets their needs.



STEP 1
Diagnosis & referral to the NPPO service

STEP 2
Screening 1 month post-diagnosis

STEP 3
Psycho-oncology support during active & maintenance treatment

Universal | **Targeted** | **Clinical**

STEP 4
Outcomes

Remission & end of treatment

Transition to adult services

Relapse & further treatment

Palliative care & end-of-life support

SURVIVORSHIP
Attend Cancer Support Centres & other relevant national organisations and future Late Effects Clinic for specific Psycho-Oncology and Neuropsychology review, when needed

Figure 7 Patient Pathway within the NPPO service

Patient Pathway in Action

Step 1 – Medical diagnosis and referral to NPPO service

The cancer journey for children and adolescents within the NCCS commences with a medical diagnosis. For patients who are diagnosed in CHI at Crumlin, medical and nursing teams will be advised to make a one-point-of access referral to the NPPO service based on their initial interaction with the patient and their family. At weekly meetings, new and relapsed patients will be discussed by the team and a plan for immediate support at time of diagnosis will be prepared. Ideally, each family will meet an allocated medical social worker (MSW) within a week of diagnosis or as soon as possible thereafter. The role of the MSW at this point will be to meet the family and support them emotionally, socially and practically, through a needs-led assessment (Standards 5 and 6).

Within the NPPO service, it is also advised that every child and adolescent meets with a play specialist within their first admission, to help adjust to initial medical procedures and the inpatient stay (Standard 8). Depending on the needs of the child/adolescent, the team may also advise that input from other members of the service is needed within this initial support phase (e.g. music therapy, psychology, complementary therapy CNSp, OT).

When significant mental health needs and/or a pre-morbid psychiatric history are identified, these will be discussed with the consultant psychiatrist within the NPPO service and a decision will be made in terms of the need for a psychiatric review, consultation or full assessment.

Step 2 – Screening post diagnosis

As advised by the international standards of care, an initial screening is needed in order to better identify the needs of each family unit. Approximately 1 month post diagnosis, a member of the NPPO service will complete an initial screening (with standardised measures) of psychosocial needs and risk with each family and explore every child and adolescent's level of distress, as recommended by the international standards of care (standards 1 & 6). The psychology service will conduct any other mental health and/or standardised assessments as necessary, based on the initial screening. Following completion of the assessment process and discussions at the NPPO service weekly meeting, a decision will be made in relation to the most appropriate care pathway for the patient/family based on their level of need (universal, targeted and clinical) (Kazak et al., 2019; figure 8). Feedback from this screening will be shared with the family, and the full NCCS MDT.

As indicated above, if any significant mental health needs, concerns, child welfare and/or child protection concerns are identified by any member of the NCCS, a protocol for urgent response will be activated by the NPPO service and screening will be prioritised for these families.

Some patients may require a consultation post diagnosis to identify and prioritise those in need of neuropsychological assessment based on known risk factors. A number of children may require pre-treatment neuropsychological assessment, for example, when on a clinical trial or if the referring consultant plans to adopt a high risk or novel surgical/oncology treatment.

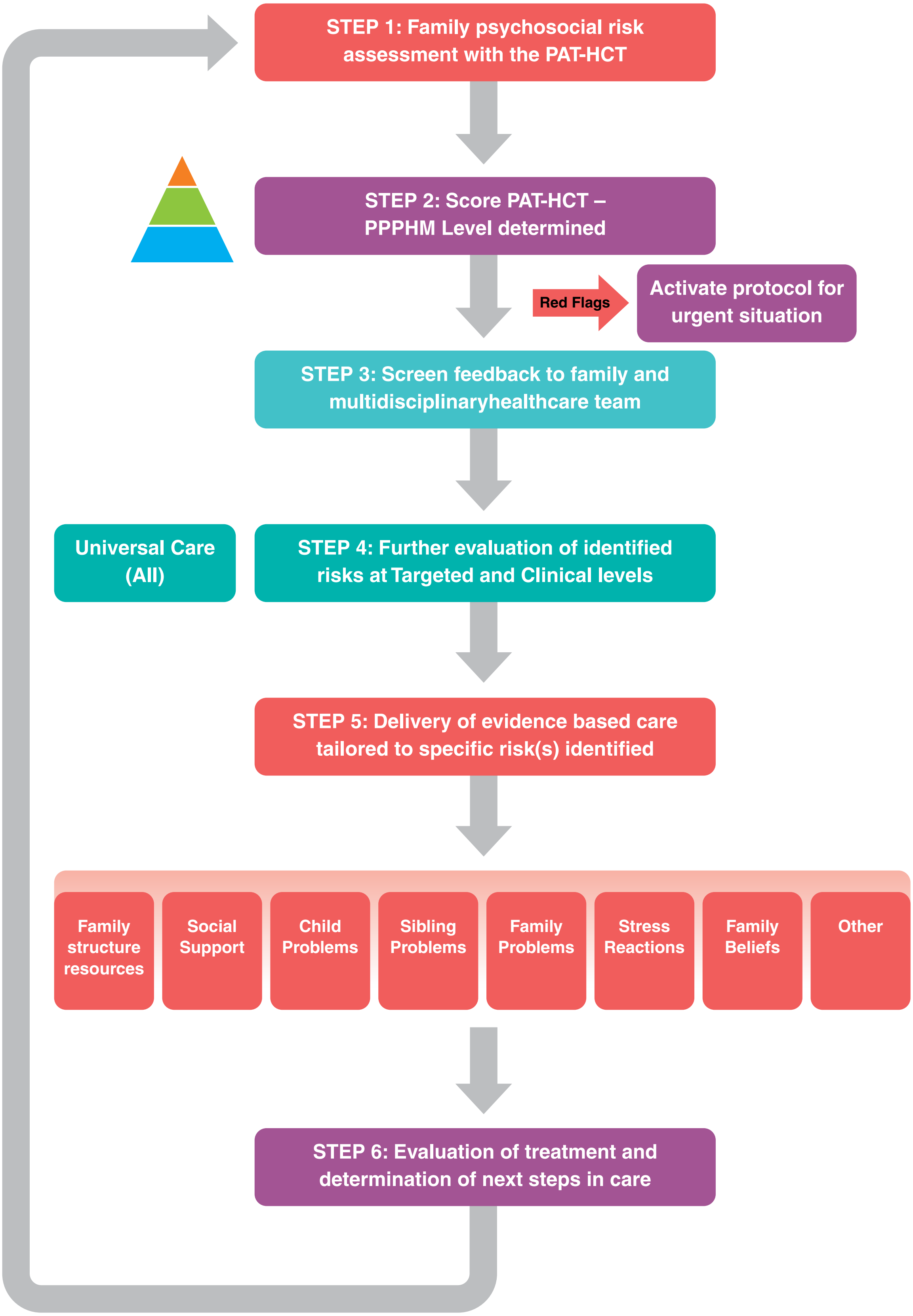


Figure 8 Psychosocial Clinical Care Pathway

Step 3 – Psycho-Oncology support during active and maintenance treatment

As indicated in the step above, patients and families will receive Psycho-Oncology care and support based on their level of need (figure 3). In line with the delivery of active medical treatment, patients will receive this care and support from the NPPO service.

Universal level of need

The literature suggests that almost 62% of families fall into the universal risk category, reporting they are psychologically quite resilient and functioning well during cancer treatment, after an initial period of high distress and adjustment. The general aim of universal interventions is to reduce the experience of transient trauma for all patients and family members and to increase psychological well-being.

Psychologists at this level will work to develop psychoeducational materials for families as well as group and educational programmes aimed at ameliorating the normal and expected distress associated with a cancer diagnosis and treatment. They will also support team members to deliver appropriate interventions to families through a consultation model. A small number of families at this level will benefit from brief assessment and short therapeutic input from the psychology service at individual level. Psychologists always work within a systemic framework while working with children and adolescents, for this reason psychologists will meet parents at different times to work together to support the child/adolescent.

Neuropsychology within Psycho-Oncology
The risk to neurocognitive function in paediatric oncology and malignant haematology is well documented, particularly within cancers affecting the CNS, those where CNS-directed treatment is required and for those receiving bone marrow transplant or CAR-T cell treatment. The neurocognitive function of children and adolescents will be monitored across their cancer journey, with specialised neuropsychology assessment carried out at key points and in response to known risk factors. See Appendix 6 for further details on the proposed model.

A tiered approach to neuropsychological assessment for children and adolescents with cancer has been proposed by Jacola et al. 2021. Similar to the PPPHM, this model acknowledges that not all patients will require the same level of intervention, and therefore provides a stratified approach, which incorporates guidance on risk factors, which will help direct the clinician and identify the appropriate level of care for each patient.

Medical evidence suggests that CAYA who are enrolled in clinical trials have better outcomes in terms of survival and quality of life. Some of the most recent international clinical trials highlight the necessity of having psychologists and neuropsychologists participate in clinical trials and conduct developmental and neuropsychological assessment at key time points. This is a new area of development within NCCS and one that will see the further integration of the discipline of Psycho-Oncology within medical treatment.

Medical Social Workers (MSWs) have specific skills and advanced competencies to assist families with adjusting to a child's illness both practically and emotionally. Families with universal level needs will require information, guidance, and sometimes community-based support services to assist with adjustment to significant illness (Standard 1 & 7). Social workers have competencies in the processes of therapeutic engagement, multidimensional assessment, and clinical intervention - all of which contribute towards a relationship-based practice, where families are seen as equal participants and experts in their own lives. MSWs support families by providing psychosocial interventions, which are achieved through working in partnership with patients, and families (Standard 4), for example empowering parents to talk to their children about their illness and also supporting siblings.

The practical requirements of a family - including the financial burden, can significantly impact psychosocial well-being following diagnosis. Social workers have core competencies in the areas of human rights, as well as economic, social and cultural challenges which allow them to intervene and advocate for families, when required (Standard 5).

Complementary Therapy Clinical Nurse Specialists will facilitate supportive, compassionate, holistic, and individualised care. Using a family-centred approach, treating both the patient and their parents/ guardians through a range of therapies, they enable patients and parents to cope with the stress of their diagnosis and to help alleviate symptoms such as fatigue, insomnia and certain types of pain associated with cancer treatment. Self-directed care is also taught, if appropriate.

The **Play Specialist Service** will help children to cope with aspects of, and reactions to cancer treatment. Play specialists will meet each child and identify their needs and fears in relation to hospitalisation and treatment and subsequently provide appropriate support through various play techniques (normal play, preparation and medical play, distraction).

Music Therapy uses techniques such as free improvisation, song writing and lyric analysis within a therapeutic relationship, to help children and adolescents with cancer to process and express their thoughts and feelings. Joint programmes with Physiotherapy, Occupational Therapy or Speech and Language Therapy can be especially beneficial for a patient undergoing rehabilitation who may be enduring a long admission and whose motivation, focus and attention may decrease over time.

Occupational Therapy enables patients to achieve maximum functional performance, both physically and psychosocially, in their day-to-day occupations (e.g. attending school (AOTA 2011)). Goals are collaboratively defined with the child and family, with specific interventions targeting those goals. Occupational Therapists (OT) will use strategies to remediate, develop, compensate and/or adapt the way the child engages in their everyday life to promote function, development and wellness. This will primarily be through therapeutic input; environmental adaption and family education (e.g. sleep and fatigue management, relaxation strategies, management of self-care activities, mobility and positioning, lifestyle management and engaging in play).

Sibling Support

As per Standard 10, siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate support services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly (Gerhardt et al., 2015).

Charities and volunteers' supports
Families at the universal level of need will also be informed of all charity-led services available to them while in hospital. It is recommended that charity and volunteer workers should be appropriately linked in with the relevant members of the NPPO service and medical and nursing teams, so that if any clinical concerns emerge they can be escalated to the relevant clinician(s).

School
All children will also be encouraged to attend the school support that is provided within CHI at Crumlin.

Physical Activity
Physical activity plays an important role in the prevention and reduction of long-term adverse psychosocial side-effects associated with cancer treatment in children and adolescents (Amanda et al., 2021). Delivering physical activity interventions which directly improve/promote mental wellbeing and the management of physical morbidities which impact on mental health are strongly encouraged and delivered by the extended Psycho-Oncology team. This includes interventions for musculo-skeletal issues post-op, major limb surgeries for osteosarcoma, reduced fitness and muscle strength, across all groups during and post treatment, as illustrated by Paula et al. (2018).

Targeted level of need

According to international literature, about 27% of families fall into the targeted category, placing them at the level of moderate psychosocial risk. These families will also receive the support described at the universal level, in addition to extra support detailed below.

Psychology will deliver interventions to children and adolescents with a higher level of mental health needs associated with complex medical procedures, or complex neurodevelopmental needs. They will also provide palliative care support in collaboration with the medical and nursing teams and the Specialist Palliative Care team. Psychological interventions include cognitive behavioural therapy (CBT), acceptance & commitment therapy (ACT), mindfulness CBT, systemic therapy and narrative therapy. For patients at this level of need, their mental health will be routinely assessed, and when needed, consultations with psychiatrist will be initiated. In particular, some children, due to their neurodiversity profile may have higher needs for psychiatric assessment and consultation.

Neuropsychology will continue to provide consultation, formulation and assessment where appropriate. Meeting with parents is part of the therapeutic plan for each young person attending psychology. While parents are supported firstly by MSW colleagues, for families at targeted and clinical level of needs, psychology will closely liaise with social work to identify parents with a higher level of mental health needs. If these needs are impacting on the ability to support the child/adolescent during treatment, parents/guardians will be offered psychological interventions from the psychologists within the NPPO service to support them with their mental health needs while parenting a child with cancer.

Medical Social Work: Parents and carers should have early and ongoing assessment of their mental health needs (Standard 6) and access to appropriate interventions to optimise their wellbeing. When needed the MSW also offers person centred counselling. One of the aims of this is to differentiate between and/or integrate multiple practice approaches to communicate professional judgements of parental mental health needs when the ability to support a child may be impacted. Parental mental health needs are discussed within the NPPO service and collaboration with colleagues in Psychology may be considered if deemed appropriate by both professions. Referral to Tulsa, whose role is to improve wellbeing and outcomes for children, as well as to offer early intervention and family support services, in addition to child protection services, will also be initiated where appropriate. While the Children's First Act 2015 places a legal obligation on certain people as mandated persons to report child protection concerns, MSWs tend to have a leading role. MSWs also provide both palliative care and bereavement support to families not specific to this level but at all levels of need (Universal, Targeted and Clinical). This encompasses anticipatory grief and allows for referral to specialist services, where needed.

The role of **Complementary Therapy CNP's** is to provide their expertise to those experiencing complex pain, severe procedural distress, and anticipatory nausea. Their role is also crucial for children who have a diagnosis of neurodevelopmental complex needs and who may struggle to engage in talking therapy but respond very well to positive touch. Therapists have a role in teaching infant baby massage to parents, and massage to older children and adolescents, thus empowering them to support their child.

The role of **Play Specialists** is to work closely with other members of the Psycho-Oncology MDT, who are delivering targeted mental health interventions and to support these interventions with the medical play techniques discussed above. They will also plan a structured timetable of play to help patients cope during lengthy parts of their treatment.

Music Therapy assists children and adolescents who are experiencing higher levels of need, including emotional, physical and spiritual distress. Therapists use musical, mindfulness and relaxation techniques within a humanistic child centred model to help lower anxiety, elevate mood and increase positive emotions. Music Therapists also provides distraction and regulating interventions for procedural distress (Knott et al., 2022).

Families and children who are at a moderate psychosocial risk may also require more targeted **Occupational Therapy** intervention. In addition to the interventions provided under the universal level of need, a more specialised approach, focusing on activity-based interventions and participation in meaningful roles and activities may be needed. This will support social interaction, self-esteem, emotional well-being and development, engagement in education and behavioral activations. In relation to running groups to promote return to school, the involvement of the extended Psycho-Oncology team is essential to ensure developmental outcomes are monitored (Götte et al., 2022).

Clinical level of need

According to the international standards of care, less than 11% of families experience the most severe difficulties, including severe psychopathology and/or significant social difficulties. The presenting problems represent a cross-section of the mental health needs of the general population. While the proportion of families who develop moderate to severe mental health problems or mental illness in the context of their cancer diagnosis or treatment is small, this cohort is extremely vulnerable and have a high level of need. The requirement to ensure appropriate psychological and psychiatric care has been outlined in several studies (Steele et al., 2015). Interventions at this level are most often focused on meeting the significant needs of patients and families with multiple pre-existing difficulties. Treatment at this level often involves extensive collaboration with the medical and nursing teams and all of the other HSCPs involved in the care of these very vulnerable families. For these families, assessment and intervention from psychology, psychiatry and medical social work is essential, to ensure the safety of the entire family. Systemic work is essential at this level and the triad of patient–family-staff needs to be considered in order to develop appropriate interventions. It is important that, for professionals working with families with the most complex needs and risk, there is access to an appropriate level of supervision within their profession.

Psychology offers complex psychotherapeutic interventions to children and adolescents at an individual level. Examples of some supports that have a strong evidence base in the paediatric literature, are a combination of CBT, ACT, Interpersonal Child Centre Psychotherapy, Mindfulness Therapy, Narrative Therapy, Systemic Therapy and Attachment-Based Therapy. Some of the mental health presentations at this level may include high levels of clinical anxiety, low mood, panic attacks, post-traumatic stress reactions, suicidal ideations and self-harm. In these cases of high risk, psychology will work very closely with psychiatry.

Psychology will also provide intense support at this level to children, adolescents and their families where the diagnosis is recognised to be high risk or incurable. This includes bereavement support. This is offered to children and adolescents, to parents (together with MSW) and to siblings when complex needs are identified. There is significant support in the literature that identifies the medical and psychological benefits of psychological intervention in this area. In particular, identifying that facilitating “death and dying” conversations within a family system, help to improve psychological wellbeing, pain management and with other symptoms. This also helps families to foster, maintain and build a sense of belonging, memory making and legacy for the dying child/adolescent (Weaver, 2015; Lichtenthal, 2015) (standard 13-14).

Other aspects of complex need that require input from psychology at this level, that are at times not linked with mental health concerns, are psychological assessment and intervention to maintain adherence to treatment (standard 12), preparation for invasive procedures (e.g. amputation) and complex palliative care and end-of-life support (standard 13 and 14).

As indicated in the international standards of care (standard 4), some families at a clinical level will require access to **paediatric child and adolescent psychiatry.** Children and adolescents with cancer, who have pre-existing psychiatric diagnoses are more vulnerable to developing a range of psychiatric disorders related to the psychological challenges of cancer treatment, as well as the physiological effects of the illness and cancer-directed therapies. Psychiatric assessment and pharmacologic treatment should be available when other approaches are not sufficient, and medications should be used in conjunction with other psychotherapeutic modalities. In a recent study at the Dana-Farber/Boston Children's Cancer and Blood Disorders Centre, of the 394 patient files reviewed, 86 (21%) of children needed psychopharmacologic medication during the course of treatment. A recent review by Liaison Psychiatry within CHI at Crumlin on children and adolescents in active treatment identified that there were 12 referrals over a 2.5year period, from 2019 to 2021 (including two pandemic years). It is quite clear that there are differing levels of need which merits further investigation, particularly in the Irish context. It has been highlighted that more studies are needed in this area (Zheng, 2021).

Effective psychopharmacologic treatments are available for depression, anxiety, and delirium, and can be used safely in children receiving oncology treatment, although more randomised controlled studies are needed in this population (Steele et al., 2015).

A number of children may also develop organic or treatment-related psychiatric symptoms, which will require specialist diagnosis and intervention. Children with CNS disease are particularly impacted and may develop neuropsychiatric complications. The role of the consultant psychiatrist, as part of the MDT within the NPPO service is to assess children/adolescents referred to them, following psychosocial screening by of the members of the NPPO service or from early identification by one of the medical consultants, and to make recommendations for pharmacological treatment and therapy. This will be provided through a collaborative MDT approach, within the Paediatric Psycho-Oncology MDT. A specialist understanding of psychopharmacology during cancer treatment is needed and appropriate treatment with psychotropic medications should be initiated where indicated. As in all areas of paediatric psychiatry, medication is utilised in conjunction with psychotherapy, which may take a variety of approaches individualised to the child's needs and evidence based. In addition, to direct work with patients, collaboration with parents and families is essential during treatment for comorbid psychiatric illness (Standard 4).

When significant and severe social and/or mental health difficulties exist, **MSWs** continue to assess and engage families supportively. Utilising systemic theory and formulation, MSWs take a multi perspective approach to working holistically with children and their families. Crucially, social work intervention at this level is trauma informed and as such, MSWs are well positioned to understand how adversities and specific environments can contribute to presenting difficulties. By using core principles of safety, trust, collaboration, and choice, MSWs assist individuals to discuss difficult memories, to reduce anxiety and to regulate emotions. Interventions at this level and indeed all levels must ensure opportunities for essential reflective practice and supervision (Standard 15). The MSW also has a key role in providing palliative care, end of life care and bereavement follow-up support.

Occupational Therapy, Complementary Therapy, Play Specialist and **Music Therapy** continue to offer support to families and children with complex needs and distress through appropriate intervention and education, to support engagement in meaningful activities and roles, promote positive sensory experiences and facilitate comfort, particularly during end-of-life.

It is important to stress that the NCCS collaborates closely with the Palliative Care Service, within CHI, where dedicated doctors and CNSp's provide palliative care support (see section below).

Neuropsychologists may also be involved at this level to provide assessment, formulation and support to the team through consultation.

Step 4 – Outcomes

As outlined in the patient pathway, after the active treatment phase, children and adolescents with cancer and their families face different scenarios in terms of their cancer trajectory:

- Remission and end of treatment
- Transition to adult services
- Relapse and further treatment
- Palliative care and end-of-life support
- Survivorship

Remission and end of treatment: moving towards survivorship

End of treatment is recognised as one of the most stressful times in a patient's cancer journey. The regular hospital visits may help some families to feel supported and contained. Children and adolescents and their families may experience a mixture of strong feelings, including joy, concern, relief, guilt, and fear. Some people report that they appreciate life more after a cancer diagnosis. Other families remain very anxious about their child's health, fear of relapse and become uncertain about coping with everyday life. Often, relationships built with the cancer care team provide a sense of security during treatment, and children, adolescents and their families miss this source of support. This may be especially true when new worries and challenges surface over time, such as any late effects of treatment, educational or school problems, emotional challenges, sexual development and fertility concerns, and/or financial issues.

Support services are essential at this stage to help with the transition to everyday life. At the end of treatment all patients and families should ideally be assessed by two members of the NPPO service for a final review/reassessment, to identify the current level of need for patients and their families. A decision will then be made in relation to the most appropriate care pathway (Kazak et al., 2007).

With appropriate resources, the extended Psycho-Oncology team within the NPPO service will develop an end-of-treatment psychoeducation programme for all children, adolescents and their families. This will be created in collaboration with key stakeholders with specific input in particular from dietitians and physiotherapists who will be involved in developing and running these end of treatment interventions to support patients and their families in this delicate transition and to address areas such as: returning to school, social interactions, returning to physical activities, healthy diet, emotional adjustment to new life circumstances and challenges ("new normal"), return to work for parents, hypervigilance and fear of recurrence. Psychology and Neuropsychology also will provide general guidance for returning to school to all patients at universal level through groups and general psycho-education. When the cognitive and neuropsychological needs are more complex, these patients should receive an assessment and more individualised support including direct liaison with schools. At present the current staffing in NPPO does not allow this individualised assessment and intervention for all who need this, not meeting international standards of care (Standard 11).

The NPPO service will provide an end-of-treatment summary to children, adolescents and their parents/carers, summarising the support and intervention they received during the cancer journey. Work is in progress between the NPPO service and the NCCS to include a Psycho-Oncology section within the medical care plan. Where appropriate a referral will be provided for further psychological and psychosocial support. See Appendix 7 for a sample Patient Discharge Form.

The role of **neuropsychology** within the Psycho-Oncology MDT is of particular importance at the end of treatment stage to screen for acquired risk factors. As indicated earlier in the pathway, all patients receive a consultation at time of diagnosis and at the end of active treatment. The neuropsychologist will review and identify which patients need a full neuropsychological assessment. Further information on the risk factors they will consider is available in Appendix 6.

Transition to adult services

Transition is defined as *'a purposeful, planned process that addresses the psychosocial, psychological and educational/vocational needs of adolescents and young adults with cancer as they move from child-centred to adult-orientated healthcare systems'* (Blum et al., 1993).

Transition is acknowledged as one of the most fraught times in the cancer experience. Preparing for transition is essential as paediatric and AYA services, which are generally family-centred and developmentally focused, differ significantly from adult services, which attempt to acknowledge patient autonomy.

Transition planning should commence well before the transfer of care to adult services and should be appropriate to the patients' cancer, treatment and developmental stage. When considering transition from paediatric/AYA to adult Psycho-Oncology services, regard to the specific needs of adolescents must be considered:

- A need for autonomy and the importance of being involved in decision making about their psychological well-being.
- The psychological needs of adolescents can be complex. For example, managing the uncertainty around the cancer diagnosis and prognosis can provoke significant anxiety. There are often no clear-cut answers, and this can cause significant disruption in the adolescents' lives.
- This is a time of rapid developmental changes, some of which can be impacted by the side-effects of treatment.
- Adolescents have a strong desire for independence and yet the diagnosis of cancer can prevent them from doing many of the things they want to do.

There is no uniform and ideal transition practice that fits each childhood cancer patient/survivor (Otth et al., 2021). Patients/survivors should be prepared well in advance and the process should be well structured and organised, ideally involving collaboration between paediatric and adult healthcare professionals, and good communication with patients/survivors.

Transition will differ from patient to patient. Psycho-Oncology teams should support children, adolescents and their families to make transition a much more navigable and manageable experience. Patients should be encouraged to have autonomy over their care and be aware of their own healthcare needs and how best to access support or seek advice and further information/education if needed.

For transition to be successful there are several key elements which need to be considered:

- Effective communication between healthcare providers.
- Flexibility with respect to timing of transition. Not all young people will be ready to make the transfer to adult services at the same time. Issues such as cognitive and physical development, emotional maturity and the status of their health should be considered when planning transition. This is particularly relevant for children and adolescents with comorbid conditions.
- Appropriate psycho-educational interventions are necessary to assist the adolescent understand the psychological impact of cancer, concerns about issues such as fertility, fear of recurrence, the medium and long-term effects of treatment on their well-being, as well as taking appropriate action and learning how to seek help from health professionals and navigate the health system. Having a key contact person is beneficial, as the key person will assist in coordination of other ancillary services and will assist the patient in terms of how to access same.

Within the NCCS, an MDT transition clinic will be developed based on these principles.

Relapse and further treatment

Children and/or adolescents who relapse at the end of treatment or with significant progression during their first line treatment will be urgently re-referred to the NPPO service. They will follow a similar pathway described in the figure 7. Whenever possible, continuity of care with the same members of the Psycho-Oncology MDT will be offered.

Palliative Care & End-of-life support

Based on the recommendations in the international standards of care and the AYA framework, a palliative care needs assessment should be undertaken following the diagnosis of a life shortening/potentially life-shortening illness. The Psycho-Oncology MDT will work in collaboration with medical consultants, nursing, and specialist palliative care teams to deliver comprehensive palliative care support. Within the NPPO service, integrating palliative care, in terms of concepts and values, into the therapeutic approach is standard, independent of the medical trajectory.

Palliative care of children and adolescents is an approach that is aimed at improving quality of life and decreasing suffering by:

- assessing and treating complex symptoms,
- identifying and responding to psychosocial needs in collaboration with the Psycho-Oncology MDT,
- co-ordination of palliative care services across settings (e.g., hospital, hospice, home), which may include bereavement care (Kaye et al., 2017).

It is an approach that involves multiple disciplines working together in a collaborative and compassionate way from diagnosis and throughout the course of the illness, whether the outcome is recovery, remission or death (Mack & Wolfe, 2006). Palliative care is concerned, not just with the patient but, with their family (Theunissen et al., 2007; Robert et al., 2012; Bousso et al., 2012; Mitchell et al., 2005; Tomlinson et al., 2011) (Standard 13). Areas that are often explored include anxiety, worry, sadness, fear of being alone, loss of independence and pain. Significant importance is also given to areas of meaning making, memory making and conversation about legacy and a sense of belonging (Weaver et al., 2015). (Standards 13 & 14).

For children and/or adolescents who are at the end of their life, having a pre-existing connection with palliative care providers can allow for timely mobilisation of necessary supports, delivered by professionals who have had an opportunity to develop trusting partnerships with those involved, and in a manner which is informed by prior planning (HSE, 2014; Together for Short Lives, 2013). In the case of bereaved parents, the benefit of engaging in bereavement activities have been demonstrated (Kassam et al., 2015), and is provided by a number of national charities, hospices and community cancer support centres.

Survivorship

> *"Cancer survivorship is a distinct period in the continuum of cancer care which begins at diagnosis and continues until the end-of-life. Providing optimal survivorship care can empower patients to achieve their best possible health outcomes while living with and beyond a diagnosis of cancer"* (Barrett et al., 2018)

At present there is no formal Survivorship Service in Ireland for this age cohort. While this development has been discussed at a medical and nursing level, it is also important that the provision of Psycho-Oncology is incorporated into the planning of these services. This includes the provision of appropriate psychosocial staffing in the future. A recent assessment of the needs of childhood cancer survivors in Ireland, from the perspective of patients, parents, guardians, and carers (Gavin, Clinton & Capra, 2022) identified psychosocial support for survivors, siblings and parents as a key priority.

It is critical that survivors are provided with support and resources to enhance their ability to function on a daily basis and to achieve the optimal level of functioning and quality of life.

Survivors are often not aware of the potential late effects of treatment and future health risks. Survivors of child/adolescent cancer are at risk of many and varied physical and psychosocial long-term and late effects (Brinkman et al., 2018; Mellblom et al., 2021; Michel et al., 2010, Oeffinger et al., 2006). Risk factors for psychological difficulties include a high burden of medical late effects and unmanaged pain (Tonorezos et al., 2022). Long term follow-up (LTFU) care is important and should be available and accessible to survivors of childhood and adolescent cancer throughout their lifespan (Michel et al., 2019). International guidelines recommend LTFU, based on risk, for child/adolescent cancer survivors to include surveillance for both physical and psychosocial effects of cancer and its treatments (COG, 2018).

The role of the extended Psycho-Oncology service in monitoring and managing the above-mentioned late effects is paramount. Exercise and physical activity interventions are effective in alleviating anxiety and depression, and are also associated with improvements in mood, fatigue and health-related quality of life (Li et al., 2023; Shi et al., 2022).

Psychological late effects are common in child/adolescent cancer survivors and these include but are not limited to:

- depression and mood disorder (2%-40%),
- anxiety (1%-27%),
- distress (2%-35%),
- PTSD (1%-18%),
- suicidal ideation (5%-12%) and suicidal behaviour (1%-4%) (Gilleland-Marchak et al., 2022).

Psychosocial impacts, of child/adolescent cancer can also have long-term impacts, in terms of educational and vocational difficulties, fear of cancer recurrence, relationship difficulties, including psychosexual concerns, body image and fertility–related distress, and risky health behaviours (Brinkman et al., 2016; Lown et al., 2016).

Studies have found that child/adolescent cancer survivors are more likely to have clinically relevant mental health impairments as compared to their counterparts without cancer (Mellblom et al., 2021). Survivors who do experience mental health problems have poorer physical health, decreased healthy life style behaviours and increased risk behaviours (Lown et al., 2016). The International Late Effects of Childhood Cancer Guideline Harmonisation Group notes that mental health support is fundamental for better quality of life and promoting the long-term physical health of survivors (Gilleland-Marchak et al., 2022).

Using an evidence-based screening tool, it is recommended that surveillance of mental health be completed at all follow-up visits and as standard of care (Gilleland-Marchak et al., 2022; Wiener et al., 2015). This aligns recommendations for physical, bio-medical and psychosocial health and provides the opportunity for this to occur at each follow-up point of care. Additional clinical and demographic risk factors should be considered such as; late effects of treatment, pain, seizures, history of depression or mental health disorder, female sex, education employment and marital status and lower annual income. Some survivors have more complex needs, and these include survivors of CNS disease, or CNS directed treatment and bone sarcoma (Fidler & Ziff, 2015). These cohorts should have access to specialist assessment and management from neuro-psychiatry/psychology.

Research suggests that the impact of LTFU care on survivor's knowledge about their treatment, and the improvement in surveillance for late effects, will result in overall long-term improvement in health and wellbeing (Signorelli et al., 2017).

Evidence-based recommendations for how the organisation of care for LTFU (including psychosocial domain) should be achieved, are largely based on lower levels of evidence, consensus and expert opinion. Recommendations on the organisation of care, the personnel involved in LTFU care, and the components of care are described in a recent project by Michel et al., (2019) and include starting LTFU care not later than five years after treatment or five years from diagnosis depending on individual healthcare system;

Components of LTFU care include

- Surveillance and preventive strategies based on evidence-based guidelines.
- Co-ordination of care.
- Education for healthcare professionals, survivors and families.
- Co-ordination of research

Children and adolescents have distinct needs during the survivorship period due to increased risk of physical long term and/or late effects of treatments, psychological health, and challenges with educational and work trajectories due to interruption and ongoing health issues. The National Cancer Survivorship Needs Assessment 2019 included a health needs assessment of adult survivors of childhood cancer (Barrett et al., 2018). This highlighted psychological and psychosocial supports as an unmet need for Irish survivors of childhood cancer. Being diagnosed and treated for cancer in childhood or adolescence had an enduring psychological impact on survivors; some survivors experience delayed trauma and mental health crises in adulthood and found specialised assessment and intervention difficult to access. Parents and siblings also had unmet psychological needs relating to the family's experience of cancer. There is a significant preventative benefit to addressing the psychosocial needs of children and adolescents early in their cancer journey.

Neuropsychology aspect of care during survivorship

Neuropsychology assessment is also an integral aspect of care for survivors of childhood cancer in order to identify possible late effects of oncology diagnosis and CNS-directed therapies. There are two crucial times when surveillance for neuropsychology deficits is imperative:

- **Assessment** at 1 – 2 years post-treatment
- **Assessment** at 4 – 6 years post-treatment

Decision making within each time point and across each level is informed by the identification of risk factors and their severity, clinical judgement on the part of the neuropsychologist and available resources within the treating team.

Conclusion

In conclusion, the psychosocial and psychological needs of childhood cancer patients are many and varied. In the past two decades, emerging research at both a national and international level has highlighted not only the needs but also the substantial gaps in services for CAYA with cancer. This MoC will be instrumental in providing a coherent blueprint for these many and varied needs over the lifetime of the current National Cancer Strategy and will bring greater clarity to the services that need to be enhanced or developed so that this age cohort of cancer patients can access all necessary supports to achieve their full potential.

AYA
Psycho-Oncology Model of Care

Overview of AYA Psycho-Oncology

Cancer is the leading cause of natural death in adolescents and young adults (AYAs) which is defined in Ireland as aged between 16 to 24 years of age. Adolescence and young adulthood are complex phases of life due to the many developmental, emotional and social transitions occurring - they face numerous challenges in several different spheres of life. A diagnosis of cancer during this complex developmental phase, is accompanied by a unique set of needs related to fertility, identity, relationships, body image, education and employment, and can cause significant delays to the important milestones achieved during these very formative years (Darlington et al., 2022). As with all cancer diagnoses, its impacts are multifactorial (see figure 9).

Young cancer patients in Ireland have reported the need for psychological support as a high priority (Barrett et al., 2020; Gavin et al., 2022). Internationally, psychological support is also the highest priority for AYA's with cancer, as highlighted in published research by Aldiss et al. (2019) and Schilstra et al. (2022).

There is a need for Psycho-Oncology and medical teams to support young people and their families to achieve the best quality of life possible and to provide space for growth, privacy, autonomy and personal medical decision making, whilst also providing containment, support with coping, and including guidance when needed/desired by the young person.

AYAs with cancer also live in the transitional space between paediatric and adult cancer services. They have been described as the 'lost tribe' with neither paediatric nor adult haemato-oncology departments able to provide developmentally-appropriate care to this group, with frequently expressed feelings of not belonging within the medical system (Ferrari et al, 2010).

The lack of specialist services for AYA was highlighted by ESMO/SIOPE (Ferrari et al., 2021) and a recent paper by Darlington et al. (2022) demonstrated that a clear delineation between patients diagnosed with cancer during childhood versus during adolescence or young adulthood, would be more appropriate for meeting the psychosocial needs of these two very distinct populations. AYA's benefit from a more holistic AYA multidisciplinary team approach to their care, which requires the provision of expert care from medical, nursing, and allied health professionals in collaboration with psychology, rehabilitation, social work, and educational experts.

Unique challenges facing 16 to 18-year-olds diagnosed with cancer

Cancer diagnosed at this age disrupts some of the most formative years in the lives of young adults and can impact their emotional, cognitive, and social development. Current and future plans are significantly disrupted especially in the area of self-image, education, career opportunities, relationships, and ability to have children.

Managing these upheavals is an unmet need for AYA patients, and clinicians can play a key role in helping them navigate the cancer trajectory, including remission and recovery. Of greatest concern is the fact that that young people diagnosed at this age can experience a feeling of no clear-cut patient pathway in that both paediatric and adult cancer services may be appropriate to their needs. Therefore, cohesion between services is of paramount importance.

There can also be many barriers to accessing support within these services including those relating to service-related and systemic factors. Service-related factors include a lack of available, appropriate, and accessible support. Systemic factors included not being offered services, a lack of integration between different health settings, e.g. paediatric and adult hospitals and inconsistency in service provision across sectors. It is acknowledged that adolescents diagnosed with cancer face a significant burden in terms of services and it can be difficult to define a patient pathway as they currently access services in both paediatric and adult cancer centres.

A recent study by Holland et al., (2021) suggests that barriers in access to psychosocial care are multifactorial. However, most are modifiable through health-service system responses. Clinicians working with this population must address not only traditional issues related to cancer but also those that come about due to the patient's life stage. It is therefore important to develop programmes that are geared specifically toward this population and include evidence-based, patient-centred multidisciplinary care. Health care professionals can better serve these patients by recognising the special challenges they face in addition to the social and psychological difficulties that come with cancer. One of the key purposes of this Model of Care is to highlight the unique challenges for this age group and begin to address these needs. The needs of this cohort are highlighted in the following quote:

> *'to have a dedicated unit/space where they are treated like adults but have all the privilege and time that children get' (Taylor et al., 2011).*

Physical

- Side-effects of treatment
- pain
- nausea
- body image
- hormonal changes
- sexual health
- fatigue
- fertility
- Loss of appetite
- weight gain/loss
- disruption to central nervous system (CNS)
- reduced physical activity

Psychological

- Self-worth
- self-esteem
- coping skills
- resilience
- loss of control
- sexuality
- fear of recurrence
- anxiety
- low mood
- maintaining personal identity

Education & Career

- Neurocognitive deficits
- impact on school attendance
- significant loss of educational opportunities
- struggle to gain/ maintain employment
- difficulties making/ maintaining vocational goals
- missing milestones

Social

- Isolation
- family distress
- sibling relationships
- peer relationships
- exploring intimate & romantic relationships
- establishing independence from parents

Informational

- Disease & late effects
- procedures
- symptom control
- coping skills
- Services available

Philosophical

- Risk-taking
- Sense of a just world
- Decision-making

Existential

- Meaning of illness
- making sense
- spiritual beliefs
- pastoral care

Figure 9 Life challenges due to a cancer diagnosis in AYA

Equality and flexibility

The development of Psycho-Oncology services for AYA cancer patients should be informed by principles of equitable access for all, as per the NCCP MoC for (adult) Psycho-Oncology in Ireland (Greally et al., 2020). Services should therefore be flexible, while always maintaining the highest standards (e.g. assessments adapted for non-English speaking patients, or virtual options provided for those who have difficulty with physical access to services). Similarly, to the medical pathway, flexibility will be practiced whereby MDM discussions will be centred on care delivery, best aligned to the young person's developmental stage. Psycho-Oncology services for AYA will replicate the medical framework and given the wide range of psychosocial issues experienced by this cohort, developing services that encompass both paediatric and adult Psycho-Oncology MDTs offers the best outcome. It is acknowledged that not all AYA with cancer will be seen in one of the AYACSN sites - some will be treated in other hospitals. Referrals to the National AYACSN MDM can however be made by any oncology team involved in the care of an AYA cancer patient. The AYA Psycho-Oncology service will be guided by developments in this area as the AYA service evolves.

Professionals working with this age group should be able to identify the cognitive challenges for AYA with cancer, as this is an important factor in terms of ensuring fully informed consent/assent and understanding of medical treatments and other interventions. They are likely to see patients who are both under the age of consent and of legal maturity.

Theoretical Framework for AYA Psycho-Oncology Services

While there is no specific theoretical framework for AYA Psycho-Oncology services, the main document has informed the development of this MoC is:

- NCCP Framework for the Care and Support of AYA with Cancer in Ireland 2021-2026

Other key documents include:

- NCCP Model of Care for (adult) Psycho-Oncology (2020)
- National Cancer Strategy (2017-2026)
- AYA Oncology Psychosocial Care Manual (Canteen, 2011).

The NCCP's AYA framework was created in response to a number of recommendations in the National Cancer Strategy 2017-2026. Those that pertain to the AYA cancer care are highlighted below.

Recommendation 30 – Each designated cancer centre will establish a dedicated service to address the psychosocial needs of patients with cancer and their families. This will operate through a hub and spoke model, utilising the MDT approach, to provide equitable patient access.

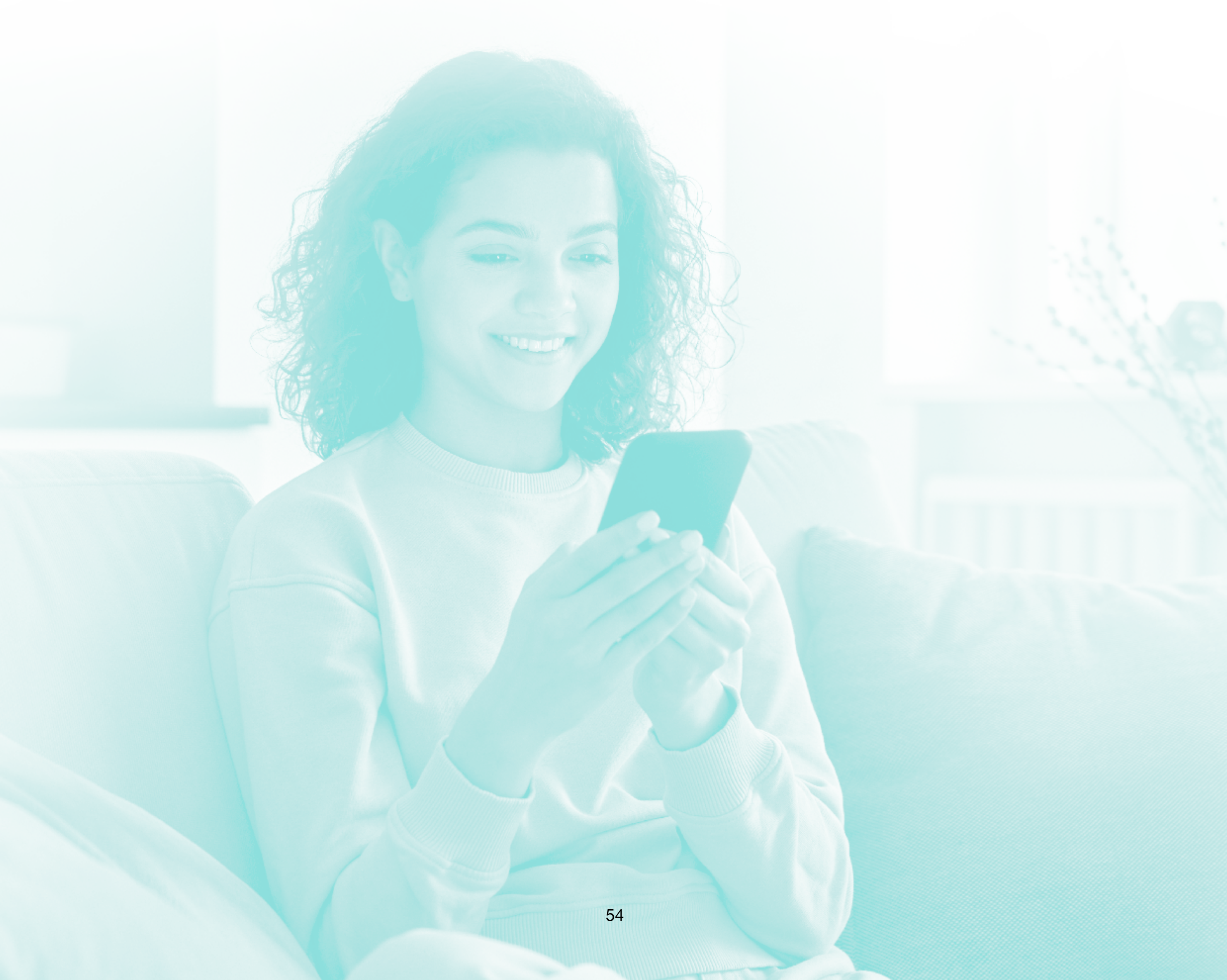
Recommendation 31 – Designated cancer centres will have a sufficient complement of specialist palliative care professionals, including psycho-oncologists, to meet the needs of patients and families (such services will be developed on a phased basis to be available over seven days a week).

The AYA framework sets out the vision and strategic aspirations for the care and support of AYA's with cancer in Ireland. The aim is to achieve accessible and equitable access to AYA cancer care across Ireland that is developmentally appropriate for all AYA diagnosed with cancer, resulting in better outcomes and improved quality of life. It will help to promote a partnership-based approach to AYA cancer care, ensuring that these young patients living with cancer and beyond, can achieve the best possible outcomes during treatment, survivorship and at the end of life.

The framework has been informed by the recently published paper by Ferrari et al. (2021) and previous work by colleagues in Scotland, the UK, Canada and Australia who all have well established AYA cancer services.

It highlights the gap in the Irish healthcare system for AYA cancer patients and is in line with the National Cancer Strategy 2017-2026. This is an ambitious document to underpin the development of dedicated AYA cancer care and services in Ireland.

It is worth noting that within Europe there are only three countries that have a strategy for AYA with cancer (Poland, France and Ireland).



National AYA Cancer Service Network (AYACSN) in Ireland

The AYA framework outlines the development of a National AYACSN. This is being supported by the NCCP with the appointment of specialist healthcare professionals across the network. There are six principles of the framework that focus on the creation of holistic services with AYA patients and their families at the centre (figure 10).

A National AYACSN has recently been established incorporating CHI at Crumlin and three centres at CUH, GUH and SJH (figure 11). Within the AYACSN, a virtual MDT is being developed in collaboration with paediatric and adult services with weekly MDMs. It is proposed that all AYAs with cancer in Ireland are discussed at the National AYACSN MDM. The purpose of this MDM is to ensure that all AYA cancer patients have equitable access to comprehensive and personalised age and developmentally appropriate care, including access to Psycho-Oncology services.

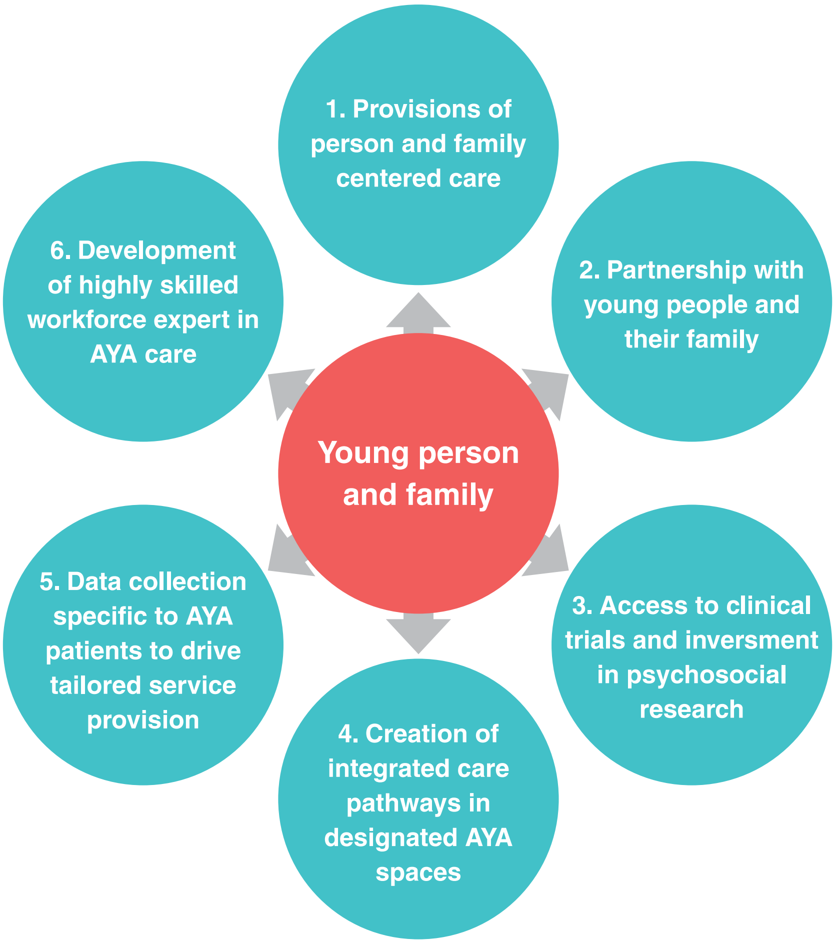
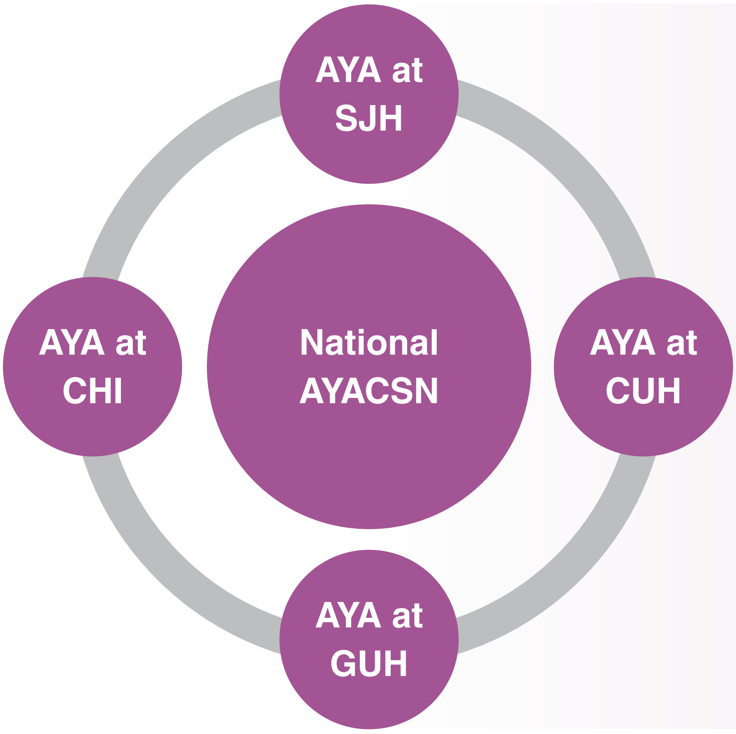


Figure 10 Principles of the AYA framework



Weekly MDM – MDT Specific Issues:

Collaboration between paediatric and adult services (at all levels)

(i) Supportive Care

(ii) Fertility preservation and counselling

(iii) Psycho-Oncology support

(iv) Education and career development

(v) Body image, sexuality and relationships

(vi) Alcohol and substance abuse

(vii) Clinical trial availability/ participation

Figure 11 AYA Cancer Service Network (AYACSN)

The national MDM commenced in Q1 2023, and is run through the NCIS MDM function. It is expected that appropriate members of the AYACSN team and/or the patients' primary treating team, will attend this weekly meeting. A holistic health needs assessment will be carried out on each AYA cancer patient to help guide their management. As this is a new MDM, it is very much an evolving process which will be evaluated on an ongoing basis and adapted based on service user and network needs.

Referrals can be made to the AYACSN MDM by any team member who is involved in the care of an AYA cancer patient in any hospital across the country. The referral proforma (Appendix 8) will be hosted on the NCCP website for all health care professionals to access. Again, this will be audited and adapted as necessary and should be used to highlight an AYA's specific needs and drive discussion at the MDM on a case-by-case basis. Recommendations will be suggested from the discussion at the MDM and recorded on NCIS, in real time.

The AYACSN MDM is the ideal setting to integrate psychological and psychosocial care into the wider care plans for this patient group. Representatives from Psycho-Oncology MDTs across the AYACSN will attend the weekly meetings to ensure there is coordinated and integrated care between medical and Psycho-Oncology professionals.

Proposed Patient Pathway

At present, AYA patients uniquely access both paediatric and adult services, depending on their age. This presents an inequity in the experience and focus of care, depending on the system entered.

The proposed cancer pathway (figure 12) for AYAs would aspire to provide the best standard of care for all young people. This pathway envisages AYAs being referred as early as possible to the AYA team for advice on diagnostics, treatment, place of care and other psychological and holistic supports to ensure a developmentally appropriate approach is taken.

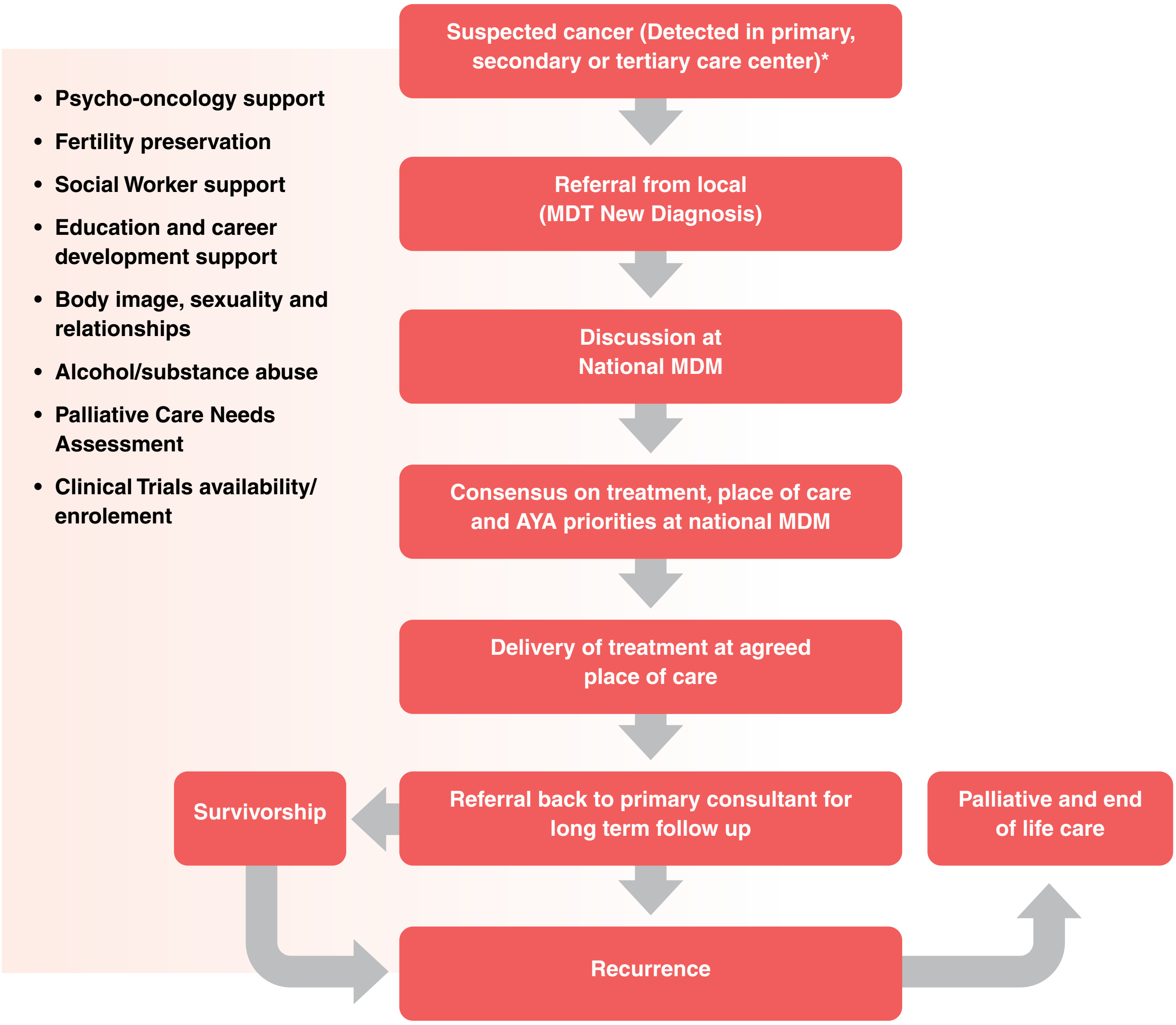


Figure 12 Proposed cancer pathway for patients aged 16-24 years

AYA Psycho-Oncology Services

AYA Psycho-Oncology MDT

Function

The AYA Psycho-Oncology MDT will provide holistic biopsychosocial assessment and intervention according to the stepped care model to ensure that the patients' needs are addressed by appropriate supports and/or interventions. The MDT will meet on a regular basis to discuss patient care and work jointly on the provision of integrated psychosocial and emotional support to patients within their families and support systems. The activities of the MDT include individual outpatient appointments and inpatient reviews, group-based interventions, communication with other services and patients' support networks, and attendance at relevant clinical and administrative meetings.

Neuropsychology within Psycho-Oncology

As per the paediatric Psycho-Oncology model, an important component of Psycho-Oncology care for this cohort is access to Clinical Neuropsychology within the Psycho-Oncology MDT, which is appropriate to the age and developmental stage of the young patient. Clinical neuropsychology input is essential both for assessment of cognitive, emotional and behavioural functioning, and for intervention, such as timely cognitive rehabilitation to maximise the young person's academic, social and vocational participation and attainments.

In certain circumstances, AYAs undergoing neurosurgical planning may require pre-operative testing or an awake craniotomy procedure. Clinical neuropsychologists play an essential role in both the planning and delivery of these procedures.

At present, AYAs with cancer in Ireland are treated across adult cancer services. Within both the acute hospital and community-based setting, however, there is currently very limited access to clinical neuropsychology as part of the adult oncology patient care pathway. As per the proposed framework by Jacola at al. (2021) in the paediatric MoC section, a tiered approach to neuropsychological assessment for AYAs with cancer is recommended. The model outlined, also acknowledges the dual role of clinical neuropsychology in assessment and intervention/cognitive rehabilitation within the AYA patient group.

Specific issues in relation to neuropsychology

As with the younger oncology patients, cognition is continuing to develop in AYA in line with on-going brain development (Hartshorne & Germine, 2015), and therefore this cohort can be particularly vulnerable to the impact of any illness or treatment that disrupts CNS functioning. John et al. (2016) noted that adolescent brain reorganisation begins during puberty and slows by the age of 25 years. Cortical plasticity during the adolescent period underpins the development of advanced cognitive functions, particularly the executive functions (John et al., 2016). This period of neural plasticity may render adolescents more vulnerable to negative impacts of chemotherapy on higher-order cognitive skills and frontally-mediated behaviours/ emotional functioning. A review by André et al. (2021) also describes the changes in brain connectivity associated with cancer-related fatigue, which can impact effort-based decision-making.

Conversely, AYA cancer survivors may demonstrate greater resilience to cognitive deficits than adult cancer survivors due to greater cognitive reserve and neuroplasticity (Jim et al., 2018), and it is vital that these protective mechanisms are maximised through timely access to cognitive rehabilitation.

Access to service

As the AYACSN it is still evolving, this MoC does not present specific descriptions of the four AYA Psycho-Oncology Services. They will develop within the NPPO service in CHI at Crumlin, and the Psycho-Oncology services in CUH and GUH and SJH.

Currently, there are approximately 69 new diagnoses of cancer per year in the 16-19 year old age group. Of these, the most critical cohort of AYA patients, in terms of current gaps in services, are the 16-18 year olds because, as mentioned, they often fall between paediatric and adult services. It should be noted that within the 16-19 year old cohort, circa 40 will be paediatric-centric cancers and will be seen within the NPPO service, once the NCH is open.

Of the remaining 29 new diagnoses per year (adult type cancers), this group will be expected to access services between CUH, GUH and SJH.

With regard to the provision of Psycho-Oncology support for 16-19 year olds, there are three options, which can be considered:

1. The NPPO service, located at CHI at Crumlin, to expand its service to all new patients from the age of 16-19 years in Ireland. New cross-site governance agreement would need to be developed between CHI and the other three AYACSNs.
2. The NPPO service to expand its service to treat all new patients from the age of 16-19 years diagnosed with paediatric-centric cancer. The other AYACSN sites will expand to see the remaining patients newly diagnosed with cancer in that age cohort.
3. A national cross-site Psycho-Oncology MDT in AYA to be developed to cater for all patients diagnosed with (non-paediatric centric) cancer between 16-24 years.

Due to the likely complexity of some of these patients and the increase in numbers for the services, it is acknowledged that there will be workforce planning implications for centres depending on what option is optimal for patients and their families. It is envisaged that the AYACSN – Psycho-Oncology group will meet regularly from September 2023, to review the options above and ensure optimal patient care.

It is also envisaged that the four AYA services will come together to work on communication, education/facilitation, workforce planning, service development and other areas of common interest.

Members of the AYA Psycho-Oncology MDT

The proposed members of the AYA Psycho-Oncology MDT are illustrated in figure 13:

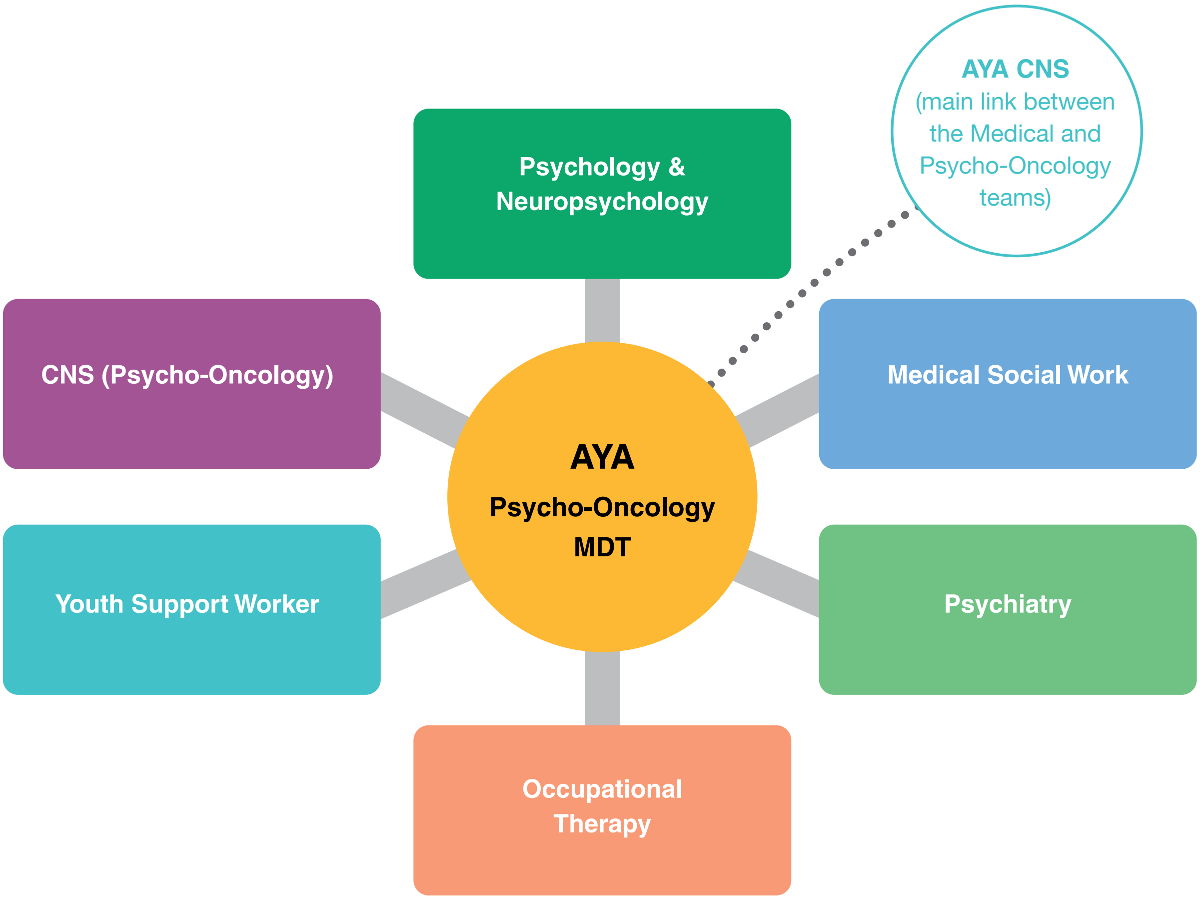


Figure 13 Proposed AYA Psycho-Oncology MDT

Training

It is important to note that the vast majority of the disciplines within the AYA Psycho-Oncology MDT are professions that have life span training, with the exception of psychiatry and neuropsychology. For the future development of MDTs in this area, it is advised that dual training opportunities are developed and funded in order to have professionals in this area that can work with patients from 0 to 25 years. Specialised training and education needs will be identified as the service develops. A collaborative approach to developing this training will be taken with third level academic institutions in Ireland.

Radiotherapy Psycho-Oncology Service

St Luke's Radiation Oncology Network (SLRON) is the national radiation oncology centre in Ireland. Their Psycho-Oncology service provides psychological support across the lifespan, which includes AYA cohort (16 to 24 years of age) requiring radiotherapy in in SLRON. The Psycho-Oncology service offers psychological assessment, intervention and therapy to meet the needs of the AYA patients, while also providing a service to siblings and parents/guardians whilst on treatment and post treatment. The Psycho-Oncology team are supported by medical social workers, radiation oncology nurses, physiotherapy, dietitians, speech and language therapy and the wider medical team. This service is clinically led by a Principal Psychologist who is also manager of the service. The medical care of this cohort is coordinated between the NCCS and the Radiation Oncologists in SLRON. These patients will usually attend SLRON for a period of 6-8 weeks before returning to the NCCS.

National Rehabilitation Hospital

NRH through its inpatient Spinal Cord System of Care, Brain Injury, Prosthetic, Orthotic & Limb Absence Rehabilitation and Outpatient Programmes, provides a range of specialist interdisciplinary rehabilitation services. As part of their overall delivery of care, each programme provides inpatient and outpatient services to those aged 18 and over, including those with physical and/or cognitive rehabilitation needs arising from cancer. Within each programme, there are psychologists and neuropsychologists providing a wide range of specialist services to individuals and their families in line with the AYA model of care. In recognition of the unique needs of this particular age cohort, NRH has a specialist consultant-led Transition to Adult Service for young people with acquired brain injury aged 18-24, including those with acquired injury relating to cancer. Some of the young people attending NRH adult services will have transitioned from the NRH Paediatric programme which caters to children and young people aged 0-18 years.

Community-based services for AYA

Community-based services can also play an integral role in supporting AYAs living with and beyond their cancer diagnosis, including but not limited to those working in cancer support centres, youth support workers, charitable organisations and other community services. As previously mentioned, Cancer Support Centres are a crucial stakeholder, providing a wide range of services for young people and their families. These services range from the provision of information, psychological support and survivorship programmes – seen as the core services – to complementary therapies, yoga and relaxation classes, support groups, financial advice, peer-to-peer support for patients and/or family members and drop-in services.

Referral to appropriate community services that can offer extensive care and support should be utilised whenever possible. These services have a number of key roles to play (e.g. information and advice, counselling, survivorship programmes) in supporting AYAs to adjust to new life circumstances and challenges. There is a need to develop specific programmes for this cohort.

The education environment is important to consider, where return to secondary or higher education is often cited as challenging by AYAs (Cameron et al., 2021; Elsbernd et al., 2018). Educators such as teachers, tutors, special needs assistants, and career guidance counsellors therefore play a vital role in fostering development during and after cancer treatment.

Reintegration into the workforce also necessitates the support of other stakeholders such as employers, occupational health staff, and human resource officers.

Transition

Transition in this context refers to an AYA being transferred to an adult cancer centre for all services. To cater for the needs of this population a Transition Clinic will need to be established. This process can only be developed when AYA services have evolved. During the process of developing a Transition Clinic, consideration will be given to establishing pathways for services for LTFU for this cohort.

Palliative Care & End-of-Life Support

Awareness should to be given to hearing the voices of AYA while planning medical care. Having to navigate illness, while experiencing the emergence of independence, identity development, and relational maturation can be further challenged when AYAs are left out of treatment discussions and decisions (Wiener et al., 2022). Medical challenges and psychosocial vulnerabilities point to a critical need for effective end-of-life communication, especially alongside disease progression or a poor prognosis. Literature suggests that when supported, most AYAs can choose and decline treatment and determine their care plans, including how they will be remembered after death (Wiener et al., 2012). Prioritising symptom management is an important component to optimise quality of life during the terminal illness phase. Early referral to palliative care service providers and cohesive integration of palliative care and Psycho-Oncology services alongside life prolonging therapies, where they exist, promotes better individual experiences and allows for holistic support of the AYA and their family through to death and bereavement.

Approximately 80% of the AYA cohort will survive their cancer diagnosis. However, for those families where their loved young person dies, bereavement support is essential. This should include access to professional bereavement support where necessary. Based on evidence from the international standards (Standard 14), the service will continue to work closely with medical and nursing members of the MDT within the NCCS, to develop bereavement support. At times this support may be offered directly, or through referral to community and charity services, based on the needs and wishes of families.

Survivorship

> *'the experience of being spat out at the end of treatment can be as traumatic as diagnosis because all of a sudden you've been radically changed, you've been through this remarkable transformation experience in lots of ways, you've faced problems that lots of adults have not had to face and you may also be fundamentally physically changed by your treatment, so you may be clear of cancer but living with long-term effects, be they psychological or physical'*
> (clic sargent and teenage cancer trust)

Survivorship services are a key driver for psychological well-being for those living with and beyond cancer and their families. Best practice indicates that the range of professionals including psychologists, neuropsychologists, psychiatrists, social workers, Psycho-Oncology CNSp's, occupational therapists, physiotherapists, speech and language therapists, dietitians, and others should be involved in survivorship care pathways. It is envisaged that these services will become available in Ireland in the future.

Education and Employment

As previously mentioned, return to education and employment is often cited as one of the main challenging for AYAs post treatment (Cameron et al., 2021; Elsbernd et al., 2018) and is compounded by the late-effects of treatment such as fatigue (van Deuren et al., 2020), anxiety and depression (Baker & Syrjala, 2018), as well as understanding by peers (Elsbernd et al, 2018). In line with missed schooling and long-term side-effects of treatment, AYAs may underperform academically in comparison to peers, which can in turn predispose them to barriers in employment and financial difficulty in later life (Barrett et al., 2018).

Long-term survivors of AYA cancer demonstrate increased rates of cognitive dysfunction, including attention, memory and executive functions (Adams et al., 2021), resulting in difficulty completing education or maintaining employment. Cognitive dysfunction goes hand in hand with psychological distress with higher rates of cognitive dysfunction predicting higher rates of psychological distress and vice versa (Jim et al. 2018; Dewar et al., 2021). With some populations more at risk (such as those with primary brain tumours or who received cranial radiotherapy [Adams et al., 2021]) AYA survivorship services should include risk stratification for those most vulnerable to neurocognitive effects. Neuropsychological assessment capacity, provision of remediation/intervention supports as well as associated mental health and employment supports are also required.

Relationships

The unit of care in AYA oncology is long recognised as involving not only the patient themselves but also their parents, partners and close others within the family or peer system. For some, missing out on experiences such as college, dating, or becoming independent, results in a sense of isolation and alienation from peers and reduced opportunities to develop significant romantic relationships at the time when this is a core developmental task. In the survivorship period, feeling ‘abnormal’, having fertility concerns, low self-esteem and body image adjustment challenges, present ongoing barriers (Janssen et al., 2021). For some, close relationships are experienced as being strengthened (Bellizzi et al., 2012) and there is a need to consider, assess, and support the relational impacts experienced by this population in order to prevent and/or address long-term and late effects.

Body Image

Adolescence and young adulthood is a period of ongoing change and adjustment to one’s physical appearance with dissatisfaction common in this population (Brierley et al., 2019). Changes to the body, particularly those that are persistent and significant (e.g. disfigurement), may result in longstanding challenges with body image, psychological distress and relational intimacy (Bolte & Zebrack, 2008, Olsson et al., 2018). Sexual function may be compromised via direct (e.g. erectile dysfunction, ejaculation issues, vaginal atrophy, altered libido, early menopause) or indirect (e.g. fatigue) treatment effects, in addition to changes to self-esteem and physical appearance arising out of diagnosis and treatment (Janssen et al., 2021, Husson et al., 2018). Information needs of AYAs regarding their sexual health may not be recognised by healthcare providers. Where sexual health is addressed, AYAs report feeling positive about the outcome however, standards of care in this area are required with training/ support for healthcare professionals (Perez et al., 2020; Pt et al., 2016).

Fertility

Consistent with their stage in human development, AYAs with cancer have variable abilities to see long-term implications of present actions, understand health risk, and make complex decisions. As survival rates are increasing for different types of cancer, survivors are living with the after-effects of lack of fertility information and preservation options provided, for a longer proportion of their lives (Carpentier & Fortenberry, 2010). The effects of treatment on reproductive capacity are especially highlighted for adolescents/ young adult survivors (Metzger et al., 2013). Lack of knowledge about treatment effects on fertility, failure to discuss preservation options pre-treatment, expense of preservation and the exploratory nature of some newer preservation methods, are all referenced as factors limiting the current uptake of fertility preservation (Lee et al., 2006). Healthcare professionals may hesitate to offer information about late effects to those who are visibly distressed by this subject, yet, AYAs seem to value information about potential late effects even if they find this information upsetting (Greenzang, 2020).

High-quality communication and information to support treatment decision making contribute to overall care satisfaction, whereas unmet information needs are associated with lower health-related quality of life (Greenzang, 2020). Providing upfront information about the risks of late effects can empower patients to make informed decisions about their care and may set the stage for future engagement in survivorship care and risk-based screening for late effects.

In an Irish context, in a study by Hession et al., (2021), 305 AYA were asked about their fertility support received, over 80% of those diagnosed reported being unsupported in preserving their fertility.

Conclusion

A diagnosis of cancer in adolescence and young adulthood has several features that make the management of the disease more challenging and unique than cancer at other ages. This is often associated with the myriad of developmental, psychological and social demands that are common for this age cohort. It is also because this is a time of transition and the demands of a cancer diagnosis directly conflict with what the young person feels they should be doing (e.g.) gaining autonomy instead of being still dependent on their parents, meeting their friends instead of having to shield from infection and being isolated. For a significant proportion of AYA, the stress of this event far outweighs their resources and for this reason, significant psychological support must be afforded to this age cohort.

It is recognised that it will take a number of years to develop the AYA Psycho-Oncology service in Ireland and as such, healthcare professionals may be required to be flexible and open to new approaches to working.

Key Recommendations

The following recommendations are in line with best practice and international standards. Recommendations should be followed subject to the healthcare professionals' judgement and patient preference on a case-by-case basis.

General

1. Psychosocial support should be available at all points in the patient journey where the focus is on the patient's developmental age and stage and with regard to all the unique features of each individual.
2. The perspective of the whole family should be included in the assessment and care planning processes.
3. A holistic biopsychosocial screening assessment should be completed by members of the Psycho-Oncology team at one month post medical diagnosis.
4. An SOP should be developed for Paediatric and AYA Psycho-Oncology MDMs.

Psycho-Oncology MDTs

5. **Paediatric**
   a. Children and adolescents with paediatric-centric cancer (0-19 years – new diagnoses; as per the AYA framework) should be seen by the NPPO service in the new National Children's Hospital.
   b. Patients receiving radiotherapy at SLRON should receive Psycho-Oncology support within that service.
   c. Patients who are 19 years and already receiving support within the NPPO service, should continue to do so until they are discharged or transition to an adult service.
   d. The core members of a Paediatric Psycho-Oncology MDT are identified as the disciplines of Psychology (incl. Neuropsychology), Social Work, Psychiatry, Complementary Therapy/Psycho-Oncology CNSp, Play Specialist, Music Therapy, and Occupational Therapy.
   e. There is recognition that there are other disciplines that play a key role in Paediatric Psycho-Oncology therapeutic and rehabilitation care, namely Physiotherapy, Speech and Language Therapy, and Dietetics.

6. **AYA**
   a. AYAs diagnosed with cancer (16-24 years) should be discussed at the National AYACSN MDM and receive appropriate support based on their level of needs. Psycho-Oncology support will be provided by the Psycho-Oncology MDTs in CHI at Crumlin, CUH, GUH, and SJH.
   b. Consultation with the NPPO service will be available for Psycho-Oncology MDT members providing a service to AYA aged 16-19 years, attending one of the other AYACSNs.
   c. Patients receiving radiotherapy at SLRON can receive Psycho-Oncology support within that service.
   d. Representatives from the Psycho-Oncology MDT should attend the weekly National AYACSN MDM to ensure there is coordinated and integrated care between the medical and Psycho-Oncology teams.
   e. A working group comprising representatives from the four AYACSNs should be convened to work on areas of service development and implementation of the MoC for AYA. The AYACSN Psycho-Oncology group should meet regularly from September 2023, to ensure the collaboration and integration of Psycho-Oncology care for all AYA in Ireland.
   f. A review of the three options for the delivery of AYA Psycho-Oncology services should be carried out in Q2 2024.

7. All disciplines within Psycho-Oncology MDTs should be adequately supported by the appointment of an MDM coordinator, administrative staff and other support workers.
8. All staff must utilise supervision in Psycho-Oncology and continue to attend training events, appropriate to their role on the MDT.

Neuropsychology

9. **Paediatric**
    a. A neuropsychology consult should be offered to all children within the paediatric oncology or malignant haematology group who are identified (time points T1 and T2, see Appendix 6) at high risk of neurocognitive impairment.
    b. A neuropsychology assessment should be offered to all children who have been identified (time points T3 and T4, see Appendix 6) at high risk of developing neurocognitive impairment following treatment.
10. **AYA**
    a. A neuropsychology consult should be offered to all AYA within the oncology or malignant haematology group who are identified as high risk for neurocognitive impairment. Based on the initial consultation, some AYA will need a screening or full neuropsychology assessment.
    b. A working group of neuropsychologists and, where appropriate clinical psychologists, with expertise in providing neuropsychology care to children and AYA, within the clinical area of oncology, malignant haematology and transplant, should be established, to review international standards of care and identify interview protocols, screening instruments, assessment batteries and neuro-rehabilitation interventions, based on international research evidence.

Patient Pathway

11. Paediatric

a. The proposed paediatric patient pathway should be disseminated to all cancer treating teams, across CHI sites, SLRON and the Shared Care Centres.

b. There are key points in the patient journey where screening for distress/reassessment of needs should be conducted to determine the impact of the cancer journey on the patient (e.g. at all pivotal treatment points or at set time intervals), especially at the end of active treatment.

Shared Care Centres

12. Paediatric

a. A hub and spoke model for psychosocial care is required to facilitate delivery of most of the care locally, with outreach from tertiary paediatric subspecialties to the regional units. Care should be provided within the network at the appropriate level, in order to use resources efficiently and to ensure access, for all children, to the required discipline within the NPPO service.

b. Training, teaching and communication across the Shared Care centres and any other Psycho-Oncology service should be facilitated.

c. A standardised transfer/communication summary should be developed and shared between services if a patient is moving from one hospital/centre to another:

- to ensure information is communicated effectively and confidentially, to all those involved in the patient's care, and
- to enable a smooth transition for patients between care settings.

Cancer Support Centres & Services

13. There should be an integrated patient pathway from hospital services to community cancer support, where appropriate, and where services are developed.

14. A directory of community services should be developed so that there is clear signposting to these services for patient and family support.

15. Services should be offered by appropriately qualified therapists to work with this age cohort.

16. Once survivorship services are established, an integrated patient pathway connecting community cancer support services back to a survivorship service should be developed.

Transition

17. A transition framework for this patient cohort should be established. Transition planning should commence at least two years before the transition process is commenced, in collaboration with the patient.

18. A key worker should be appointed within the Psycho-Oncology team to act as liaison for the patient and their family, whereby their role, in the transition phase, is to ensure that the patient's psychological needs are met.

19. There should be an identified point of transition and until that time the NPPO service should provide psychosocial support.

20. Transfer of information from Paediatric and AYA Psycho-Oncology services to adult services should be on a formal basis via a standardised transfer/communication summary to ensure good communication and continuity when moving from Paediatric/AYA-based to adult-based healthcare systems.

Palliative Care & End-of-Life

21. Specialist palliative care teams should be embedded within primary paediatric and AYA oncology services to ensure that all aspects of palliative medicine are available to patients and their families and to establish palliative care as a key component of the patient pathway as necessary.

22. Clearly defined bi-directional communication and referral pathways should be developed in respect of the psychosocial care of paediatric and AYA patients, between acute and community-based hospice and palliative care services and bereavement services.

23. Families should receive support in their anticipatory grief and, when necessary, end-of-life care that is based on a biopsychosocial model which is developmentally appropriate, family-oriented, tailored to their needs and wishes, and in accordance with their religious, secular, ethnic, social and cultural values.

24. Following the death of a child, adolescent or young adult, a member of the Psycho-Oncology MDT should contact the family to provide continuity of care or make a referral to an appropriate service.

Survivorship

25. Late effects clinics should be established as a standard of care.

26. Surveillance of distress and psychosocial issues should be completed at all follow-up visits and as a standard of care, to include brief assessment, referral and intervention, as necessary for all patients.

27. Appropriate neuropsychology assessment should be offered based on patient needs.

28. There should be a single point of contact for survivors of cancer to facilitate co-ordination of care.

29. Survivorship care should address the social and relational context of the patient. In addressing long-term and late effects, screening for relational distress/discord and the availability of appropriate intervention services, such as family and relationship therapy, should be provided.

30. Fertility-preservation options should be discussed as early as possible with all patients of reproductive age whose treatment carries a risk of infertility.

Genetics & Genomics

31. With the proposal to offer genetic testing to all CAYA with cancer (pending the development and implementation of the National Strategy for Genetics & Genomics), the distress caused, as a result of a genetic cancer diagnosis, to this cohort of patients should receive appropriate psychosocial support.

Workforce Planning

The development of Paediatric and AYA Psycho-Oncology services has workforce planning implications. In order to achieve the recommendations in this MoC and maintain standards of care in line with international best practice, services should have a suitable skill mix for their setting and type of service. Specific staffing needs and business planning will need to be submitted on a yearly basis.

Workforce calculations must include provision for both ‘direct’ and a range of ‘indirect’ activities delivered by Psycho-Oncology teams such as:

- clinical screening and assessment,
- development of individual and group interventions,
- provision of training, consultation and support for medical, nursing and other HSCP colleagues,
- ongoing supervision of all team members,
- specialist advice on complex cases within MDT meetings,
- specialist advice, supervision, skills training and consultation to multi-disciplinary colleagues across the whole pathway, including primary care and community settings when needed,
- provision of reflective practice groups, multi-disciplinary support and education groups for medical, nursing, and other HSCPs,
- dedicated time for the clinical leads in the four AYACSNs to work collaboratively on developing research, clinical trials, service development and collaboration cross-site.

A recent audit indicated that paediatric Psycho-Oncology services in Ireland will continue to struggle to meet the international standards of psychosocial care without additional personnel (Besani et al., 2021). The NCCP, in conjunction with the NPPO service and guided by international best practice, have identified the essential staff needed to deliver the recommendations in this MoC. Similarly, a scoping study carried out by the NCCP in 2022, highlighted the current gaps in psychosocial services across the 16 Shared Care Centres.

A number of gaps/resource deficits have been identified across AYA Psycho-Oncology services also, which may benefit from the submission of collaborative business cases across sites/services. There is a need to complete a workforce planning review (prospectively as part of the AYACSN MDT) of the various disciplines involved which would focus on the numbers of staff required for service provision, but also consider new ways of working.

Education & Training

As paediatric and AYA services continue to grow over the next decade, specialised training and education will also develop.

1. **Supervision of staff within the Psycho-Oncology MDT**

   The Clinical Lead and senior members within different Psycho-Oncology services have a responsibility to provide supervision to members of the MDT and to offer training for new staff when they join the service.

2. **Education and training for all staff working in cancer services**

- The Psycho-Oncology MDT is responsible for developing education and training workshops/modules to emphasise the importance of communication and collaboration between healthcare professionals and patients/families affected by cancer.
- All disciplines should receive training in the recognition of psychosocial distress and other common psychological needs in this age cohort from the Psycho-Oncology MDT. Appropriate referral pathways should be included in this training.
- The development of the new AYACSN should be supported by the education and training of the wider oncology workforce. Psychosocial support encompasses the entire cancer journey and necessitates the involvement of most clinical and non-clinical oncology professionals.

3. **Training and education in collaboration with palliative care teams**

- The Psycho-Oncology MDT has an important role in collaborating with the Palliative Care Service to educate, model, and encourage the incorporation of palliative care principles and resources into routine patient care as a member of the multidisciplinary team.
- Expert guidance in the context of complex or difficult to manage symptoms and/or challenging psychosocial scenarios should be offered, to provide an additional layer of support to patients, families, and clinicians during difficult decision-making processes.
- Training in self-care as well as bereavement support for all healthcare professionals involved in the care of CAYA patients should be provided.

4. **Psychoeducation**

   It is important that Psycho-Oncology services facilitate collaboration with charities in Ireland and the UK to develop and/or adapt psychoeducation booklets and material for people with cancer, their families, and staff working in the community.

5. **Specialised training and education needs**

   This will be identified as services develop for both paediatric and AYA cohorts. A collaborative approach to developing this training will be taken with third level academic institutions in Ireland.

Dedicated funding will be required at national, regional and local level to facilitate training, supervision and CPD.

Implementation

This MoC details the Psycho-Oncology service that should be provided in Ireland to align with international standards and to inform future service planning and developments.

Implementation will be based on the following principles

- Care will be provided based on the level of needs of CAYA and the family,
- Care will be provided within the Psycho-Oncology team at the appropriate level, in order to use resources efficiently,
- Where appropriate, outpatient care will be provided in preference to inpatient care.

Implementation of the MoC will mean

- Recognition that paediatric and AYA cancer patients are unique cohorts and as such have specific psychosocial and psychological needs that must be addressed in a different way to adult patients with cancer.
- Investment in initial psychosocial screening for all children and adolescents.
- Ongoing assessment of patients along the cancer journey in recognition of changing needs.
- Commitment to the continued development of the NPPO service at CHI.
- Recognition that the best practice dictates a multi-disciplinary approach with the addition of an Extended Psycho-Oncology team to reflect the many and varied needs of this cohort.
- Investment in developing AYA services on a network basis so that expertise can be developed for this unique cohort of patients.
- Investment in neuropsychological services for CAYA patients whose cognitive functioning is impaired by either a diagnosis of cancer or as a treatment side-effect.
- Development of specific training opportunities and supervision for staff to meet the unique needs of CAYA patients.
- Collaboration between acute, primary and community services, working together to achieve the aims and objectives of the MoC.
- Enhancement of community services to cater for the CAYA cohort.
- Recognition that all healthcare providers are responsible for implementing the MoC.

Barriers to implementation

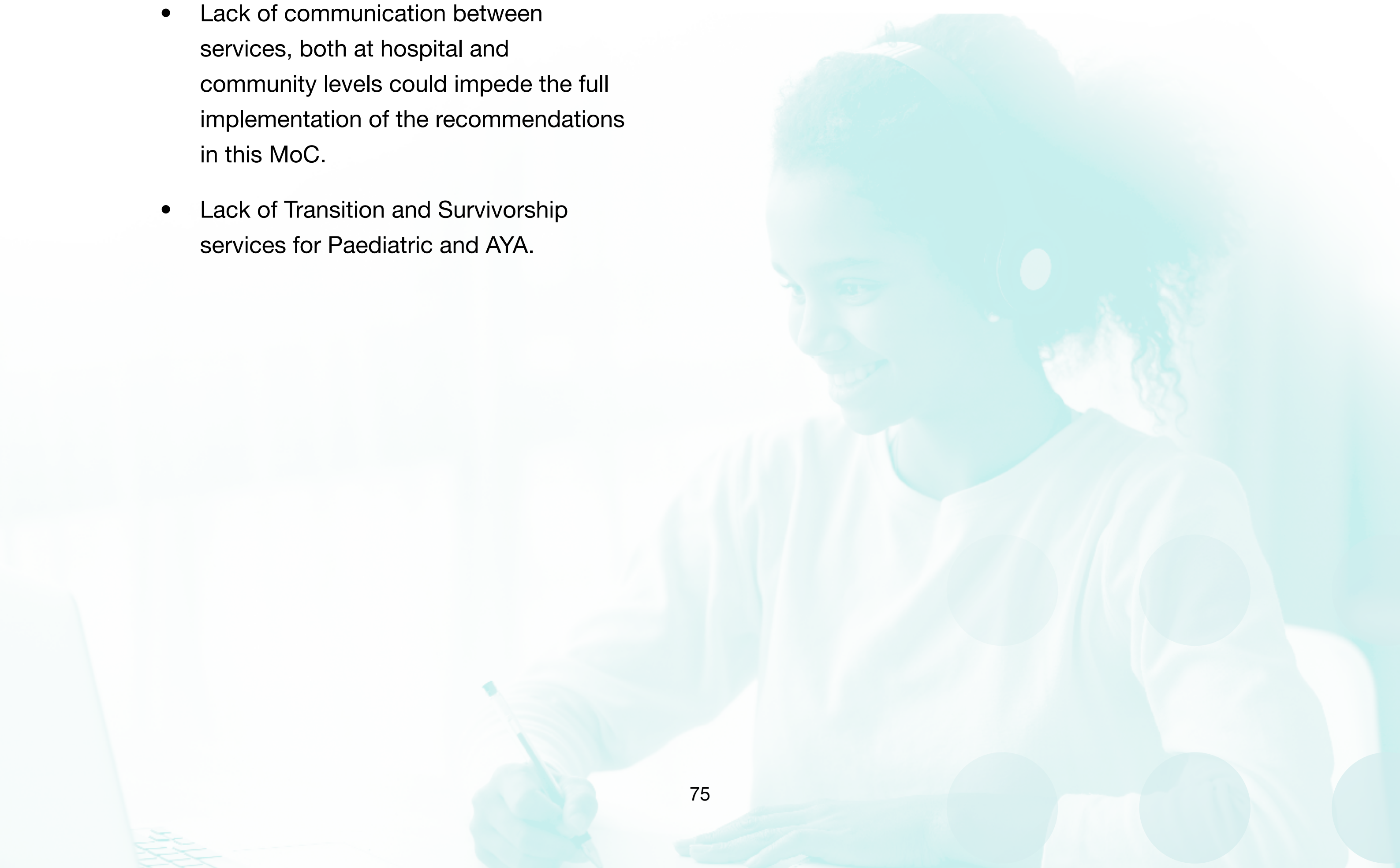
A number of barriers have been identified that will have an impact on the implementation of the MoC and should be considered during the implementation phase.

- The lack of fully developed Psycho-Oncology MDTs is the most significant barrier that will impede the delivery of the recommendations in this MoC. Adequate staffing levels are essential to deliver this MoC and to meet international standards of care. They are also crucial in terms of improving staff retention and safe practice. This MoC acknowledges that there are significant gaps in staffing.
- With regard to the provision of Psycho-Oncology support for 16-19 year olds, a number of options have been proposed to fill the current gap in services for some patients within this cohort. These options should be piloted and reviewed in Q2 2024 to ascertain the optimal delivery of Psycho-Oncology services.
- Lack of communication between services, both at hospital and community levels could impede the full implementation of the recommendations in this MoC.
- Lack of Transition and Survivorship services for Paediatric and AYA.

Data collection and impact monitoring

The need for robust data for monitoring the outcome of Psycho-Oncology assessments and interventions is crucial. To ensure quality oversight of psychosocial care for CAYA, service providers should undertake frequent quality improvement projects, use of patient/family feedback and satisfaction surveys, and an annual review of metrics and process measures (e.g., number of referrals, access, follow-ups, adherence to established treatment pathways and practice guidelines, healthcare utilisation, and cost). Visibility and promotion of the service will impact on referrals. The development of an SOP for MDMs is crucial.

The National AYACSN MDM will be run through the National Cancer Information System (NCIS). Referrals can be made using the referral form (see Appendix 8) hosted on the NCCP website. The use of a single national computerised system that records and stores information relevant to a patient's healthcare will enable data collection and facilitate monitoring and impact evaluation.



Overall conclusion

This MoC defines what a comprehensive Psycho-Oncology service for CAYA should look like and offers actionable steps to help develop these services at a national and regional level. It is advised that the recommendations in the MoC be followed by all healthcare teams treating CAYA with cancer and delivered via a collaborative, integrated and shared care approach. While it is recognised that some recommendations are already common practice, it is also acknowledged that full implementation will take time and may occur at different rates across different settings. The MoC also acknowledges that staffing resources need to be added to current services to deliver this model and its recommendations.

This MoC offers a unique opportunity for patients and their families so that they may experience positive psychosocial care; access to appropriate assessment, support and intervention for psychosocial distress; improved wellbeing and quality of life; improved clinical outcomes; a clear pathway to services in both the acute and community settings and finally a better signposting to services in the community. These are very crucial outcomes for patients and their families.

In addition, for healthcare professionals, the MoC offers a pathway for integrated team working; improved psychological skills and understanding across all members of cancer treating teams; and better awareness within teams of the full range of psychosocial supports that are available for patients and their families.

This MoC addresses the needs of the whole family and ensures that the many and varied adjustment issues that arise for these people with cancer and their families are addressed in a comprehensive and timely manner, so that the best quality of life possible is achieved.

References

Adams S.C., Herman J., Lega I.C., Mitchell L., Hodgson D., Edelstein K., Travis L.B., Sabiston C.M., Thavendiranathan P., Gupta A.A. (2021). Young Adult Cancer Survivorship: Recommendations for Patient Follow-up, Exercise Therapy, and Research. JNCI Cancer Spectr;5:pkaa099

Aldiss, S., Fern, L.A., Phillips, R.S., Callaghan, A., Dyker, K., Gravestock, H., Groszmann, M., Hamrang, L., Hough, R., McGeachy, D. and Morgan, S (2019). Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance. Bmj Open, 9(8), p.e028119.

André, N., Gastinger, S., & Rébillard, A. (2021). Chronic Fatigue in Cancer, Brain Connectivity and Reluctance to Engage in Physical Activity: A Mini-Review. Frontiers in oncology, 11, 774347.

Baker, K. S., & Syrjala, K. L. (2018). Long-term complications in adolescent and young adult leukemia survivors. Hematology. American Society of Hematology. Education Program, 2018(1), 146–153.

Barrett P, Mullen L, McCarthy C. (2018) Survivorship after childhood cancer – health needs assessment, 2018. National Cancer Control Programme: Dublin.

Bellizzi K.M., Smith A., Schmidt S., Keegan T.H.M., Zebrack B., Lynch C.F., Deapen D., Shnorhavorian M., Tompkins B.J., Simon M., et al. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. Cancer;118:5155–5162.

Besani, C., Dunne, A., D'Arcy-Bewick, S., Owens, C., Pears, J., O'Marcaigh, A., Malone, A., Fortune, G., Capra, M. & Smith, O.P. (2021). The Development of a National Paediatric Psycho-Oncology Service. *Ir Med J,* 114, 400.

Bitsko, M.J., Cohen, D., Dillon, R., Harvey, J., Krull, K. & Klosky, J.L. (2016). Psychosocial Late Effects in Pediatric Cancer Survivors: A Report From the Children's Oncology Group. *Pediatr Blood Cancer,* 63, 337-43.

Bolte S., Zebrack B. (2008). Sexual Issues in Special Populations: Adolescents and Young Adults. Semin. Oncol. Nurs;24:115–119. doi: 10.1016/j.soncn.2008.02.004.

Bousso, R. S., Misko, M. D., Mendes-Castillo, A. M., & Rossato, L. M. (2012). Family management style framework and its use with families who have a child undergoing palliative care at home. Journal of family nursing, 18(1), 91–122. https://doi.org/10.1177/1074840711427038

Brierley M.E.E., Sansom-Daly U.M., Baenziger J., McGill B., Wakefield C.E. (2019). Impact of physical appearance changes reported by adolescent and young adult cancer survivors: A qualitative analysis. Eur. J. Cancer Care;28:e13052.

Brinkman TM, Recklitis CJ, Michel G, et al. (2018). Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviours among survivors of childhood cancer: current state of the literature. J Clin Oncol; 36: 2190-97.

Cameron M. Magrath, Deborah J. Critoph, Luke A.M. Smith, and Helen M. Hatcher. (2021). "A Different Person Entirely": Adolescent and Young Adults' Experiences Returning to Education after Cancer Treatment. Journal of Adolescent and Young Adult Oncology; 562-572. http://doi.org/10.1089/jayao.2020.0168

Canteen. (2011). Adolescent and Young Adult Oncology Psychosocial Care Manual (Rev. ed.2021). Australia: Canteen.

Carpentier, M., & Fortenberry, J. (2010). Romantic and Sexual Relationships, Body Image, and Fertility in Adolescent and Young Adult Testicular Cancer Survivors: A Review of the Literature. Journal of Adolescent Health, 47(2), 115-125. doi: 10.1016/j.jadohealth.2010.04.005

Castelli, L., Castelnuovo, G. & Torta, R. (2015). Editorial: PsychOncology: clinical psychology for cancer patients-Cancer: the key role of clinical psychology. *Front Psychol,* 6, 947.

Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 5.0. 2018. http://www.survivorshipguidelines.org.

Darlington, A.E., Wakefield, C.E., van Erp, L.M.E., van der Graaf, W.T.A., Cohn, R.J. & Grootenhuis, M.A. (2022). Psychosocial consequences of surviving cancer diagnosed and treated in childhood versus in adolescence/young adulthood: A call for clearer delineation between groups. Cancer, 128, 2690-2694.

Department of Health (2017). National Cancer Strategy 2017-2026.

Dewar E.O., Ahn C., Eraj S., Mahal B.A., Sanford N.N. (2021). Psychological distress and cognition among long-term survivors of adolescent and young adult cancer in the USA. J. Cancer Surviv;15:776–784.

Elsbernd, A., Pedersen, K. J., Boisen, K. A., Midtgaard, J., & Larsen, H. B. (2018). "On Your Own": Adolescent and Young Adult Cancer Survivors' Experience of Managing Return to Secondary or Higher Education in Denmark. Journal of Adolescent and Young Adult Oncology, 7(5), 618–625. https://doi.org/10.1089/jayao.2018.0058

Fiala EM, Jayakumaran G, Mauguen A, et al. Prospective pan-cancer germline testing using MSK-IMPACT informs clinical translation in 751 patients with pediatric solid tumors. Nature Cancer. 2021;2:357-365. doi: 10.1038/s43018-021-00172-1

Ferrari, A., Stark, D., Peccatori, F.A., Fern, L., Laurence, V., Gaspar, N., Bozovic-Spasojevic, I., et al. (2021). Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). *ESMO Open*, 6, 100096.

Ferrari A., Thomas D., Franklin A.R. (2010). Starting an adolescent and young adult program: some success stories and some obstacles to overcome. J Clin Oncol;28(32):4850–4857.

Fidler M, Ziff O, on behalf of British Childhood Cancer Survivor Study (BCCSS). (2015). Aspects of mental health dysfunction among survivors of childhood cancer. British Journal of Cancer; 113, 1121-32.

Gavin, K.T, Clinton, F, Capra, M. (2022). Childhood Cancer Survivorship Project. Assessment of the needs of childhood cancer survivors in Ireland 2022: patient, parent/guardian/carer perspectives. National Children's Cancer Service, CHI at Crumlin Hospital, Dublin.

Gerhardt, C.A., Lehmann, V., Long, K.A., Alderfer, M.A. (2015). Supporting Siblings as a Standard of Care in Pediatric Oncology. Pediatr Blood Cancer; 62 Suppl 5:S750-804. doi: 10.1002/pbc.25821

Gilleland-Marchak J, Christen S, Mulder R, et al. (2022). Recommendations for the surveillance of mental health problems in childhood, adolescent, and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonisation Group. Lancet Oncology Vol23.

Götte, M., Gauß, G., Dirksen, U., Driever, P.H., Basu, O., Baumann, F.T., Wiskemann, J., et al. (2022). Multidisciplinary Network ActiveOncoKids guidelines for providing movement and exercise in pediatric oncology: Consensus- based recommendations. *Pediatric Blood & Cancer, 69*(11), p.e29953.

Greally, H., Love, D., & Mullen, L. (2020). Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology. National Cancer Control Programme: Dublin.

Greenzang, K.A. & Fasciano, K.M. (2020). Early information needs of adolescents and young adults about late effects of cancer treatment. Cancer, 126(14), 3281-3288.

Gröbner SN, Worst BC, Weischenfeldt J, et al.; ICGC PedBrain-Seq Project; ICGC MMML-Seq Project . The landscape of genomic alterations across childhood cancers. Nature. 2018;555(7696):321-327. doi: 10.1038/nature25480

Hartshorne JK, Germine LT (2015). When does cognitive functioning peak? The asynchronous rise and fall of different cognitive abilities across the life span. Psychol Sci; 26:433-443.

Hession, N., Habenicht, A., Connolly, A. & Deimling Johns, L. (2021). We Need to Talk about Fertility – Cancer support among Irish patients. The Irish Psychologist, 47(5), 120-123.

Holland, L.R., Walker, R., Henney, R., Cashion, C.E., & Bradford, N.K. (2021). Adolescents and Young Adults with Cancer: Barriers in Access to Psychosocial Support. Journal of Adolescent and Young Adult Oncology; 46-55.

HSE. (2022). National Strategy for Accelerating Genetic and Genomics Medicine in Ireland. Retrieved from: https://www.hse.ie/eng/about/who/strategic-programmes-office-overview/national-strategy-for-accelerating-genetic-and-genomic-medicine-in-ireland/national-strategy-for-accelerating-genetic-and-genomic-medicine-in-ireland.pdf

HSE. (2014). Palliative Care Needs Assessment Guidance, National Clinical Programme for Palliative Care. Retrieved from: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/palliative-care-needs-assessment-guidance-.pdf

Husson O., Huijgens P.C., Van Der Graaf W.T.A. (2018). Psychosocial challenges and health-related quality of life of adolescents and young adults with hematologic malignancies. Blood; 132:385–392.

Ikonomidou C. (2018). Chemotherapy and the pediatric brain. Molecular and cellular pediatrics, 5(1), 8.

Jacola, L.M., Partanen, M., Lemiere, J., Hudson, M.M. & Thomas, S. (2021). Assessment and Monitoring of Neurocognitive Function in Pediatric Cancer. *J Clin Oncol*, 39, 1696-1704.

Janssen SHM, van der Graaf WTA, van der Meer DJ, Manten-Horst E, Husson O. (2021). Adolescent and Young Adult (AYA) Cancer Survivorship Practices: An Overview. Cancers (Basel);13(19):4847. doi: 10.3390/cancers13194847.

Jim H.S., Jennewein S.L., Quinn G., Reed D.R., Small B.J. (2018). Cognition in Adolescent and Young Adults Diagnosed With Cancer: An Understudied Problem. J. Clin. Oncol; 36:2752–2754

John, TD, Sender, LS, & Bota, BA. (2016). Cognitive impairment in survivors of adolescent and early young adult onset non-CNS cancers: does chemotherapy play a role? Journal of Adolescent and Young Adult Oncology, Volume 5, No. 3.

Kassam, A., Skiadaresis, J., Alexander, S., & Wolfe, J. (2015). Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. Pediatric blood & cancer, 62(8), 1409–1413.

Katz, L.F., Fladeboe, K., King, K., Gurtovenko, K., Kawamura, J., Friedman, D., Compas, B., Gruhn, M., Brieger, D., Lengua, L., Lavi, I. & Stettler, N. (2018). Trajectories of child and caregiver psychological adjustment in families of children with cancer. *Health Psychol,* 37, 725-735.

Kaye, E. C., Snaman, J. M., & Baker, J. N. (2017). Pediatric Palliative Oncology: Bridging Silos of Care Through an Embedded Model. Journal of clinical oncology: official journal of the American Society of Clinical Oncology, 35(24), 2740–2744. https://doi.org/10.1200/JCO.2017.73.1356

Kazak, A.E. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health,* 24, 381-395.

Kazak, A.E., Abrams, A.N., Banks, J., Christofferson, J., Didonato, S., Grootenhuis, M.A., Kabour, M., et al. (2015). Psychosocial Assessment as a Standard of Care in *Pediatric Cancer.* Pediatr Blood Cancer, 62 Suppl 5, S426-59.

Kazak, A.E., Hwang, W.T., Chen, F.F., Askins, M.A., Carlson, O., Argueta-Ortiz, F., Barakat, L.P. (2018). Screening for Family Psychosocial Risk in Pediatric Cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3. J Pediatr Psychol;43(7):737-748. doi: 10.1093/jpepsy/jsy012.

Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M.A. & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *J Pediatr Psychol,* 31, 343-55.

Kazak, A.E., Rourke, M.T., Alderfer, M.A., Pai, A., Reilly, A.F. & Meadows, A.T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: a blueprint for comprehensive services across treatment. *J Pediatr Psychol,* 32, 1099-110.

Kazak, A.E., Swain, A.M., Canter, K., Vega, G., Joffe, N., Deatrick, J. A., et al. (2019). A psychosocial clinical care pathway for pediatric hematopoietic stem cell transplantation. *Pediatr Blood Cancer,* 66, e27889.

Knott, D., Krater, C., MacLean, J., Robertson, K., Stegenga, K., & Robb, S.L. (2022). Music therapy for children with oncology and haematological conditions and their families: Advancing the standards for psychosocial care. Journal of Pediatric Hematology/Oncology Nursing, 39(1), 49-59.

Langenberg KPS, Meister MT, Bakhuizen JJ, et al. Implementation of paediatric precision oncology into clinical practice: The Individualized Therapies for Children with cancer program ‘iTHER’. Eur J Cancer. 2022;175:311-325. doi:10.1016/j.ejca.2022.09.001

Lee, S. J., Schover, L. R., Partridge, A. H., Patrizio, P., Wallace, W. H., Hagerty, K., Oktay, K. et al. (2006). American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. Journal of clinical oncology, 24(18), 2917-2931.

Lewandowska, A., Zych, B., Papp, K., Zrubcová, D., Kaducáková, H., Šupinova, M., Apay, S.E. et al. (2021). Problems, Stressors and Needs of Children and Adolescents with Cancer. *Children (Basel),* 8.

Li, L., Wang, L., Duan, Y., Xiao, P., Zhou, Y., Luo, X., Liu, X., Xie, J., & Cheng, A. S. K. (2023). Intelligent physical activity versus modified behavioral activation in adolescent and young adult cancer patients with psychological distress: A randomized, controlled pilot trial. Cancer medicine, 12(2), 1935–1948

Liptak C, Zelter L, Recklitis C. (2015). Psychosocial care of the child and family. In: Noathan O, editor. Hematology and Oncology of Infancy and Childhood; 8.

Lown EA, Hijiya N, Zhang N et al. (2016). Patterns and predictors of clustered risky health behaviours among adult survivors of childhood cancer. A report from the childhood cancer survivor study. Cancer; 122:2747-56.

Mack, J. W., & Wolfe, J. (2006). Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. Current opinion in pediatrics, 18(1), 10–14.

Mellblom A, Kiserud C, Rueegg C et al. (2021). Self-reported late effects and long-term follow-up care among 1889 long-term Norwegian Childhood, Adolescent, and Young Adult Cancer Survivors (the NOR-CAYACS study). Supportive Care in Cancer; 29: 2947-57.

Metzger, M., Meacham, L., Patterson, B., Casillas, J., Constine, L., & Hijiya, N. et al. (2013). Female Reproductive Health After Childhood, Adolescent, and Young Adult Cancers: Guidelines for the Assessment and Management of Female Reproductive Complications. Journal of Clinical

Oncology, 31(9), 1239-1247. doi: 10.1200/jco.2012.43.5511

Meyerson, D.A., Grant, K.E., Carter, J.S. & Kilmer, R.P. (2011). Posttraumatic growth among children and adolescents: a systematic review. *Clin Psychol Rev*, 31, 949-64.

Michel G, Mulder R, H. van der Pal H, et al. (2019). Evidence-based recommendations for the organisation of long-term follow-up care for childhood and adolescent cancer survivors: a report from the PanCareSurFup Guidelines Working Group. Journal of Cancer Survivorship:5;759-772.

Michel G, Rebholz CE et al. (2010). Psychological distress in adult survivors of childhood cancer: The Swiss childhood cancer survivor study. J Clin Oncol; 28: 1740-48.

Mitchell, W., Clarke, S., & Sloper, P. (2005). Survey of psychosocial support provided by UK paediatric oncology centres. Archives of disease in childhood, 90(8), 796–800.

Mullen, L. Hanan, T. (2019). National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland. National Cancer Control Programme: Dublin.

NCCP (2022). Framework for the Care and Support of Adolescents and Young Adults (AYA) with Cancer in Ireland 2021-2026. National Cancer Control Programme (NCCP).

Oeffinger, K.C., Mertens, A.C., Sklar, C.A., Kawashima, T., Hudson, M.M., Meadows, A.T., et al., 2006. Chronic health conditions in adult survivors of childhood cancer. N.Engl. J. Med. 355 (15), 1572–1582.

Oireachtas Committee on the Future of Healthcare (2017). Sláintecare Report. Houses of the Oireachtas.

Olsson M., Enskär K., Steineck G., Wilderäng U., Jarfelt M. (2018). Self-Perceived Physical Attractiveness in Relation to Scars Among Adolescent and Young Adult Cancer Survivors: A Population-Based Study. J. Adolesc. Young-Adult Oncol; 7:358–366.

Otth, M., Denzler, S., Koenig, C., Koehler, H., Scheinemann, K. (2021) Transition from pediatric to adult follow-up care in childhood cancer survivors – a systematic review. Journal of Cancer Survivorship; 15: 151-162.

Perez G.K., Salsman J.M., Fladeboe K., Kirchhoff A.C., Park E.R., Rosenberg A.R. (2020). Taboo Topics in Adolescent and Young Adult Oncology: Strategies for Managing Challenging but Important Conversations Central to Adolescent and Young Adult Cancer Survivorship. Am. Soc. Clin. Oncol. Educ. Book; 40:e171–e185.

Pt M.L.M., Med J.K.P., Jones J.M., Amin L., Chang E., Korenblum C., Mina D.S., McCabe L., Mitchell L., Giuliani M. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. Cancer; 122:1038–1046

Rehse, B. & Pukrop, R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Educ Couns,* 50, 179-86.

Robert, R., Zhukovsky, D. S., Mauricio, R., Gilmore, K., Morrison, S., & Palos, G. R. (2012). Bereaved parents' perspectives on pediatric palliative care. *Journal of social work in end-of-life & palliative care,* 8(4), 316–338.

Robinson, P.D., Oberoi, S., Tomlinson, D., Duong, N., Davis, H., Cataudella, D., Culos-Reed, N., et al. (2018). Management of fatigue in children and adolescents with cancer and in paediatric recipients of haemopoietic stem-cell transplants: a clinical practice guideline, The Lancet Child & Adolescent Health, 2(5); 371-378.

Schilstra, C.E., Sansom-Daly, U.M., Schaffer, M., Fardell, J.E., Anazodo, A.C., McCowage, G., Fletcher, J.I., Marshall, G.M., Buchhorn-White, J., Evtushenko, M. and Trahair, T.N., (2022). "We Have All This Knowledge to Give, So Use Us as a Resource": Partnering with Adolescent and Young Adult Cancer Survivors to Determine Consumer-Led Research Priorities. Journal of Adolescent and Young Adult Oncology, 11(2), pp.211-222.

Shi, Q., Zheng, J., & Liu, K. (2022). Supervised Exercise Interventions in Childhood Cancer Survivors: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. Children (Basel), 2;9(6):824.

Signorelli C, Wakefield CE, Fardell JE, Wallace W, Robertson EG, McLoone JK, Cohn RJ. (2017). The impact of long-term follow-up care for childhood cancer survivors: a systematic review. Crit Rev Oncol Hematol; 114:131-8.

Steele, A.C., Mullins, L.L., Mullins, A.J. & Muriel, A.C. (2015). Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer,* 62 Suppl 5, S585-618.

Taylor RM, Fern L, Whelan J, et al. (2011). "Your place or mine?" priorities for a specialist teenage and young adult (tya) cancer unit: disparity between tya and professional perceptions. J Adolesc Young Adult Oncology; 1:145–51.

Theunissen, J.M., Hoogerbrugge, P.M., van Achterberg, T., Prins, J.B., Vernooij-Dassen, M.J., & van den Ende, C.H. (2007). Symptoms in the palliative phase of children with cancer. Pediatr Blood Cancer, 49, 160–165.

Together for shorter lives. (2013). A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions, 3rd edition.

Tomlinson, D., Hendershot, E., Bartels, U., Maloney, A. M., Armstrong, C., Wrathall, G., & Sung, L. (2011). Concordance between couples reporting their child's quality of life and their decision making in pediatric oncology palliative care. Journal of pediatric oncology nursing: official journal of the Association of Pediatric Oncology Nurses, 28(6), 319–325.

Tonorezos E, Cohn R, Glaser A, Lewin J, Poon E, Wakefield C, Oeffinger K. (2022). Long-term care for people treated for cancer during childhood and adolescence. The Lancet; Vol 399: 10334, 1561-72.

van Deuren, S., Boonstra, A., van Dulmen-den Broeder, E., Blijlevens, N., Knoop, H., & Loonen, J. (2020). Severe fatigue after treatment for childhood cancer. The Cochrane database of systematic reviews, 3(3), CD012681.

Weaver, M.S., Heinze, K.E., Kelly, K.P., Wiener, L., Casey, R.L., Bell, C.J., Wolfe, J., Garee, A.M., Watson, A., Hinds, P.S. (2015). Palliative care as a standard of care in pediatric oncology. Pediatr Blood Cancer 2015;62(Suppl 5): 829–833.

Wiener, L., Bedoya, S., Battles, H., et al. (2022). Voicing their choices: Advance care planning with adolescents and young adults with cancer and other serious conditions. Palliative and Supportive Care; 20, 462-470.

Wiener, L., Kazak, A.E., Noll, R.B., Patenaude, A.F. & Kupst, M.J. (2015). Standards for the Psychosocial Care of Children With Cancer and Their Families: An Introduction to the Special Issue. *Pediatr Blood Cancer,* 62 Suppl 5, S419-24.

Wiener, L., Zadeh, S., Battles, H., et al. (2012) Allowing adolescents and young adults to plan their end-of-life care. Pediatrics; 130(5), 897-905.

Wong M, Mayoh C, Lau LMS, et al. (2020) Whole genome, transcriptome and methylome profiling enhances actionable target discovery in high-risk pediatric cancer. Nat Med. 26(11):1742-1753. doi: 10.1038/s41591-020-1072-4

Wurz, A., McLaughlin, E., Lategan, C., Ellis, K., Culos-Reed, S.N. (2021) Synthesizing the literature on physical activity among children and adolescents affected by cancer: evidence for the international Pediatric Oncology Exercise Guidelines (iPOEG), Translational Behavioral Medicine, Volume 11(3); 699–708.

Zapotocky, M., Ramaswamy, V., Lassaletta, A. & Bouffet, E. (2018). Adolescents and young adults with brain tumors in the context of molecular advances in neuro-oncology. *Pediatr Blood Cancer,* 65.

Zhang J, Walsh MF, Wu G, et al. (2015) Germline mutations in predisposition genes in pediatric cancer. N Engl J Med;373(24):2336-2346. doi: 10.1056/NEJMoa1508054

Appendices

Appendix 1 – Working Group Members & Contributors

CAYA Psycho-Oncology Working Group		
Name	**Title**	**Organisation/Hospital**
Dr Helen Greally (co-chair)	National Clinical Programme Lead for Psycho-Oncology	NCCP
Dr Chiara Besani (co-chair)	Psycho-Oncology Clinical Lead National Paediatric Psycho-Oncology service	CHI at Crumlin
Dr Aidan McKiernan	Principal Clinical Psychologist	LauraLynn Ireland's Children's Hospice
Dr Amy Cadden	Senior Clinical Paediatric Neuropsychologist	CHI at Temple Street
Dr Aoife Twohig	Consultant Psychiatrist	CHI at Temple Street
Carol O'Connor	Play Specialist	CHI at Crumlin
Cathleen Osborne	Assistant Director of Nursing (Cancer Survivorship)	NCCP
Dr Cathy Madigan	Principal Specialist in Paediatric Clinical Neuropsychology	CHI at Temple Street
Deirdre Love	Project Manager	NCCP
Dorothy Thomas	Patient Engagement Manager	NCCP
Eileen Nolan	Programme Manager – CAYA	NCCP
Evelyn Griffith	Patient Advocate	CanTeen
Fiona Bonas	Deputy Director	NCCP
Fiona O'Loughlin	Manager for Shared Care	CHI at Crumlin
Dr Hannah Linane	Fellow in AYA Palliative Medicine	CHI at Temple Street
Imelda Hurley	CNSp Palliative Care	CHI at Crumlin
Dr John Allen	Fellow in Paediatric Palliative Medicine	CHI at Crumlin
Louise Mullen	National Lead for Cancer Survivorship	NCCP
Dr Mairead Brennan	Senior Clinical Psychologist	Cancer Care West

CAYA Psycho-Oncology Working Group		
Name	**Title**	**Organisation/Hospital**
Marese Damery	Programme Manager Healthcare – Dying Well at Home	Irish Hospice Foundation
Mary-Claire Rennick	Parent representative/Patient Advocate	Childhood Cancer Ireland
Dr Maurice Clancy	Consultant Psychiatrist	Beaumont Hospital
Dr Natalie Hession	Principal Counselling Psychologist	Galway University Hospital
Niamh O'Sullivan	Assistant Director of Nursing AYA Cancer	CHI at Crumlin
Dr Nicola Lally	Principal Specialist Clinical Psychologist (Paediatrics)	Cork University Hospital
Niya Mateeva	Project Manager for Survivorship & Psycho-Oncology	NCCP
Olive O'Neill	Complementary Therapy CNSp	CHI at Crumlin
Prof Owen Smith	National Clinical Programme Lead for CAYA with Cancer	NCCP CHI at Crumlin
Patricia McColgan	Parent representative/Patient Advocate	Childhood Cancer Ireland
Paula Loughnane	Clinical Specialist **Physio**therapist	CHI at Crumlin
Dr Rosie Plunkett	Consultant Psychiatrist – Psycho-Oncology	St James's Hospital
Dr Sarah O'Doherty	Principal Paediatric Neuropsychologist	National Rehabilitation Hospital
Dr Scheryll Alken	Consultant in AYA Cancer	CHI at Crumlin
Prof Siobhan McHale	Consultant Psychiatrist	Beaumont Hospital
Dr Sonya Collier	Principal Clinical Psychologist	St James's Hospital
Susan Hurley	Senior Music Therapist	CHI at Crumlin
Teresa Slevin	Clinical Nurse Manager	CHI at Crumlin
Dr Una Kennedy	GP Advisor	NCCP
Dr Vicky Cooper-Lunt	Principal Clinical Psychologist	Beaumont Hospital

Contributors		
Name	**Title**	**Organisation/Hospital**
Aileen Kelly	Speech & Language Therapist	CHI at Crumlin
Alison Devlin	Senior Occupational Therapist	CHI at Crumlin
Bernadette Donnellan	Senior Medical Social Worker & Play Specialist	St Luke's Hospital
Catherine O'Brien	ANP Cancer Survivorship	St James's Hospital
Claire McCall	CNSp	CHI at Crumlin
Cliona Godwin	Senior Dietitian	CHI at Crumlin
Denise Dockery	Occupational Therapy Manager	CHI at Crumlin
Dr Diane Gillan	Senior Clinical Neuropsychologist	Beaumont Hospital
Eimear Kinsella	Nurse Manager	Barretstown
Elaine Smith	Children's Cancer Coordinator	Irish Cancer Society
Ellen Stafford	Graduate	NCCP
Dr Gina MacDonnell	Senior Clinical Paediatric Neuropsychologist	CHI at Temple Street
Dr Irwin Gill	Consultant Paediatrician (s.i. Neurodisability)	National Rehabilitation Hospital
Dr Jane Pears	Consultant Paediatric Oncologist (s.i. brain tumour)	CHI at Crumlin
Dr Louise O'Driscoll	Senior Clinical Psychologist	St Vincent's University Hospital
Kim Murray	Social Worker (until Jan 2022)	CHI at Crumlin
Miriam Hunter	CNSp Neuro-Oncology	CHI at Temple Street
Dr Naomi Algeo	Senior Occupational Therapist	St James's Hospital
Dr Nicola Elmer	Senior Psychologist	SLRON
Dr Noelle Cullinan	Paediatric Oncologist (s.i. Cancer Genetics)	CHI at Crumlin
Pamela Lannon	CNSp Haematology	CHI at Crumlin
Patricia Behan	Complementary Therapy CNSp	CHI at Crumlin
Dr Peter McCarthy	Locum Consultant in AYA Cancer	CHI at Crumlin
Ríona O'Connell	Senior Medical Social Worker	CHI at Crumlin
Ruth McMenamin	AYA Cancer Programme Manager	CHI at Crumlin
Dr Sandra Hayes	Principal Neuropsychologist	CHI at Crumlin
Dr Sarah Clarke	Senior Clinical Neuropsychologist	Beaumont Hospital
Stephanie Brogan	CNSp Specialist Palliative Care Community Services	Milford Care Centre
Stephanie O'Brien	Senior Medical Social Worker	CHI at Crumlin
Dr Tara Houlihan	Senior Clinical Psychologist	Mercy University Hospital

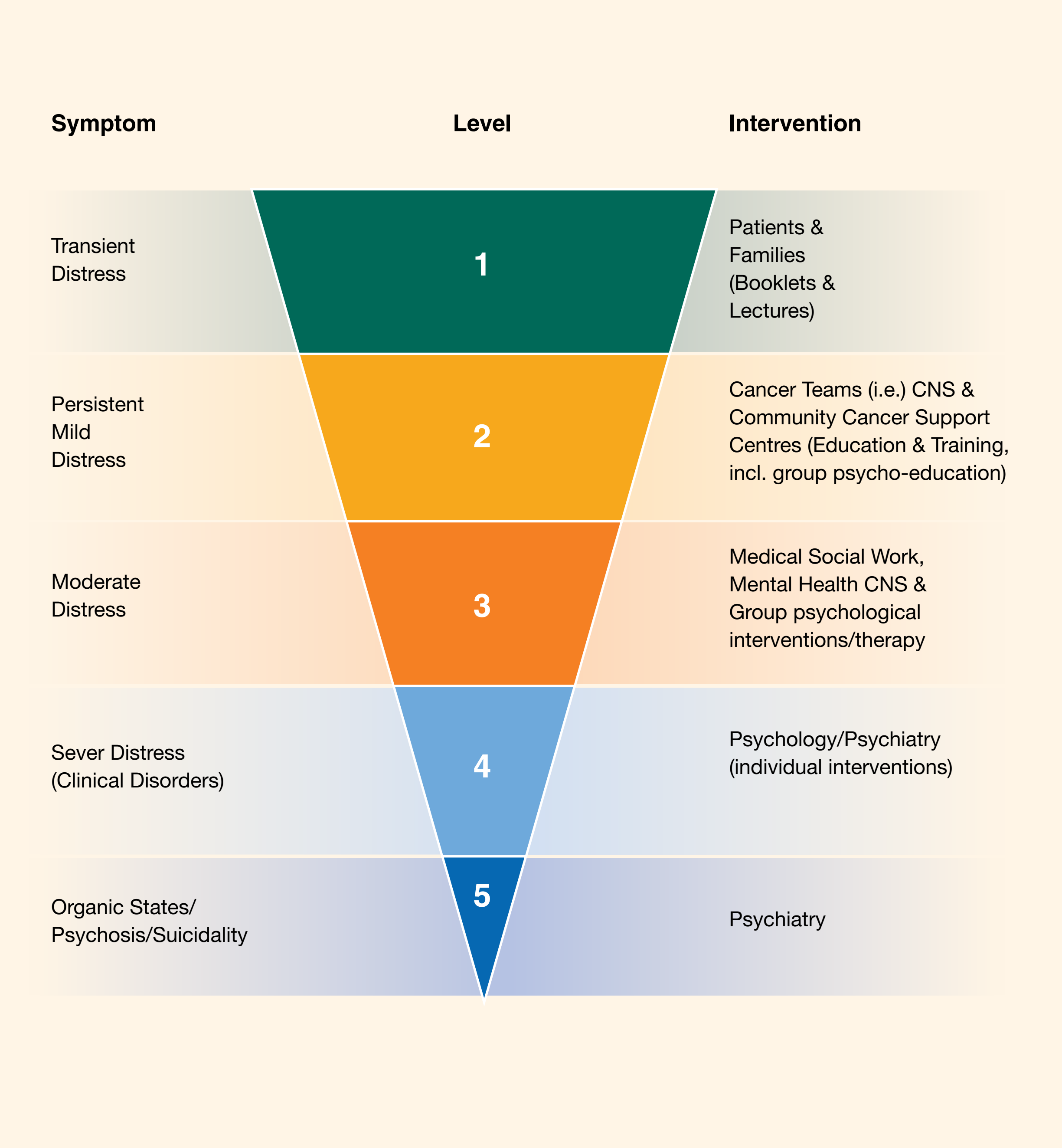
Appendix 2 – Summary of the Standards for Psychosocial Care of Children with Cancer and their families

Standard	
1	Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs.
2	Patients with brain tumours and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment.
3	Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: a) adverse educational and/or vocational progress, social and relationship difficulties; b) distress, anxiety, and depression and c) risky health behaviours. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.
4	Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.
5	Paediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health. Assessment of risk for financial hardship should be incorporated at time of diagnosis for all paediatric oncology families. Domains of assessment should include risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating centre, anticipated long/intense treatment protocol, and parental employment status. Targeted referral for financial counselling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.
6	Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimise parent, child and family well-being.
7	Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalisation, procedures, and psychosocial adaption. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.
8	Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures.

	Standard
9	Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients' unique characteristics, including developmental level, preferences for social interaction, and health status. The patient, parent(s) and a psychosocial team member (e.g., designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment and when the patient enters survivorship; it may be helpful to include school personnel or additional providers.
10	Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate support services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly.
11	In collaboration with parents, school-age youth diagnosed with cancer should receive school re-entry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience. Paediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the healthcare team.
12	Adherence should be assessed routinely and monitored throughout treatment.
13	Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary youth and families should receive developmentally appropriate end-of-life care [which includes bereavement care after the child's death].
14	A member of the health care team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.
15	Open, respectful communication and collaboration among medical and psychosocial providers, patients and families is essential to effective patient- and family- centred care. Psychosocial professionals should be integrated into paediatric oncology care settings as integral team members and be participants in patient care rounds/meetings. Paediatric psychosocial providers should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practice in accordance with ethical requirements of their profession and state/federal law. Paediatric psychosocial providers must have specialised training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with cancer and their families. Experience working with children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support.

Reference - Wiener et al. (2015). Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue. Pediatric Blood; 62: S419-S424

Appendix 3 – Proposed Model of Hospital-Community Psycho-Oncology & Psychosocial Care



Symptom	Level	Intervention
Transient Distress	1	Patients & Families (Booklets & Lectures)
Persistent Mild Distress	2	Cancer Teams (i.e.) CNS & Community Cancer Support Centres (Education & Training, incl. group psycho-education)
Moderate Distress	3	Medical Social Work, Mental Health CNS & Group psychological interventions/therapy
Sever Distress (Clinical Disorders)	4	Psychology/Psychiatry (individual interventions)
Organic States/ Psychosis/Suicidality	5	Psychiatry

Figure 14 Proposed Model of Hospital-Community Psycho-Oncology & Psychosocial Care – National Cancer Strategy 2017-2026

(modified from O'Dwyer & Collier, St. James's Hospital, 2003)

Appendix 4 – Psychosocial support in the community

A list of national organisations/charities and Community Cancer Support Centres providing psychosocial support to CAYA and their families (no endorsement):

National Organisations/Charities	
Aoibheann's Pink Tie	Cliona's Foundation
Aoife's Clown Doctors	Daisy Lodge
Barretstown	Hand-in-Hand
Brain Tumour Ireland	Irish Cancer Society
Bubblegum Club	Julie Wren Trust
BUBMLEance	LauraLynn Ireland's Children's Hospice
CanTeen Ireland	Make-A-Wish Ireland
Childhood Cancer Ireland	Marie Keating Foundation
Children in Hospital Ireland	Paediatric Brain Tumour Group (online)
Children's Leukaemia Association	Ronald McDonald House
Cancer Fund for Children (NI)	The Gavin Glynn Foundation
Cian's Kennels	YouCan

Community Cancer Support Centres	
Offering services to all patients (incl. 0-18 years; 18 years +)	
ARC Dublin	Greystones Cancer Support Centre
Arklow Cancer Support Centre	Hope Cancer Support Centre
Cancer Care West Donegal	Mayo Cancer Support
Cancer Care West Galway	North Kildare Community Cancer Caregivers
Cancer Support Sanctuary LARCC	Purple House
Cuisle Cancer Support Centre	Recovery Haven
Dochas Cancer Support Group	Roscommon Cancer Support Centre
Donegal Cancer Flights & Services (16+)	Sligo Cancer Support Centre
East Galway & Mildlands Cancer Support	SOLAS Cancer Support centre
Gort Cancer Support Centre	Tuam Cancer Care

Community Cancer Support Centres	
Offering services to adult-only patients (18 years+)	
Athenry Cancer Care	Gary Kelly Centre
Ballinasloe Cancer Support Centre	Kerry Cancer Support Group
Cancer Information & Support Centre (Limerick)	Little Way Cancer Support Centre
Cara Cancer Support Centre	Rathdrum Cancer Support Group
Cara Iorrais	Roundwood Cancer Support
Care Cancer Support Centre	Sláinte an Chláir, Clare Cancer Support
Circle of Friends	Suaimhneas Cancer Support Centre
Cois Nore	Suir Haven Cancer Support Centre
Cork ARC	Tallaght Cancer Support Group
Cork Cancer Care Centre	West Clare Cancer Centre
Cuan Cancer Support Centre	Wicklow Cancer Support
Éist Cancer Support Centre	

Appendix 5 – Extended Psycho-Oncology MDT within the NPPO service

The roles of various members of the Extended Psycho-Oncology MDT within the NPPO service are detailed below:

Physiotherapy

Survivors of childhood cancer are at risk of significant medical and psychological morbidity due to late effects of therapy (Oeffinger et al., 2006; Hudson et al., 2013). Depression, anxiety, somatisation, fatigue, poor health-related quality of life, suicidal ideation, impaired cognitive function, and reduced psychological well-being have been well-documented among childhood cancer survivors (Marchak et al., 2022; Fitch et al., 2021; Tonorezos et al., 2019).

Exercise as either a single therapy, adjuvant therapy or combination therapy has already been shown to positively influence the mental health of the general healthy population (Xie et al., 2021). In the childhood cancer setting, structured exercise interventions undertaken during and after (childhood) cancer treatment have been found to improve physical and physiological functioning, in addition to social and psychological outcomes. Specifically, exercise interventions are associated with reduced anxiety and depressive symptoms, and improvements in mood, fatigue and health-related quality of life (Shi et al., 2022; Baumann et al., 2013). Furthermore, structured exercise interventions are feasible and safe for children with cancer, with no adverse effects reported when completed according to protocol and under therapeutic supervision (Braam et al., 2016; Baumann et al., 2013).

During and after treatment, children with cancer have decreased physical activity levels (Roussenq et al., 2022; Götte et al., 2014), with low levels of physical activity persisting into long-term survivorship (Florin et al., 2007). Cancer survivors frequently report challenges related to re-establishing pre-diagnosis physical activity levels, in addition to difficulties accessing rehabilitation services and physical activity education and interventions (Fitch et al., 2021; Barrett et al., 2018; DoH, 2017). Physiotherapists, with their expertise in physical rehabilitation, assessment and screening of physical activity needs, physical activity counselling, and individualised exercise prescription, are perfectly positioned to provide a tailored, flexible and co-ordinated approach to addressing these needs (Dennett et al., 2020; Irish Society of Chartered Physiotherapists, 2020).

Speech and Language Therapy (SLT)

Different cancers and their treatments can have an impact on the speech, language and communication abilities of the child and young person not just during treatment but also in the time following it. It is well documented that communication issues both language and speech difficulties can be evident in children post operatively with cerebellar tumours (Paquier et al., 2019, Shrieber et al., 2017). There is also evidence for vocal cord palsy with chemotherapy treatment vincristine which can affect a child or young person's voice. A person's voice is a huge part of a person's identity and changes in it can often cause changes in participation in activities which require communication such as; social interactions with peers, participation in conversations with family/healthcare worker or participation in school. The oncology cohort can also be vulnerable to difficulty with communication development over time after treatment (Cornwell et al., 2003; Kuruvilla et al., 2009). For example, Buttsworth et al. (1992) state the importance of monitoring language and communication abilities in children post treatment of acute lymphoblastic leukaemia (ALL) for any difficulties/delays.

Changes in language abilities such as word finding, reduced speech intelligibility and change in vocal quality can negatively impact a person's ability to participate in the world around them. Anecdotally children and young people who are undergoing oncology treatment have reported that; they cannot participate in group conversations with their peers because of word finding difficulties and reduced auditory processing and that they are worried they come across as rude because of this; they feel under pressure to participate in the classroom setting when they cannot think of the right word to say; and that they're embarrassed by how their voice sounds so they do not want to talk to their friends.

Good communication skills are known to be a good protective factor against mental health problems (RSCLT, 2019) with evidence stating that poor communication abilities are a risk factor. Children with language difficulties have been reported to have a reduced quality of life in terms of moods and emotions and are more at risk in terms of social acceptance and bullying (Lindsay & Dockrell, 2012). Deficits in pragmatic language, which is how we use language to communicate in social interactions, have been reported to precede early and late adolescent psychotic experiences and early adolescent depression (Sullivan et al., 2016). Difficulty with communication can impede both the diagnosis and accessing mental health interventions which tend to be verbally delivered. Many psychological therapies rely heavily on the person's ability to use language to; identify treatment goals, articulate the difficulties they are experiencing, reflect on their behavioural strengths and resources and regulate their own behaviour and interactions (RCSLT, 2019). Despite the fact that therapies are verbally based it has been found that systematic language assessments are rarely undertaken (Cohen et al., 2000).

In addition, with an oncology cohort palliative care is also a consideration. In the Palliative Care Competence Framework released by the HSE in 2014 it lists that a domain of competence is communication. As we have already outlined this cohort of patients can have communication issues. The competence framework states how important it is to understand the different ways of communication to enable people to communicate effectively with the person and their family. By having a SLT as a member of the MDT it will ensure that this domain is upheld to ensure effective patient appropriate communication methods are used at this difficult time.

Given our knowledge that: 1) types of cancer and its treatment can have a negative impact on a child or younger person's communication difficulties, 2) having reduced communication ability is a risk factor for having mental health issues, 3) children and young people receiving oncology treatment are at risk of mental health difficulties and 4) that the therapies used to assist these children are often 'talking therapies', the SLT should be considered as an important part of the MDT working with this cohort. The SLT can assess a person's communication abilities, provide therapy to improve or support communication, provide staff and family training to facilitate improved communication with the person and provide support to staff and the person to allow them to better access treatment for their mental health difficulties. Indeed, in 2020 the IASLT submitted a review which recommended that timely consideration of speech, language, communication and swallowing needs and provision of appropriate supports which can include practical advice to other professionals about how to modify or scaffold interaction, to improve accessibility is within the scope of the SLT practice. It is hoped that this will reduce barriers to engagement and participation in talking therapies which will allow these children and young people to fully participate in their own therapy journey.

Dietetics

During the paediatric cancer journey, nutrition plays an integral role from both a physiological and psychological perspective. The psychosocial impact of eating and nutrition extends beyond the child and can engulf the entire family. As dietitians we work with the wider psychosocial MDT to support families in navigating the intricacies of nutrition and diet during cancer treatment. In our experience, the two areas which require the most support are enteral tube feeding and developing a healthy relationship with food after treatment.

Anxiety and stress associated with enteral tube feeding

It is well documented that children undergoing cancer treatment who maintain a healthy weight have better tolerance to treatment, improved recovery, less hospital admissions and experience an overall better quality of life. In circa 50% of our patients, tube feeding is required to prevent malnutrition.

Patients and parents who have had an enteral feeding tube, report it to have been a positive addition to their cancer care citing decreased stress and anxiety at meal times, improved mood and energy levels and an overall enhanced parent-child relationship. “It took the pressure off me trying to provide all those calories! I’m an awful lot more laid back at meal times than I used to be. I am sure it improved my relationship with P” (Sleigh et al., 2005).

Despite these benefits, in practice patients and parents have very negative attitudes towards discussions around enteral tube feeding, with some families reporting this to be the singular most stressful element of their treatment journey. This is particularly true for adolescent patients for whom distorted body image is a major concern. Other concerns include the invasive insertion procedure, discomfort and additional burden of care. Many parents attribute a sense of failure or guilt when not able to feed their child. This can result in parents delaying enteral tube feeding and using the threat of an enteral tube as a way to coerce their child to eat. (Cohen et al., 2017). In our practice, this can make for a more traumatic experience for the child and their parents.

Re-establishing relationship with food post-treatment

By the end of treatment many children and adolescents have had a sustained negative relationship with feeding and food due to treatment related side-effects, environmental factors and persistent parental pressure with respect to eating. These negative experiences can make it difficult to establish a positive relationship with food post-treatment.

In the last 40 years there have been significant advances in paediatric cancer treatment and the result has been increased survival outcomes in this population. With this increased survival the challenges healthcare professionals now face include minimising the long-term secondary effects of cancer treatment. Long-term effects include a significantly increased risk of developing secondary cancers, metabolic syndrome and cardiovascular disease. Health behaviours, such as healthy eating, being physically active and abstaining from certain high-risk lifestyle behaviours have all been shown to be important and modifiable protective factors in paediatric cancer survivors to protect their cardio-metabolic health and improve overall quality of life. Research looking at the diet quality of paediatric cancer survivors has shown inadequate intake of micronutrients, excessive energy intake, increased intake of high fat and high sugar convenience foods. Studies have shown that cancer survivors are willing and interested in engaging in lifestyle interventions, with a preference for face-to-face engagement. (Touyz et al., 2019). Evidence from other chronic illnesses would suggest that engaging with patients as part of a psychosocial MDT has the best outcomes in terms of compliance with these interventions (Viana et al., 2016).

References available as Supplementary Material

Appendix 6 – Neuropsychology care for paediatric oncology, malignant haematology, and those undergoing transplant and CAR-T Cell treatment

Paediatric neuropsychology is the study of brain-behaviour relationships, within the dynamic context of the child's developing brain and the implementation of that knowledge into clinical practice (Andersen et al., 2001). There is a well-documented risk to neurocognitive function in paediatric oncology, malignant haematology, and those undergoing transplant and CAR-T cell treatment; particularly within cancers affecting the CNS or those where CNS-directed treatment is required. This section proposes an evidence-based framework for providing a neuropsychology service to all children who attend the national paediatric oncology and malignant heamatology service. Rather than outline a specific pathway for each oncology or malignant haematology diagnosis / therapy at risk for neurocognitive impairment, the document will outline the key purpose and timing of neuropsychology input, in order to identify and prioritise those children most at risk of neurocognitive sequelae.

This model of care was greatly influenced by the work of Jacola et al. (2021), which presented a tiered model of neuropsychological care for childhood cancer survivors. There is consistent support for a clinical surveillance model of neuropsychology input, where clinical judgement must be carefully employed at specific time points, to identify and prioritise the high risk children in need of neuropsychology assessment (Jacola et al., 2021; Baum et al., 2017; Hardy et al., 2017; Annett et al., 2015). The neurocognitive function of paediatric cancer patients must be monitored across their cancer journey, within the dynamic context of their developing brain, with specialised neuropsychology assessment carried out at key points and in response to known risk factors, as outlined below;

T1. Consult at time of diagnosis to identify known risk factors, including but not limited to;

- Age at diagnosis (i.e.) younger age more vulnerable
- Pre-existing neurocognitive deficits (e.g.) developmental delay, global/specific learning difficulties, neurodevelopmental diagnoses or hearing/visual/sensory impairments
- Nature and extent of neurological symptoms pre-diagnosis (e.g.) hydrocephalus or seizure activity
- High risk diagnoses (e.g.) CNS tumours, ALL, posterior fossa tumours
- CNS-directed therapies planned (e.g.) neurosurgery, cranial radiation, intrathecal chemotherapy or bone marrow transplant
- Psychosocial supports within the family system
- Some children may require a pre-treatment neuropsychological assessment (e.g.) when on a clinical trial or the referring consultant plans to adopt a high risk or novel surgical/oncology treatment approach. In each case, the paediatric neuropsychologist and referring consultant will consider whether the assessment is in the best interests of the child.

T2. Consult at end of treatment to screen for acquired risk factors

- Nature and extent of CNS-directed treatment received (i.e.) treatment load
- Additional unexpected symptoms during treatment (e.g.) treatment-induced toxicity, cerebellar mutism, seizure activity, brain bleed or hydrocephalus
- Parent or child observing/reporting symptoms of neurocognitive impairment
- Any immediate support or advice needed by preschool/school/college to support graded return to academia
- At this time point, the possible need and timing of neuropsychology follow-up is decided.

T3. Assessment 1 – 2 years post-treatment

- Neuropsychology assessment offered to those children identified at earlier time points at high risk of neurocognitive impairment
- If an exceptional clinical decision is made to assess a child sooner, the guidance should be a minimum of 6 months' post end of treatment
- Neuropsychology assessment battery chosen will be evidence-based, depending on oncology diagnosis/ CNS-directed therapy/neurocognitive impairments reported.
- At the end of this assessment, the possible need and timing of neuropsychology follow-up is decided

T4. Assessment 4 – 6 years post-treatment (most relevant if < 5 at time of diagnosis; Limond et al., 2020)

- Neuropsychology assessment to identify possible late effects of oncology diagnosis and CNS-directed therapies
- At the end of this assessment, the possible need and timing of further follow-up is decided

At each time point, the 3-tiered model for neurocognitive monitoring first proposed by Hardy et al. (2017) and built upon by Jacola et al. (2021) may be employed to identify each child's risk factors for neurocognitive impairment and so those to be prioritised for more comprehensive neuropsychology assessment.

The primary level of screening is for all paediatric oncology or malignant haematology patients. The Secondary level of input/targeted support is for those paediatric oncology or malignant haematology patients who; present with risk factors for neurocognitive deficit, report subjective neurocognitive deficits or who performed poorly at the primary level. The Tertiary level of neuropsychology input/assessment is for paediatric oncology or malignant haematology patients with neurocognitive deficits or vulnerabilities, for whom a neuropsychology assessment is warranted based on the referral question or for those who performed poorly on earlier levels. Decision making within each time point and across each level is informed by the identification of risk factors and their severity, clinical judgement on the part of the neuropsychologist and international standards. In order for this to be achieved a significant increase in staffing capacity needs to be funded.

References available as Supplementary Material.

Appendix 7 – Sample Psycho-Oncology Patient Discharge Form

Sláinte Leanaí Éireann
CHI
Children's Health Ireland

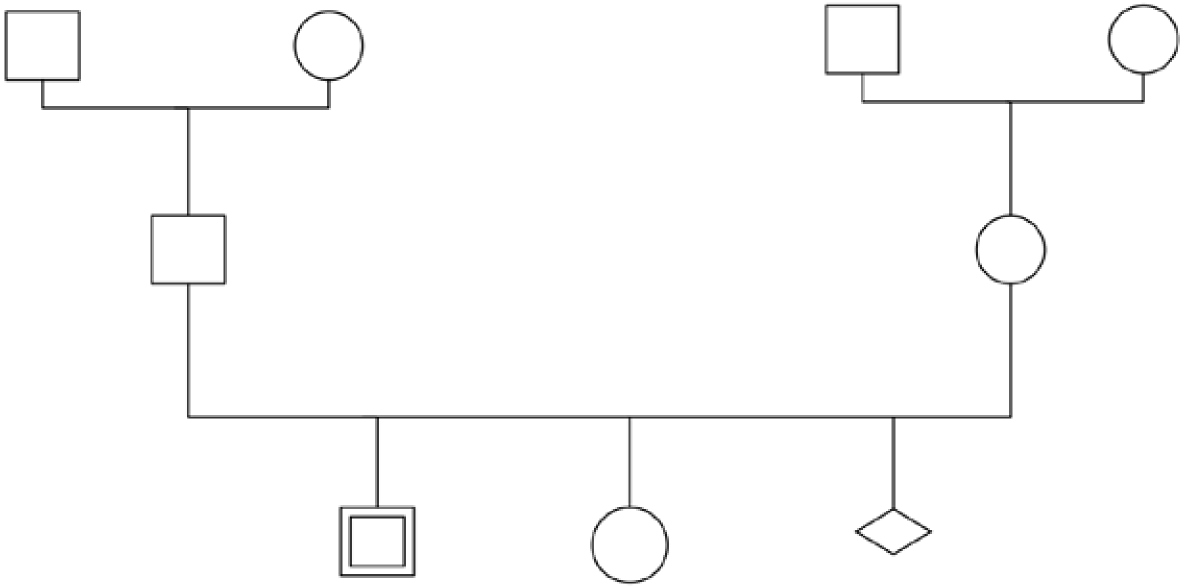
National Paediatric Psycho-Oncology Service
Clinical Discharge Report

Patient details

Member of Psycho-Oncology MDT:	Name Discipline/role
Date referral received:	
Number of sessions/weeks:	
Final session:	

Key professional/teams involved to date:				
NCCS	Lead Consultant	Name		
	CNSp	Name		
	Other	Name		
NPPO service			*Support to:*	
	Psychologist	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Social Worker	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Complementary Therapy CNSp	Name	Patient ☐	Mother ☐
			Father ☐	
	Play Specialist	Name	Patient ☐	Sibling(s) ☐
	Music Therapist	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Occupational Therapist	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Psychiatrist	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
Other Hospital/ Shared Care Centre *(e.g. CHI at Temple Street, St Luke's Hospital)*			*Support to:*	
	Psychology	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Social Work	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Other	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
Voluntary Organisation/ Charity *(e.g. LauraLynn Ireland's Children's Hospice)*			*Support to:*	
	Psychology	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐
	Play Therapy	Name	Patient ☐	Sibling(s) ☐
	Other	Name	Patient ☐	Mother ☐
			Father ☐	Sibling(s) ☐

(sample) Genogram with members of the family that attended the Psycho-Oncology Service:



Reason for referral	Psycho-Oncology support for child and parents. ALL, second relapsed. Preparation and support during transplant. Patient procedural distress from previous hospital experience. History of maternal anxiety and complex grief re loss of first pregnancy.
Assessment	Psycho-Oncology Neuropsychology
Key themes explored/content of work	Patient Mother/ Father Sibling(s)
Progress made	
Recommendations/continued support	- Referral to another Psycho-Oncology service for patient - Community Centre for siblings - GP letter to ask for Adult Mental Health support for mother

Name ____

Title ____

Signed: ____ **Date:** ______________

Appendix 8 – National AYACSN MDM referral proforma

Referral Details – NCIS* **			
Patient consents to referral to the AYA MDM	Choose an item.		
Date of referral			*e.g. new diagnosis, EOT, death* Choose an item.
Referring consultant		CNS	
Principal treatment centre			
GP Name		GP address	

Patient Details - NCIS******					
Name		Age		Gender	
Twin	Choose an item.	Ethnicity	Choose an item.		
Address		Postcode			

Cancer Details - NCIS******					
Diagnosis	Choose an item.		Stage/Grade		
Primary site			Metastatic sites		
Morphology (if relevant)			Prognostic score & system used	Choose an item.	If yes, which system?
Estimated date of onset symptoms		Est. date first presented to primary care		Est. date first presented to primary care	
Date of diagnosis			Start of treatment date		
			Anticipated EOT date		
Investigations	Please include dates if applicable		Tumour markers		
Treatment plan	e.g. surgery / chemotherapy and / or radiotherapy				
Treatment intent	e.g. curative, palliative,+ other Choose an item.				
Palliative care	Needs assessment performed	Yes ☐	No ☐		
	Palliative care referral sent	Yes ☐	No ☐		

Clinical Information	
Presenting history	*Please include comment on diagnostic pathway with dates / involved specialties where relevant*
Relevant family history	*Please include comment on additional health issues which may impact on therapy*
Address	

Psychosocial status/support			
HNA completed	Choose an item.	*Please indicate which tool was used*	
	Date:	Choose an item.	
Home	*Please consider details of family and significant others/ who patient lives with.*		
Education & Employment	*Please consider details of attendance, subjects, future education/employment plans, bullying*		
Eating	*Please consider details stress from eating habits, weight or body shape changes*		
Activities	*Please consider details of exercise, hobbies, music, with peers and on own*		
Drugs/Drinking	*Please consider details of use, peer use, frequency*		
Sex	*Please consider details of orientation, partners, comfort with sexual activity*		
Self-harm, low mood, suicide, spirituality	*Please consider details of Sleep, appetite, isolation, suicidal ideation*		
Safety (including online)	*Please consider details of any risk taking, online presence, social media use*		
AHP referrals required	Choose an item.	*If "yes" please indicate which teams involved*	
		Physiotherapy ☐ | Dietician ☐	OT ☐
		Other e.g. Community services	
Psycho-Oncology input required	Choose an item.	*If "yes, required" please select which team is required*	

Clinical Trial				
Clinical trial available			Name of trial	
If yes to above, please complete information below				
Eligible	Offered	Consented	If 'no', please specify reason	
Choose an item.	Choose an item.	Choose an item.		

Fertility Issues			
Fertility discussed & documented	Choose an item.	*If 'no' please provide comment on reasons*	
Fertility preservation undertaken	Choose an item.	*If none undertaken please provide comment on reasons*	*If 'yes' – which type of fertility preservation*
			Choose an item.

Discussion points for MDT – NCIS					
Outcome of MDT (for completion by MDT coordinator with Chair)					
Summary of discussion					
Recommendations from AYA MDM					
Documented by			Date of AYA MDM		
Approved by	Signature			Date	

National Cancer Control Programme
Kings Inn House
200 Parnell Street
Dublin 1

For further information, please contact info@cancercontrol.ie