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

2021-2026

National Cancer
Control Programme

Contents

Contents 1

1. Foreword 3

2. Acknowledgements 5

3. Executive Summary 7

4. Background 8
   - 4.1 Introduction to adolescent and young adult cancer in Ireland 8
   - 4.2 Introduction to the framework 9
   - 4.3 Strategic alignment 9
   - 4.4 Patient population and demographics 9

5. International Best Practice 10
   - 5.1 Principles of the AYA framework 10
   - 5.2 Global AYA age ranges 11
   - 5.3 Current service challenges 11

6. Current Context 12
   - 6.1 Current infrastructure of cancer care 12
   - 6.2 Diagnostic pathway for children 14
   - 6.3 Diagnostic pathway for AYAs 15
   - 6.4 Cancer care pathway 15

7. Vision of the Framework 15
   - 7.1 Strategic priorities 15
   - 7.2 Safeguarding, inclusion and diversity 17

8. Implementation 18
   - 8.1 Proposed infrastructure improvements 18
   - 8.2 Proposed dynamic of hub and spoke model 18
   - 8.3 Key forecasted observations of the proposed model of care 19
   - 8.4 Clinical trials and research 19
   - 8.5 AYA services delivered in partnership with patients 20
   - 8.6 The proposed cancer pathway for patients aged 16-24 years' old 21

9. Benchmarks of Success 22

10. Implementation Plan/ Next Steps 24
    - 10.1 CAYA key performance indicators (KPIs) 25

11. Bibliography 26

12. Appendices 29
   Appendix 1 29
   Appendix 2 30
   Appendix 3 31
   Appendix 4 33
   Appendix 5 33
   Appendix 6 34
   Appendix 7 34
   Appendix 8 35
   Appendix 9 36
13. Glossary 45

Foreword

The future is not a result of choices
among alternative paths offered by the present,
but a place that is created,
first in mind, next in will, then in activity.
The future is not a place we are going to,
but a place we are creating.
The paths are not to be discovered, but made,
and the activity of making the future
changes both the maker and the destination

John Schaar
University of California

Adolescent and young adult (AYA) patients constitute a unique group that deserves special attention. Although there is marked variability between the definitions of AYAs, ranging from 15-20 to 15-39 years, cancer continues to be the leading disease-related cause of death in this population. Studies over the past three decades have shown that while paediatric and older adult cancers have seen a large increase in survival rates, the same however, cannot be said for some specific AYA cancers. This has therefore become an increased area of focus in the oncology community in the recent past.

AYAs with cancer are a diverse group as defined not simply by their age and distinct biology of their cancer, but in terms of the challenges they face with regards to adequate access to age-appropriate oncological care, representation on clinical trials, short- and long-term health and psychosocial issues, that include, fertility considerations, transition to survivorship care, psychosocial support, adherence to treatment difficulties and other dilemmas and problems exclusive to this group of patients.

In 2017, these unique and distinct needs of the AYA cancer patients in Ireland were recognised in the National Cancer Strategy [2017 – 2026] and specific recommendations were made to address this health disparity. In early 2019 the NCCP appointed a National Clinical Lead for Children, Adolescent and Young Adult Cancer (CAYA) and created and established a CAYA Clinical Leads Group (CLG) to focus on the specific needs and risks of AYA cancer patients with a view to improving the care and outcomes for this population over the lifetime of the Strategy.

This CLG meets on a regular basis and continues to give unstintingly of their time, their knowledge and their expertise. The group comprises of highly motivated, passionate healthcare workers that includes nurses, advanced nurse practitioners, clinical nurse specialists, psychologists, social workers, paediatric and adult oncologists / haemato-oncologists, palliative care physicians, fertility preservation experts. Also included in the group are members of established patient advocacy and support groups (Irish Cancer Society, Barretstown, Canteen, CanCare4Living and Childhood Cancer Foundation), and perhaps most importantly, survivors of child and adolescent cancer.

I would like to express my gratitude to the CLG whose discussions and presentations over the past two years have helped define the challenges and opportunities that are embodied within the Framework for the Care and Support of Adolescent and Young Adults (AYA) in Ireland [2021-2026] report. The framework succinctly outlines strategies to coordinate state-of-the-art integrated AYA care to be delivered locally when possible but centralized when necessary by providing separate facilities and specialist care teams for these patients. Once this has been achieved the challenge will then be to secure the future through education, research/innovation and future service developments. The ultimate aim of the framework is to improve the standards and quality of cancer care provided to AYAs and at the same time define outcome measures of high-quality care for AYA patients across the proposed AYA cancer network as outlined in the National Cancer Strategy.

I would especially like to thank Eileen Nolan, Fiona Bonas, Scheryll Alken, Niamh O'Sullivan, Peter McCarthy and Jennifer Clarke in pulling this report together for their huge commitment over a relatively short time period generously embracing the task.

Lastly, we should endeavour to continue to embrace the future, as advised by Dr. Schaar and I believe this Framework report offers the best possible overarching future vision for AYA cancer for the Republic of Ireland based around the National Cancer Strategy recommendations.

Owen Patrick Smith, CBE, Hon FTCD
MA, MB, BA Mod.(Biochem), FRCPCH, FFPRCPI, FRCP (Ire., Edin., Lon., Glasg.), FRCPath, FFpathRCPI, DHMSA

National Clinical Lead for Children, Adolescent and Young Adult Cancers at NCCP

2. Acknowledgements

The NCCP CAYA CLG would like to acknowledge the patients and their families whose experience, expertise and advice has shaped the development of this Framework.

NCCP Childrens Adolescents/Young Adults (CAYA) Cancer Clinical Leads Group Membership

1. Professor Owen Smith, CBE, NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI at Crumlin
2. Survivorship Chair: Dr Michael Capra, Consultant Medical Oncologist, CHI at Crumlin
3. Palliative Care Chair: Dr Fiona McElligott, Palliative Care Consultant, CHI at Temple Street
4. Communications Chair: Ms Patricia McColgan, Chair & Co-founder, CanCare4Living
5. Shared Care Chair: Dr Jane Pears, Consultant Medical Oncologist, CHI at Crumlin
6. Fertility Chair: Professor Mary Wingfield, Clinical Director, Merrion Fertility Clinic.
7. Dr Scheryll Alken, Consultant in Adolescent & Young Adult Cancer, CHI at Crumlin and St James's Hospital
8. Ms Dee Ahearn, CEO, Barretstown
9. Mr Brice Antao, Paediatric Network Lead, CHI & Consultant Paediatric Surgeon, CHI at Crumlin
10. Ms Fiona Bonas, Interim Deputy National Director
11. Dr Larry Bacon, Consultant Haematologist, St James's Hospital
12. Dr Chiara Besani, Principal Clinical Psychologist, National Children Cancer Service, CHI, Crumlin
13. Dr Noelle Cullinan, Consultant Medical Oncologist, CHI at Crumlin
14. Professor Imelda Coyne, Professor of Nursing, Trinity College Dublin
15. Ms Frieda Clinton, Advanced Nurse Practitioner Haematology/Oncology, CHI at Crumlin
16. Dr Ian Dawkins, Senior Data Analyst, Cancer Intelligence Unit, NCCP
17. Dr Patricia Daly, Consultant Radiation Oncologist, St Luke's Hospital
18. Dr Helen Greally, Clinical Lead for Psycho Oncology, NCCP
19. Dr Katherine Gavin, Project Manager Childhood Cancer Survivorship Project, CHI at Crumlin
20. Ms Rebecca Gorman, Advocacy Officer (Children, Adolescents, Young Adults), Irish Cancer Society
21. Ms Patricia Heckmann, Assistant National Director (AND), Chief Pharmacist, NCCP
22. Professor Michaela Higgins, Consultant Medical Oncologist, St Vincent's University Hospital
23. Dr Zanusz Krawczyk, Consultant Haematologist, University Hospital Galway
24. Ms Louise Mullen, National Lead for Cancer Survivorship, NCCP

25. Dr Peter McCarthy, Haematology Specialist Registrar and Clinical Research Fellow, CHI at Crumlin
26. Ms Kim Murray, Medical Social Worker, CHI at Crumlin
27. Ms Eileen Nolan, National Programme Manager for AYA E-Referral & Urological Cancers, NCCP
28. Ms. Niamh O'Sullivan, Assistant Director of Nursing, CAYA Programme CHI at Crumlin
29. Ms Cathleen Osbourne, Assistant Director of Nursing, Cancer Survivorship, NCCP
30. Dr Karen O'Neill, Patient Representative, Specialist Registrar, Neonates, Coombe Hospital
31. Ms Fiona O'Loughlin, Shared Care Manager Haematology / Oncology Unit, CHI at Crumlin
32. Dr Clodagh Ryan, Consultant Paediatric Haematologist, Mercy University Hospital, Cork
33. Ms MaryClaire Rennick, Director, ChildhoodCancer Foundation
34. Ms Evelyn Griffith, Manager, Canteen Ireland
35. Ms Lorna Storey, Advanced Nurse Practitioner Haematology, CHI at Crumlin
36. Ms Elaine Smyth, Children's Cancer Coordinator, Irish Cancer Society
37. Dr Orla Walsh, Adolescent Medicine and General Paediatrician, Children's Health Ireland at Temple Street Children's University Hospital

National TYA Cancer, Beatson WoS Teenage Cancer Trust Unit, Glasgow

1. Ms Kirsten Duncan, MDT Co-ordinator, Beatson WoS Teenage Cancer Trust Unit, Glasgow.
2. Dr Nick Heaney, TYAC National Clinical Lead, Consultant Haematologist Beatson WoS Teenage Cancer Trust Unit, Glasgow.
3. Ms Liz Watt, Lead Nurse, Managed Service Network for Children & Young People with Cancer in Scotland, Beatson WoS Teenage Cancer Trust Unit, Glasgow.

3. Executive Summary

The National Cancer Strategy 2017-2026 (NCS) provides the vision and recommendations for optimum cancer services for the population of Ireland over a 9-year period. The NCS builds on the previous two National Cancer strategies for Ireland (A Strategy for Cancer Control 2006, and Cancer Services in Ireland: A National Strategy, 1996).

The NCS highlights the significant gaps in the Irish healthcare system for AYA cancer patients, with services limited and access delayed. The NCS proposes nine foundational recommendations which underpin all cancer services and two specifically for AYA cancer service development (see appendix 1).

The two recommendations state:

- The HSE/NCCP will ensure that an age appropriate facility is designated for AYA cancer within the new children's hospital.
- The HSE/NCCP will develop closer links, on a hub and spoke model, between the National Children's Cancer Service (child and adolescent cancer – 0 to 20 years) 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 psycho-social support for these patients.

This framework gives a background to AYA cancer in Ireland and details an implementation structure for the service development laying out the key strategic priorities for stakeholders over the next 5 years. These 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. The partnership will enhance support for AYAs and their families during the transition of care from paediatric to adult services. Key priorities of the framework include building an expert workforce for the future ensuring all parts of the system are invested in and utilised appropriately. Additionally, improved access to clinical trials for AYA patients will lead to better clinical outcomes and reduced mortality. Finally, data collection in a systematic and streamlined way will advance current knowledge which can be continuously improved upon. The framework is ambitious but grounded in the work of the Clinical Leads Group, NCCP, patients, families and charities. The clear timeframe will enable this document to guide the progress over the next 5 years.

Fiona Bonas
Interim Deputy National Director NCCP

4. Background

4.1 Introduction to Adolescent and Young Adult Cancer in Ireland

Cancer is a major health problem for the older adolescent and young adult (AYA) defined in Ireland as aged 16-24 years of age. Cancer is the leading cause of natural death in this population, with approximately 30% due to haematological malignancies. The incidence rate of some cancers is higher in this age group (e.g. germ cell tumours, sarcomas, Hodgkin lymphoma) than in both adults and children and the incidence rate of cancer overall is rising.

In recent years AYAs have been recognised as a unique population within the oncology community in terms of distinct biology of disease, as well as other age-related issues. Although recent studies show that child and older adult cancers have seen a large increase in survival rates, the same cannot be said for some AYA cancers. The causes of this relative lack of survival improvement is most likely multifactorial, including host and tumour-related factors, poor medication adherence and compliance, low clinical trial enrollement, unique pharmacodynamics that accompany puberty and perhaps most importantly complex psychological factors.

The AYA period is marked by rapid developmental changes: physical and hormonal changes, development in cognitive functioning, and changes in ability to manage emotional reactivity. This is also the time when young people feel more self-conscious and strive to develop their identity and self-esteem. Participation in school/vocational activities and social activities is crucial for AYA to develop their identity. This is also a crucial time within the cycle of the family life, where young people face the challenge of separation from parents to align with peers and develop independence, sense of mastery and identity and where boundaries and rules are needed and renegotiated. With the multitude of changes and challenges occurring in the life of any AYA, it is not uncommon that sometimes they struggle with problems of low self-esteem, anxiety, depression, self-harm, disordered eating, emotion regulation and they manifest risk-taking behaviour. The normal challenges and developmental tasks of adolescence and young adulthood still must be faced by a young person with a cancer diagnosis, together with very complex challenges associated with the disease and its treatment. A specific task of AYA services for this age group is to help young people navigate so that the cancer journey may impact or delay at times their development but not fragment nor interrupt the developing sense of identity and self-concept.

It is now widely accepted that traditional models of cancer care are not adequately meeting the needs of the AYA population. Many AYA patients do not feel comfortable in either paediatric or adult settings and they have a unique set of needs which are often not sufficiently met by either service. Indeed, the provision of a more consistent psychological and medical therapeutic approach taking into consideration their unique needs, such as fertility considerations, survivorship issues, psychological support, adherence to treatment difficulities and other problems exclusive to this group of patients, remains a significant challenge. Therefore, a more tailored comprehensive multidisciplinary approach to the specific service needs of this population who are undergoing intensive physiological and psychosocial change during their cancer journey needs urgent consideration.

The Framework for the Care and Support of Adolescent and Young Adults (AYA) with cancer in Ireland is intended to be a starting point for setting the direction of AYA cancer services in Ireland. The landscape of healthcare in Ireland is changing and so will our goal will continue to be to best meet the needs of the AYA patients.

4.2 Introduction to the framework

This framework will set out the vision and strategic aspirations for the care and support of AYA with cancer in Ireland. It will outline the ambition to achieve accessible and equitable access to AYA cancer care. The framework is necessary to promote and embed a partnership-based approach to AYA cancer care, ensuring AYAs living with cancer and after cancer can have meaningful engagement and achieve best outcomes throughout cancer treatment, survivorship, and at the end of their life. It sets out plans to improve AYA cancer services and priorities to close the gap of unmet needs for those with AYA cancer.

A Clinical Leads Group established by the NCCP in early 2019 comprising of nurses, advanced nurse practitioners, clinical nurse specialists, psychologists, social workers, paediatric and adult oncologists / haemato-oncologists, palliative care physicians, fertility preservation experts, patient advocacy / support groups and survivors of child and adolescent cancer significantly contributed to the content of this framework. The framework has also been informed by the recently published paper by Ferrari et. al. - *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 2021 Apr;6(2):100096* and previous work of colleagues in Scotland (The Cancer Strategy for Children and Young People in Scotland 2021-2026, 2021), United Kingdom (The Blueprint of Care for teenagers and young adults with Cancer, Second edition), Canada (Canadian Partnership Against Cancer: Canadian Framework for the care and support of adolescents and young adults with cancer, 2019) and Australia (Australian youth cancer framework, 2017).

4.3 Strategic alignment

The National Cancer Strategy 2017-2026 provides the vision and recommendations for optimum cancer services in Ireland up to the year 2026. This document highlighted the gap in the Irish healthcare system for AYA cancer patients and proposed nine recommendations directly pertaining to AYA cancer service development (Appendix 1).

4.4 Patient Population and Demographics

Cancer is the leading cause of disease related death in the AYA age group. The average annual number of children and AYA cancers diagnosed in Ireland by age at diagnosis is approximately 200 (0 – 15 years + 364 days), 70 (16-19-years + 364 days) and 110 (20-24-years + 364 days) [source: data request 2016-2019, National Cancer Registry (NCRI); 15/11/2021] (Appendix 2). There is no dedicated centralised database of AYAs with cancer in Ireland. As a result, there is an incomplete understanding of pathways to diagnosis for this group. Addressing this data shortage is a strategic focus of the national AYA programme.

5. International best practice

The need for developmentally appropriate and specific care for AYA patients has been recognised internationally. There is a particularly evident challenge in providing this complex care where integration and alignment of services between paediatric and adult healthcare systems is required. A diverse spread of disease groups and range of treatments combined with challenges related to developmentally appropriate assessments and provision of care adds to the complexity of finding appropriate space and approaches to care for this unique patient group. Providing holistic, evidence-based care should include:

- Increased access to clinical trials
- Delivery of a clear pathway of referral to AYA specific services
- Provision of regular standardised assessment of palliative care need and individualised care plans are co-developed to meet identified need, with the aim of optimising their quality of life
- Development of national multi-disciplinary team meeting (MDM) with diverse membership encompassing relevant medical and surgical fields, psychosocial supports, family and community services and voluntary sector supports
- Provision of comprehensive and ongoing training and educational opportunities for specialist AYA workforce
- Integration of care between paediatric and adult providers
- Creation of developmentally appropriate healthcare spaces for AYAs to receive care
- Provision of AYA specific approaches to care that caters to their unique needs
- Delivery of a person and family centred approach to care
- Use of developmentally appropriate tools to aid assessment and communication with AYAs and their families
- Provision of dedicated transition services for those in acute treatment and those in attending survivorship services
- Provision of AYA specific approaches to survivorship care and palliative care and end of life care

International research has identified several unique issues relating to AYA care that require further investment and consideration. To align with international best practice, the principles and strategic goals within this framework have been formed in parallel with the ESMO/SIOPE European working group consensus and form the basis of the AYA model of care in Ireland (Appendix 3).

5.1 Principles of the AYA framework

Six principles are described that focus on the creation of holistic services with AYA patients and their families at the centre (Appendix 4). This complex network of care is centred on striving for improved survival outcomes through systemic and medical strategies. In support of the development of appropriate care, these strategies require a holistic approach to the care of AYAs, understanding the development and impact of their diagnosis. The use of AYA specific assessments and tools tailored to their developmental stage will help promote a strengths-based approach. Therapeutic approaches which empower young people to have their voice heard, and to take the lead in their own care, fostering greater autonomy and independency should be utilised. Equally, the importance to some AYAs of having their parents acknowledged as key partners in supporting them make medical decisions should be recognised. Encouraging AYAs to communicate their needs allows them to develop greater insight and awareness into the needs of their family and wider community. Within psycho-oncology, psychology and mental health clinical practice well balanced patient-centred and family-centred approaches to care have proven to be effective.

At present, the Irish National Cancer Registry does not collect and process data specific to the AYA cancer group. Hence, there is a paucity of research focused on the needs of both the AYA cancer and AYA survivors of childhood cancer populations in Ireland. A key focus for the AYA programme is to create Information Technology (IT) systems to comprehensively include both populations encouraging progress through collaborative research.

5.2 Global AYA age ranges

Globally, AYA cancer is a growing sub-specialism in cancer services. There is, however, no international consensus on what age ranges constitute specific AYA cancer care. Discrepancies in age ranges depicting emerging adulthood and younger adolescence have contributed to this. Vast differences in healthcare service delivery structures around the world impact on the delivery and accessibility of care across age groups and healthcare services. Appendix 5 demonstrates the variance of European AYA cancer care treatment age ceilings. Ireland considers AYA cancer care to centre on those aged between 16-24 years. This age range aligns with the World Health Organisations (WHO) definitions of adolescence and young adulthood. The transitions between the different phases of life are a continuous and a variable path for each individual influenced by geographic, social, economic, individual physiological factors and life-events.

5.3 Current service challenges

Adolescence and young adulthood are complex phases of life due to the many developmental, emotional and social transitions occurring. A cancer diagnosis and the treatment required challenge or delay the ability of AYAs to achieve developmental milestones such as completing education, establishing personal or financial autonomy, forming significant personal relationships (friendships, romantic and if desired having children).

When diagnosed with cancer, AYAs face added challenges because of the intersection of the cancer experience with everyday aspects of their lives. Cancer-related issues such as premature confrontation of mortality, changes in physical appearance, increased dependence on parents, disruption of social life and school/employment due to treatment and loss of reproductive capacity, all become particularly distressing.

The delivery of quality care for AYA patients with cancer, and survivors requires understanding of the unique qualities of this group – the shared norms, attitudes and beliefs that determine their behaviour as well as the unique stresses they regularly face.

AYAs have often been described as the “lost tribe” with neither paediatric nor adult haemato-oncology departments able to provide developmentally-appropriate care single-handedly to this group. Much work has taken place internationally over recent years to establish AYA-specific programmes. AYAs benefit from a more holistic AYA multidisciplinary team (MDT) approach to their management. Facilitating holistic care requires provision of expert care from medical, nursing, allied health professionals in conjunction with psychology, rehabilitation specialists and social, educational, spiritual and vocational experts. The health care environment can also be used to support AYA patients through provision of AYA specific spaces and facilities.

Irish survivorship reports have looked at the needs of survivors of childhood and adult cancer which leaves a gap of knowledge on the unmet needs of the AYA group. Five overarching challenges have been recognised from the childhood cancer survivorship report (Appendix 6). The AYA programme of care will actively seek to understand the challenges specific to this population to enhance research and evaluation of services. International research has identified difficulties in relation to delivering tailored and appropriate information and providing emotional and psychological support. Also highlighted are practical needs such as, social supports and financial concerns. The diverse spread of these challenges across biopsychosocial domains requires a careful and cohesive approach for comprehensive delivery of care.

6. Current Context

6.1 Current infrastructure of cancer care

Irish healthcare currently provides universal access to paediatric patients at primary, secondary, and tertiary care levels. Adult access to healthcare is split across private and public sectors, creating an inequitable division to elements of healthcare.

Paediatric cancer care is centralised to one centre of excellence at Children's Health Ireland (CHI) at Crumlin. This centre is supported by a network of 16 shared care centres that deliver robust evidence-based supportive care protocols and work in a hub and spoke manner so that comprehensive cancer care is delivered to children all over Ireland. This network is known as the National Children's Cancer Service (NCCS) and serves children and young adolescents (Appendix 7).

Adult cancer care is coordinated through 8 designated cancer centres (DCCs), which administer chemotherapy, perform oncological surgeries, and provide radiotherapy where required. There are also 5 hospitals with medical oncology/haematology consultant services and 12 hospitals with visiting or part-time services. These units are linked to the cancer centre of their hospital groups, facilitating continued Multi-disciplinary Team (MDT) working (Appendix 8). Every adult cancer patient should be discussed at a disease specific Multi-disciplinary Meeting (MDM) and a treatment pathway documented. Disease specific MDMs occur within hospital groups (for example, breast MDMs), and at regional or national level (for example, Sarcoma MDM hosted by St Vincent's University Hospital)

Adolescents and Young Adults with cancer between 16 and 24 years + 364 days of age are currently treated across adult cancer services. Their diagnosis, staging and treatment take place within this care pathway (Figure 1).

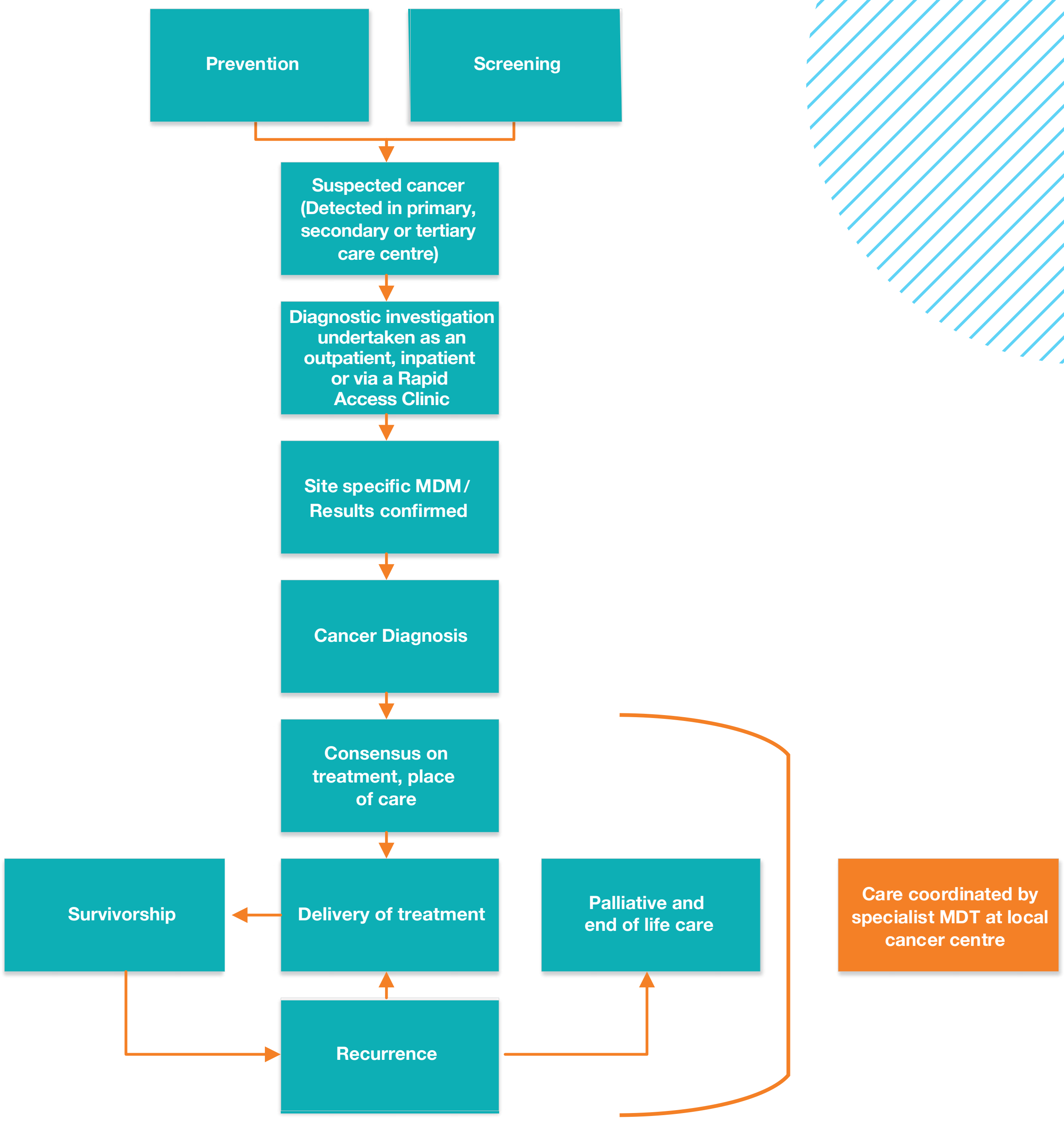


Figure 1:
The current care pathway for patients above 16 years of age with site-specific MDM.

6.2 Diagnostic pathway for children

Current referral processes mandate all patients aged 15 years, 364 days and under are referred to the NCCS at CHI, Crumlin (Figure 2). Diagnostic confirmation, treatment, planning and follow-up care are performed at this site, and/or in collaboration with designated sub-specialty expertise (for e.g. neurosurgical and retinoblastoma pathways). The NCCS also acts as an advisory centre and response service for the integrated shared care network shown in Appendix 7. Care of patients with suspected cancers is immediately assumed by the services at NCCS (and designated sub-speciality sites) before a definitive diagnosis is made. In the event of a non-cancer diagnosis, the patient will return to their referring paediatrician. This pathway is highly successful due to ongoing cooperation inherent in the shared care model.

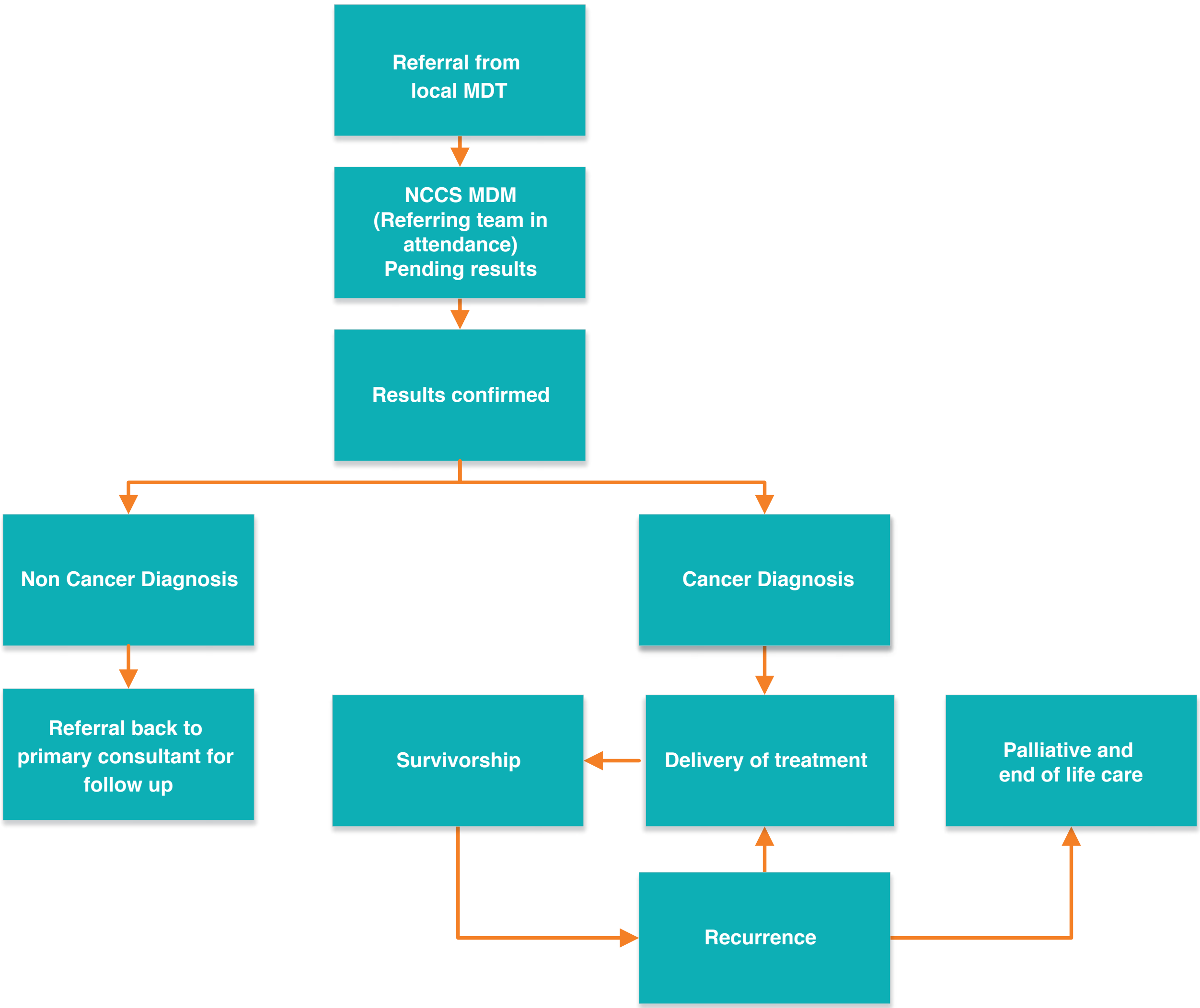


Figure 2:
The existing paediatric cancer care pathway for Children (0-15 years 364 days)

6.3 Diagnostic pathway for AYAs

AYA patients currently present to adult cancer services via primary or secondary care. Whilst rapid access programmes exist for some of the common adult cancers such as bowel, breast, lung and prostate cancer, many of the cancers which affect AYAs, such as leukaemia, lymphoma, germ cell tumours brain and central nervous system tumours and sarcomas do not have a clear diagnostic pathway or rapid access programme. A low level of patient and physician suspicion of cancer in this age group may lead to delays in further investigations and international evidence demonstrates these delays in diagnosis are often multifactorial.

A lack of a clear pathway to diagnosis, unlike in paediatrics, leads to delays once patients reach secondary care. This is most true of patients with rarer cancers, where one or two such patients may present to an individual hospital each year. The establishment of a National AYA MDM would be expected to streamline this process.

6.4 Cancer care pathway

The cancer care pathway [figure 1] shows the general path through cancer care for most adult patients and therefore most AYA patients. AYA patients uniquely access both paediatric and adult services, depending on their age. This presents an inequity in experience and focus of care depending on the system entered.

7. Vision of the framework

Table 1: Detailed vision of the AYA framework

Outlook	Detail
Vision	Accessible, equitable and developmentally appropriate care for all AYA diagnosed with cancer across the spectrum of care resulting in better outcomes and improved quality of life
Aspiration	Comprehensive provision of AYA cancer care to every AYA diagnosed with cancer in Ireland Services delivered across primary, secondary, tertiary and quaternary care from prevention to end of life and survivorship

7.1 Strategic Priorities

Table 2: The Strategic priorities required for the AYA framework

Priorities		Detail
	Partnerships/MDT working	A networked approach to all public services treating AYA population across the state A systematic and collaborative approach to the private and charity sector supporting AYA patients Creation of new services specific to the needs of AYAs with cancer Development of a National MDM Development of a Hub and Spoke model for service All service providers are aware of palliative care needs assessment and able to refer to a specialist palliative care service based on identified unmet need Co-design of research and services by those with lived experience of cancer as a young person Development of a national young person's advisory group to support co-design of research and clinical programmes Representation by AYA's with lived experience on working groups within the NCCP Representation by parent/family members within key working groups
	Workforce	Integrated network of healthcare professionals with specialist education and training in unique aspects of AYA cancer All AYA cancer centres should have appropriately trained and skilled palliative care consultants, nurses and wider MDT team for those patients with unmet needs requiring specialist input. This will help to reduce any potential disparities in Palliative Care Services relating to socioeconomic backgrounds, geographic location and diagnosis

	Workforce	Create, promote and nurture a network of skilled and highly motivated professionals across the spectrum of health and social care professions that are educated and skilled in the specific and unique care needs of AYA cancer patients Prioritise the needs of essential workers, and provide adequate staffing levels across paediatric, adult and community services Partner with the voluntary sector to create specific support to the AYA cohort
	Research	Strengthen research community of AYA group in Ireland Increase access to clinical trials for AYA patients and provide support to funding applications Increase participation in multi-site international research to further develop evidence-based practice for/with AYA in Ireland
	Data	Development, collection and monitoring of a national database and dataset unique to AYA cancer cohort Creation of Key Performance Indicators and benchmarking against international colleagues

7.2 Safeguarding, inclusion and diversity

Inclusion and diversity

Health services users from diverse ethnic and cultural backgrounds, members of religious groups along with members of the LGBTQ+ community and those in areas of lower socio-economic status often experience barriers in accessing healthcare. All staff have a duty to be open, respectful and treat service users with dignity. Inclusion, fairness and equity are central values to the AYA services. Creation of AYA services will be designed with patients and families. Barriers to healthcare will be considered in order to create accessible, fair and equitable services for all AYA cancer patients. All staff will follow local policies and HSE guidance on social health inclusion.

Safeguarding

Children and young people have the right to be safe and protected from harm. In line with the Children's First Act 2015, every staff member has a duty of care to ensure that every child/young person attending or availing of services is safe and protected from harm. All staff engaging with this service are required to have Garda vetting and must complete the mandatory children's first education. In the event of disclosure of assault, neglect or sexual abuse local reporting structures must be followed and reported accordingly.

8. Implementation

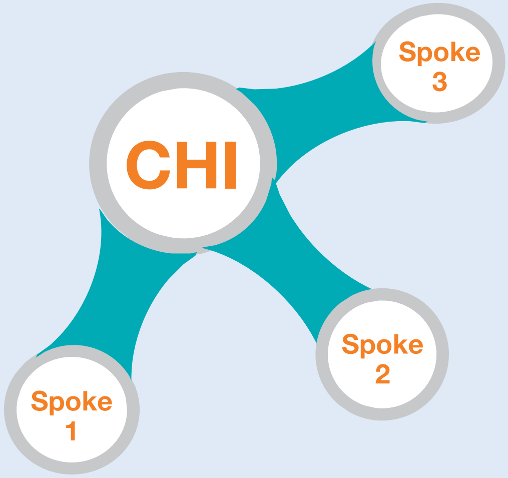
8.1 Proposed infrastructure improvements

CHI are developing a new National Children's Hospital (NCH) co-located on the St. James's hospital campus, Dublin. CHI aims to deliver integrated healthcare for children and adolescents. This facility integrates the opportunity to establish a facility for adolescents with cancer, and to develop a cohesive service for AYAs with cancer across Ireland, in line with the National Cancer strategy.

The age range for treatment in the new NCH will increase from 0 - 15 and 364 days (presently in CHI Crumlin) to 0 - 19 years and 364 days in order to accommodate those older teenage patients with paediatric centric cancers with clinically driven medical conditions - estimated to be an additional 40 - 45 patients per year. The schedule of developmentally appropriate accommodation of the NCCS unit in the new NCH will significantly increase the capacity (19 up to 28 inpatient beds). This accommodation includes an increase from 2 to 4/6 designated AYA beds within the Haematology/Oncology Wards and an increase in the number of bone marrow transplant beds from 4 to 6. The new children's hospital accommodation includes a dedicated AYA lounge/den within the haematology/oncology in-patient and out-patient units. These service improvements will enable a more comprehensive cancer care program to be delivered, in conjunction with an increased clinical trials portfolio.

8.2 Proposed dynamic of hub and spoke model

The establishment of a dedicated AYA Cancer Service Network (AYACSN) involving three of the eight DCCs will function on a hub and spoke model (Figure 3). CHI at Crumlin (and, when it opens as the new NCH) will function as the hub, with a strong input from dedicated haematologists/oncologists and allied healthcare professionals with an interest in AYA cancer from the three chosen DCCs. These proposed service improvements fall in line with recommendation 26 from the National Cancer strategy, and allow for the provision of age and developmentally appropriate care which cater to the unique needs of AYAs. Flexibility in place of care will be practiced in Ireland, whereby MDM discussions around place of care will be centred on care delivery best aligned with the young person's developmental stage. The National Cancer Control Programme is currently selecting the hospital membership for the AYACSN.



AYA Spoke Selection underway – due to complete Q4 2021 – Q1 2022

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 3:
Proposed hub and Spoke model

8.3 Key forecasted observations of the proposed model of care

Development of AYA Designated Units

The development of a network of three designated AYA Units will enable the treatment of this cohort of patients in a more appropriate environment and enable access to clinical trials, and other supports such as onco-fertility, educational, social work and psycho-oncology supports as required.

Identification of AYA Cancer Patients

A more structured pathway will require collaboration with national organisations such as the National Cancer Registry Ireland and national IT systems to identify patients early in their cancer treatment journey.

Referral of AYA Cancer Patients to National AYA MDM

Referral of AYA Cancer Patients to the National AYA MDM will be encouraged through AYACNS and close collaboration with colleagues around Ireland. The goal is to ensure all AYA cancer patients are referred to an AYA service that delivers care in accordance with international best standards.

AYA Cancer Local Treatment, Centralised when Required

The framework outlines strategies to coordinate AYA care to be delivered locally when possible, but centralised when necessary. State-of-the-art integrated care will be provided by separate facilities and specialist care teams. Once this has been achieved the challenge will then be to secure the future through education, research/innovation and future service developments.

Workforce Planning for AYA Network

A dedicated workforce of medical and nursing staff, working with health and social professionals with specific AYA expertise will be further developed over the lifetime of this document. This workforce will include those directly involved in delivering cancer directed therapy but also integrate supportive therapies such as fertility preservation and palliative care.

8.4 Clinical Trials and Research

It is well documented that enrolment into clinical trials is fundamental to improve clinical outcomes for cancer patients. The NCCS at CHI has an established track record in providing world-leading clinical trials to Irish children and young adolescents with cancer that has contributed to significant improvements in overall and event free survival outcomes. To date this activity has been delivered by the NCCS Cancer Clinical Trials Unit (NCCS CCTU) which is focused on multi-site, international academic phase III trials. Through partnership with the University College Dublin Clinical Research Centre, additional expertise will be made available to the NCCS CCTU, following the successful application for funding over 5 years from the Health Research Board (HRB). The award - Children’s Health Ireland Cancer Trials Group**,** *a HRB partnership supporting cancer clinical trials to improve health and care* **(**CTIC-2021-006**) -** is an ambitious programme of work that seeks to further enhance the profile of clinical trials not only for children and young adolescents but also for the AYA population across the Island of Ireland.

The overall intention is to include young adolescents from 12 years of age in adult early phase I/II clinical trials, including first-in-class drug trials whilst at the same time we intend to include AYA in paediatric protocols for paediatric-centric malignancies, with no upper age limit. The 3 AYA units (16 – 24 yrs) and CHI (0 – 20 yrs) will participate with CHI centrally managing the trial/protocol activity, ensuring that the vast majority of AYA cancer patients in the country will be offered participation in a clinical trial. All AYA patients will be discussed at the weekly AYA MDM and treatment / trial availability will be discussed and agreed. For example: patients with Acute Lymphoblastic Leukaemia will be entered into ALLTogether 1 - A Treatment Study Protocol of the ALLTogether Consortium for Children and Young Adults (1-45 years of age) with Newly Diagnosed Acute Lymphoblastic Leukaemia [EudraCT Number: 2018-001795-38] recruiting to commence Q4 2022 and will run for 8 years. CHI will be responsible for recruitment to this trial and it will be open across the AYACSN. The 3 AYA units will be able to recruit in their own right. It is envisioned that the AYA (16-20) patients treated in CHI will also avail of trial recruitment where a trial is open within the AYACSN.

The award will also leverage these partnerships to identify new research opportunities for patients on an all-island basis. For example, genomic diagnostics and research will be made available to all paediatric and AYA cancer patients in Ireland. A pipeline will be established that enables whole genome sequencing and gene expression analysis for children and AYA (CAYA) cancer patients that is integrated in the Irish frontline healthcare system, scalable in terms of capacity, and future proofed to accommodate the still rapid advances in the field. The aims of this molecular diagnostic pipeline are: (i) stratify CAYA cancers by molecular genetic aberrations to improve diagnostics, (ii) identify possible genetic modulators of treatment toxicities in order to anticipate side-effects early and adjust treatment accordingly and (iii) identify actionable targets for therapy resistant patients.

8.5 AYA Services Delivered in Partnership with Patients

The voice of AYA cancer patients and their families will be central to the development of AYA services and will be heard throughout the continuum of care. Research and service improvements will be co-designed with young people through a dedicated young person's advisory group. Young people will be empowered through opportunities to participate in clinical trials and research.

8.6 The proposed cancer pathway for patients aged 16-24 years old

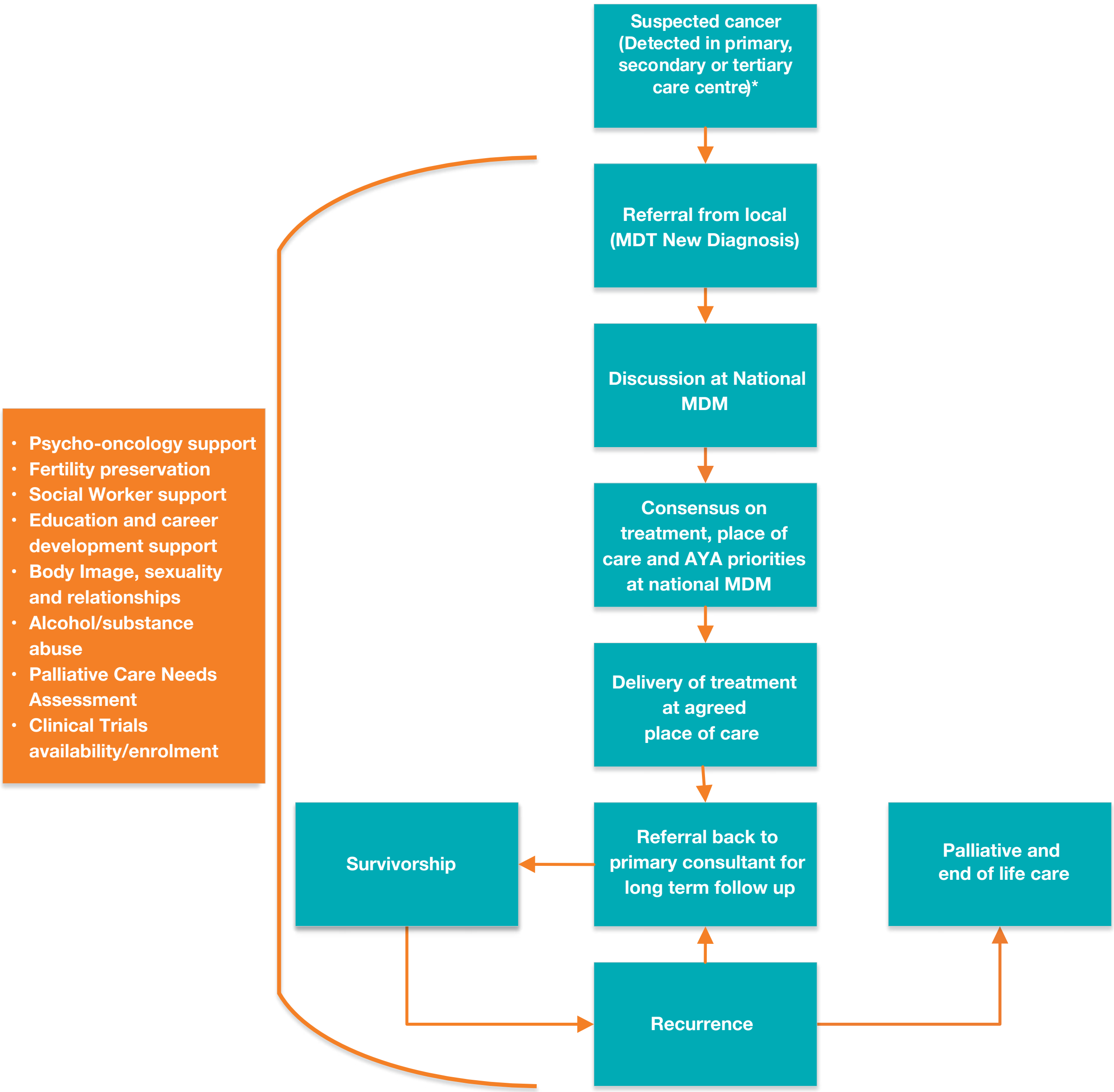


Figure 4:
The proposed cancer pathway for patients aged 16-24 years old.

**Early referral to the AYA team for advice on diagnostics, clinical trial availability and other psychosocial supports to ensure a developmentally appropriate approach is taken.*

9. Benchmarks of success

Table 3: Benchmarks of success

Benchmarks of Success	
• System level	• Implement national policies • Strategically plan, and successfully provide comprehensive integrated care for AYA patients • Create accessible services by removing barriers to healthcare for AYA cancer patients • Provide facilities that promote AYA care in an appropriate and age-specific environment • Advocate and provide services that are accessible throughout the cancer trajectory (acute treatment, transition, late effects, survivorship and palliative care) • An enabling environment is created where hospital, community and primary healthcare providers are supported to provide palliative care as part of their normal service provision • Provide supportive and tailored care which is evidence-based and meets the unique needs of AYA patient and their families • Develop a workforce plan and ensure capacity to deliver specialist AYA cancer care across disciplines, to meet the developmental and health related needs of the AYA patients • Create evidence-based pathway for AYA cancer care delivery • Create partnerships with young people and their families to create and maintain services that are truly enhanced by service user input and expertise • Work to include AYA patients in research populations by increasing age eligibility criteria to include AYA patients in clinical and psychosocial research • Create and monitor KPIs regularly (Appendix 9)
• Service level	• Provide holistic, developmentally appropriate care to AYA patients and their families • Care providers understand developmental changes of AYA patients and tailor their care and communication to be developmentally relevant • Access to specialist palliative care is provided for those patients with complex needs and the capability of services is developed • Create national MDT network to provide comprehensive, family centred care and document and adapt plans as needs dictate • Provide education and support to healthcare teams with specific focus on AYA needs

	• Provide supportive procedures and coordination of services of multiple disciplines and across levels of care delivery and integration of these services • Ensure access to healthcare is facilitated for diverse and minority groups • Appropriate sign-posting to patient-specific support services such as, financial, educational, vocational and survivorship programs • Provide mechanisms of communication across primary and secondary care networks • Enhance access to current clinical trials nationally and internationally for AYA cancer patients • Collect data related to patient experience and outcomes, review and monitor outputs and implement change where indicated • Service planning in partnership with AYA patients and families to ensure their needs are met • Collaborate across sectors to provide holistic care for AYA patients
• **Patient level**	• All AYA patients receive an agreed and documented treatment plan, updated regularly and communicated with relevant healthcare workers • All AYA patients are discussed and referred to members of national MDT network to ensure evidence-based, supportive specialist care • All AYA patients and families feel empowered, dignified, respected and listened to • AYAs feel their strengths and abilities are respected, enriched and facilitated by their healthcare teams and healthcare environment • All AYA patients have access to supportive, empowering, specialist care tailored to their unique stage of development, that adapts to their needs as time dictates • AYA patients and families are communicated with about their needs and care across all stages of their cancer trajectory • AYAs and families receive transition services that ensure smooth movement and strengths-based approaches to empower young people in their healthcare • AYAs and their families are aware of current opportunities to engage in research and clinical trials and understand the risks and benefits of these • AYA and their families are helped to plan for the future in a timely and sensitive manner • AYA patients and families receive timely access to services • AYAs and their families receive tailored information that communicates the many unique aspects facing AYA cancer patients in an easily understandable and relatable format • Continuous and meaningful partnerships with AYA patients and their families to design and enhance services, policy making and healthcare delivery • In-depth national patient survey will be performed every 3 - 5 years

10. Implementation plan/ next steps

Table 4: Quarterly priorities for the AYA model of care

Quaterly priorities			2021-2022												
Summary of milestones	**Start Date**	**Ongoing**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**
Organisational/Infrastructural															
Framework Approval from NCCP Executive Management Team & other HSE Stakeholders	1/1/2022	31/1/2022	🟦												
Framework Approval from CAYA CLG	1/1/2022	31/1/2022	🟦	⬜											
Public Consultation on Framework	1/2/2022	30/3/2022		⬜	⬜	⬜									
Designation of AYA Spoke Centres	1/12/2021	31/1/2022	🟦	⬜											
Development of Governance Structure for Framework Implementation	1/2/2022	1/7/2022			⬜	⬜	🟩	🟩	🟩						
Workforce															
Appointment of AYA Programme Manager	1/1/2022	1/3/2022		⬜	⬜	⬜									
Ensure key workforce in post	1/4/2022	30/6/2022					🟩	🟩	🟩						
Clinical Service Development and Implementation															
Transition Clinic Pilot	1/2/2022	1/6/2022			⬜	⬜	🟩	🟩							
Develop National Transition Programme	These three are year-long tasks			⬜	⬜	⬜	🟩	🟩	🟩	🟧	🟧	🟧	⬛	⬛	⬛
Develop National AYA Survivorship Programme, integrated with NCCP Survivorship Programme				⬜	⬜	⬜	🟩	🟩	🟩	🟧	🟧	🟧	⬛	⬛	⬛
Develop publicly funded fertility preservation services, including gonadal tissue cryopreservation				⬜	⬜	⬜	🟩	🟩	🟩	🟧	🟧	🟧	⬛	⬛	⬛
Evaluate Pilot Transition Clinic	1/7/2022	1/9/2022								🟧	🟧	🟧			
National AYA MDM Structure															
Agree national AYA data set	1/1/2022	31/3/2022		⬜	⬜	⬜									
Develop referral protocol to the AYA MDM	1/1/2022	31/3/2022		⬜	⬜	⬜									
Agree "Go-Live" date for national MDM and referal pathway	1/4/2022	30/6/2022					🟩	🟩							
Begin formal referral process from spokes	1/4/2022	30/6/2022					🟩	🟩							
Agree a "Go-Live" date for integration with national computer systems	1/7/2022	30/9/2022								🟧	🟧	🟧			
Clinical Audit and Data															
Agree National AYA Key Performance Indicators (KPI)	1/1/2022	30/3/2022		⬜	⬜	⬜									
Agree AYA unit to pilot collection of AYA KPI's	1/4/2022	30/6/2022					🟩	🟩	🟩						
Liaise with NCCP Cancer Intelligence to agree reporting of AYA KPI	1/4/2022	30/6/2022					🟩	🟩	🟩						
Integration with National Systems															
Link with National IT Systems	1/7/2022	31/12/2022								🟧	🟧	🟧	⬛	⬛	⬛
Service Evaluation and Planning															
Evaluate KPIs	1/10/2022	31/12/2022											⬛	⬛	⬛
Interium report for the project	1/10/2022	31/12/2022											⬛	⬛	⬛
Agree proposals for 2023 and NSP funding	1/10/2022	31/12/2022											⬛	⬛	⬛
Review governance structure and approval process	1/10/2022	31/12/2022											⬛	⬛	⬛

🟦 Dec-21 ⬜ Quarter 1 🟩 Quarter 2 🟧 Quarter 3 ⬛ Quarter 4

10.1 AYA Key Performance Indicators (KPIs)

(Appendix 9)

- **Diagnostic timeliness - KPI No 1:** AYA cancer patients should receive a diagnosis within 30 days of referral to a specialist service
- **Time to treatment - KPI No 2a: Haematological:** All AYA patients with a new haematological cancer diagnosis should have their first therapeutic intervention within 10 days of diagnosis
- **Time to treatment - KPI No 2b: Solid Tumours:** All AYA patients with a new cancer diagnosis should have their first therapeutic intervention within 30 days of diagnosis.
- **Multidisciplinary working - KPI No 3:** All AYA patients who are diagnosed with a new cancer shall be discussed at the National AYA Cancer MDM within 30 days of their diagnosis.
- **Clinical trial availability - KPI No 4:** All AYA patients who are diagnosed with a new cancer shall be offered enrolment in a clinical trial
- **Consent - KPI No 5:** All AYA cancer patients should have documented informed consent prior to commencing systemic anti-cancer therapy (SACT) in keeping with the Drug Safety Review Action Plan 2014
- **End of treatment Summary - KPI No 6:** AYA cancer patients will receive an end of treatment summary within 60 days of their final treatment
- **Fertility Preservation - KPI No 7:** AYA cancer patients will have a fertility preservation discussion at the time of diagnosis
- **Palliative Care - KPI No 8:** AYA cancer patients with a life limiting diagnosis will have a palliative needs assessment performed

11.Bibliography

Barr RD, Ferrari A, Ries L, et al. Cancer in adolescents and young adults: a narrative review of the current status and a view of the future. *JAMA Pediatr*. 2016;170(5):495-501. doi: 10.1001/jamapediatrics.2015.4689.

Barr RD. Common cancers in adolescents. *Cancer Treat* Rev. 2007;33(7):597-602. doi: 10.1016/j.ctrv.2006.11.003.

Barr RD, Holowaty EJ, Birch JM. Classification schemes for tumors diagnosed in adolescents and young adults. *Cancer*. 2006;106(7):1425-1430. doi: 10.1002/cncr.21773.

Barr RD, Ries LAG, Trama A, et al. A system for classifying cancers diagnosed in adolescents and young adults. *Cancer*. 2020;126(21):4634-4659. doi: 10.1002/cncr.33041.

Bleyer A, Montello M, Budd T, et al. National survival trends of young adults with sarcoma: lack of progress is associated with lack of clinical trial participation. *Cancer.* 2005;103(9):1891-1897. doi: 10.1002/cncr.20995.

Bleyer WA, Tejeda H, Murphy SB, et al. National cancer clinical trials: children have equal access; adolescents do not. *J Adolesc Health*. 1997;21(6):366-373. doi: 10.1016/s1054-139x(97)00110-9.

Boissel N, Baruchel A. Acute lymphoblastic leukemia in adolescent and young adults: treat as adults or as children? Blood. 2018;132(4):351-361. doi: 10.1182/blood-2018-02-778530.

De Rojas T, Neven A, Terada M, et al. Access to clinical trials for adolescents and young adults with cancer: a meta-research analysis. *JNCI Cancer Spectr*. 2019;3(4):pkz057. doi: 10.1093/jncics/pkz057.

Department of Health and Human Services, National Institutes of Health, National Cancer Institute, LiveStrong Young Adult Alliance. Closing the gap: research and care imperatives for adolescents and young adults with cancer: a report of the Adolescent and Young Adult Oncology Progress Review Group. https://www.livestrong.org/sites/default/files/what-we- do/reports/ayao_prg_report_2006_final.pdf. Published 2006. Accessed July 4, 2020.

Department of Health and Social Care, 2004. “Manual for Cancer Services”. London, UK

Department of Health. (2017) *National Cancer Strategy 2017-2026.* 6f1592a09583421baa87de3a7e9cb619.pdf (assets.gov.ie)

Department of Health. (2006) *A Strategy for Cancer Control in Ireland*. https://www.hse.ie/eng/services/list/5/cancer/pubs/reports/a-strategy-for-cancer-control-in-ireland.pdf

Department of Health. (1996) *Cancer Services in Ireland: A national strategy.* https://www.hse.ie/eng/services/list/5/cancer/pubs/reports/national%20cancer%20strategy%201996.pdf

Desandes E, Stark DP. Epidemiology of adolescents and young adults with cancer in Europe. Prog Tumor Res. 2016;43:1-15. doi: 10.1159/000447037.

Fardell JE, Patterson P, Wakefield CE, et al. A narrative review of models of care for adolescents and young adults with cancer: barriers and recommendations. *J Adolescent Young Adult Oncol*. 2018;7(2):148-152. doi: 10.1089/jayao.2017.0100.

Fern L, Davies S, Eden T, et al. Rates of inclusion of teenagers and young adults in England into National Cancer Research Network clinical trials: report from the National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Development Group. *Br J Cancer*. 2008;99(12):1967-1974. doi: 10.1038/sj.bjc.6604751.

Fern LA, Bleyer A. Dynamics and challenges of clinical trials in adolescents and young adults with cancer. *Cancer J. 2018*;24(6):307-314. doi: 10.1097/ppo.0000000000000347.

Fern LA, Lewandowski JA, Coxon KM, et al. Available, accessible, aware, appropriate, and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials. *Lancet Oncol*. 2014;15(8):e341-350. doi: 10.1016/s1470-2045(14)70113-5.

Ferrari A, Aricò M, Dini G, et al. Upper age limits for accessing pediatric oncology centers in Italy: a barrier preventing adolescents with cancer from entering national cooperative AIEOP trials. *Pediatr Hematol Oncol*. 2012;29(1):55-61. doi: 10.3109/08880018.2011.572963.

Ferrari A, Barr RD. International evolution in AYA oncology: current status and future expectations. *Pediatr Blood Cancer*. 2017;64(9):e26528. doi: 10.1002/pbc.26528.

Ferrari A, Bleyer A. Participation of adolescents with cancer in clinical trials. Cancer Treat Rev. 2007;33(7):603-608. doi: 10.1016/j.ctrv.2006.11.005.

Ferrari A, Dama E, Pession A, et al. Adolescents with cancer in Italy: entry into the national cooperative paediatric oncology group AIEOP trials. *Eur J Cancer*. 2009;45(3):328-334. doi: 10.1016/j.ejca.2008.12.003.

Ferrari A, Thomas D, Franklin AR, et al. Starting an adolescent and young adult program: some success stories and some obstacles to overcome. *J Clin Oncol*. 2010;28(32):4850-4857. doi: 10.1200/jco.2009.23.8097.

Ferrari A, Trama A, De Paoli A, et al. Access to clinical trials for adolescents with soft tissue sarcomas: Enrollment in European pediatric Soft tissue sarcoma Study Group (EpSSG) protocols. *Pediatr Blood Cancer*. 2017;64(6). doi: 10.1002/pbc.26348.

Ferrari, A., Stark, D., Peccaori, F.A., Fern, L., Laurence, V., Gaspar, N., Bozovic-Spasojevic, I., Smith, O., De Munter, J., Derwich, K., Hjorth, L., van der Graaf, W.T., Soanes, L., Jezdic, S., Blondeel. A., Bielack, S., Douillard, J.Y., Mountzios, G., and Saloutros, E. (2021) '*Adolescents and young adults (AYA) with cancer: a position paper from the YA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)*'. ESMO Open 6 (2) DOI: doi.org/10.1016/j.esmoop.2021.100096

Haupt R, Essiaf S, Dellacasa C, Ronckers CM, Caruso S, Sugden E, Zadravec Zaletel L, Muraca M, Morsellino V, Kienesberger A, Blondeel A, Saraceno D, Ortali M, Kremer LCM, Skinner R, Roganovic J, Bagnasco F, Levitt GA, De Rosa M, Schrappe M, Hjorth L, Ladenstein R. *The 'Survivorship Passport' for childhood cancer survivors*. Eur J Cancer. 2018 Oct;102:69-81. doi: 10.1016/j.ejca.2018.07.006

HSE 2020. Report "Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland- Final Report and Recommendations"

Marshall S, Grinyer A, Limmer M. The experience of adolescents and young adults treated for cancer in an adult setting: a review of the literature. *J Adolescent Young Adult Oncol*. 2018;7(3):283-291. doi: 10.1089/jayao.2017.0123.

National Cancer Institute. (2021) Acute Lymphoblastic Leukemia. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/acute-lymphoblastic-leukemia

National Cancer Care Pathway (NCCP), HSE. 2021. Technical specifications for Key Performance Indicators for Children, Adolessants, and Young Adults (CAYA)

National Clinical Programme for Palliative Care, HSE.2019. *Adult Palliative Care Services, Model of Care for Ireland. https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf*

O'Connor M, O'Donovan B, Drummond F, Donnelly C. The Unmet needs of cancer survivors in Ireland: A Scoping Review 2019. National Cancer Registry Ireland; Cork

Sender L, Zabokrtsky KB. Adolescent and young adult patients with cancer: a milieu of unique features. *Nat Rev Clin Oncol*. 2015;12(8):465-480. doi: 10.1038/nrclinonc.2015.92.

Siegel SE, Stock W, Johnson RH, et al. Pediatric-inspired treatment regimens for adolescents and young adults with Philadelphia chromosome-negative acute lymphoblastic leukemia: a review. *JAMA Oncol*. 2018;4(5):725-734. doi: 10.1001/jamaoncol.2017.5305.

Sironi G, Barr RD, Ferrari A. Models of care-there is more than one way to deliver. *Cancer J*. 2018;24(6):315-320. doi: 10.1097/ppo.0000000000000338.

Smith MA, Seibel NL, Altekruse SF, et al. Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *J Clin Oncol*. 2010;28(15):2625- 2634. doi: 10.1200/jco.2009.27.0421.

Social Care Institute for Excellence (SCIE).2021 Multidisciplinary teams working for integrated care. https://www.scie.org.uk/integrated-care/research-practice/activities/multidisciplinary-teams

Stark D, Bielack S, Brugieres L, et al. Teenagers and young adults with cancer in Europe: from national programmes to a European integrated coordinated project. *Eur J Cancer Care* (Engl). 2016;25(3):419-427. doi: 10.1111/ecc.12365.

Steliarova-Foucher E, Stiller C, Lacour B, et al. International Classification of Childhood Cancer, third edition. *Cancer J*. 2005;103(7):1457-1467. doi: 10.1002/cncr.20910.

Tai E, Buchanan N, Eliman D, et al. Understanding and addressing the lack of clinical trial enrollment among adolescents with cancer. *Pediatrics*. 2014;133 Suppl 3 (Suppl 3):S98-S103. doi: 10.1542/peds.2014-0122D.

Tai E, Buchanan N, Westervelt L, et al. Treatment setting, clinical trial enrolment, and subsequent outcomes among adolescents with cancer: a literature review. Pediatrics. 2014;133 Suppl 3(Suppl 3):S91-97. doi: 10.1542/peds.2014-0122C.

Trama A, Bernasconi A, McCabe MG, et al. Is the cancer survival improvement in European and American adolescent and young adults still lagging behind that in children? *Pediatr Blood Cancer.* 2019;66(1):e27407. doi: 10.1002/pbc.27407.

Trama A, Botta L, Steliarova-Foucher E. Cancer burden in adolescents and young adults: a review of epidemiological evidence. *Cancer J*. 2018;24(6):256-266. doi: 10.1097/ppo.0000000000000346.

Treadgold C,What should the age range be for AYA oncology? *J Adolesc Young Adult Oncol*. 2011;1(1):3-10. doi: 10.1089/jayao.2011.1505.

Zebrack BJ, Block R, Hayes-Lattin, Embry L, Aguilar C, Meeske K, Li Y, Butler M, Cole S. Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer J*. 2013. 119 (1) 201-214. doi 10.1002/cncr.27713

World Health Organisation, (2021) Recognising Adolescence. https://apps.who.int/adolescent/second-decade/section2/page1/recognizing-adolescence.html

12. Appendices

Appendix 1

Table 1: National Cancer Strategy recommendations and alignment with this framework

Recommendation Number	Detail of Recommendation
25	The NCCP will develop a systematic, evidence-based mechanism to prioritise the establishment of MDTs for further rare cancers. The centralisation of diagnosis, treatment planning and surgical services for these cancers will be organised in line with best international practice. Lead: NCCP HSE/DoH
26	The HSE will ensure that an age appropriate facility is designated for AYA cancer within the new children's hospital.
27	The HSE will develop closer links, on a hub and spoke model, between the National Children's Cancer Service (child and adolescent cancer – 0 to 20 years) 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 psycho-social support for these patients.
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.
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).
32	Oncology staff will have the training and education to ensure competence in the identification, assessment and management of patients with palliative care needs and all patients with cancer will have regular, standardised assessment of their needs.
33	The HSE will oversee the further development of children's palliative care to ensure that services are available to all children with a life limiting cancer.
36	The NCCP will develop, publish and monitor a programme of national quality healthcare indicators for cancer care, involving both process and outcome measures, in line with international standards. Lead: NCCP
40	All hospitals will offer patients a Patient Treatment Summary and Care Plan as part of their support. These plans will allow patients to store information about their cancer, their cancer treatment and their follow up care. The plans will also inform future healthcare providers. Lead: NCCP/HSE Designated Cancer Centres/ Primary Care settings.
41	The NCCP, in conjunction with the ICGP, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare. The Needs Assessment will be completed by the end of 2018. Lead: NCCP
42	The NCCP, in conjunction with the cancer centres, will develop shared care protocols for patients with cancer following treatment. These protocols will span the hospital and primary care settings.

Appendix 2

Table 2: Annual average numbers of childhood /adolescent / young adult cancers diagnosed in Ireland, between 2016-2018 and 2017-2019.

(*Segregated age ranges from 0-15 years + 364 days; 16-19 years + 364 days; 20-24 years + 364 days)

	2016-2018 average annual cases			2017-2019 average annual cases		
International Classification of Childhood Cancer group	**age 0-15**	**age 16-19**	**age 20-24**	**age 0-15**	**age 16-19**	**age 20-24**
I-XII. Total ICCCC-classified neoplasms (invasive cancers, or benign/uncertain-behaviour brain/CNS tumours of specified morphologies)	195	63	107	198	69	111
I. Leukaemias, myeloproliferative diseases, & myelodysplastic syndromes	54	3	8	50	4	6
II. Lymphomas & reticuloendothelial neoplasms	23	17	20	24	17	20
III. Central nervous system & miscellaneous intracranial/intraspinal neoplasms*	49	10	16	53	13	17
IV. Neuroblastomas & other peripheral nervous system tumours	9	<1	<1	9	<1	<1
V. Retinoblastoma	5	0	0	3	0	0
VI. Renal tumours	7	0	<1	6	0	<1
VII. Hepatic tumours	1	1	0	3	0	0
VIII. Malignant bone tumours	11	4	1	10	4	2
IX. Soft tissue & other extraosseous sarcomas	9	5	5	11	2	5
X. Germ cell tumours, trophoblastic tumours, & neoplasms of gonads*	6	5	14	5	6	18
XI. Other malignant epithelial neoplasms & malignant melanomas**	17	18	41	19	21	40
XII. Other & unspecified malignant neoplasms	4	0	1	7	<1	2

*Groups III & X include benign & uncertain-behaviour brain/CNS tumours of specified morphologies.

**Group XI provisionally include all carcinoids of the appendix (recoded to malignant in line with the latest WHO ICDO).

Appendix 3

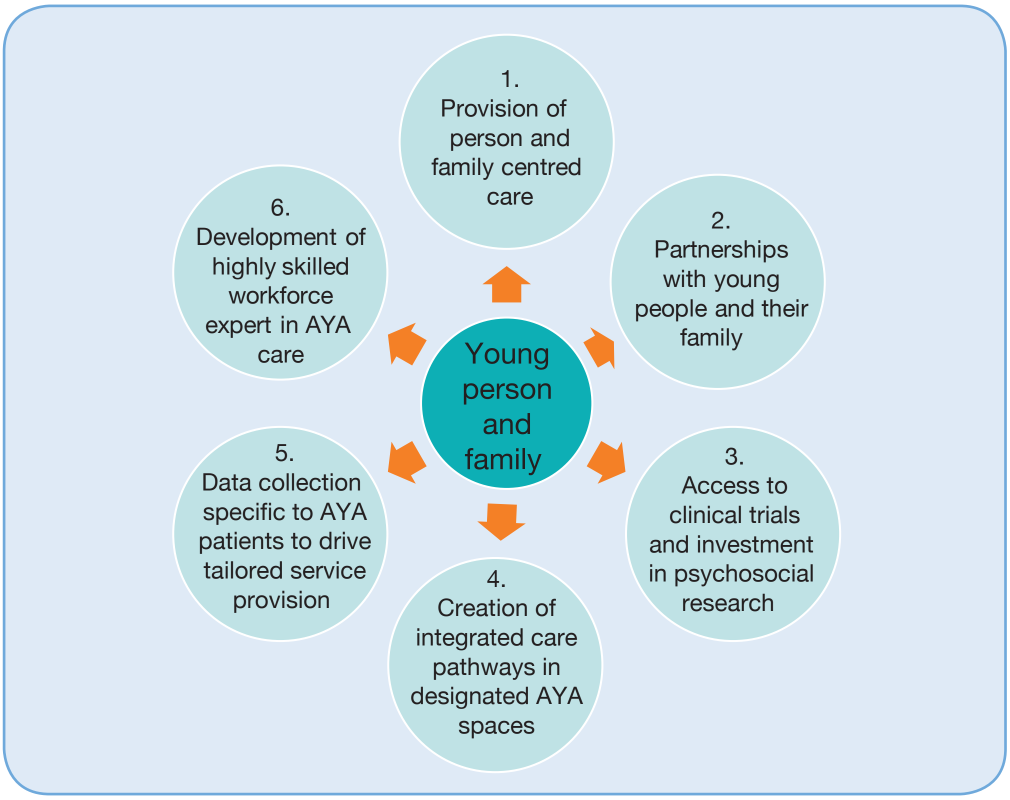
Table 3: Special cancer care issues in the AYA (age 15-39) cancer population, as recognised in the *European Society for Medical Oncology ESMO position paper.*

Issue	Uniqueness
Epidemiology	A unique spectrum of cancer types, with both paediatric- and adult-type tumours (need for multidisciplinary competencies with both paediatric and adult oncologists) Most common malignancies (>90% of cases) are leukaemias lymphomas, sarcomas, melanoma, breast cancer, testicular cancer, colorectal cancer, thyroid cancer and brain tumours.
Biology	For many histotypes, tumour genomics, biology and clinical behaviour may differ in AYA compared with children and older adults. Age-specific molecular features are poorly understood for most AYA cancers The biology of the host may also differ according to age, with distinct pharmacokinetics and potential impact on therapy efficacy and toxicity profiles. Clinical management cannot simplistically be a children's or adult's standard of care approach to AYA.
Hereditary cancer issues	The percentage of AYA with cancer who carry pathogenic variants in genes that predispose to cancer is significant. Counselling and genetic testing is essential for cancer prevention of both the patient and their family.
Early diagnosis and awareness	Insufficient awareness (among the general population and scientific community) that cancer may occur in this age group; complex symptom appraisal process and pathway to diagnosis, with risks of long and complex diagnostic pathways and/or difficult access to specialised care.
Accrual to clinical trials	Internationally-recognised limited participation in clinical research (reported rate of entering clinical trials ranges from 5% to 34% in published series).
Survival rates	Only modest survival gains compared with other age groups. For some tumour types, survival in AYA is poorer than in children with the same disease.
Fertility	Impaired reproductive function and possible infertility are major concerns for survivors of AYA cancers. Need for age-specific counselling and fertility preservation before the initiation of any cancer treatment.
Psychosocial care	Complex (and often unmet) psychological needs: • Physical changes • Development of self-image, identity, relationships, sexuality and independence. • Age-appropriate information and communication challenges shared decision making, compliance and treatment adherence.

	• Privacy and peer support • Peculiar behaviours of this age and risk-taking (including alcohol/ substance abuse). • need for age-specific psychological support.
Survivorship and transition	Multiple medical, psychosocial and behavioural late effects. Specific transitions from cancer patients to cancer survivors (and to independent adulthood); transitions in medical management Comprehensive assessment for patients' needs and hospital and community support (rehabilitation programmes screening physical and psychosocial late effects and support services, occupational and financial support services, individual tailored survivorship care plan).
Holistic approach	Need for multi-disciplinary care by a team that focuses on AYA-specific issues and concerns (e.g. age-specific supportive care, fertility counselling, appropriate psychological support, education and career development body image, sexuality and relationships, and alcohol/substance abuse). Need for special staff training and continuous education.
Environment	Referral to age-appropriate clinical environments with dedicated facilities and programmes, tailored to their unique developmental needs is essential.
End of life care	Challenging aspects of palliative and end-of-life care, death and bereavement: difficult adjustment to short life expectancy in this age group, difficult acceptance of treatments of non-curative intent. Early referral to palliative care services pathway, coordination between hospital and community of the decision-making process, are highly recommended.
Advocacy, patient and public involvement	Young patients are eloquent advocates for the services they value; need to actively listen to the patient's voice; importance of partnership with patient advocates and networking with health care policy and research groups

Appendix 4

Principles of the AYA framework



Appendix 5

Table 4: Age range for growth period termed adolescent and young adult across European countries

Country	AYA age bracket
France	15-25 years old
Ireland and United Kingdom	16-24 years old 13-24 in some
Germany, Poland, Czech Republic and Hungry	Precise cut off 18 years old
Italy	15-19 years old
Spain	14-30 years old
Netherlands	18-35 years old
Denmark	15-29 years old
Sweden, Belgium, Greece, Slovenia and Norway	Variable age range

Appendix 6

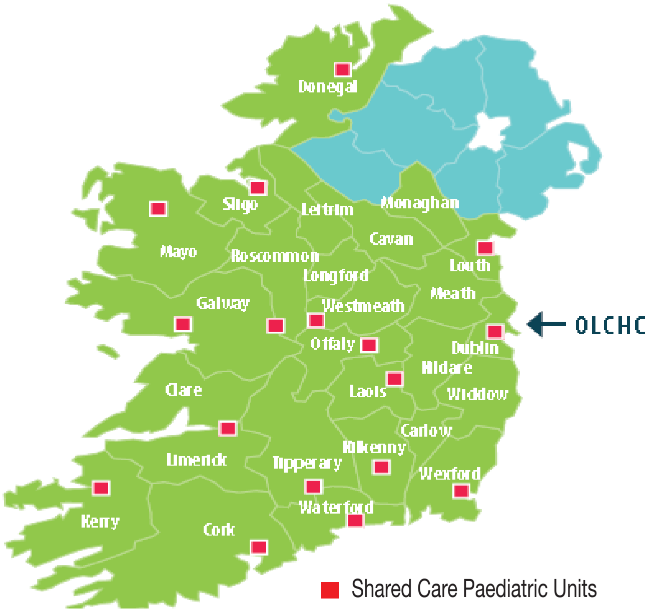
Table 5: Challenges recognised from childhood cancer survivorship

Need	Detail
Information for empowerment	- Gaps in knowledge of late effects from treatment such as: pain, disruption to urinary and bowel systems, sexual dysfunction, body image, fatigue and sleep disturbance - Need for age-appropriate information, and care summaries
Communication and co-ordinated care	- Need for single point of contact, particularly in transition and follow-up care
Psychological supports	- Cognitive and emotional disruption. Difficulties associated with: fear of recurrence, shock, distress, anxiety, depression and low self-esteem - Psychological support required from partners, family and friends. Additional psychological support required through public means and enhanced peer support networks
Social supports and adjustment	- Challenges in education and vocational realms which lead to further difficulties in employment and financial strains
Navigating the system	- Lack of comprehensive and streamlined care pathways for general and specific patient populations preventing equitable access

Appendix 7

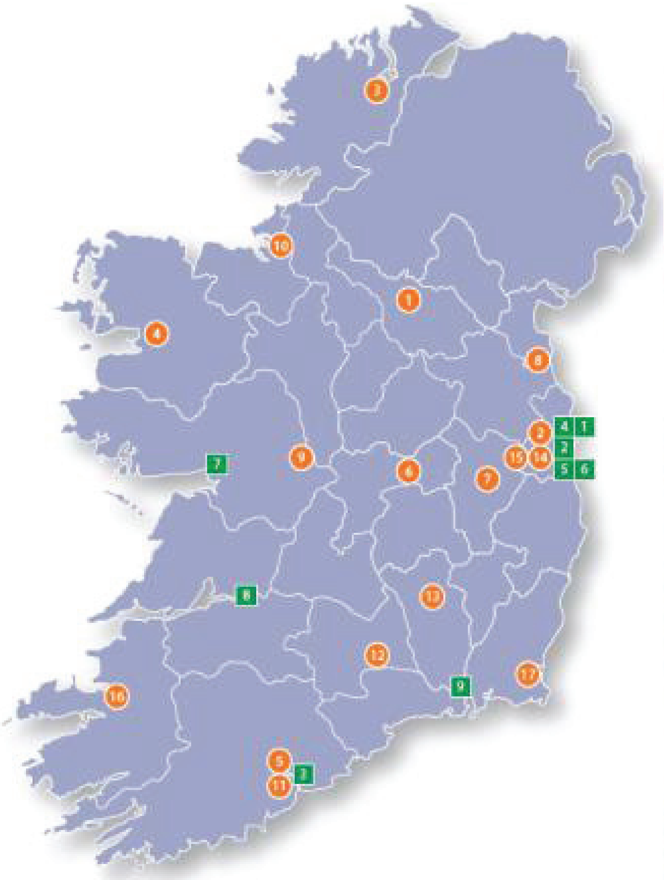
The National Children's Cancer Service (NCCS) incorporating the 16 shared care centres

Figure 10.2 Shared Care Paediatric Units in Ireland



Appendix 8

Map of Ireland with the name and location of the 26 publically funded SACT hospitals.



Designated Cancer Centre

1 Beaumont Hospital
2 CHI at Crumlin
3 Cork University Hospital
4 Mater Misericordiae University Hospital
5 St James's Hospital
6 St Vincent's University Hospital
7 University Hospital Galway
8 University Hospital Limerick
9 University Hospital Waterford

SACT Hospitals

① Cavan General Hospital
② Connolly Hospital
③ Letterkenny University Hospital
④ Mayo University Hospital
⑤ Mercy University Hospital
⑥ Midlands Regional Hospital Tullamore
⑦ Naas General Hospital
⑧ Our Lady of Lourdes Hospital Drogheda
⑨ Portiuncula University Hospital
⑩ Sligo University Hospital
⑪ South Infirmary Victoria University Hospital
⑫ South Tipperary General Hospital
⑬ St Luke's General Hospital Kilkenny
⑭ St Luke's Hospital Rathgar
⑮ Tallaght University Hospital
⑯ University Hospital Kerry
⑰ Wexford General Hospital

Appendix 9

Table 6: Diagnostic Timeliness

Diagnostic Timeliness KPI No 1
AYA cancer patients should receive a diagnosis within 30 days of referral to a specialist service.
Data variables 1. Record the date of receipt of the referral letter in the cancer centre. 2. Record the date of the first appointment offered to the patient 3. Record the date of histological diagnosis
Numerator: The number of patients who receive a diagnosis within 30 days.
Denominator: The total number of AYA patients who are diagnosed with cancer
Additional Notes (i) Referrals: includes all sources of referrals and not just GP referrals. (ii) DNAs excluded. Reporting Period: Monthly Monthly Inclusion Determinant: Date of attendance at rapid access clinic
Implementation • Dedicated referral pathway from primary care • Early access to specialist advice on diagnostics • Patient informed of diagnosis and availability of specialist AYA services • Patient referred to specialist AYA centre

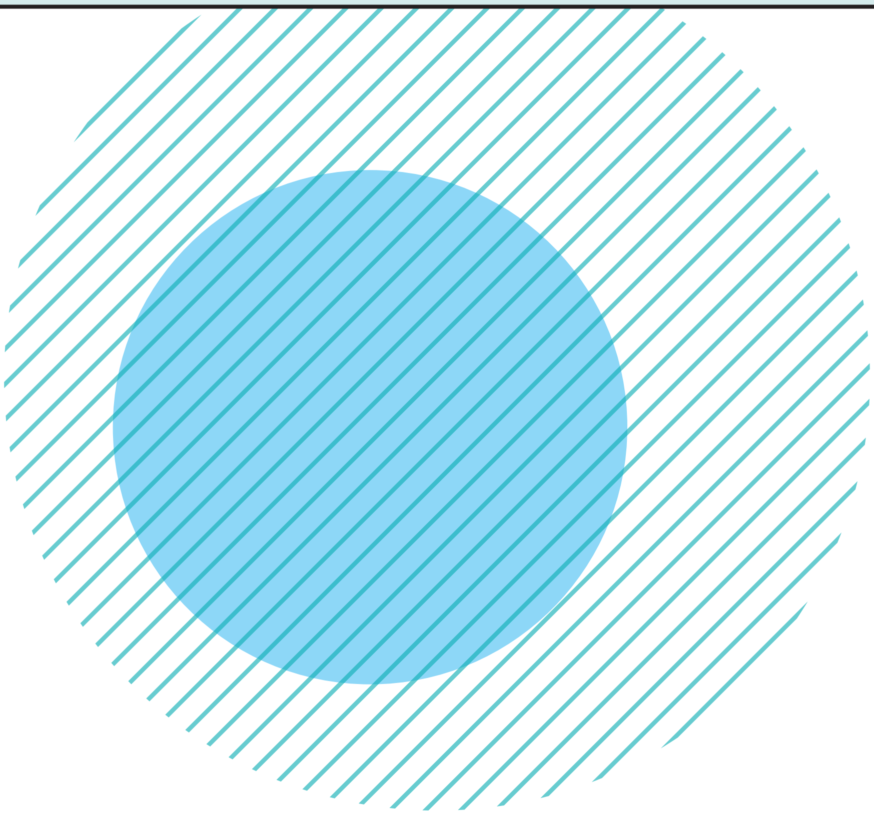


Table 7: Time to treatment - Haematological

Time to treatment KPI No 2a – Haematological
All AYA patients with a new haematological cancer diagnosis (solid tumour) should have their first therapeutic intervention within 10 days of diagnosis
Data variables 1. Record the patient's diagnosis 2. Record the date that the patient is placed on the waiting list for intervention 3. Record all therapeutic interventions as per data definition 4. Record date of first therapeutic intervention
Numerator: The total number of AYA patients diagnosed with a haematological cancer whose first therapeutic intervention occurs within 10 days of diagnosis
Denominator: The total number of AYA patients diagnosed with a haematological cancer
Additional notes: Cohort includes all AYA patients who undergo a therapeutic intervention in the cancer centre for a new cancer diagnosis, during the reporting period, irrespective of their mode of referral *Therapeutic intervention – includes radiotherapy, surgery and active surveillance and excludes hormone treatment. If the patient is prescribed hormones and subsequently undergoes surgery, then in that case, surgery is deemed to be the first treatment Reporting Period: Annual Quarterly Inclusion Determinant: Date of first therapeutic intervention
Implementation • Care accepted by specialist AYA centre or team • Treatment plan discussed with AYA centre (to allow for patient preference for non-paediatric centric cancers) • Central venous access considered • Treatment initiated as per protocol

Table 8: Time to treatment – Solid Tumours

Time to treatment   KPI No 2b – Solid Tumours
All AYA patients with a new cancer diagnosis (solid tumours) should have their first therapeutic intervention within 30 days of diagnosis
Data variables 1. Record the patient's diagnosis 2. Record the date that the patient is placed on the waiting list for intervention 3. Record all therapeutic interventions as per data definition 4. Record date of first therapeutic intervention
Numerator: The total number of AYA patients diagnosed with a cancer whose first therapeutic intervention occurs within 30 days of diagnosis
Denominator: The total number of AYA patients diagnosed with a cancer
Additional notes: Cohort includes all AYA patients who undergo a therapeutic intervention in the cancer centre for a new cancer diagnosis, during the reporting period, irrespective of their mode of referral *Therapeutic intervention – includes radiotherapy, surgery and active surveillance and excludes hormone treatment. If the patient is prescribed hormones and subsequently undergoes surgery, then in that case, surgery is deemed to be the first treatment Reporting Period: Annual Quarterly Inclusion Determinant: Date of first therapeutic intervention
Implementation • Care accepted by specialist AYA centre or team • Treatment plan discussed with AYA centre (to allow for patient preference for non-paediatric centric cancers) • Central venous access considered • Treatment initiated as per protocol

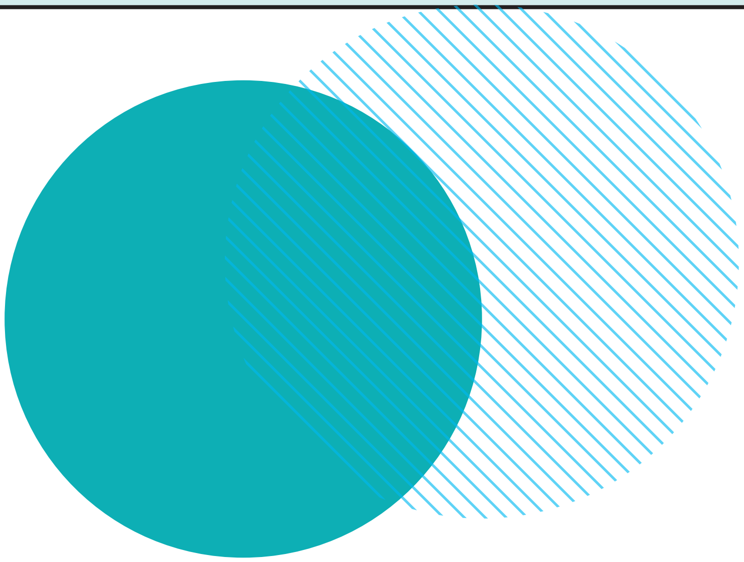


Table 9: Multidisciplinary working

Multidisciplinary working KPI No 3
All AYA patients who are diagnosed with a new cancer shall be discussed at the National AYA Cancer MDM within 30 days of their diagnosis
Data variables 1. Record the patient's diagnosis 2. Record the date of Diagnosis 3. Record date of first MDM discussion 4. All treatment Details 5. Fertility Preservation discussion offered 6. Psycho-oncology services offered 7. Social Worker services offered
Numerator: The number of Adolescent and Young Adults (AYA) cancer patients aged 16-24 years that were discussed at MDM
Denominator: The number of Adolescent and Young Adults (AYA) cancer patients aged 16-24 years
Additional notes Cohort includes all AYA patients who are diagnosed and/or treated in the cancer centre during the reporting period, irrespective of their mode of referral Therapeutic intervention includes radiotherapy, surgery, chemotherapy, targeted therapy *All patients must be discussed at their site specific MDM* Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of biopsy report/histological confirmation of diagnosis
Implementation • A dedicated publicly accessible referral route will be available • MDT coordinators nationwide will be contacted about the AYA service and the referral route • The AYA team will proactively seek out cases through the AYA network • AYA lead clinicians/CNS at each site will lead local identification and referral • A specific SOP will be developed for the running of the MDM

Table 10: Clinical Trial Availability

Clinical Trial Availability KPI No 4
All AYA patients who are diagnosed with a new cancer shall be offered enrolment in a clinical trial
Data variables 1. Record the patient's diagnosis 2. Record the date of diagnosis 3. Record if clinical trial offered 4. Record why clinical trial not offered 5. Record if enrolled on trial 6. Record type of trial
Numerator: The number of Adolescent and Young Adults (AYA) cancer patients offered enrolment in a clinical trial
Denominator: The number of Adolescent and Young Adults (AYA) cancer patients aged 16-24 years
Additional notes Cohort includes all patients who are diagnosed and/or treated in the cancer centre for Children, Adolescent and Young Adults (CAYA) cancer service 16 to 24 years during the reporting period, irrespective of their mode of referral Clinical trial includes interventional or registration trial Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of MDM discussion
Implementation • A centralized database of clinical trials available for AYA patients will be developed and maintained by the AYA Programme Manager • An SOP will be developed to facilitate rapid access to clinical trial patient information leaflets and screening tools for referred patients • The AYA programme will seek international collaborative studies and aim to increase clinical trial availability for these patients • Clinical trials as a general principle should be discussed (and that discussion documented) with each patient, even in the absence of a currently open available trial

Table 11: Consent

Consent KPI No 5
All AYA cancer patients should have documented informed consent prior to commencing systemic anti-cancer therapy (SACT) in keeping with the Drug Safety Review Action Plan 2014
Data variables 1. Record the informed consent discussion 2. Record date of this discussion
Numerator: The number of patients for whom documented informed consent is available
Denominator: The number of patients who receive cancer directed therapy
Additional notes Cohort includes all patients who undergo a systemic anti-cancer therapy, during the reporting period, irrespective of their mode of treatment. Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of first receipt of SACT
Implementation • The NCCP SACT Consent Form should be completed for each patient • The completed form should be scanned into the patient's NCIS record (once available) • Each new line of treatment requires a new informed consent process and form

Table 12: End of Treatment

End of Treatment Summary KPI No 6
AYA cancer patients will receive an end of treatment summary within 60 days of their final treatment
Data variables 1. Record the date of final treatment 2. Record date of the creation of treatment summary
Numerator: The number of patients who receive an end of treatment summary within 60 days of their final treatment
Denominator: The number of patients who receive cancer directed therapy
Additional notes Cohort includes all patients who undergo a therapeutic intervention, during the reporting period, irrespective of their mode of treatment. Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of first biopsy report
Implementation • The treating physician, and all relevant members of the MDT shall complete the EOT • The secretarial support for the lead clinician will be responsible for typing of this summary • The summary will not be considered complete until the patient receives either a hard or soft copy, as per their preference

Table 13: Fertility Preservation

Fertility Preservation KPI No 7
AYA cancer patients will have a fertility preservation discussion at the time of diagnosis
Data variables 1. Record the date of discussion 2. Record the fertility risks associated with cancer treatment 3. Record the decision to refer for preservation (yes/no) 4. Record the reason why referral not done
Numerator: The number of AYA patients with a new cancer diagnosis with a documented fertility discussion
Denominator: The number of AYA patients who receive cancer directed therapy
Additional notes Cohort includes all patients who undergo a therapeutic intervention, during the reporting period, irrespective of their mode of treatment. Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of first biopsy report
Implementation • The lead clinician is responsible for ensuring this discussion takes place • The discussion should be led by the most appropriate/trained member of the team • Documentation of discussion should include: date of discussion, fertility risks associated with the specific treatment, rationale to refer or not for preservation, the options for post treatment assessment

Table 14: Palliative Care

Palliative Care KPI No 8
AYA cancer patients with a life-limiting diagnosis will have a palliative care needs assessment (PCNA) performed
Data variables 1. Record the date of diagnosis 2. Record the outcome of palliative care needs assessment in the patient record
Numerator: The number of AYA patients with a life-limiting diagnosis with a palliative care needs assessment
Denominator: The number of AYA patients with a new life-limiting diagnosis*
Additional notes Cohort includes all patients who undergo a therapeutic intervention, during the reporting period, irrespective of their mode of treatment. Reporting Period: Quarterly Quarterly Inclusion Determinant: Date of first biopsy report
Implementation • The lead clinician or an appropriate member of the team will carry out a palliative care needs assessment when a diagnosis of a life-limiting condition is made • This assessment will be documented in electronic health records • Should the palliative care needs assessment identify a need for specialist palliative care input, the referral should be made by the healthcare professional completing the needs assessment • It is recognized that not every patient will wish to engage with palliative care services; this wish should be respected • *Episodes of deterioration/change in physical condition require a new PCNA

13. Glossary

ALL Acute lymphoblastic leukaemia **is** a type of leukaemia (blood cancer) that comes on quickly and is fast growing. In acute lymphoblastic leukaemia, there are too many lymphoblasts (immature white blood cells) in the blood and bone marrow (NCI,2021).

AYA Adolescent and young adult. The international age ranges for AYA cancer care are diverse (Appendix 5). For the purposes of this document, the age range of 16-24 years denotes a person deemed an adolescent/ young adult.

AYACSN Adolescent Young Adult Cancer Service Network

CHI Children's Health Ireland. Governing body of children's healthcare in Ireland, located across Dublin over 4 sites; Crumlin, Tallaght, Connolly, Temple Street.

CCTU Cancer Clinical Trials Unit

DCC Designated Cancer Centre. A designated cancer centre is a specialist hospital which administers chemotherapy, performs oncological surgeries, and provides radiotherapy when required. Each of the hospital groups within Ireland has at least one designated cancer centre.

MDT Multidisciplinary Team: MDTs consist of practitioners and professionals from healthcare and allied disciplines and sectors that work together to provide holistic, person-centred and coordinated care and support. The composition of MDTs varies depending on delivery models and settings but it may include: GPs, specialist doctors, nurses, physiotherapists, occupational therapists, pharmacists, social workers and, increasingly, representatives of the housing and voluntary sectors (SCIE.2021).

MDM Multidisciplinary Team Meeting: The MDT Meeting involves a group of people from different health care disciplines, which meets together at a given time (whether physically in one place, or by video or tele-conferencing) to discuss a given patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient. (Department of Health and Social Care, 2004).

NCS National Cancer Strategy 2017-2026

NCH National Children's Hospital

NCCS National Children's Cancer Services, based at CHI, Crumlin.

NCCP The National Cancer Control Programme.

The National Cancer Strategy 2017-2026. This document produced by the NCCP for the strategic planning of cancer care in Ireland through the period 2017-2026.

TYA Teenage and Young Adult.

National Cancer
Control Programme

Framework-NCCP-COM-076
Email: info@hseprint.ie Ref: Framework Care Support 04/22