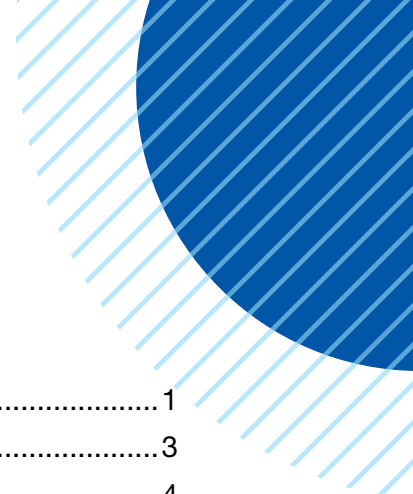




# NCCCP Child, Adolescent and Young Adult (CAYA) Cancer Annual Report

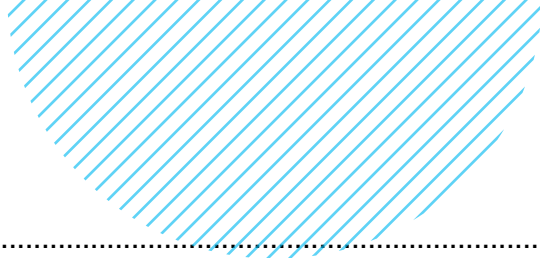
## 2021





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## 2. Foreword

Child, adolescent and young adult (CAYA) cancer patients constitute a unique group that deserve special attention. Studies conducted over the past three decades have demonstrated substantial increases in overall survival rates for paediatric cancers. However, cancer survival rates vary in some AYA groups. Understanding the reasons for heterogeneity in cancer survival rates has become a major focus for the oncology community.

CAYAs with cancer are a diverse group that are defined not simply by their age and distinct biology of the underlying cancer types, but also arising from the challenges that they face in seeking appropriate access to oncology care, inclusion in clinical trials, short and long-term health and psychosocial issues. Major issues for CAYAs 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, the unique and distinct needs of the CAYA 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 CAYA 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, knowledge and expertise. The group comprises of highly motivated, passionate healthcare workers which includes nurses, advanced nurse practitioners, clinical nurse specialists, psychologists, social workers, paediatric and adult oncologists / haemato-oncologists, palliative care physicians, and fertility preservation experts. Importantly, the group also includes members of established patient advocacy and support groups (Irish Cancer Society, Barretstown, Canteen, CanCare4Living and Childhood Cancer Foundation), and most importantly, survivors of child and adolescent cancer.

I would like to express my gratitude to the CLG for discussions and presentations over the past two years that have helped to 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]*. The framework succinctly outlines the strategies needed to coordinate state-of-the-art integrated AYA care to be delivered locally where possible, but centrally where necessary to provide separate facilities and specialist care teams for this patient population. When established, the challenge will be to secure the future through education, research and innovation and develop future services. The overall aims of the framework are to improve the standards and quality of cancer care provided to CAYAs and define outcome measures of high-quality care for AYA patients across the proposed CAYA cancer network as outlined in the National Cancer Strategy.

I would especially like to thank Ms Eileen Nolan, Ms Fiona Bonas, Dr Scheryll Alken, Ms Niamh O'Sullivan, Dr Peter McCarthy and the Subgroup leads (Ms Patricia McColgan, Dr Jane Pears, Professor Mary Wingfield, Dr Helen Greally, and Dr Michael Capra) for their help in preparing this report and for generously embracing the task.

**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**

### 3. 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, Assistant National Director (AND), NCCP
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, for AYA Cancer CHI at Crumlin and St James's Hospital, Dublin

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 Mary-Claire Rennick, Director, Childhood Cancer 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
38. Ms. Sally Downing, Client Director, Primary Care Communications Division, HSE

### **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.

## 4. Background

### 4.1 Table 1:

**Age ranges for growth period termed adolescent and young adult (AYA) 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 Hungary	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

### 4.2 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 (Figure 1).

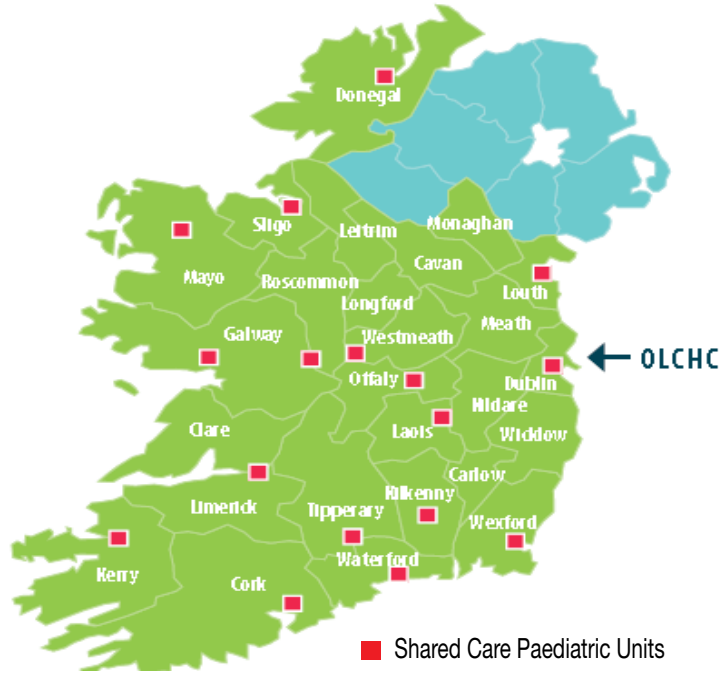
By contrast, adolescents and young adults with cancer between 16 and 24 years + 364 days of age are currently treated across adult cancer services. Adult cancer care is coordinated through 8 designated cancer centres (DCCs), which administer chemotherapy, perform oncological surgeries, and provide radiotherapy 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 MDT working (Figure 2).



**Figure 1:**

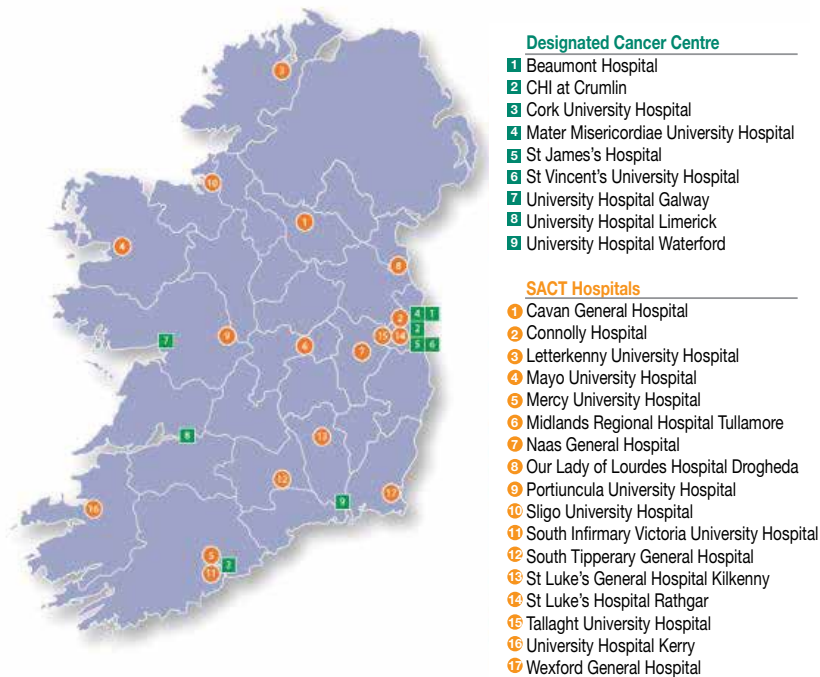
**The National Children’s Cancer Service (NCCS) incorporating the 16 shared care centres**

Figure 10.2 Shared Care Paediatric Units in Ireland



**Figure 2:**

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



## 5. Communications Group

### 5.1 Highlight of achievements to date

- During 2021, a Child, Adolescent, Young Adult Cancer and Survivorship Communications Subgroup committee was established to ensure effective communication and engagement with those impacted by cancer following an updated mapping of all relevant stakeholders.
- The NCCP CAYA Programme disseminated progress using the following platforms:
  - NCCP Twitter Account and other social media platforms.
  - Interviews on National Radio and the National and Medical Press.
  - Health Matters HSE Publication in 2022 (see appendix 2).
- A Communications Workshop was given by Ms Sally Downing, Client Director, Primary Care Communications Division, HSE, to enhance communication with the defined target audience (Children, adolescents, young adults, their families, staff and other stakeholders) about services available and the advances in cancer care (Appendix 3).
- An inaugural CAYAS conference was hosted on 9<sup>th</sup> September 2021. This event was a collaboration between CanCare4living, CanTeen Ireland, Childhood Cancer foundation Ireland and the Irish Cancer Society and was deemed a great success.
  - The CAYAS Conference provided educational updates and an opportunity to engage with CAYA cancer patients, survivors and their support networks. It is hoped that such events will continue to be held in the future, as they provide valuable opportunities for these communities to forge partnerships for co-design and service development.

### 5.2 Work in progress

- Will continue to publicise the on-going work undertaken within the CAYA health sector.
  - A formal launch of the “Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland” will be published in January 2022. An official communications strategy will be agreed prior to the launch of this report.
  - The Communications Subgroup will also help identify any current unmet needs of patients and forward these through the appropriate channels.
  - Will continue to provide signposting of services available

### 5.3 Development opportunities from 2022-2026

- The CAYA Communications Subgroup plan will serve the CAYA community and support the implementation of the NCCP strategy.
- A second CAYAs Conference in Ireland will take place in September 2022.
- Between 2022-2026, the communication plan will continue to support the NCCP strategy including the definition of Terms of Reference, evaluation of effectiveness and recommendations for future changes.

## 6. Shared Care Subgroup

### 6.1 Highlight of achievements to date

- The implementation of Healthlink software has enabled the sharing of laboratory results and shared electronic access between two sites CHI Crumlin and Our Lady of Lourdes Hospital, Drogheda.
- The following site visits were undertaken to potential “spoke” hospitals for AYA care to examine facilities and resources.
  - Cork University Hospital
  - University Hospital Galway
  - Mercy University Hospital Cork
  - University Hospital Waterford
- Expressions of Interest have been sought from sites interested in becoming formal AYA designated centres.
- During 2021, quarterly virtual clinical updates to existing Paediatric Shared Care Centres were held to promote training and development.
- A quarterly Shared Care Newsletter updating advances in the field was sent to the 16 Paediatric Shared Care Centres.
- A collaboration of the relevant hospitals with the Childhood Cancer Foundation was initiated to support the implementation of ward enhancements in Paediatric Shared Care Centres settings.
  - To date: Nine clinical rooms (including treatment and inpatient rooms) have been updated.
- A survey of Paediatric Shared Care Centres, at all relevant hospitals was undertaken to evaluate availability of allied health care staff.



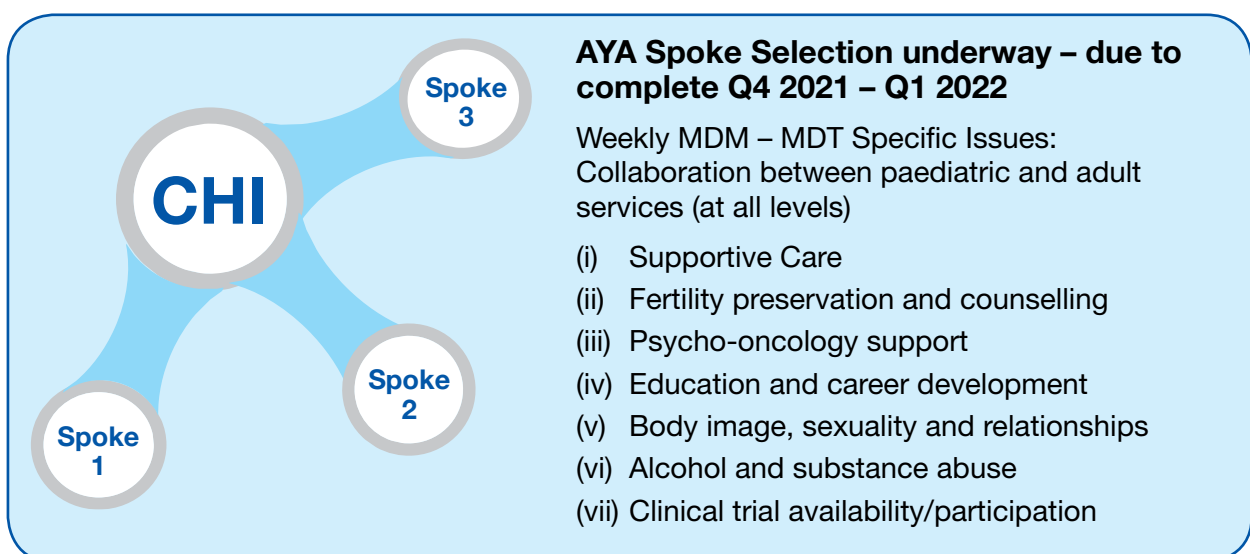
**Figure 3:**  
**Photo of new updated clinical room in Our Lady of Lourdes Hospital.**

## 6.2 Work in progress

- To plan the delivery of services in the relevant hospitals, an assessment of the available staff and anticipated training needs for dedicated paediatric oncology/malignant haematology Shared Care Consultants will be undertaken.
- An assessment of the opportunities for a dedicated training scheme for paediatric oncology/malignant haematology will also be undertaken.
- The regular Childhood Cancer Foundation webinar series will continue for patients, carers and Healthcare professionals.
- A collaboration with the Irish Cancer Society will continue to develop “Patient Passports”, and “Discharge Summaries” in addition to carer information leaflets and other practical supports.

## 6.3 Development opportunities for 2022-2026

- A further rollout of Healthlink to the remainder of the 16 Shared Care Centres.
- The completion of site visits between 2022-2026 will be undertaken.
- Confirmation of “spoke” AYA hospitals will be decided in 2022.
- Educational site visits (in person or virtually) will continue in order to improve on-going communication with the Shared Care Centres.
- Childhood cancer nursing educational opportunities will be fostered.
- The establishment of a dedicated AYA Cancer Service Network (AYACSN) involving three of the eight designated cancer centres will function on a hub and spoke model (Figure 4). CHI at Crumlin (and, when it opens as the new National Children’s Hospital) will function as the hub with a strong input from dedicated haematologists/oncologists and allied healthcare professionals with an interest in AYA cancer at the three chosen DCCs as spoke centres.



**Figure 4:**  
**The proposed Hub and Spoke Model**

## 7. CAYA Fertility Subgroup

### 7.1 Highlight of achievements to date

- A Fertility Model of Care will be developed and implemented. The sperm and oocyte cryopreservation program at Merrion Fertility Clinic (MFC) for AYA patients attending CHI has been working effectively. Currently, 23 samples have been stored for boys, and 8 samples have been stored for girls.
- An assessment clinic has been established for female cancer survivors aged 16 to 24 years.
- An Information leaflet on Fertility Preservation has been drafted.
- The Merrion Fertility Clinic team visited the Future Fertility Trust in Oxford, in September 2021.
- The educational sessions delivered by the CAYA Fertility Subgroup included:
  - A presentation given by Dr Lucia Hartigan on “Fertility preservation and contraception (before/ during/after treatment)’ as part of the RCPI Course - The Acute Medicine Series: Hot Topics in AYA Haemato-Oncology, in August 2021.
  - An information session on fertility and cancer was hosted by Dr Lucia Hartigan and Dr Scheryll Alken at the CAYAS Conference in September 2021.
  - A presentation on Ireland’s CAYA Fertility Preservation program was delivered by Prof. Wingfield to ESHRE Campus Workshop on Reproductive Tissue Engineering and Fertility Preservation in September 2021.

### 7.2 Work in progress

- The development of National Guidelines on Fertility Preservation for CAYA with cancer and survivors of cancer treatment.
- The completion of patient information leaflets for the AYA cohort.
- The development of an ovarian and testicular tissue cryopreservation service for pre-pubertal children in Ireland.

### 7.3 Development opportunities for 2022-2026

- The development of National Guidelines on Fertility Preservation for CAYA with cancer and survivors.
- Further refinement of patient information leaflets in response to feedback for the AYA cohort.
- Further enhancements to the ovarian and testicular tissue cryopreservation service for pre-pubertal children in Ireland.

## 8. CAYA Psycho-Oncology Subgroup

### 8.1 Highlight of achievements to date

- The first two meetings of the National CAYA Psycho-Oncology Model of Care working group were held in October and December 2021.
- Several areas of clinical need have been explored and will be undertaken in 2022.
- A National Paediatric Psycho-Oncology Service (NPPOS), within the National Children's Cancer Service (NCCS), located in Children's Health Ireland at Crumlin, has been developed, under the clinical lead of Dr Chiara Besani and will be launched on the 15<sup>th</sup> of February 2022 - International Childhood Cancer Day.

### 8.2 Work in progress

- The National CAYA Psycho-Oncology working group will continue to develop a Model of Care during 2022, which should be completed by Quarter 3 2022 and submitted to NCCP Executive Team for approval and endorsement.
- The first annual Paediatric Psycho-Oncology training day (workshop format) for healthcare professionals is in development. The programme will be launched on the 15<sup>th</sup> of February 2022 and will run in May 2022.
- Specific areas for further improvement in 2022 will include:
  - The establishment of a Psycho-Oncology Model of Care for the CAYA National Service in CHI Crumlin.
  - The Neuropsychological needs of patients in Psycho-Oncology require further evaluation and refinement.
  - In addition, the Psychiatric needs of patients in Psycho-Oncology will also be evaluated.
  - A Shared Care Model of Care will be developed for use in Acute Hospitals and Shared Care Centres. This will include Palliative and End-of-Life Care; the coordination of patient transition to survivorship care; community and charity support.

### 8.3 Development opportunities for 2022-2026

- Dr Greally and Dr Besani will continue to work within the CAYA implementation group to help develop integrated care for CAYAs, where the psycho-oncology needs of patients and families are recognised as an essential part of holistic care.
- Further opportunities for training will be explored in consultation with Shared Care Centres, community services and schools.
- Research on the Psycho-Oncology needs of CAYA cancer patients across different hospital sites will commence.

## 9. Palliative Care Subgroup

### 9.1 Highlight of achievements to date

- Two successful candidates were awarded RCPI fellowships, one in Paediatric Palliative Care and a second in AYA Palliative Medicine.
- The continued support and liaison with the HSE, to help implement Clinical Governance and operational structures which underpin the Model of Care for Children with Life Limiting Conditions.
- The continued support and liaison with the HSE, to help implement operational structures in paediatric end of life care settings within the community, consistent with best practice.

### 9.2 Work in progress

- The development of KPIs relevant to the CAYA population; in conjunction with the HSE Palliative Care Program.
- The continued support in the development of a business case and job description for additional CAYA consultants in palliative medicine as part of the HSE Palliative Care Program.
- The Palliative Care Subgroup will be consulted about the NCCP Model of Care for Paediatric Psycho-Oncology.

### 9.3 Development opportunities for 2022-2026

- The Palliative Care Subgroup will progress funding applications and continue service development in delivering palliative medicine to the CAYA population.
- The Palliative Care Subgroup will continue to support the HSE Clinical Governance and operational structures which underpin the Model of Care for Children with Life Limiting Conditions.
- The Palliative Care Subgroup will continue to develop end of life care provided within community care settings in Ireland.

## 10. CAYA Survivorship Subgroup

### 10.1 Highlight of achievements to date

- The CAYA handheld Medical Summary/Survivorship Passport Template has been agreed. A paper copy will be made available for all CAYA survivors graduating to adult care or being discharged from childhood cancer services.
- The development of the CAYA Cancer Survivorship Database is at an advanced stage, and will be hosted by CHI Crumlin on the REDCap platform. Ethics approval will be sought by CHI to host the platform and to hold confidential medical records. An IT Specialist Engineer will be employed at CHI Crumlin to support the database.
- A needs assessment qualitative study, (Patient, Parents/Guardian/Carer, Health care Provider Perspectives) was submitted to Ethics committee at CHI Crumlin and has been granted provisional approval.

### 10.2 Work in progress

- The implementation of a handheld Medical Summary/Patient Passport for survivors is ongoing.
- The Ethics Committee amendment to the survivorship database project is to be submitted in January 2022. The amendment will reflect CHI hosting the database. Entry of data to database will commence in February 2022, to enable the analysis of a 5-year cohort of patients (2012-2016) retrospectively.
- The CAYA Survivorship Needs Assessment project will focus on the needs, priorities and preferences of patients, carers, patient families and service providers. This has been submitted to the CHI Ethics Committee for final approval.
- The recruitment of participants to the “Needs Assessment” project will commence in January 2022.

### 10.3 Development opportunities for 2022-2026

- The Handheld Medical Summary/Survivorship Passport will be made available electronically prospectively. It will aim to integrate the Survivorship Patient Passport into NCIS if possible.
- The development and progression of survivorship services across the CAYA spectrum, integrating existing services and developing areas that are currently underserved.



## 11. Cancer Clinical Trials

### 11.1 Highlight of achievement to date

- The National Children's Cancer Service (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) and is focused on multi-site, international academic phase III trials.
- In 2022, 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). Children's Health Ireland Cancer Trials Group, **(The 'Award')**, 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.

### 11.2 Work in progress

- 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.

### 11.3 Development opportunities for 2022-2026

- The 3 AYA units (16 – 24 years) and CHI (0 – 20 years) 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 regular 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 Q1 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 AYA Cancer Service Network.

## 12. Research and Innovation

### 12.1 Highlight of achievement to date

- The AYA team continue to develop collaborative links across institutions and health care domains. To date, they have secured research funding for several projects and applications continue.

**Table 2:**  
**AYA Team Research Projects**

Grant Title	Awarding Body	Lead Applicant and organisation	Status
Underrepresented communities scoping award 2021	Irish Cancer Society	Professor Dr. Suzanne Guerin- UCD	Approved, commences January 2022
Irish Cancer Society Cancer Research Engagement Award	Irish Cancer Society	Professor Dr. Suzanne Guerin- UCD	Approved 2021
Seed Funding Grant Application	CHI Research & Innovation Office	Ms Niamh O'Sullivan	Approved 2021- commencing Q1 2022

- The AYA cancer team also conducted a survey of young people with cancer. This survey was launched at the inaugural CAYAs conference, and ran from 9<sup>th</sup> September 2021 - 30<sup>th</sup> November 2021. It focused on the experiences of young people with a cancer diagnosis when aged 0-24 years in Ireland (Appendix 4).
- The results are currently undergoing analysis, and findings will be disseminated in Q2 2022.

### 12.2 Work in progress

- A pipeline is being established that will enable whole genome sequencing and gene expression analysis for children and AYA (CAYA) cancer patients to be 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 '**Award**' will also leverage its partnerships to identify new research opportunities on an all island basis. For example, genomic diagnostics and research will be made available to all paediatric and AYA cancer patients in Ireland.

### 12.3 Development opportunities for 2022-2026

- The aims of the 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.

## 13. CAYA Education update

### 13.1 Highlight of achievements to date

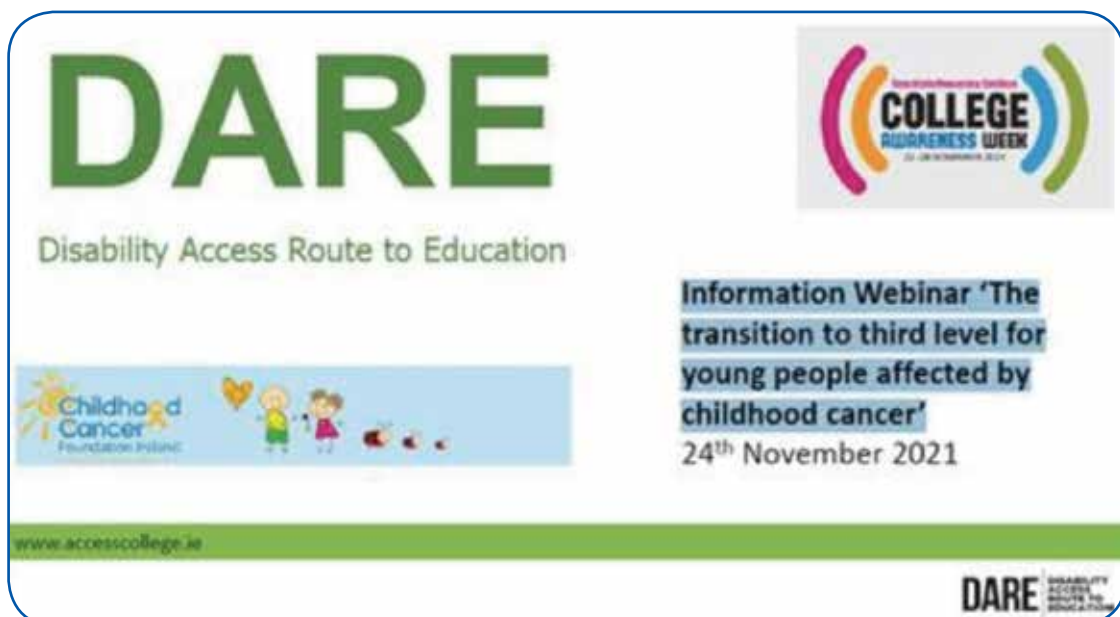
- The NCCP Report National Cancer Survivorship Needs Assessment: Survivorship after Childhood Cancer published in 2018 highlighted how educational challenges were commonly experienced by Childhood Cancer Survivors. Survivors had difficulties keeping up with their peers on return to school both academically and socially, and often experienced memory and cognitive challenges. To view report please go to the following link: <https://tinyurl.com/5n7en5fx>
- The NCCP CAYA Programme presented to the Steering Committee of the Irish Association of Universities on the 12th October 2021. The discussion focused on automatic access to DARE for young people affected by cancer.
- A letter was sent in November to Minister Simon Harris to request automatic access to DARE for young people affected by childhood cancer.
- An information Webinar ‘The transition to third level for young people affected by childhood cancer’ was held on the 24th November 2021.

### 13.2 Work in progress

- To undertake further collaboration with the Irish Association of Universities to ensure automatic entitlement to the DARE programme for CAYA cancer survivors.
- To improve signposting and awareness of resources available among CAYA cancer patients.
- To engage with TUSLA regarding primary and secondary school supports.

### 13.3 Development opportunities for 2022-2026

- The development of a long-term plan to support the educational needs of CAYA cancer survivors.



**Figure 5: DARE Webinar**

## 14. Peer to peer AYA Education

### 14.1 Highlight of achievements to date

- The AYA team have been integral to the successful delivery of ongoing nursing education programmes delivered across the haematology and oncology directorates in St. James's Hospital.
- Ms Niamh O'Sullivan has delivered several teaching sessions which included foundation level knowledge for oncology and haematology nursing staff, and more advanced sessions for postgraduate students undertaking the Graduate Diploma in Cancer Nursing. Postgraduate students included those from paediatric and general nursing backgrounds, some of whom had pre-existing knowledge / training in oncology or haematology specialisms.
- These courses were delivered on St John's ward in CHI at Crumlin by members of the AYA cancer team, and are affiliated with both Trinity College, Dublin and University College Dublin.
- Dr. Scheryll Alken and Dr. Peter McCarthy hosted a webinar with the Royal College of Physicians of Ireland (RCPI) in August 2021. This webinar titled "*Hot Topics in AYA Haemato-oncology*" covered many aspects of AYA cancer care from its distinct biology to some of the unique needs of this age group such as, fertility.
- Dr Scheryll Alken and Ms. Niamh O'Sullivan presented a webinar on AYA cancer for an internal audience at the Irish Cancer Society in December of 2021.
- Dr. Peter McCarthy and Dr. Scheryll Alken published an article in the September 2021 edition of Hospital Professional News Ireland, titled '*Acute Lymphoblastic Leukaemia in the Adolescent & Young Adult*'. This is available at: <https://tinyurl.com/2p8e7zpv> (Appendix 5).

### 14.2 Work in progress

- Ms Niamh O'Sullivan will continue to deliver oncology and haematology foundation and postgraduate training during 2022.
- Dr Scheryll Alken and Dr. Peter McCarthy will deliver education sessions to NCHDs on the topic of AYA cancer and its intricacies.



# Irish Cancer Society

## 15. Irish Cancer Society

### 15.1 Highlight of achievements to date

- The Irish Cancer Society has developed a roadmap outlining specific targets for children's cancer services. This road map seeks to ensure every child, teenager and young adult has access to the appropriate services and supports they require. By increasing access to services and supports, it is hoped that the burden of disease will be reduced and patient quality of life increased.

### 15.2 Work in progress

- To enhance, develop and expand innovative support services available to children, adolescents and young adults (CAYA) affected by cancer, in line with the Irish Cancer Society 2020-2025 strategy.
- The successful appointment of a Policy Officer, and a new Head of Children, Adolescent and Young Adults within the Irish Cancer Society.

### 15.3 Development opportunities for 2022-2026

- Further collaboration with CAYA stakeholders to ensure a comprehensive survivorship service is delivered, informed by robust research.
- Continue to develop future initiatives for the provision of lifesaving treatment for children, and ensure this does not come at the cost of their life time dreams.

# BARRETSTOWN

a seriousfun camp

## 16. Barretstown

### 16.1 Highlight of achievements to date

- In November 2021, Barretstown charity piloted its first therapeutic residential program for Adolescents and Young Adults aged 18 to 24 years old. The programme was designed for those living with a serious illness to provide emotional support, and as opportunity for them to cultivate their support networks.
- In 2021 Prof. Owen Smith was appointed Medical Patron to Barretstown ‘Hole in the Wall Gang’ Camp.
- The program was aligned to the Challenge, Success, Reflection, Discovery and Fun Model. Thereby, helping young participants grow in confidence, self-esteem and enhance their independence. Globally this has been recognised as a useful tool amongst families and children, and has now been adopted to the adolescent and young adult cohort.



**Figure 6:**  
**Barretstown AYA 2021 Group**

- The Concepts of Transition were included in the program, as identified in research undertaken by the NCCP. These included: Independent Health Behaviour, Psychosocial Needs, Health & Lifestyle, Education, Vocation and Self Advocacy.
- The pilot programme provided an opportunity for peer-to-peer interactions through activities, aligned with Barretstown’s existing model of Therapeutic Recreation, and is part of the organisation’s philosophy.
- Guest speakers were invited to present useful insights regarding mindfulness, and provide informative sessions regarding career development and health.
- Participant feedback regarding the programme was sought, and will be incorporated into the planning of future events.

### 16.2 Work in progress

- During 2022 Barretstown’s will seek to expand and develop the Adolescent and Young Adult Program. The organisations will seek to host three further programs in May, August, and November.



## 17. CanTeen Ireland

### 17.1 Highlight of achievements to date

- CanTeen Ireland has provided valuable contributions to the ongoing work of the NCCP through its membership of the Child, Adolescents/Young Adults (CAYA) groups including the: Clinical Leads Group, Fertility, Survivorship, and Psycho Oncology.
- Throughout 2021, CanTeen has continued to support its members online, and via telephone including text support.
- A variety of workshops were held on a regular basis and bimonthly including music, art, mindfulness, resilience, and makeup workshops such as, “Look Good Feel Better”.
- A weekly online gaming meeting via Discord was held and provided members with the opportunity to chat and connect with each other.
- In November 2021 we commenced our exercise programme in collaboration with “ExWell Medical”. This was held both online and in person on Saturdays. This is currently running as a 12-week pilot programme, and is the first exercise programme for young people with cancer in Ireland. The course comprises of two, one-hour exercise sessions per week, and has been deemed a great success.

### 17.2 Work in progress

- To continue to collaborate with “ExWell Medical” and hold the 12-week exercise program for members throughout 2022.

## 18. Childhood Cancer Foundation Ireland

### 18.1 Highlight of achievements to date

- Childhood Cancer Foundation Ireland has provided valuable contributions to the ongoing work of the NCCP through its membership of the Child Adolescents/Young Adults (CAYA) groups including the: Clinical Leads Group Shared Care, Survivorship and Psycho-Oncology.
- The Childhood Cancer Foundation Ireland has continued to work as a voluntary charity founded and led by parents of children and young people with cancer.
- In 2021, the Childhood Cancer Foundation Ireland sought to:
  - Raise awareness of child, adolescent and young adult cancers via the “Light It Up Gold Campaign” and the “Gold Ribbon Conversations Podcast Series.
  - Provide continued support for the Parent Peer to Peer Support Network in collaboration with Irish Cancer Society, CanTeen Ireland and CanCare4Living
  - Fund additional services such as:
    - Emotional support for CAYAs and their families, through “Beads of Courage
    - Play Services
    - Treatment room upgrades and equipment for Shared Care Hospitals.





## 19. CanCare4Living

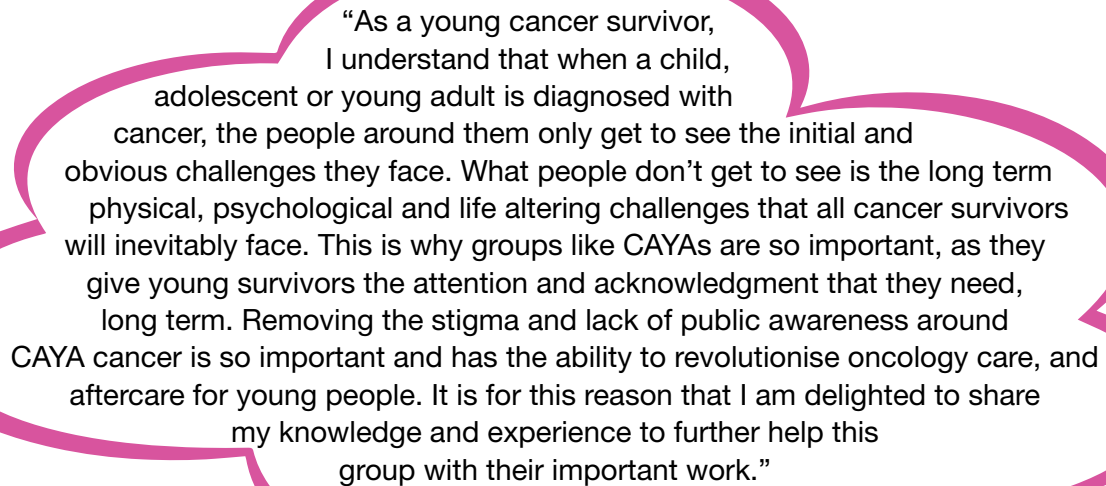
### 19.1 Highlight of achievements to date

- CanCare4Living has continued to function as a volunteer advocacy group for children, adolescents, young adults (CAYA) who have had cancer, and their families, to achieve social and health justice.
- CanCare4Living has provided valuable contributions to the ongoing work of the NCCP through its membership of the following CAYA groups: Fertility, Survivorship and Psycho Oncology.
- CanCare4Living has continued to collaborate with allied cancer organisations such as:
  - The Irish Cancer Society, as part of a stakeholders group assisting in the delivery of a CAYA Strategy
  - Childhood Cancer International (CCI) as part of the Survivorship Strategy Pillar
  - PanCare Network



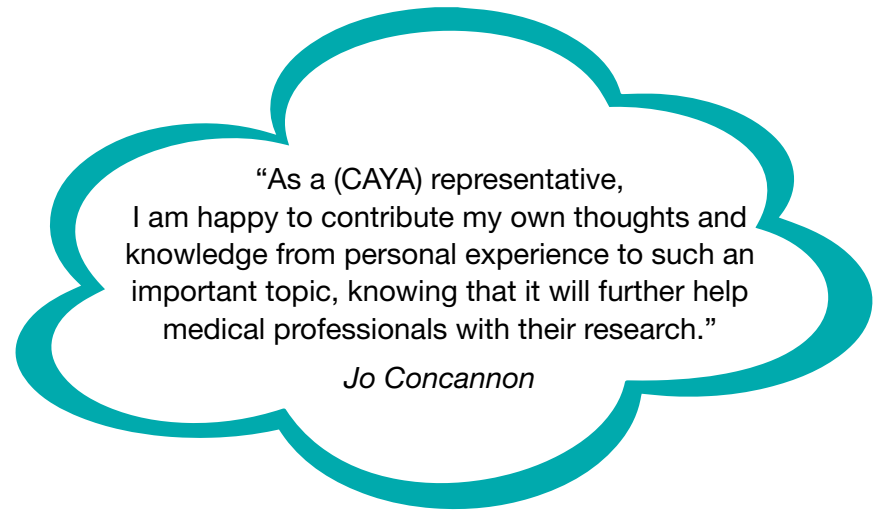
## 20. CAYA Patient perspective

### 20.1 Individual patient feedback



“As a young cancer survivor, I understand that when a child, adolescent or young adult is diagnosed with cancer, the people around them only get to see the initial and obvious challenges they face. What people don’t get to see is the long term physical, psychological and life altering challenges that all cancer survivors will inevitably face. This is why groups like CAYAs are so important, as they give young survivors the attention and acknowledgment that they need, long term. Removing the stigma and lack of public awareness around CAYA cancer is so important and has the ability to revolutionise oncology care, and aftercare for young people. It is for this reason that I am delighted to share my knowledge and experience to further help this group with their important work.”

*Ellen Merrins*



“As a (CAYA) representative, I am happy to contribute my own thoughts and knowledge from personal experience to such an important topic, knowing that it will further help medical professionals with their research.”

*Jo Concannon*

## 21. Appendix 1

### 21.1 Active Subgroup members

#### Communication Subgroup

Communication Subgroup Membership	
Ms Patricia McColgan	NCCP CAYA Communications Board Meeting Chair, Chair & Co-founder, CanCare4Living
Professor Owen Smith CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI, Crumlin
Dr Scheryll Alken	Consultant in AYA Cancer, CAYA Programme, CHI at Crumlin & St James's Hospital
Ms Dee Ahern	CEO, Barretstown
Ms Eileen Nolan	Programme Manager Urological Cancers, Children, Adolescents/Young Adults (CAYA) Cancers, and GP E-Referral Systems NCCP
Dr Peter McCarthy	Clinical Research Fellow, Paediatric Haematology CHI Crumlin and UCD Dublin
Ms Niamh O'Sullivan	Assistant Director of Nursing, for AYA Cancer CHI at Crumlin
Ms Elaine Smyth	Children's Cancer Coordinator, Irish Cancer Society
Ms Mary-Claire Rennick	Director, Childhood Cancer Ireland
Ms Sally Downing	Client Director, Primary Care Communications Division, HSE
Dr Chiara Besani	Psycho-oncology Lead, National Children's Cancer Services (NCCS), OLHSC
Ms Ellen Merrins	Patient perspective, and Cancer Survivor

## Shared Care Subgroup

Shared Care Membership	
Dr Jane Pears	Chair NCCP CAYA Shared Care Group, Consultant Medical Oncologist, CHI at Crumlin
Professor Owen Smith CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI at Crumlin
Ms Eileen Nolan	Programme Manager Urological Cancers, Children, Adolescents/Young Adults (CAYA) Cancers, and GP E-Referral Systems NCCP
Ms Fiona O'Loughlin	Shared Care Manager, Haematology Oncology Unit, CHI at Crumlin
Dr Clodagh Ryan	Consultant Haematologist, Mercy University Hospital, Cork
Ms Anne Matthews	CNM3 Paediatrics, University Hospital Galway
Dr Orla Walsh	Consultant Paediatrician with s.i. Adolescent Medicine, CHI at Temple Street
Ms Mary-Claire Rennick	Director, Childhood Cancer Ireland
Ms Elaine Smyth	Children's Cancer Coordinator, Irish Cancer Society
Dr Scheryll Alken	Consultant in AYA Cancer, CAYA Programme, CHI at Crumlin & St James's Hospital
Ms Connie Crehan	Paediatric Nurse Specialist, Our Lady of Lourdes Hospital, Drogheda
Dr Peter McCarthy	Clinical Research Fellow, Paediatric Haematology CHI Crumlin and UCD Dublin
Dr Chiara Besani	Psycho-oncology Lead, National Children's Cancer Services (NCCS), OLHSC
Ms Niamh O'Sullivan	Assistant Director of Nursing, for AYA Cancer CHI at Crumlin
Dr Zanusz Krawczyk	Consultant Haematologist, Galway University Hospital
Ms Lorna Storey	Advanced Nurse Practitioner, Haemato-Oncology, CHI at Crumlin
Dr Karen O'Neill	Patient Representative, Paediatric Specialist Registrar
Ms Amanda Peoples	St Bernadette's CNM2 Paediatrics, University Hospital Galway
Ms Anne Marie Furlong	Ambulatory Care, CNM2 Paediatrics, University Hospital Galway
Prof. Imelda Coyne	Professor of Nursing, Trinity College Dublin (TCD)

## Fertility Sub-group

Fertility Membership	
Professor Owen Smith, CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI at Crumlin
Professor Mary Wingfield	Clinical Director, Merrion Fertility Clinic, Consultant Obstetrician Gynaecologist, National Maternity Hospital,
Ms Niamh O’Sullivan	Assistant Director of Nursing, for AYA Cancer CHI at Crumlin
Ms Caroline Rooney	Candidate Advanced Nurse Practitioner (ANP) Haematology/ Oncology, CHI at Crumlin
Dr Karen O’Neill	Patient Representative, Paediatric Senior House Officer (SHO)
Dr Lucia Hartigan	Consultant Obstetrician and Gynaecologist, National Maternity Hospital, Holles Street and Merrion Fertility Clinic
Dr Scheryll Alken	Consultant in AYA Cancer, CAYA Programme, CHI at Crumlin & St James’s Hospital
Dr Maebh Horan	Clinical Fellow and Doctorate of Medicine (MD), Merrion Fertility Unit
Ms Helen Greally	National Clinical Programme Lead in Psycho-Oncology, NCCP
Ms Venita Broderick	Consultant Gynaecologist, Merrion Fertility Unit
Dr Louise Glover	PhD – Clinical Research Co-ordinator, Merrion Fertility Unit
Dr John Fitzgerald	Quality Manager Haematology Lab/Tissue Establishment/JACIE, Haematology Laboratory, CHI at Crumlin
Dr Karen O’Neill	Patient Representative, Paediatric Specialist Registrar
Dr Rachel Albert	Clinical Research Fellow, Merrion Fertility Clinic
Ms Cathleen Osbourne	Assistant Director Nursing, Cancer Survivorship NCCP
Ms Eileen Nolan	Programme Manager Urological Cancers, Children, Adolescents/ Young Adults (CAYA) Cancers, and GP E-Referral Systems NCCP
Dr Sarah Curry	Consultant Paediatric Oncologist, CHI at Crumlin
Ms Sarah Lyndon	Clinical Nurse Specialist, Merrion Fertility Clinic
Ms Helen Groake	Clinical Nurse Specialist, Merrion Fertility Clinic
Ms Eileen Barrett	Nurse Manager, Merrion Fertility Unit
Ms Sinead Hassett	Consultant Paediatric Surgeon, CHI at Crumlin
Dr Andrea Malone	Consultant Haematologist, CHI at Crumlin
Dr Pamela Evans	Consultant Haematologist, CHI at Crumlin
Ms Grainne O’Toole	Clinical Nurse Specialist Paediatric Haematology, CHI at Crumlin
Ms Elaine Smyth	Children’s Cancer Coordinator, Irish Cancer Society
Ms Evelyn Griffith	CEO, Canteen Ireland
Ms Patricia McColgan	Chair & Co-founder, CanCare4Living

## Psych-oncology subgroup

Psych-oncology Membership	
Dr Helen Greally	National Clinical Programme Lead for Psycho-Oncology, NCCP
Dr Chiara Besani	Principal Clinical Psychologist, National Paediatric Psycho-Oncology Service
Ms Deirdre Love	Project Manager (NCCP)
Professor Owen Smith, CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI at Crumlin
Dr Andrea Malone	Consultant Haematologist, CHI at Crumlin
Dr Scheryll Alken	Consultant in AYA Cancer, CAYA Programme, CHI at Crumlin & St James's Hospital
Ms Kim Murray	Social Worker, CHI Crumlin
Ms Olive O'Neill	Complementary Therapy, CHI at Crumlin
Ms Carol O'Connor	Play Specialist, CHI Crumlin
Ms Teresa Slevin	CNM 3 in Paediatric Haematology/Oncology, CHI at Crumlin
Ms Paula Loughnane	Principal Clinical Specialist, Physiotherapy, CHI at Crumlin
Ms Susan Hurley	Senior Music Therapist, CHI at Crumlin
Ms Niamh Bergin	Senior Occupational Therapist, CHI at Crumlin
Ms Fiona O'Loughlin	Shared Care Manager, Haematology Oncology Unit, CHI at Crumlin
Dr Gillian Fortune	Principal Clinical Neuropsychologist, CHI at Crumlin
Dr Cathy Madigan	Principal Specialist in Paediatric Clinical Neuropsychology, Neurology Department, Children's Health Ireland (CHI) at Temple Street
Dr Sarah O'Doherty	Senior Neuropsychologist, National Rehabilitation Hospital
Dr Amy Cadden	Senior Paediatric Clinical Psychologist,
Dr Natalie Hession	Principle Specialist Clinical Psychologist, St Luke's Oncology Network
Dr Mairead Brennan	Senior Clinical Psychologist, Cancer Care West
Dr Aidan McKiernan	Clinical Psychologist, Laura Lynn Children's Hospice

Psych-oncology Membership	
Dr Nicola Lally	Principle Specialist Clinical Psychologist, Cork University Hospital
Dr Aoife Twohig	Paediatric Psychiatrist, CHI at Crumlin
Dr Siobhan McHale	Consultant Psychiatrist, Beaumont Hospital
Dr John Allen	Fellow in Paediatric Palliative Medicine
Dr Hannah Linane	Fellow in AYA Palliative Medicine
Ms. Mary-Claire Rennick	Director, Childhood Cancer Ireland
Ms Patricia McColgan	Chair & Co-founder, CanCare4Living
Ms Evelyn Griffith	CEO, Canteen Ireland
Ms Marese Damery	Irish Hospice Foundation
Ms Fiona Bonas	Assistant National Director (AND), NCCP
Ms Eileen Nolan	National Programme Manager for CAYA E-Referral & Urological Cancers, and GP E-Referral Systems NCCP
Ms Louise Mullen	NCCP National Lead for Cancer Survivorship
Ms Cathleen Osborne	Assistant Director Nursing, NCCP
Dr Una Kennedy	GP Advisor to NCCP
Ms Dorothy Thomas	Patient Engagement Manager
Dr Hannah Linane	Palliative Care Aspire Fellow, CHI at Template Street, Crumlin
Ms Jane Garland	Clinical Nurse Specialist, CHI at Crumlin

## Palliative Care Subgroup

Palliative Care Membership	
Professor Owen Smith, CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (CAYA) Cancers, Consultant Haematologist, CHI, Crumlin
Ms Annette Hanlon	Assistant Director of Nursing, Laura Lynn Hospice
Ms Eileen Nolan	Programme Manager Urological Cancers, Children, Adolescents/Young Adults (CAYA) Cancers, and GP E-Referral Systems NCCP
Ms Niamh O’Sullivan	Assistant Director of Nursing, for AYA Cancer CHI at Crumlin
Ms Elaine Smyth	Children’s Cancer Coordinator, Irish Cancer Society
Ms Sheilagh Reaper-Reynolds	Strategy and Planning Lead for Palliative Care, HSE
Ms Mary-Claire Rennick	Director, Childhood Cancer Ireland
Ms Liz O Donoghue	Clinical Nurse Specialist, Palliative Care, CHI at Crumlin
Dr Marie Twomey	Consultant in Palliative Care, CHI at Crumlin
Dr Maeve O’Reilly	Palliative Care Consultant, CHI at Crumlin
Dr Scheryll Alken	Consultant in AYA Cancer, CAYA Programme, CHI at Crumlin & St James’s Hospital
Dr Chiara Besani	Psycho-oncology Lead, National Children’s Cancer Services (NCCS), OLHSC
Ms Alison Cashell	Children’s Nurse Coordinator (CNC), Dublin, Kildare and Wicklow
Dr Norma O’Leary	Palliative Care Consultant, St James’s Hospital
Dr Mary Devins	Palliative Care Consultant, CHI at Crumlin
Dr Hannah Linane	Palliative Care Aspire Fellow, CHI at Temple Street, Crumlin
Ms Jane Garland	Clinical Nurse Specialist, CHI at Crumlin



## Survivorship Subgroup

Survivorship Subgroup Membership	
Dr Michael Capra	Consultant Medical Oncologist, CHI at Crumlin
Dr Katherine Gavin	Project Manager Childhood Cancer Survivorship Project, CHI at Crumlin
Professor Owen Smith CBE	NCCP National Clinical Lead for Children and Adolescent/Young Adult (AYA) Cancers, Consultant Haematologist, CHI at Crumlin
Dr Scheryll Alken	Consultant in AYA Cancer, St James's Hospital & CHI at Crumlin
Ms Niamh O'Sullivan	Assistant Director of Nursing, for AYA Cancer CHI at Crumlin
Dr Helen Greally	Chartered Psychologist, National Clinical Lead in Psycho-Oncology, NCCP
Ms Evelyn Griffith	CEO, Canteen Ireland
Ms Bernie O Loughlin	Cancer Survivorship Manager, NCCP
Dr Noelle Cullinan	Consultant Paediatric Oncologist, CHI at Crumlin
Ms Fiona Bonas	Assistant National Director, NCCP
Ms Frieda Clinton	Advanced Nurse Practitioner (ANP) Paediatric Oncology CHI at Crumlin
Ms Cathleen Osborne	Assistant Director of Nursing Cancer Survivorship, NCCP
Ms Eileen Nolan	National Programme Manager for AYA E-Referral & Urological Cancers, and GP E-Referral Systems NCCP
Ms Patricia McColgan	Chair and Co-founder CancerCare4Living
Ms MaryClaire Rennick	Director, Childhood Cancer Foundation
Ms Louise Mullen	Cancer Survivorship Manager, NCCP
Ms Elaine Smyth	Children's Cancer Coordinator, Irish Cancer Society
Ms Chiara Besani	Psychologist, Psycho-Oncology, CHI at Crumlin
Dr Una Kennedy	GP Advisor, NCCP

## 22. Appendix 2:

### 22.1 Health Matters Article “Young Adult Cancer Care; Are we there yet?”

# ADOLESCENT, YOUNG ADULT CANCER CARE ARE WE THERE YET?

National Cancer Control Programme appoints new Clinical Lead

**E**ach year some 400 – 450 people under the age of 25 are diagnosed with cancer in Ireland. There is almost an equal split between the children (0-15 years) and AYA (16 – 24 years) group. While studies have shown that paediatric and older adult cancers have seen a large increase in survival rates, the same cannot be said for some specific adolescent, young adult (AYA) cancers. AYAs with cancer are a diverse group and face many challenges. These challenges include access to age-appropriate oncological care and representation in clinical trials. They also face short and long term health and psychosocial issues. These issues can include fertility considerations, transition to survivorship care and psychosocial support. Difficulties following a treatment plan can often be a challenge for this group.

#### National Cancer Strategy

The National Cancer Strategy [2017 – 2026] recognises the unique and distinct needs of AYA cancer patients in Ireland. It sets out specific recommendations to address this health disparity:

- **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 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



Professor Owen Smith

#### Progress

The National Cancer Control Programme (NCCP) appointed Professor Owen Smith as the National Clinical Lead for Children and Adolescent/Young Adult Cancers in early 2019. He is a Professor of Paediatric and Adolescent Medicine at University College Dublin. He is also a Consultant Paediatric Haematologist at Children’s Health Ireland at Crumlin and Chief Academic Lead to the Children Hospital Group.

Following his appointment, Professor Smith and colleagues from the NCCP convened the Children, Adolescents and Young Adult Clinical Leads Group. This group focuses on the specific needs and risks of AYA cancer patients. The group’s aim is to improve the care and outcomes for this group over the lifetime of the Strategy. It meets on a regular basis and continues to give of their time, knowledge and expertise and consists of healthcare workers, patient advocacy and support groups. Perhaps most importantly, the group includes survivors of child and adolescent cancer.

Speaking about the next steps, Prof Smith said, “Treating AYAs with cancer, is very different from treating cancer in AYAs. Adolescents and young adults undergoing cancer treatment have unique needs that are complex. The NCCP plans to fully implement the recommendations of the strategy. This includes creating a state-of-the-art integrated AYA cancer care programme to be delivered locally when possible but centralised when necessary, by providing separate facilities and specialist care teams in the new Children’s Hospital and in a number of the eight designated cancer centres around the country. The ultimate aim being is to improve the standards and quality of cancer care provided to AYAs.”



*“Treating AYAs with cancer, is very different from treating cancer in AYAs. Adolescents and young adults undergoing cancer treatment have unique needs that are complex.”*

## 23. Appendix 3:

### 23.1 Stakeholders for Children, Adolescent and Young Peoples (CAYA) Cancer



## 24. Appendix 4.

### 24.1 Poster advertisement for CAYA survey

**We need you!**

Calling all young people with cancer in Ireland

**Are you:**

- Currently aged over 16 years?
- AND were diagnosed with cancer between the ages of 0 and 24 years?

Would you like to tell us about your experience of cancer care in Ireland to help inform the development of services specifically for young people with cancer in Ireland?

To find out more:

Scan:  
The QR Code with your phone

Email:  
cayas\_survey2021@protonmail.com

**The National Children's Cancer Service**

## 25. Appendix 5.

### 25.1 Title page of article from Hospital Professional News Ireland

#### 66 Childhood Cancer

# Acute Lymphoblastic Leukaemia in the Adolescent & Young Adult

Written by Dr Peter McCarthy<sup>1,2</sup>, Clinical Research Fellow and Dr Scheryll Aiken<sup>1,3</sup>, Consultant in Adolescent and Young Adult Cancer, Children's Hospital Crumlin with thanks to Professor Owen Smith<sup>1,2</sup>, Professor of Paediatric & Adolescent Medicine, UCD



- 1: National Children's Cancer Service, Children's Health Ireland at Crumlin
- 2: Systems Biology Ireland, School of Medicine, University College Dublin
- 3: Department of Medical Oncology, St. James's Hospital

Dr Peter McCarthy,  
Clinical Research Fellow

Dr Scheryll Aiken,  
Consultant in Adolescent and  
Young Adult Oncology,  
Children's Hospital Crumlin



Adolescent and young adult (AYA) patients with acute lymphoblastic leukaemia (ALL) are increasingly recognised as a unique population with specific characteristics and needs. Traditionally AYA patients with ALL had worse outcomes compared to their paediatric counterparts. Mounting evidence has shown the benefit of paediatric or paediatric-inspired treatment approaches in dramatically improving outcomes. These advances are underpinned by increasing knowledge of the underlying biology of the disease and improved access to specialised age-appropriate supportive care. In addition to their unique disease biology, these patients also have unique physical, psychosocial, and supportive care needs.

#### Background

According to the World Health Organisation definition, adolescents are individuals aged 10 to 19 years, with age ranges adopted for adolescent and young adult age ranges varying across the world – in the United States from age 15 to 39 years and more commonly across Europe to be until 29 years. In Ireland, services for AYA cancer patients will include young people aged 15 to 24 years. Such distinctions are not insignificant as they affect

access to treatment centres and potentially treatment protocols.

ALL is a type of cancer that affects the white blood cells. Most cases of the disease develop in children, adolescents, and young adults. There are approximately 5-10 new cases per year in AYA patients in Ireland. It is the most common type of cancer seen in those under 21 years old. It affects slightly more males than females. In most cases, the cause is unknown. Genetic predisposition syndromes include Down syndrome and Li Fraumeni syndrome. Environmental risk factors include prior chemotherapy.

#### Diagnosis and Risk Stratification

Patients often present with non-specific symptoms due to pancytopenia and proliferation of abnormal leukaemia cells (or lymphoblasts). Presenting symptoms and signs include fatigue, easy bruising, increased risk of infection, fever, pallor, and hepatosplenomegaly. Initial investigations include a Full Blood Count (FBC) and blood film examination. An increase in the white blood cell count and the presence of circulating lymphoblasts can be suspicious for the presence of acute leukaemia, and referral to a haematologist

should follow. Bone marrow aspirate and biopsy will be performed to confirm the diagnosis. In addition to the morphological features seen down the microscope (see image 1), further specialised testing is performed. This includes immunophenotyping (a laboratory technique to identify proteins expressed on the surface of the lymphoblast) and cytogenetic/molecular investigations. This determines the subtype and stage of maturation of the ALL (B-cell or T-cell lineage) and the underlying driver mutations. A lumbar puncture is also performed to look for the presence of disease in the Cerebrospinal Fluid (CSF).

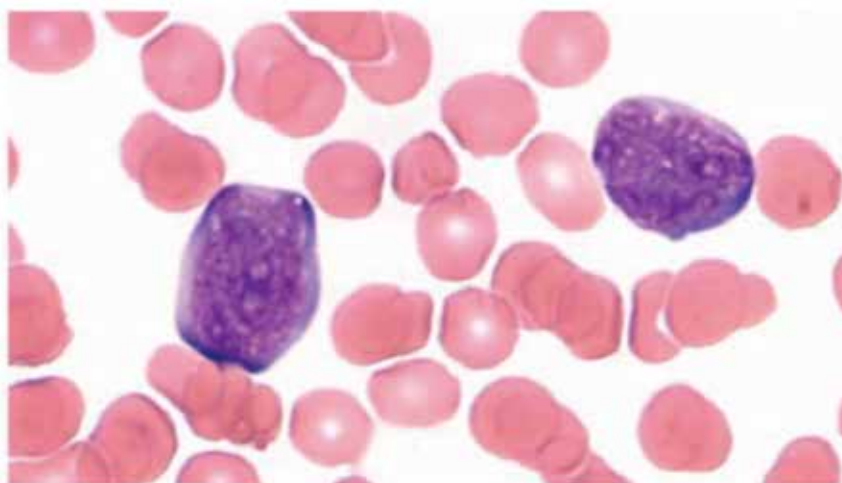


Image 1: A microscopic image of a peripheral blood film from a patient with Acute Lymphoblastic Leukaemia showing two lymphoblasts

## 26. Glossary

**ANP** Advanced Nurse Practitioner

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

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

**CNM:** Clinical Nurse Manager

**CNS:** Clinical Nurse Specialist

**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).

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

**NCCP** The National Cancer Control Programme.

**The award** is an ambitious programme of work, funded by the Health Research Board (HRB) for the next 5 years. The program will seek to further enhance the profile of clinical trials for children and young adolescents and for the AYA population across the Island of Ireland.

**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.

