



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

## 2022



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## 2. Foreword

I am delighted to write the foreword for the National Cancer Control Programme (NCCP) Children Adolescent and Young Adults (CAYA) Annual Report 2022. The National Cancer Strategy 2017-2026 (NCS) provides the vision and recommendations for optimum cancer services for the population of Ireland and builds on the previous National Cancer Strategies, in 1996 and 2006.

One of our key achievements in 2022 was the nomination of three National Adolescent and Young Adult (AYA) Cancer Units, located in St James's Hospital in Dublin, Cork University Hospital and Galway University Hospital. This builds on the designation of Children's Health Ireland as the hub for CAYA cancer care. The implementation of AYA cancer services at these hospitals will enable the delivery of the following two recommendations from the National Cancer Strategy 2017-2026:

- 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 report outlines the progress and achievements in 2022 in the area of AYA cancer care. I would like to express my gratitude to the multi-disciplinary cancer teams, cancer charities, and AYA cancer patients and their families, who have worked tirelessly to develop optimum cancer care for AYA cancer patients.

I would especially like to thank Professor Owen Smith, Fiona Bonas, Eileen Nolan, Peter McCarthy, and Ruth McMenamin for compiling this report and I look forward to further progress being made to meet the particular needs of adolescents and young adults with cancer.

**Professor Risteárd Ó Laoide,**  
National Director,  
National Cancer Control Programme

## 2. Acknowledgements

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

### **NCCP Children's 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. Communications Chair: Ms Patricia McColgan, Chair & Co-founder, CanCare4Living
3. Fertility Chair: Professor Mary Wingfield, Clinical Director, Merrion Fertility Clinic
4. Palliative Care Chair: Dr Fiona McElligott, Palliative Care Consultant, CHI at Temple Street
5. Shared Care Chair: Dr Jane Pears, Consultant Medical Oncologist, CHI at Crumlin
6. Survivorship Chair: Dr Michael Capra, Consultant Medical Oncologist, CHI at Crumlin
7. Ms Amy Nolan, Head of Children Adolescent and Young Adults at Irish Cancer Society.
8. Mr Brice Antao, Paediatric Network Lead, CHI & Consultant Paediatric Surgeon, CHI at Crumlin
9. Ms Cathleen Osborne, Assistant Director of Nursing, Cancer Survivorship, NCCP
10. Dr Chiara Besani, Principal Clinical Psychologist, National Children Cancer Service, CHI, Crumlin
11. Ms Dee Ahearn, CEO, Barretstown
12. Dr Clodagh Ryan, Consultant Paediatric Haematologist, Mercy University Hospital, Cork
13. Ms Eileen Nolan, National Programme Manager for AYA E-Referral & Urological Cancers, NCCP
14. Ms Elaine Smyth, Children's Cancer Coordinator, Irish Cancer Society
15. Dr Eoghan Molloy, AYA Clinical Lead Consultant Haematologist, CUH
16. Ms Evelyn Griffith, Manager, Canteen Ireland
17. Ms Fiona Bonas, Assistant National Director (AND), NCCP
18. Ms Fiona O'Loughlin, Shared Care Manager Haematology / Oncology Unit, CHI at Crumlin
19. Ms Frieda Clinton, Advanced Nurse Practitioner Haematology/Oncology, CHI at Crumlin
20. Dr Helen Greally, Clinical Lead for Psycho Oncology, NCCP
21. Dr Ian Dawkins, Senior Data Analyst, Cancer Intelligence Unit, NCCP
22. Professor Imelda Coyne, Professor of Nursing, Trinity College Dublin
23. Dr Karen O'Neill, Patient Representative, Specialist Registrar, Neonates, Coombe Hospital
24. Dr Katherine Gavin, Project Manager Childhood Cancer Survivorship Project, CHI at Crumlin

25. Dr Larry Bacon, AYA Clinical Lead, Consultant Haematologist, St James's Hospital
26. Ms Louise Mullen, National Lead for Cancer Survivorship, NCCP
27. Ms Mary-Claire Rennick, Director, Childhood Cancer Foundation
28. Professor Michaela Higgins, Consultant Medical Oncologist, St Vincent's University Hospital
29. Dr Niamh Keane, AYA Clinical Lead, Consultant Haematologist, GUH
30. Ms. Niamh O'Sullivan, Assistant Director of Nursing, for AYA Cancer CHI at Crumlin and St James's Hospital, Dublin
31. Dr Noelle Cullinan, Consultant Medical Oncologist, CHI at Crumlin
32. Dr Orla Walsh, Adolescent Medicine and General Paediatrician, Children's Health Ireland at Temple Street Children's University Hospital
33. Dr Patricia Daly, Consultant Radiation Oncologist, St Luke's Hospital
34. Ms Patricia Heckmann, Assistant National Director (AND), Chief Pharmacist, NCCP
35. Dr Peter McCarthy, Locum Consultant in Adolescent & Young Adult Cancer, CHI at Crumlin and StJames's Hospital
36. Ms Rebecca Gorman, Advocacy Officer (Children, Adolescents, Young Adults), Irish Cancer Society
37. Ms Royina Saha, Project Support, NCCP
38. Ms Ruth McMenamin, AYA Programme Manager, CHI at Crumlin
39. Ms. Sally Downing, Client Director, Primary Care Communications Division, HSE
40. Dr Scheryll Alken, Consultant in Adolescent & Young Adult Cancer, CHI at Crumlin and St James's Hospital
41. Dr Zanusz Krawczyk, Consultant Haematologist, University Hospital Galway

**The NCCP CAYA CLG would also like to acknowledge the members of the following Subgroups for their active contribution and participation.**

- Adolescent and Young Adult (AYA) Cancer Unit at CUH Project Board
- Adolescent and Young Adult (AYA) Cancer Unit at GUH Project Board
- Adolescent and Young Adult (AYA) Cancer Unit at SJH Project Board
- Adolescent and Young Adult (AYA) Hangout Clinics
- Adolescent and Young Adult (AYA) MDM Development Project Board
- AYA Cancer Communications Project Board
- AYA Cancer Unit Implementation Project Board
- CAYA Education – Disability Access Route to Education (DARE) Project Board
- CAYA Fertility Project Board
- National Children's Cancer Service at Children's Health Ireland at Crumlin Project Board
- CAYA Palliative Care Project Board
- CAYA Psycho-Oncology Project Board
- CAYA Radiation Oncology
  - CAYA Research and Innovation
  - CAYA Shared Care Project Board
  - CAYA Survivorship Project Board
  - Young Person's Advisory Group (YPAG) at the National Children's Cancer Service



## 4. Executive Summary

Children, adolescent and young adult (CAYA) patients 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, 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 CAYA Cancer 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. The CLG met on a regular basis throughout the Covid pandemic and in the Spring of 2022 produced a Framework document that was officially launched by Minister of Health, Mr. Stephen Donnelly in Farmleigh, Phoenix Park, Dublin on May 19th 2022.

This Framework for the Care and Support of Adolescent and Young Adults (AYA) in Ireland [2021-2026] report succinctly outlines strategies to coordinate state-of-the-art integrated AYA care to be delivered locally when possible but centralised when necessary, by providing separate facilities and specialist care teams for these patients. It then goes on to say that 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 Cancer Strategy [2016-2026].

Significant progress has been made in implementing the Framework throughout 2022. For example, the network construct was completed and consists of Children's Health Ireland and three AYA designated units base at St. James's Hospital, Cork University Hospital and Galway University Hospital. Site visits took place to each hospital in Q3 and Q4 of 2022. The AYA clinical leads for each site have been nominated and the on-boarding of staff has commenced and will continue into 2023.

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

### **Owen Patrick Smith, CBE, Hon FTCD**

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

Professor of Child, Adolescent & Young Adult Oncology, Trinity College Dublin

Professor of Haematology, Trinity College Dublin

Visiting Full Professor, University College Dublin

Consultant Paediatric Haematologist, Children's Health Ireland

Chair, European Society of Paediatric Oncology (SIOPE) - AYA Committee

Academic Lead, Children's Health Ireland

## 5. Update Summary

We are delighted to share progress on the implementation of the NCCP Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland 2021-2026. The NCCP nominated the following three AYA Cancer Units in 2022:

- St James's Hospital
- Cork University Hospital
- Galway University Hospital

The NCCP has also set up an AYA Cancer Unit Implementation Project Board who meet on a regular basis. AYA Cancer Unit Clinical Leads have been appointed in all three AYA Cancer Units.

We were delighted to have the Minister for Health launch of the following NCCP CAYA Reports on the 9th May 2022 in Farmleigh.

- Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland 2021-2026 <https://www.hse.ie/eng/services/publications/framework-for-the-care-and-support-of-adolescent-and-young-adults-in-ireland.pdf>
- NCCP CAYA Annual Report 2021 <https://www.hse.ie/eng/services/publications/child-adolescent-young-adult-cancer-programme-annual-report-2021.pdf>

NCCP have successfully obtained funding via the HSE National Service Plan for CAYA positions nationwide.

In 2023 we hope to commence pilot of national AYA MDM in Q1, as well as the national AYA Key Performance Indicators (KPI). We will continue to work with our key stakeholders to implement the recommendations of the NCCP AYA Framework 2022-2026, and work with the three national AYA Cancer Units to develop age appropriate AYA cancer units.

**Ms Fiona Bonas** Msc BA RN  
Assistant National Director  
National Cancer Control Programme

**Ms Eileen Nolan** R.G.N., R.M., B.B.Sc., M.B.A.  
National Programme Manager for Urological,  
CAYA Cancers & GP E-Referral

## 6. Background

### 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 (Figure 1).

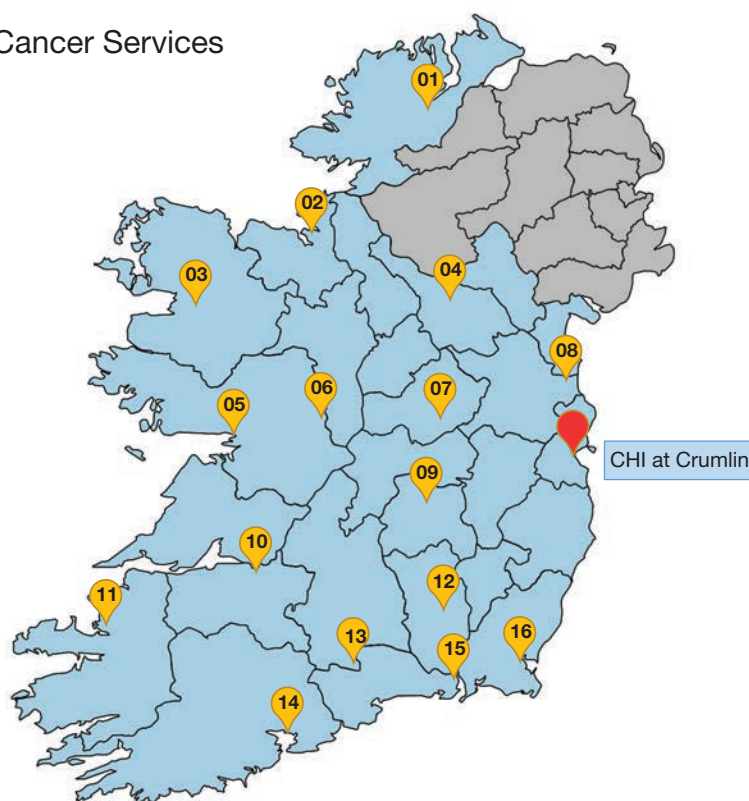
By contrast, adolescents and young adults with cancer between 16 and 24 years + 364 days of age are currently treated across adult cancer services. Adult cancer care is coordinated through 8 designated cancer centres (DCCs), which administer chemotherapy, perform oncological surgeries, and provide radiotherapy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

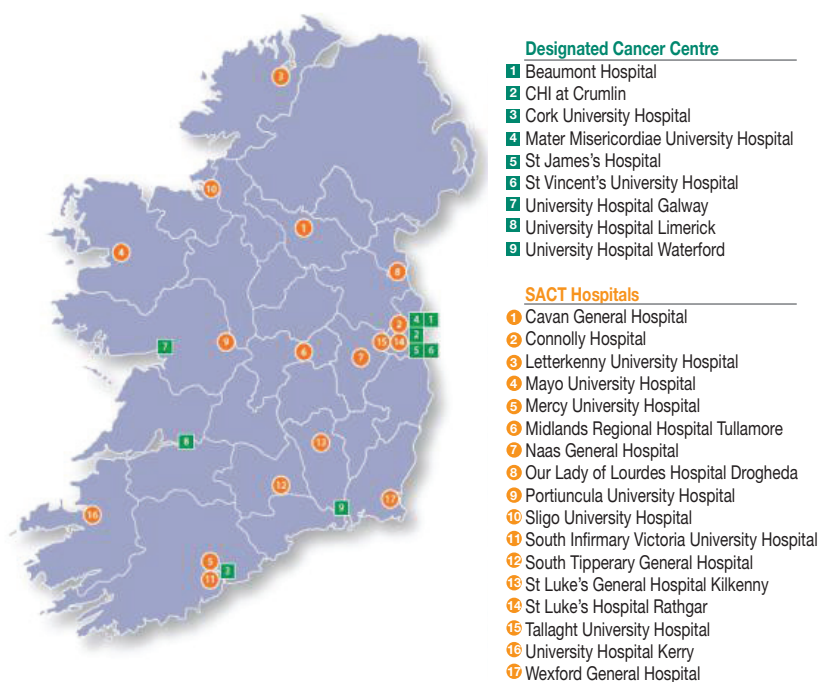
CHI at Crumlin National Children's Cancer Services  
& 16 Shared Care Centre Locations

01	Letterkenny University Hospital
02	Sligo University Hospital
03	Mayo University Hospital, Castlebar
04	Cavan General Hospital
05	Galway University Hospital
06	Portlincula University Hospital, Ballinasloe
07	Midland Regional Hospital Mullingar
08	Our Lady of Lourdes Hospital, Drogheda
09	Midland Regional Hospital Portlaoise
10	University Hospital Limerick
11	University Hospital Kerry, Tralee
12	St Luke's Hospital, Kilkenny
13	Tipperary University Hospital, Clonmel
14	Mercy University Hospital, Cork
15	Waterford University Hospital
16	Wexford General Hospital



**Figure 2:**

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





## 7. Adolescent and Young Adult (AYA) Framework Implementation Update

### 7.1 Highlight of achievements to date

The NCCP nominated the following three AYA Cancer Units in 2022:

- St James's Hospital
- Cork University Hospital
- Galway University Hospital

The NCCP have set up an AYA Cancer Unit Implementation Project Board who meet on a regular basis. AYA Cancer Unit Clinical Leads have been appointed in all three AYA Cancer Units.

Formal launch of the following NCCP CAYA Reports on the 9th May 2022 in Farmleigh and was launched by the Minister for Health.

- Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland
- NCCP CAYA Annual Report 2021



**Launch of the Framework for the care and support of Adolescents and Young Adults (AYAs) with cancer in Ireland 2021-2026.**

NCCP have successfully obtained funding via the HSE National Service Plan for CAYA positions nationwide.

## 7.2 Work in progress

- Pilot of National AYA MDM planned for Q1 2023.
- Pilot of National AYA Key Performance Indicators.
- Implementation of the recommendations of the NCCP AYA Framework 2022-2026.
- Work with three national AYA Cancer Units to develop age appropriate AYA cancer units.

## 7.3 Development opportunities for 2022-2026

- Work with European Society for Paediatric Oncology (SIOP Europe/SIOPE)
- Work with AYA Cancer Patient Survivors to ensure their involvement in service planning and development



## 8. Adolescent and Young Adult (AYA) Cancer Unit at SJH Update

### 8.1 Highlight of achievements to date

- Development and Opening of AYA unit on Denis Burkitt Ward.
- Appointment of CAYA Clinical Nurse Specialist(CNS), to take up appointment in March 2023
- Appointment of leads in Medical (Dr Larry Bacon), Psycho-Oncology (Dr Roisin Plunkett), SCOPE (Ms Alison Enright)
- Multidisciplinary attendance at AYA 'hang out' in Guinness enterprise centre, including delivery of psycho-oncology 'bite size' psycho-education sessions
- Occupational Therapy attendance at AYA "Hang Out" – focus of assessments and intervention prioritised to managing brain fog and fatigue, reintegration into education/work, study skills, stress management skills.
- Clinical Nutrition
  - Intervention in the Hangout is led by the expressed needs of the young people and typically includes participation in group education sessions and discussions. 1:1 consultation is also available.
- Physiotherapy
  - Physiotherapy interventions in the Hangout include group activities, relaxation classes, exercise classes and 1:1 sessions. The Physiotherapist also attended the Barretstown Day in November.

### 8.2 Work in progress

- Creation of Monthly Multidisciplinary meeting to plan and develop a comprehensive service for AYAs
- Setting up AYA MDT with colleagues in CHI
- Collaborating with NCCP on drafting model of care for CAYA Psycho-Oncology
- Irish Cancer Society Allied Health Professional Researcher Award 2022 – awarded to senior OT, Naomi Algeo. Researcher role commenced in Jan 2023. The 18 month study, in collaboration with TCD, aims to identify the support needs of adolescents and young adult cancer survivors for successful return to education and/or work.

### 8.3 Development opportunities for 2022-2026

- Multidisciplinary OPD for AYAs
- Development of dedicated Psycho-Oncology team for AYA patients
- Inclusion of medical social work and Speech and Language therapy as part of the GEC hangout
- Expansion of inpatient AYA beds

## 9. Adolescent and Young Adult (AYA) Cancer Unit at GUH Update

### 9.1 Highlight of achievements to date

- In August 2022, we were delighted to welcome the National Adolescent and Young Adults (AYA) Cancer Unit Steering Group to GUH, led by Professor Owen Patrick Smith, National Clinical lead for Children, Adolescents and Young adult cancers.
- Professor Margaret Murray, Clinical Director, Laboratory Directorate and Associate Director of the Cancer MCAN led a discussion around the needs of the AYA population within Saolta, focusing on the need to create a safe and sustainable programme for AYA patients at UHG. The UHG representation included the Director of Nursing, and the ADON in Cancer Services and Galway University Hospitals Deputy General Manager, as well as representation from the Cancer MCAN and the wider multidisciplinary team. Medical oncology, radiation oncology, haematology and palliative care and nursing representation from Cancer services, palliative care and psycho-oncology were in attendance. Speech and Language Therapy, Social Work, Occupational Therapy, Physiotherapy and Dietetics also attended.

### 9.2 Work in progress

- Dr Niamh Keane, Consultant Haematologist will lead out on the AYA programme in Galway.
- The AYA CNS post is advertised.
- Local preliminary meetings have been commenced with a view to setting up a more expanded project steering group in 2023.

### 9.3 Development opportunities for 2022-2026

- Appoint AYA CNS
- Develop data capture system for AYA
- Set up regular steering group meetings for AYA development
- Progress Business case to develop AYA facilities on site
- Attend NCCP meetings and network with CHI and other units development of National Guidelines on Fertility Preservation for CAYA with cancer and survivors.





## 10. Adolescent and Young Adult (AYA) Cancer Unit at CUH Update

### 10.1 Highlight of achievements to date

In November 2022, we were delighted to welcome the National Adolescent and Young Adults (AYA) Cancer Unit Steering Group to Cork University Hospital (CUH), led by Professor Owen Patrick Smith, National Clinical lead for Children, Adolescents and Young adult cancers.

### 10.2 Work in progress

- CUH are recruiting the CNS and this will structure the pathway for AYA patients
- AYA designated den in the GB ward

### 10.3 Development opportunities for 2022-2026

- AYA pathway
- National MDM participation
- Paediatric phase 2 space for AYA



## 11. National Children's Cancer Service at Children's Health Ireland at Crumlin

### 11.1 Highlight of achievements to date

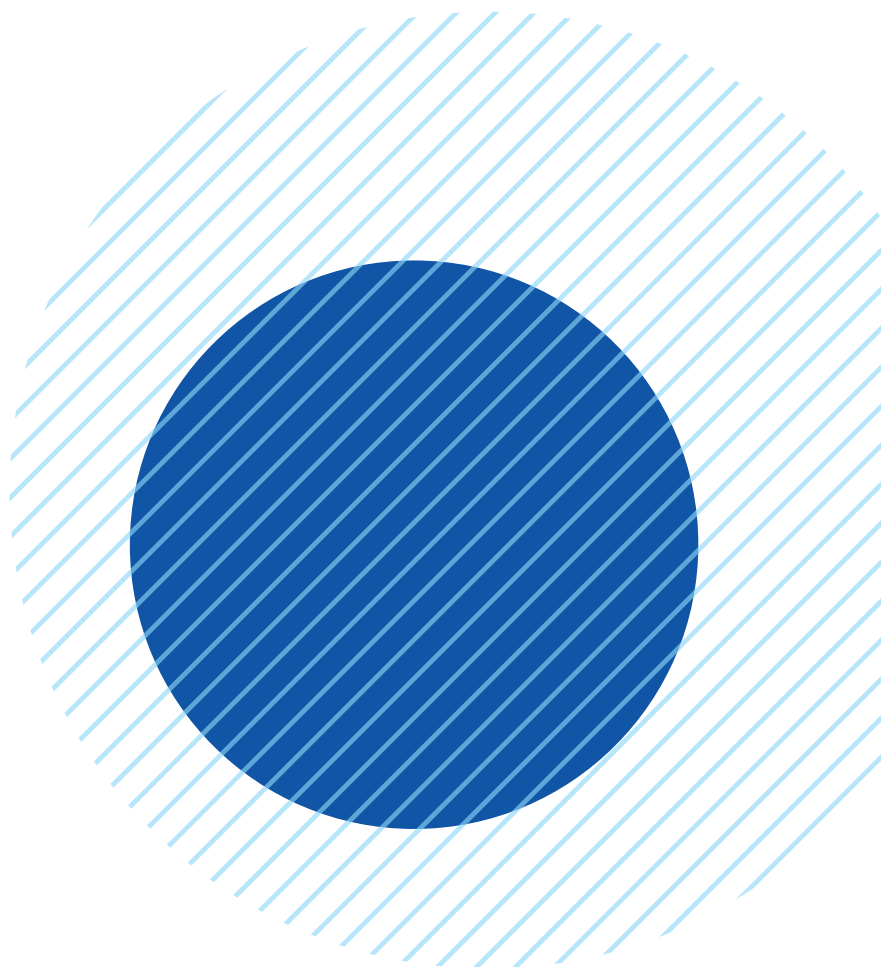
- The National Children's Cancer Service (NCCS) provides a national service for all children and young people diagnosed with cancer between 0 – 16 years. This service is provided in conjunction with 16 shared care units across the country.
- Achievements to highlight in 2022 include:
  - The launch of the National Cancer Information System (NCIS) for electronic chemotherapy prescribing and administration.
  - Car-T therapy is now available for children and young people in Ireland with Acute Lymphoblastic Leukaemia (ALL) and the first patient received the treatment in 2022. There was a successful and well-publicised media launch with the support of CHI, the NCCP and the Department of Health in April 2022.
  - The NCCS was successfully awarded funding from the Health Research Board to support cancer clinical trials in patients aged 0 – 24 years ( Cancer Cluster)
  - Completion of the Childhood Cancer Survivorship Project: assessment of the needs of childhood cancer survivors in Ireland from a patient, parent/guardian/carer perspective.

### 11.2 Work in progress

- Work continues on a number of key areas of strategic importance for the NCCS, these include:
  - Ongoing work to support the roll out of NCIS across the service
  - Supporting the preparations for the new electronic health record which will be used in the New National Children's Hospital
  - Development of a new purpose built facility to allow for intrathecal chemotherapy to be administered on the haematology-oncology day unit (previously required to be performed in main theatre)
  - Significant work supporting the opening of international clinical trials including: ALL-Together1, an international phase 3 trial in ALL; FaR-RMS, a frontline and relapsed rhabdomyosarcoma trial
  - Commencement of the "Molecular and Genomic Interrogation of Childhood Cancer – Ireland" (MAGIC-I) study offering universal next generation sequencing for all new patients with cancer supported by Genuity Science, with wider ongoing development of the cancer genetics service (see Noelle's section)
  - Preparation for an international peer review of the service provided by the NCCS
  - Ongoing development for the launch of the National Adolescent and Young Adult Cancer Multidisciplinary Team Meeting

### 11.3 Development opportunities for 2022-2026

- Development of proton beam therapy for paediatric patients in Ireland (patients currently have to travel overseas to receive this treatment)
- Creation of an “academic pharmacy” to support the work of the Cancer Clinical Trials Unit
- Ongoing work to prepare for the move to the new National Children’s Hospital
- Development of an electronic app and simulation programme to support education and training for the new CAR-T programme and HSCT
- In conjunction with the NCCP, securing funding for novel therapies, such as blinatumomab, to ensure equality of access to a broad cohort of paediatric patients
- Ongoing work to strengthen and develop the fertility preservation service in conjunction with Merrion Fertility Clinic (see Fertility section)



## 12. AYA Cancer Communications

### 12.1 Highlight of achievements to date

- During 2022, the NCCP CAYA Communications Project Board worked 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 as follows:
  - NCCP Twitter Account and other social media platforms.
  - Interviews on National Radio and the National and Medical Press.
  - Health Matters HSE Publication in 2022
  - AYA Assistant Director of Nursing Day in the Life in Irish Examiner
  - NCCP CAYA Clinical Lead interview in Health Matters
  - CAYA Patient Survivor Article in Health Matters.
  - Launch of NCCP AYA Framework on the 9th May 2022
  - Launch of NCCP CAYA Annual Report 2021 on 9th May 2022
  - Presented NCCP AYA Framework at EU Conferences
  - Highlight AYA site visits on social media
  - Press release re access for cancer survivors to DARE programme
  - Second CAYAS conference took place on 23rd September 2022. This event was a collaboration between Childhood Cancer Foundation (formerly CanCare4living & Childhood Cancer foundation Ireland) with support from NCCP 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.

### 12.2 Work in progress

- 15 Feb 2023 – International Childhood Cancer Awareness Day #ICCD
- 15 Feb 2023 – launch of NCCP CAYAS 2022 Report
- April 2023 – AYA awareness + framework development
- May 2023 – launch of CAYA Psycho-oncology Model of Care
- May 2023 - Brain Tumour Awareness Month
- June 2023 – Survivorship awareness
- September 2023 – Childhood Cancer Awareness Month / Light it Up Gold
- September 2023 – CAYAS Conference
- September 2023 – Palliative Care awareness

### 12.3 Development opportunities for 2022-2026

- The CAYA Communications Subgroup plan will serve the CAYA community and support the implementation of the NCCP strategy.
  - Showcase new CAYA health professionals
  - Feature patients, survivors and families to highlight lived experience and commitment to PPIE
  - 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.
  - Work closely with our EU partners

## 13. Shared Care

### 13.1 Highlight of achievement to date

- Healthlink project: During 2022, CHI at Crumlin's access to lab results in Our Lady of Lourdes Hospital in Drogheda using the Healthlink platform was restored following a long delay due to the cyber-attack. Staff in Healthlink also worked with colleagues in the Mercy University Hospital Cork to overcome technical obstacles to allow its use there successfully.
- Education: Shared Care in-person study days took place in 3 paediatric units during 2022 – Sligo University Hospital, Midland Regional Hospital Mullingar and Wexford General Hospital. Attendance was limited to staff of the host hospitals only due to ongoing COVID 19 restrictions
- Developing Chemotherapy Administration: Nursing staff in Mayo University Hospital paediatric unit underwent education and training in order to administer a cytotoxic drug locally to one of their patients. This drug has been administered to MUH paediatric patients in CHI at Crumlin to date, but this was undertaken in response to a specific patient's needs. It has gone extremely well from the family's perspective and with significant commitment from the nursing, medical and pharmacy staff in the paediatric unit.
- SACT Education: Nursing staff from 2 shared care centres attended a chemotherapy study day in CHI at Crumlin. This study day is organised as part of the Haematology/Oncology Foundation Programme for nurses working within the inpatient and day unit setting in CHI at Crumlin, so the support of the Centre of Children's Nurse Education (CCNE) was pivotal.

### 13.2 Work in progress

- A review of the further education opportunities in haematology/oncology nursing available to staff within CHI at Crumlin and those working in the shared care paediatric units is underway. It will look at recent developments in the Children's Cancer and Leukaemia Group (CCLG) for nurses in the paediatric setting, along with the current NCCP National SACT Competency Programme for Nurses Working in Cancer Care as well as the current CHI at Crumlin and international programmes. It will examine what direction future education, training and support might take

### 13.3 Development opportunities for 2022-2026

- The continued roll out of the laboratory access platform Healthlink to more shared care centres.
- It is anticipated the National Haematology Oncology Conference will be held in the spring of 2023 and to have 2-4 individual shared care unit study days during the year.
- To develop haematology/oncology resources for paediatricians and NCHD's in the shared care centres
- To produce a new edition of the Supportive Care Guidelines in 2023
- To develop a training and education framework for nurses working in the shared care centres..

## 14. Fertility

### 14.1 Highlight of achievements to date

- Model of care fully operational and working very well for sperm and egg freezing at Merrion Fertility Clinic (MFC) for AYA requiring fertility preservation prior to gonadotoxic treatment – to date gametes stored for 32 boys and 13 girls. Currently funded by Irish Cancer Society research grant.
- Assessment clinic and fertility preservation services established for female cancer survivors, extended to include young women up to 26 years.
- Funding provided by Merrion Fertility Clinic to enable storage free of charge for CAYA gametes until age 30.
- Information booklets on Fertility Preservation for AYA groups (pre-treatment and survivors) professionally designed for national distribution.
- Visits to new AYA regional sites at Galway and Cork University Hospital.
- Presentation on CAYA fertility preservation by Dr Rachel Elebert at the Haematology Association of Ireland Nurses and Allied Healthcare Professionals AGM, Oct 2022 in Cork.
- Collaborative study between CHI and MFC on 24-month follow-up of female childhood cancer survivor ovarian reserve; manuscript submitted to peer-reviewed journal.
- Education/training: participation by MFC embryology team member in ovarian tissue cryopreservation technique workshop at ISFP, Nov 2022, Brussels

### 14.2 Work in progress

- Drafting proposal/business model for urgent HSE & Department of Health funding of AYA sperm and egg freezing services. These are currently funded by an Irish Cancer Society grant, due to expire mid-2023.
- Development of ovarian and testicular tissue freezing service for pre-pubertal children in Ireland.
- Outreach to oncology/haematology AYA healthcare providers at adult hospitals to ensure fertility preservation service offered to all AYA (<18yrs) patients in Ireland.
- Patient and parent/guardian survey to evaluate satisfaction with the CAYA service (planned for Jan 2023).
- Development of National Guidelines on Fertility Preservation for CAYA with cancer and survivors.

### 14.3 Development opportunities for 2022-2026

- Planned Irish Cancer Society-led initiatives for Q1 2023:
  - Healthcare provider study day with MFC team: CAYA fertility preservation services.
  - Public information webinar on CAYA fertility services.
- Development of national site, methodologies and procedures for gonadal tissue freezing service

## 15. Psycho-Oncology

### 15.1 Highlight of achievements to date

- Draft Model of Care for Psycho-Oncology Services for CAYA with cancer and their families has been prepared and was circulated to the working group in Q4 2022 for feedback. Comments have been reviewed and the draft is currently being updated. National consultation planned for Q1 2023, followed by approval and endorsement by the NCCP Executive Team and official launch thereafter.
- Preparation of the launch of the National Psycho-Oncology Service in CHI @ Crumlin on the day of the first Irish Psycho-Oncology Paediatric Conference (planned for March 2023).
- Agreement with Professor Kazak to launch a pilot for the Irish-PAT (psycho—social assessment tool) to assess psycho-social needs of families at the beginning of their cancer journey.
- The CAYA Psycho-Oncology team received further funding this year, allowing the appointment of a Principal Neuropsychologist and a Senior Psychologist. Funding has also been received for a CAYA Senior Social Worker and a Senior Play Specialist and it is hoped that they will be in post in early 2023.

### 15.2 Work in progress

- Development of the National Model of Care for Psycho-Oncology Services for CAYA with cancer and their families in Ireland.

### 15.3 Development opportunities for 2022-2026

- Launch of National Model of Care for Psycho-Oncology Services for CAYA with cancer and their families.
  - Further development of the CAYA National Psycho-Oncology Service in CHI @ Crumlin. First training day for the Psycho-Oncology MDT Service in January. To start Irish-PAT Psycho-social assessment tool in Q1 2023.
  - Development of the AYA Psycho-Oncology service in the three AYACSN's.



## 16. Palliative Care

### 16.1 Highlight of achievements to date

- The AYA Palliative Medicine Fellow appointed for a second year.
- 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.
- Incorporation of KPI 8 within Framework for CAYA palliative care in conjunction with the HSE Palliative Care Program.
- Delivery of education on AYA palliative care for Royal College of Physicians Ireland and to both paediatric and adult based healthcare services.
- Representation on international and national groups focused on the provision of palliative care for the AYA population.

### 16.2 Work in progress

- Collaborating with the Steering Group to develop a new Palliative Care Policy for Adults, specifically advocating for AYA palliative care to be an identified component of the National Policy for Palliative Care 2023.
- 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.

### 16.3 Development opportunities for 2022-2026

- The Palliative Care Subgroup will progress funding applications and continue service development in delivering palliative medicine to the AYA 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.

## 17. Radiation Oncology

### 17.1 Highlight of achievements to date

- Assisted in development of national proton panel to streamline referrals abroad for proton therapy.
- Participation the AYA neuro clinic in Beaumont.
- Mask painting of radiotherapy mask now on offer in St Luke's to reduce anxiety around the masks.

### 17.2 Work in progress

- Review of CAYA need in radiation oncology and undertaking workforce planning to ensure the needs of these patients are met by CAYA radiation oncologists.

### 17.3 Development opportunities for 2022-2026

- Forming dedicated CAYA radiation oncology service with appropriate staffing
- Need to formalise the follow up procedure in AYA neuro clinic and develop formal stand-alone clinic with appropriate support staff
- Need to develop follow up clinics for non neuro groups.

## 18. Laura Lynn

### 18.1 Highlight of achievements to date

- Laura Lynn, Ireland's Children's Hospice mission statement is to provide a community of care that delivers evidence-based personalised services to children and adolescents (0 – 18years) with palliative care needs.
- The Model of Care in LauraLynn Hospice describes the support provided within five pillars of children's and adolescent's hospice care: Direct Care, Family Support, Symptom Management, End of Life Care, and Bereavement Support.
- Children and adolescents are cared for by an interdisciplinary team to ensure care delivered is personalised to the needs of each child/adolescent and their family. The palliative care team consists of medical staff, nurses, pharmacist, social worker, psychologist, play therapist, music therapist, speech and language therapist, occupational therapist, physiotherapist, dietician, and bereavement coordinator.

### 18.2. Work in progress

- During 2022, a total of 286 families were supported by the LauraLynn Hospice team in their home, hospital, and hospice.
- 120 new referrals, of which 31 were for a child/adolescent with cancer. Sadly 18 children/adolescents with a cancer diagnosis cared for by the LauraLynn Hospice team died during the year.
- The first regional hub was opened in Mallow, Co. Cork in September providing in-home nursing care and music therapy to children/adolescents and their families in the counties of Cork and Kerry.

### 18.3 Development opportunities for 2022-2026

- Further collaboration with state and voluntary organisations involved in the delivery of care for children/adolescents with cancer.
- Planning and establishment of additional regional hubs.



**Laura Lynn Hospice**

## 19. AYA Nursing

### 19.1 Highlight of achievements to date

- One whole time equivalent clinical nurse specialist position funded for each AYA Cancer network site.
- AYA Educational Day 21<sup>st</sup> November 2022

### 19.2 Work in progress

- Recruitment underway in all areas. CHI at Crumlin CNS commencing January 2023, active recruitment process underway in all other sites and all will be in position in 2023.
- AYA CNS post is in place
- Awaiting start date AYA CNS SJH
- CUH recruitment in progress
- GUH recruitment in progress



## 20. Young Persons Advisory Board (YPAG)

### 20.1 Highlight of achievements to date

- At YPAG, we believe that children and young people with cancer should have a voice, share their opinions, and be actively involved in the design and delivery of clinical research and services, to make sure they are relevant and suited to their needs.
- We are a group of interested young people who have or had cancer. We meet a number of times per year to give our views and advice on new research or service developments. We also get a chance to learn about research, medicine and science while having fun!
- The group was founded in 2022 and we had two meetings. Both meetings took place at Barretstown.
- We used our first meeting to get to know each other with some team games and decided how YPAG can work best.
- At our second meeting we heard from three researchers and discussed several important issues including the presentation and content of support information for young people with cancer (from the Irish Cancer Society), biobanking and consent (from Systems Biology Ireland) and how to structure a research focus group for young people with lymphoma after radiotherapy (from Trinity College Dublin). Our feedback so far has been resoundingly positive!
- We also shared the work of our YPAG in May 2022 as part of the DCU Seminar Series: PPI in Research with Children and Young People.





## 20.2 Work in progress

- Planning is well underway for our meetings in 2023. We are lucky that our next meeting will be taking place in Systems Biology Ireland, University College Dublin where we will tour the lab there and hear from some new researchers.
- We are always looking for new members to join YPAG and also for researchers or healthcare professionals who may be interested in working with us – to find out more and how to get involved please check out our website: [www.ypag.ie](http://www.ypag.ie).

## 20.3 Development opportunities for 2022-2026

- Further expansion of the YPAG group members.
- Continued engagement with the research and healthcare community to ensure all interested and relevant parties can engage with and learn from the YPAG.
- Working with other partners to learn how to improve and expand PPI in research with children and young people with cancer.



**The first YPAG meeting held at Barretstown**

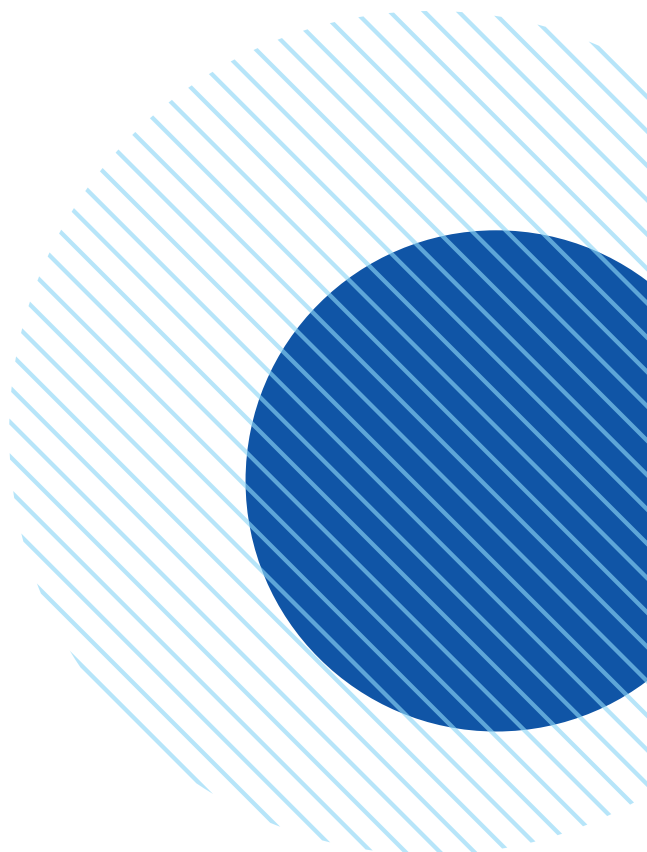
## 21. Adolescent and Young Adult (AYA) Hangout Clinics

### 21.1 Highlight of achievements to date

- ‘The Hangout’ A six month pilot programme between St James’s Hospital (SJH), Trinity St. James’s Campus Cancer Institute (TSJHCI) and Guinness Enterprise Centre (GEC).
- The programme aimed to create a non- clinical environment for Adolescent and Young Adult cancer (AYAC) patients in SJH. The sessions are attended by SJH patients that are under active care of an oncologist or haematologist in St James’s. The current consultant will assess patient readiness and refer to the service. The format of the session is co-designed by attendees and then facilitated by AYAC programme staff, SJH staff, and GEC partners.
- The sessions are based on increasing peer support, empowering young people in a strengths-based manner and creating a positive environment to learn and understand about career planning and workplace skills. It also provides a single point of access to health and social care professionals.
- GEC’s partnership is an innovative approach to support learning from successful businesses who have often had non-traditional paths to success.
- This pilot is being evaluated and may continue in to 2023, with the aim of expanding this model throughout the AYA Cancer network.

### 21.2 Work in progress

- Some highlights so far include, working on a design brief to capture the essence of ‘The Hangout’. Learning and understanding about a variety of businesses working in GEC and creating a youth-friendly atmosphere and approach to care.



## 22. Adolescent and Young Adult (AYA) MDM Development

### 22.1 Highlight of achievements to date

- The AYA team has developed the AYA National MDM SOP
- A Pilot AYA MDM was held in December 2022 and run through the National Cancer Information System (NCIS) programme.
- The National AYA MDM is leading the way in the roll out of the shared MDM functionality on NCIS in CHI.

### 22.2 Work in progress

- The National AYA MDM will go live in early 2023
- There is ongoing development of the AYA dataset in conjunction with the AYA network
- The recruitment of a MDM coordinator is underway.

### 22.3 Development opportunities for 2022-2026

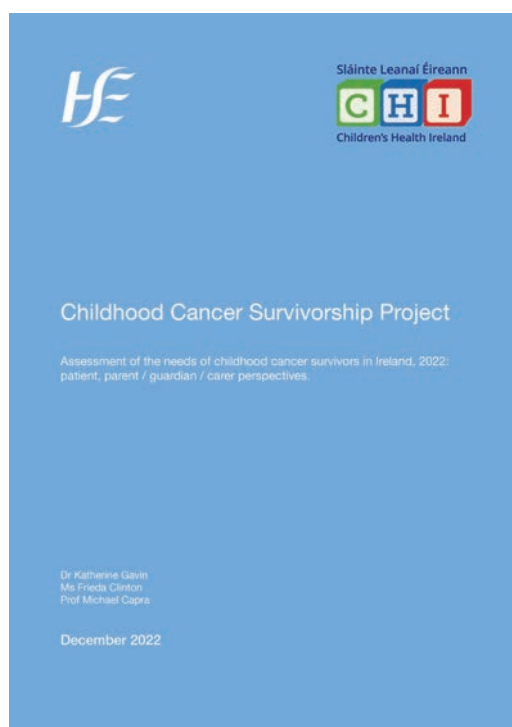
- To enhance, develop and expand the National AYA MDM to include referrals from all cancer centres in Ireland.
- Further collaboration with AYA stakeholders and AYA's to ensure the development of a comprehensive AYA service.
- The development of a prospective AYA cancer registry, ethical approval will sought in 2023 for this registry.



## 23. Survivorship

### 23.1 Highlight of achievement to date

- Needs Assessment Project, a national qualitative study on survivorship care after childhood cancer in Ireland.
- The study aims to identify identifies the needs, preferences and priorities for care of childhood cancer patients from the perspectives of patients, parents/guardians/carers and healthcare providers.
- The study is part of the national Cancer Survivorship Needs Assessment in accordance with the National Cancer Strategy 2017-2026 (recommendation 41).
- In Phase 1 of the project, focus groups were held with:
  - childhood cancer survivors from brain tumour, solid tumour and leukaemia diagnostic subgroups respectively
  - parents of childhood cancer survivors from brain tumour, solid tumour and leukaemia diagnostic subgroups respectively
  - a mixed teen focus group with representation from brain tumour, solid tumour and leukaemia diagnostic subgroups.
- This project captured information from a wide sample of cancer survivors including previously under-represented cancer subgroups.
- The findings will be used to ensure survivor and parent/guardian/carer needs, priorities and preferences are reflected in the development of the Survivorship Service for childhood cancer survivors in Ireland.
- Publication of the report on - Assessment of the needs of childhood cancer survivors in Ireland, 2022: patient, parent / guardian / carer perspectives. s



## 23.2 Work in progress

- Phase 2, Assessment of the needs of childhood cancer survivors in Ireland, 2022: health-care professional perspective.
  - Interviews completed
  - Report in progress
- Continued implementation of a Patient Hand Held Treatment Summary and Care Plan. The Treatment Summary is currently being used with all patients in the national service and arrangements are in place to provide this for patients retrospectively on request.
- Collaboration with CAYA Clinical Leads group to scope and align processes for transitioning and graduation from CAYA services and the development of support for patients and families at these important junctures.
- REDCap survivorship database
  - Creation of a population-based database on childhood cancer survivors in Ireland and the incidence and range of direct cancer and/or cancer treatment-related effects they experience.
  - Ongoing work with DPO/CHI at Crumlin

## 24. Research and Innovation

### 24.1 Highlight of achievements to date

- The appointment of a Consultant Oncologist with a special interest in cancer genetics in January 2022, via funding awarded by the Irish Cancer Society in collaboration with Children's Health Ireland (CHI) at Crumlin, has seen the development of a multidisciplinary paediatric cancer genetics service within the National Children's Cancer Service (NCCS), based at CHI, Crumlin.
- Highlights to date:
  - A monthly Paediatric Cancer Genetics Multidisciplinary team meeting has now been established to expedite, streamline, mainstream and prioritise access to genetic testing, evaluation and evidence-based follow-up care for children with cancer and their families. This new initiative facilitates streamlining of patients from the Haematology / Oncology service to the Clinical Genetics service in an expedited manner, enables prompt discussion of genetic testing results, facilitates onward referral for predictive (cascade) testing of family members and ensures appropriate onward referrals for evidence-based cancer surveillance for individuals with a proven cancer predisposition syndrome
  - Following review of emerging clinical evidence, a change in genetic testing practice for children with Wilms tumour has been initiated at CHI, Crumlin
  - Children with a confirmed cancer predisposition syndrome who have a high risk of cancer development in paediatric age are now being referred to a dedicated Cancer Predisposition Syndrome Surveillance Clinic based at CHI, Crumlin
  - Early data from this initiative was presented at the Irish Society of Human Genetics Annual Meeting in Dublin in September 2022, and was further highlighted in an article in the Irish Examiner, also in September 2022.
  - The establishment of this initiative has been practice-changing, clinically impactful for patients and families, clinically meaningful for healthcare professionals and aligns with the goals of the recently launched National Genetics and Genomics Strategy.

### 24.2 Work in progress

- The NCCP recently approved funding for a dedicated Paediatric Haematology / Oncology Genetic Counsellor post based at the NCCS. This post is due for recruitment in Q1 2023.
- Work is ongoing to further develop the Paediatric Cancer Genetics Service at CHI, Crumlin, in collaboration with the Department of Clinical Genetics, with additional resources needed to ensure the provision of a comprehensive cancer genetics service for all children with cancer
- Collaborations with academic institutions and funding partners are ongoing with a view to establishing a research initiative that will offer expanded access to genetic testing for all children with cancer (both somatic [tumour-based] and germline analysis)

### 24.3 Development opportunities for 2022-2026

- This initiative aims to provide a comprehensive service that, going forward, incorporates hereditary cancer risk assessment for all children with cancer, with particular focus at time of diagnosis, but also, at time of transition from paediatric to adult services.
- With additional resources, this service will engage with survivors of childhood cancer, at time of transition from paediatric to adult services, who may be eligible for genetic evaluation based on new and emerging evidence
- Patient and public engagement opportunities will be explored to help ensure the development of a comprehensive cancer genetics programme for paediatric patients
- The development of comprehensive, evidence-based and up-to-date electronic resources for patients and families will be explored so that patients and families will have easy access to relevant paediatric cancer genetics resources

# DARE

## DISABILITY ACCESS ROUTE TO EDUCATION

## 25. Education – Disability Access Route to Education (DARE)

### 25.1 Highlight of achievements to date

- The NCCP welcomed the inclusion of childhood, adolescent and young adult cancer in the 'significant ongoing illness' criteria of DARE (Disability Access Route to Education).
- This addition gives greater access to the scheme for young people whose education has been impacted by cancer, no matter when they were diagnosed.
- DARE is an alternative admissions route to third level for students whose disability or ongoing illness has had a negative impact on their second level education. The addition of childhood cancer, including those in remission, to the definition of 'significant ongoing illness' by the Irish Universities Association has come in time for the 2023 CAO application process.
- Prof Owen Smith CBE, FTCD, National Clinical Programme Lead for Children and Adolescent/Young Adults with cancer at the National Cancer Control Programme.

“The life-saving treatments required to save children and adolescents are toxic and can have long-lasting effects on all aspects of their lives, including education. More children, adolescents and young adults now survive but this cure comes at a cost and we know that treatment can cause ongoing issues like lung, bone and brain disease. On the clinical side, we are working hard to provide a better quality of life for young survivors and we are pleased that there is now greater awareness of the ongoing impact on education.”

- Up to now, childhood cancer survivors who were more than three years out of treatment and whose treatment impacted their education did not have automatic access to DARE as a result of their illness.
- To find out more please go to <https://accesscollege.ie/dare/>

### 25.2 Work in progress

- Working to promote awareness of the update and are partnering with Childhood Cancer Ireland to facilitate this.
- Childhood Cancer Ireland held a webinar for parents and survivors on DARE last year, which can be found at <https://youtu.be/L7sehBZn3E4>.

### 25.3 Development opportunities for 2022-2026

- Working to explore other Educational supports that we can put in place to support CAYA cancer patients and their families.



# Irish Cancer Society

## 26. Irish Cancer Society

### 26.1 Highlight of achievements to date

- **The Our On-site Presence at CHI Crumlin**

This year, we have installed a Children's Cancer Coordinator; Elaine Smyth, on-site within CHI Crumlin one day per week. Our Coordinator provides crucial holistic supports and information to families attending with children for cancer treatment.

- **Volunteer Driver Service**

We have further-expanded the catchment of our 'Volunteer Driver Service' for families bringing children for cancer treatment appointments at CHI Crumlin, from counties Dublin, Meath, Kildare and Wicklow. This free-of-charge and vital service connects our volunteers with families who require logistical assistance transporting children to hospital appointments and treatments.

- **The Children's Fund**

In 2021, we published research on the "Real Cost of Childhood and Adolescent Cancer", which highlighted the harsh realities of financial struggle for families facing a cancer diagnosis. In response to those findings, we have modified our Children's Fund. This is a once-off payment of €3,000 paid to families upon the diagnosis of a child in their family with cancer. We are proud that we have received a record number of funding applications this year.

- **Barretstown Camps**

We are delighted to have established an ongoing partnership with Barretstown this year, to host three camps designed for families, with another three camps for young people impacted by cancer. The feedback from these camps has been excellent, and really encourages further Camp engagement during 2023. The Irish Cancer Society provides complimentary 'Welcome Packs', which contain useful items, branded merchandise and resource details. In addition, our team are present during each Camp to provide on-site support as needed by our Camp participants.

- **CAYA cancer Information**

We continue to develop bespoke materials for families navigating through cancer with a young person. During 2022 we published two booklets to support CAYA patients, and their families and supporters;

Supporting siblings during a cancer journey

When my child's cancer comes back.

- **Multi-disciplinary AYA Study Day**

In conjunction with the Irish Cancer Society, the NCCP & CHI, a national study day was hosted on the St. James's Hospital campus, to provide participants with the opportunity to explore and understand the 'principles of care' related to working with young persons with cancer.

## 26.2 Work in progress

- Our CAYA cancer work program and successes at the Irish Cancer Society continues to expand and further-support CAYA patients and families.
- Our future work programme of projects to support families include:
  - Advocating for improved early-detection of CAYA cancers, including the development of GP referral guidelines.
  - Further enhancement and expansion of innovative support services for children, adolescents and young adults (CAYA) affected by cancer, in line with the 'Irish Cancer Society 2020-2025' strategy.
  - Advocating for additional financial, practical and psychological supports to be provided by Government to families affected by a CAYA diagnosis.

## 26.3 Development opportunities for 2022-2026

- We are committed to the needs of CAYA patients and families in the immediate term in addition to keeping focused on an ongoing pipeline of support needs and services which we frequently develop through partnership and collaboration with other CAYA stakeholders nationally. Key work programme elements include;
- Development of cancer information resources for the AYA community, through collaborative work with the Young Person Advisory Group (YPAG) group.
- Expansion of the CAYA Volunteer Driver Service.
- Further research of the experiences of families throughout the cancer journey and their unmet needs.
- Continue to collaborate with CAYA stakeholders to ensure a comprehensive services are provided.
- There is tremendous commitment and impetus within the Irish Cancer Society to deliver as much CAYA support as we can, to patients and families. We maintain focus on fine-tuning and expanding our portfolio of free CAYA-specific services and, in-tandem with our commitment to strengthen the national services available for CAYA patients and families through our impactful advocacy campaigns.





## 27. Barretstown

### 27.1 Highlight of achievements to date

- Hosted 6 programmes (3 x Family Weekend Programmes and 3 x Young Adult Programmes) in 2022 in partnership with the Irish Cancer Society serving 52 Families (225 family members) and 33 Young Adults.

### 27.2 Work in progress

- A key element of the partnership was the referral of families and young adults to these specific programmes through the Irish Cancer Society. There were also families who expressed interest directly to Barretstown's Family Liaison team which meant we were engaging with families in multiple ways to ensure awareness of these programmes was high and that we could serve as many families as possible. We advertised across all social media channels as well as our websites and also created dual branded social posts to highlight the partnership.
- Weekly progress meetings were scheduled to maintain engagement and to ensure both Barretstown and the Irish Cancer Society were working together to provide a memorable, life-changing experience for families and young adults.

- **Family Programmes**

Family Weekend Programmes ran from Friday to Sunday following the traditional family programme model in Barretstown. As well as a full day of programming on Saturday, the Irish Cancer Society also provided support services throughout the day. Families could access these supports and spend as much time as necessary with the ICS staff.

- **Young Adult Programme (YAP)**

Partnering with the ICS on the three Young Adult Programmes meant we are able to focus solely on young adults who have or have had cancer. The programme is designed to provide a perfect balance of camp activities and educational workshops to help us meet all six concepts of transition in a weekend programme. Through the partnership, we were fortunate to have some external speakers and support services from the Irish Cancer Society onsite during our YAPs. The programme has grown across the three weekends and while recruitment was initially challenging during the pilot, we are seeing a steady rise in the number of young adults participating. Awareness of the programme is growing thanks to social media, through the use of testimonials and through word of mouth as more young adults get involved. The Irish Cancer Society provided comprehensive welcome packs which the young adults received on arrival and Barretstown supplied dual branded sweatshirts for each participant.



### 27.3 Development opportunities for 2022-2026

- The structure of the Young Adult Programme is currently under review to allow more time for the concepts of transition and this may involve the programme becoming a three cycle programme where campers would attend three weekend programmes instead of one.
- We are also considering the introduction of a Family Camp for children who have lost a parent to cancer. This new programme will be piloted in October 2023.



**NCCP CAYA Clinical Leads Group meeting held at Barretstown in October 2022**



## 28. CanTeen Ireland

### 28.1 Highlight of achievements to date

- **CAYAS conference**

The second annual CAYAS conference took place in September, hosted by CanTeen Ireland and Childhood Cancer Ireland and supported by the NCCP, CHI at Crumlin and the Irish Cancer Society. This conference was held in person for the first time, with online attendance also available. The day places the lived experience of survivors and parents at the centre of discussions on our services, education and psychosocial supports, helping to highlight the unmet needs, as well as looking at progress made since the inaugural conference in 2021.

- In February we concluded our Pilot Exercise Programme with Ex Well Medical. This was the first exercise programme for young people with cancer in Ireland. We commenced our new 12 week programme in November with weekly exercise sessions via Zoom. This has been a great success so far and we plan to continue to offer this to our members throughout 2023 and in the future as part of peer support programme.

### 28.2 Work in progress

- CanTeen Ireland is pleased to contribute to the ongoing work of the NCCP through its membership of the Children's Adolescents/Young Adults (CAYA) Clinical Leads Group, Psycho Oncology and Communications Committees.
- CanTeen is affiliated with the Irish Cancer Society and are members of their CAYA stakeholders group to assist and support the delivery of their strategy.
- CanTeen is delighted to be a partner with the NCCS YPAG with many of our members as representatives on the YPAG.
- CanTeen Ireland is a member of Childhood Cancer International Europe and are one for the Associated Partners for the EU-CAYAS-NET Programme.



## 29. Childhood Cancer Ireland

### 29.1 Highlight of achievements to date

- Childhood Cancer Ireland provided valuable contributions to the ongoing work of the NCCP through its membership of the Children Adolescents and Young Adults (CAYA) groups including the: Clinical Leads Group, Shared Care, Survivorship and Psycho-Oncology.

- **New name**

In August of 2022, Childhood Cancer Foundation Ireland joined together with CanCare4Living under the new name Childhood Cancer Ireland. Together, we will continue to represent the voice of children, adolescents and young adults with cancer, survivors and their families as the national parent and survivor-led childhood cancer charity.

- **Our services**

We continued our work as a charity founded and led by parents of children and young people with cancer and survivors by:

- Raising awareness of childhood, adolescent and young adult cancers via the Light It Up Gold Campaign and the Gold Ribbon Conversations Podcast Series.
- Providing continued support to parents and adult family members as trained Parent Peer to Peer Support volunteers, in collaboration with Irish Cancer Society and CanTeen Ireland.
- Funding and growing Beads of Courage ®.
- Continuing to fund treatment room upgrades and equipment for Shared Care Hospitals – completing Wexford and in 2022 and Limerick is almost complete.
- Our support of Play Services ended in November 2022. Childhood Cancer Ireland provided significant financial support for Play Services every year since 2015 but we are glad that the value of this vital service has been recognised and taken over by the HSE, ensuring it's continuity.

- **CAYAS conference**

The second annual CAYAS conference took place in September, hosted by Childhood Cancer Ireland and CanTeen Ireland and supported by the NCCP, CHI at Crumlin and the Irish Cancer Society. This conference was held in person for the first time, with online attendance also available. The day places the lived experience of parents and survivors at the centre of discussions on our services, education and psychosocial supports, helping to highlight the unmet needs, as well as looking at progress made since the last conference in 2021.



- **Access to education**

- In late 2021, Childhood Cancer Ireland held an educational webinar on DARE (Disability Access Route to Education) for survivors of childhood and adolescent cancer interested in applying to higher education. The webinar informed parents, educators and young people about this option and how to access it. We subsequently successfully lobbied the Minister for Education, with the support of the NCCP, to ensure that DARE was open to CAYA survivors, no matter when their diagnosis. DARE is now open to CAYA survivors in remission, taking into account the often-significant impact on education, no matter how many years it has been since diagnosis and treatment.
- We continued our webinar series in 2022 with an exploration of alternative pathways to further and higher education, with a focus on non-traditional routes

- **Awareness**

- Childhood Cancer Ireland's Gold Ribbon Conversations Podcast grew further in 2022. Launched in September 2021, a further two seasons were released in 2022, with six episodes in September and a further five in November. Gold Ribbon Conversations explores various aspects of childhood cancer to support families living with and beyond childhood, adolescent and young adult cancer.
- Guests include parents who are going through treatment, parents of survivors, bereaved parents, parents who have struggled with their own mental health and that of siblings, siblings, adult survivors, oncologists, psychologists and teachers. The podcast is available on all podcast platforms and has over 5,500 downloads to date.

- **Engagement**

- In 2022, we had significant engagement with parents and survivors through surveys and focus groups, ensuring that we are listening to and learning from childhood cancer families and survivors to campaign for their unmet needs to be met.
- We also facilitated parents and survivors to attend European conferences, providing an opportunity for shared learning and participation. In 2022, parents and survivors attended the CCI (Childhood Cancer International) Europe conference, PanCare (focus on survivorship) and SIOP Europe.

## 30. CAYA Patient Perspective

### 30.1 Highlight of achievements to date

- The presence of multiple patient representatives at the NCCP AYA framework launch in April 2022 demonstrates the central role patients have played in the development of this new framework to guide service needs.
- The development of the YPAG group, made up of CAYA patient representatives, by coordinated Dr Peter McCarthy to encourage PPI in CAYA cancer research.
- The design of the new AYA space in St James' Hospital led by patient representatives.
- The success of CAYAS survivorship conference in September 2022 which brought together patients, parents and professionals to knowledge share.

### 30.2 Work in progress

- CAYA patient representatives in Ireland have an ever-increasing presence in using their own experience to shape age-appropriate service provision, research and design of new units.

### 30.3 Development opportunities for 2022-2026

- To expand patient representatives amongst the NCCP subgroups to represent a broader wealth of experiences.
- To engage with CAYA representatives in shaping the design of dedicated spaces in new children's hospital and AYA units.
- To continue recruitment of CAYA patient representative to the YPAG group to encourage ongoing engagement with PPI in relevant research.
- To improve supports for our CAYA community in returning to education and the workplace after treatment.
- To make our voices heard on the proposed EU directive "The Right to Be Forgotten" to ensure our CAYA community are not facing financial burdens with life-long penalties on insurance premiums.

## 31. AYA Education Day 2022

### 31.1 Highlight of achievements to date

- The first multidisciplinary Adolescent and Young adult cancer education day was held on the 21st November 2022 at St. James's Hospital in conjunction with the Irish Cancer Society and the NCCP.
- 41 people attended the study day and there was a range of disciplines there including, nursing, medical, genetic counselling, medical social work and radiation therapy.
- Sessions were delivered by Dr Maria Cable, Prof Owen Smith and Dr Peter McCarthy.
- Topics covered included AYA cancer care in Ireland, Adolescent Cancer, the impact of cancer on an AYA and engaging with AYAC. There was also a talk from an AYA patient.

### 31.2 Development opportunities for 2022-2026

- We aim to hold similar education days across the AYA network in 2023.



**AYA patient Karl Corcoran with Niamh O'Sullivan, AYA Cancer ADON**



**Attendees at the AYA Education day held at St. James's Hospital in November 2022**

## 32. 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.

**CLG:** Clinical Leads Group: The Clinical leads Group is a group of multidisciplinary health professionals with expertise in a particular area. The group consists of highly motivated professionals, which might include medical doctors, consultants, nursing, programme managers, allied health professionals, cancer data managers, charities, and patient reps.

**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 National Cancer Strategy 2017-2026:** This document produced by the Cancer Policy Unit, Department of Health for the strategic planning of cancer care in Ireland through the period 2017-2026.



