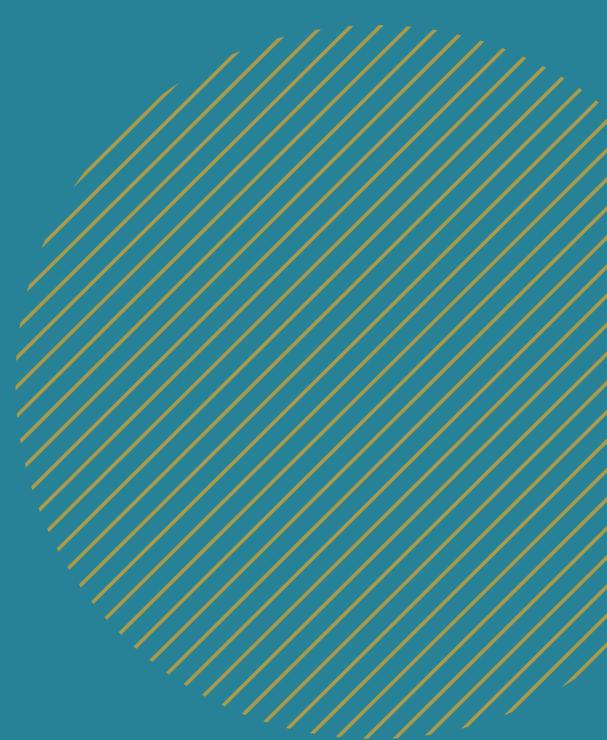
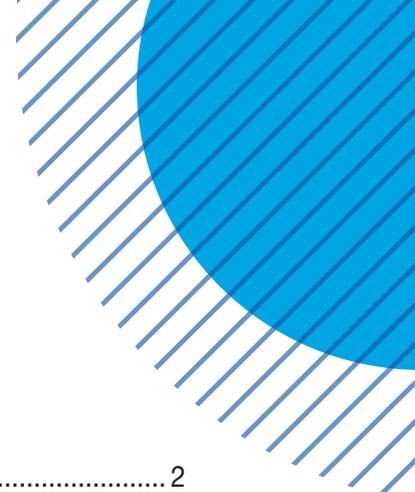


NCCCP Child, Adolescent and Young Adult
(CAYA) Cancer Annual Report

2023





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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 2023. 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.

During 2023, the multidisciplinary and multi-agency partners involved continued to make significant progress towards implementing the strategy and improving cancer care for children, adolescents and young people with cancer and their families. The particular focus on implementation of cancer services for adolescents and young adults (AYA) at the three designated AYA centres is supporting 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.

Some of the key achievements in 2023 included the following:

- Development of the Standard Operating Procedure for the regional AYA units.
- Development of the key performance indicators for the AYA units, which will be piloted in 2024
- Appointment of an AYA Cancer MDM Co-ordinator and Data Manager at CHI at Crumlin
- Appointment of three NCCP AYA Data/MDM Managers at each AYA Cancer Centre
- Appointment of two NCCP AYA Clinical Nurse Specialists (CNS), one each at Galway University Hospital and St James's University Hospital
- Appointment of a Paediatric Oncologist with a special interest in cancer genetics in CHI at Crumlin.

This report outlines the progress and achievements in 2023 in the area of CAYA cancer care. I would like to express my gratitude to the multi-disciplinary cancer teams, cancer charities, and CAYA cancer patients and their families, who have worked tirelessly to develop optimum cancer care for CAYA cancer patients.

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

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

3. Acknowledgements

We would also like to acknowledge in particular the following:

1. NCCP CAYA Clinical Lead: 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, Childhood Cancer Ireland
3. Fertility Chair: Dr Maebh Horan, Consultant Obstetrician & Gynaecologist at the National Maternity Hospital and Merrion Fertility Clinic
4. Palliative Care Chair: Dr Fiona McElligott, Palliative Care Consultant, CHI at Temple Street
5. Survivorship Chair: Dr Michael Capra, Consultant Medical Oncologist, CHI at Crumlin
6. CUH AYA Clinical Lead: Dr Eoghan Molloy, AYA Clinical Lead Consultant Haematologist, CUH
7. GUH AYA Clinical Lead: Dr Amjad Hayat, Consultant Haematologist, GUH & Dr Niamh Keane, AYA Clinical Lead, Consultant Haematologist, GUH
8. SJH AYA Clinical Lead: Dr Larry Bacon, AYA Clinical Lead, Consultant Haematologist, St James's Hospital
9. Dr Scheryll Alken, Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
10. Dr Peter McCarthy, Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
11. Ms. Niamh O'Sullivan, Assistant Director of Nursing, for AYA Cancer CHI at Crumlin and St James's Hospital, Dublin
12. Dr Noelle Cullinan, Consultant Medical Oncologist, CHI at Crumlin
13. Ms Sarah Lawrence, AYA Cancer MDM Co-ordinator & Data Manager, CHI at Crumlin
14. Ms Fiona Bonas, Assistant National Director (AND), NCCP
15. Ms Eileen Nolan, National Programme Manager, NCCP
16. Mr Brice Antao, Paediatric Network Lead, CHI & Consultant Paediatric Surgeon, CHI at Crumlin
17. Ms Cathleen Osborne, Assistant Director of Nursing, Cancer Survivorship, NCCP
18. Dr Chiara Besani, Principal Clinical Psychologist, National Children Cancer Service, CHI, Crumlin
19. Ms Dee Ahearn, CEO, Barretstown
20. Dr Clodagh Ryan, Consultant Paediatric Haematologist, Mercy University Hospital, Cork
21. Ms Evelyn Griffith, Manager, Canteen Ireland
22. Ms Fiona O'Loughlin, Shared Care Manager Haematology / Oncology Unit, CHI at Crumlin
23. Ms Frieda Clinton, Advanced Nurse Practitioner Haematology/Oncology, CHI at Crumlin
24. Dr Helen Grealley, Clinical Lead for Psycho Oncology, NCCP
25. Dr Ian Dawkins, Senior Data Analyst, Cancer Intelligence Unit, NCCP
26. Professor Imelda Coyne, Professor of Nursing, Trinity College Dublin

27. Dr Karen O'Neill, Patient Representative, Specialist Registrar, Neonates, Coombe Hospital
28. Dr Katherine Gavin, Project Manager Childhood Cancer Survivorship Project, CHI at Crumlin
29. Ms Louise Mullen, National Lead for Cancer Survivorship, NCCP
30. Ms Mary-Claire Rennick, Director, Childhood Cancer Ireland
31. Professor Michaela Higgins, Consultant Medical Oncologist, St Vincent's University Hospital
32. Ms Amy Nolan, Head of Children Adolescent and Young Adults at Irish Cancer Society.
33. Dr Patricia Daly, Consultant Radiation Oncologist, St Luke's Hospital
34. Ms Patricia Heckmann, Assistant National Director (AND), Chief Pharmacist, NCCP
35. Ms Rebecca Gorman, Advocacy Officer (Children, Adolescents, Young Adults), Irish Cancer Society
36. Ms Ruth McMenamin, AYA Programme Manager, CHI at Crumlin
37. Ms. Sally Downing, Client Director, Primary Care Communications Division, HSE
38. Dr Zanusz Krawczyk, Consultant Haematologist, University Hospital Galway

The NCCP CAYA Programme would also like to acknowledge the members of the following 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 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 Subgroup
- 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. This includes 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 established the following:

- 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 launched 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. This will include developing separate facilities and specialist care teams for these patients.

Once this has been achieved, the challenge will then be to secure the future through education, research/innovation and future service developments. The ultimate aim of the framework is to improve the standards and quality of cancer care provided to AYAs and at the same time define outcome measures of high-quality care for AYA patients across the proposed AYA cancer network as outlined in the Cancer Strategy [2016-2026].

Significant progress has been made in implementing the Framework throughout 2023. For example, the network of Children’s Health Ireland and three AYA designated units base at St. James’s Hospital, Cork University Hospital and Galway University Hospital continue to develop. Site visits took place to each hospital in Q4 of 2023. The AYA clinical leads for each site are in place, and the appointment of two AYA Clinical Nurse Specialists and four AYA Data/MDM Manager Coordinators in 2023. The national AYA MDM has been a significant development in 2023.”

I would especially like to thank Dr Scheryll Alken, Dr Peter McCarthy, Ms Niamh O’Sullivan, Ms Sarah Lawrence, Ms Ruth McMenamin, Ms Fiona Bonas and Ms Eileen Nolan and the subgroup leads (Ms Patricia McColgan, Dr Jane Pears, Dr Maebh Horan, Dr Helen Grealley, 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

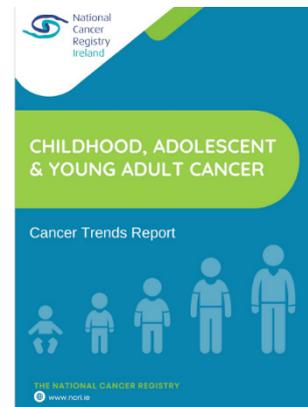
We are delighted to share progress on the implementation of the NCCP Framework for the Care and Support of Adolescents and Young Adults with Cancer in Ireland 2021-2026. Ongoing investment in the three NCCP AYA Cancer Units continued in 2023:

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

This included making a site visit to each NCCP AYA Cancer Unit. The NCCP AYA Cancer Unit Implementation Project Board continues to provide oversight. AYA Cancer Unit Clinical Leads have been appointed in all three AYA Cancer Units. The National AYA MDM was established in 2023, and results are very positive. In 2024 we plan to do a pilot of the national AYA Key Performance Indicators (KPI).

The National Cancer Registry, Ireland (NCRI) published the first report to include cancers in adolescents and young adults (AYA) (up to 24 years of age) in 2023, called "Childhood, Adolescent and Young Adult Cancer-Cancer Trends Report". The main points include:

- Over the period, 2011-2020 on average 191 cancers were diagnosed per year in children (0-15 years). 5-year observed survival for all cancers combined was 87% in children (0-15 years) diagnosed 2011-2019. This has increased from 5-year observed survival of 82% in those diagnosed 2002-2010.
- Over the period, 2011-2020 on average 178 cancers were diagnosed per year in adolescents and young adults (16-24 years). 5-year observed survival for all cancers combined was 90% in adolescents and young adults (16-24 years) diagnosed 2011-2019, this had increased from 87% in those diagnosed 2002-2010.



We will continue to work with our key stakeholders to implement the recommendations of the NCCP AYA Framework 2021-2026, and work with the three national AYA Cancer Units to develop age appropriate AYA cancer units.

Ms Fiona Bonas

Assistant National Director
National Cancer Control Programme

Ms Eileen Nolan

Programme Manager
National Cancer Control Programme

6. Adolescent and Young Adult (AYA) Framework Implementation Update

6.1 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 are appointed in all three AYA Cancer Units. Launch of the NCCP CAYA Annual Report 2022 took place in February 2023.

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

6.2 Work in progress

- Pilot of National AYA MDM planned for Q1 2024.
- Implementation of the recommendations of the NCCP AYA Framework 2021-2026.
- Work with the three national AYA Cancer Units to develop age appropriate AYA cancer units.

6.3 Development opportunities for 2024-2026

- 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.

7. Adolescent and Young Adult (AYA) Cancer Programme at St James's hospital, Dublin (SJH)

7.1 Highlight of achievements to date

The AYA Cancer Team at SJH are meeting regularly and include the following:

- Prof Larry Bacon, AYA Cancer Clinical lead and Consultant Haematologist, SJH
- Ms Louise Kelly, MDM/Data Manager, SJH
- Dr Scheryll Alken, Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
- Dr Peter McCarthy, Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
- Dr Roisin Plunkett, Psycho-oncology
- Dr Sonya Collier, Psycho-oncology
- Ms Alison Enright, SCOPE
- Niamh O'Sullivan, Assistant Director of AYA Cancer Nursing, SJH, CHI at Crumlin
- Joy Lewis, AYA Cancer CNS, SJH
- Joanne O'Mahony, AYA Cancer, CNS SJH, CHI at Crumlin
- Cairenn McDonnell, AYA Cancer Medical Social Worker, SJH, CHI at Crumlin
- Naomi Algeo, Specialist Occupational Therapist, SJH
- Lauren O'Sullivan, Senior Occupational therapist, SJH
- Kelly Coghlan-Lynch, Senior Physiotherapist, SJH
- Laura Kehoe, Medical social worker, SJH



Some Members of AYA Cancer Steering Group, SJH

- Ms Joy Lewis, CNM AYA, Ms Louise Kelly AYA administrator, Cairenn McDonnell (medical social work) and Dr Peter McCarthy (Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin) joined the AYA team in 2023 on a part time basis. All new team members bring extensive experience to their roles.
- Ms Joy Lewis works in a cross- site capacity with 0.2 weekly in CHI at Crumlin.
- Cross-site working is supported across SJH and CHI with co-located appointments. Ms Joanne O’Mahony (CNS), Dr McCarthy and Cairenn McDonnell attend SJH in 0.2 capacity, weekly.
- Weekly outpatient clinic with Dr Scheryll Alken and Dr Peter McCarthy supported by CNS team and SCOPE services in SJH.
- The weekly outpatient’s department catered for 22 new patients in 2023, an increase of 13 from 2022.
- Weekly inpatient AYA Cancer team ward round has also commenced.
- The Hangout is a space for current St. James’s Cancer patients aged 16-24 years to meet monthly non-clinical environment located off hospital site at the *Guinness Enterprise Centre*. It is a unique partnership between The Guinness Enterprise Centre and academic health sciences at The Trinity St James’s Cancer Institute (TSJCI).
- Bite-sized psychology education delivered by Dr Sonya Collier.
- Occupational therapy and Physiotherapy consultations delivered by Kelly Coghlan Lynch, Naomi Algeo and Lauren O’Sullivan.

listened to
 access to hcps
 relaxed
 informal
 chill
 1 to 1 support as needed
 fun
 laugh
 more than cancer
 interactive
 making the plan together
 unique social donut



Attendees say:

- The Hangout has highlighted the continued need for Health and Social Care Professions (HSCP) input for AYA’s with cancer even after acute treatment phases. Building support for further resource in this area.
- AYA unit on Denis Burkitt ward. Four AYA rooms opened for AYA transplant and high dose therapy inpatients. These rooms were co-designed with input from AYA cancer patients.

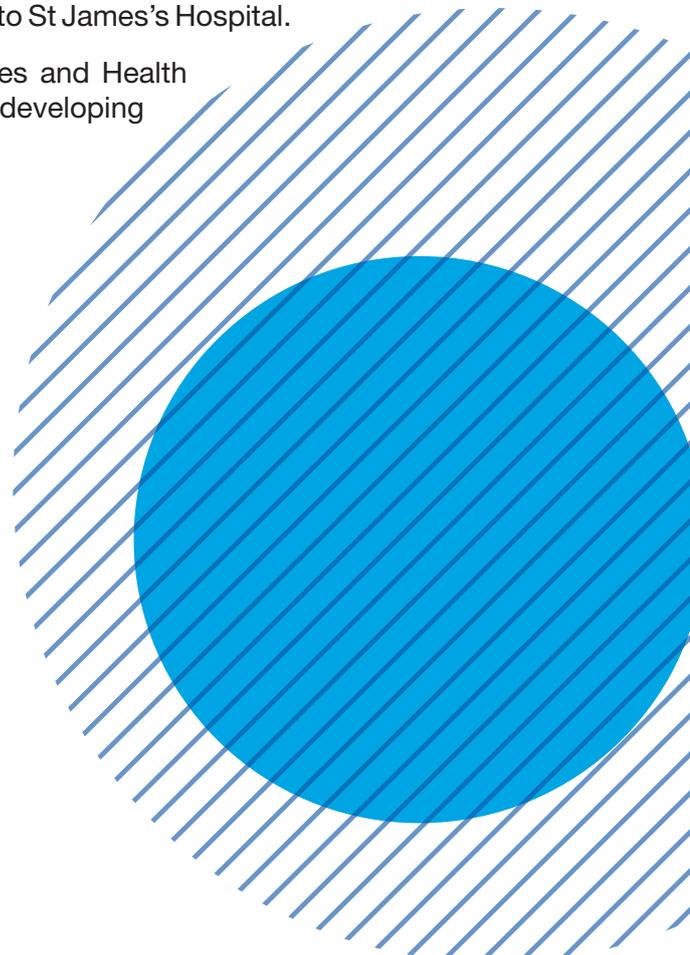
7.2 Work in progress

- Contribute to Organisation of European Cancer Institutes (OECI) accreditation.
- Further development of outpatient service potential.
- Review of AYA Cancer patients of recent years to offer support.
- Identify funding for psychiatry and psychology services.
- Obtain access for AYA cancer clinical trials.
- Research:
 - Naomi Algeo Clinical Specialist Occupational Therapist in collaboration with Trinity College Dublin (TCD) is currently working on an 18-month study which aims to support the needs of adolescents and young adult cancer survivors for successful return to education and/or work.



7.3 Development opportunities for 2024-2026

- The AYA Cancer programme is supported by psychiatry and psychology at SJH on an ad hoc basis due to lack of dedicated staffing. It is a priority for further development.
- Obtain funding for 'The Hangout'. Explore research opportunities and expansion of this forum across Adolescent Young Adult Cancer Service Network (AYACSN).
- Continue regular steering group meetings for AYA facilities on site.
- Development of patient pathway transitioning from CHI to St James's Hospital.
- Secure funding for psychiatry and psychology services and Health and Social Care Professionals (HSCP) support for the developing AYA Cancer Programme at SJH.



8. Adolescent and Young Adult (AYA) Cancer Unit at Galway University Hospital (GUH) Update

The AYA Cancer Team at GUH continues to meet regularly and includes the following:

- Dr Niamh Keane Consultant Haematologist, GUH
- Dr Amjad Hayat, Consultant Haematologist, GUH
- Patricia Gleeson CNS AYA, GUH
- Gillian Ferguson Grade V Data manager AYA, GUH
- Pauline McGough Business Manager Cancer Managed Clinical and Academic Networks (MCAN), GUH
- Olive Gallagher DON MCAN, GUH
- Marie Burns DON GUH
- Maria Molloy Deputy General Manger GUH
- Ellen Wiseman ADON Cancer Services GUH
- Donal Gill Senior Social Worker, GUH
- Aoife Dirrane Social Worker, GUH
- Natalie Hession Principal Psychologist Psycho-oncology, GUH
- Karen Leonard ADON Women and Children’s MCAN, GUH
- Michael McCarthy Medical Oncologist, GUH
- Ronan McDermott Radiation Oncologist, GUH

8.1 Highlight of achievements to date

- Ms Patricia Gleeson commenced as AYA CNS, and Ms Gillian Ferguson Data manager joined the team.
- The establishment of the National AYA MDM.
- Regular steering group meetings held to discuss implementation of AYA supports/facilities.
- On 23rd Oct 2023 the “Building the foundations: Adolescents and Young Adults Education Day” was held in the newly opened Radiation Oncology centre in Galway with great attendance from all centres.
- Scheduled meetings commenced for AYA cancer Psycho-oncology involving the Principal Psychologist, Oncology Social Worker and AYA CNS.

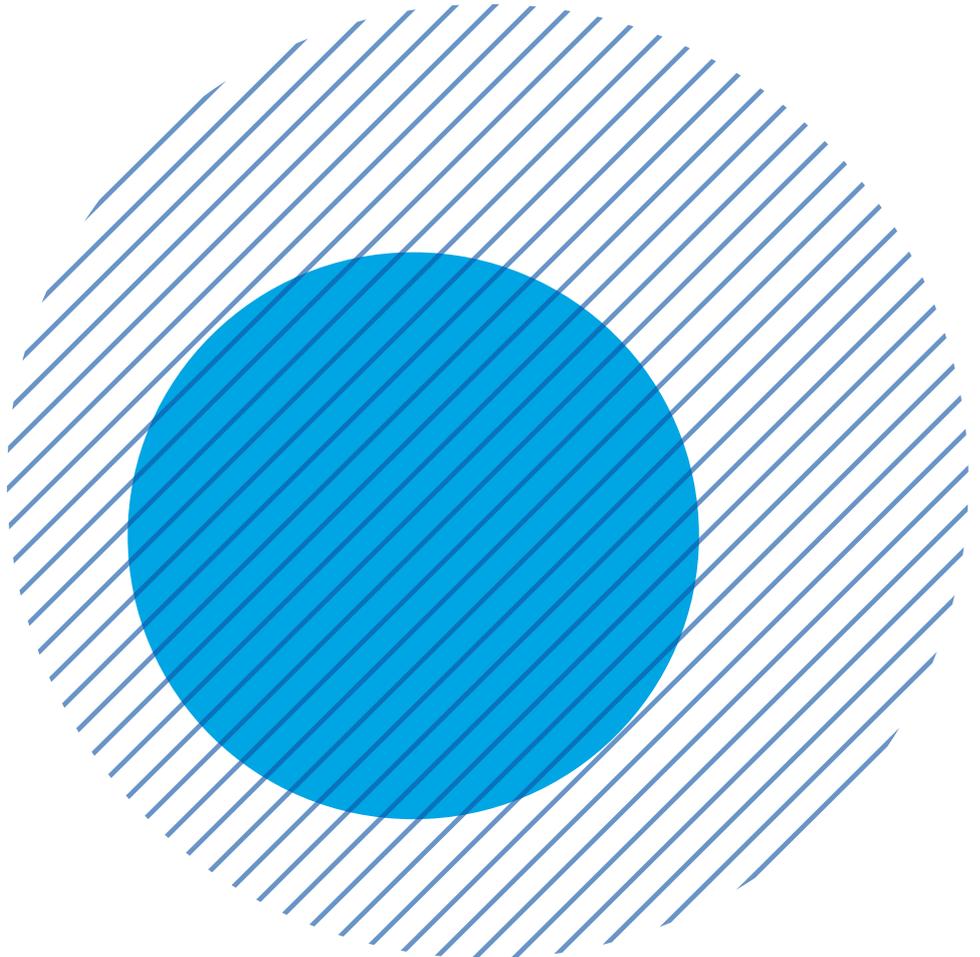


8.2 Work in progress

- Steering group meetings are being held and are well attended regularly.
- A sub-group has been set up with local artist, designer and Arts director GUH, maintenance and Childhood Cancer Ireland to progress décor for AYA facilities in-house.

8.3 Development opportunities for 2024-2026

- The continued development of a data capture system for AYA.
- Continue to develop AYA facilities on site.
- Strengthen AYA psycho-oncology services.
- Attend NCCP meetings and network with CHI and other units.





9. Adolescent and Young Adult (AYA) Cancer Unit at Cork University Hospital (CUH) Update

9.1 Highlight of achievements to date

- The AYA Cancer team at Cork University Hospital (CUH) include:
- Psycho-oncology: Dr Fahmi Ismail, Consultant Psychiatrist.
- Radiation Oncology: Dr Sean O’Cathail, Consultant Radiation Oncologist.
- Haematology: Dr Eoghan Molloy, Consultant Haematologist, AYA Clinical Lead.
- Medical Oncology: Dr Bambury, Consultant Oncologist.
- Palliative Care: Dr Aoife Lowney, Consultant Palliative Medicine.
- ADON Cancer Services: Ms. Jane Shanahan.
- Business Manager Cancer Services: Ms. Michelle Coleman.
- AYA Data Manager: Ms. Paula O’Byrne.
- AYA nurse being recruited.

In 2023, we were delighted to welcome the National Adolescent and Young Adults (AYA) Cancer Unit Steering Group to CUH, led by Professor Owen Patrick Smith, National Clinical lead for Children, Adolescents and Young adult cancers.

- Successful Recruitment of AYA Data Manager.
- AYA Designated Den in GB Ward.
- Fertility Care: patients aged 18-24 confirmed to have access to Cork SIMS IVF.
- National MDM Participation.
- Improvement of timely an KPI mandated access to Systemic Anti Cancer Therap (SACT) treatment for all AYA patients.
- Opening of new Aseptic Compounding Unit to facilitate improved SACT access.

9.2 Work in progress

- CUH are recruiting the CNS and this will structure the pathway for AYA patients.
- AYA designated den in the GB ward.
- AYA Cancer Data Manager now in place.
- Childhood Cancer Ireland are working with the AYA Cancer Team at CUH to develop appropriate clinical spaces for AYA Cancer Patients.

9.3 Development opportunities for 2024-2026

- Working with CUH Cancer Programme Board to plan AYA inpatient beds in planned new Haem/Onc infrastructure project 2025/26.
- Access to Clinical Trials (Local and National).
- Development of care pathways for AYA patients in Regional Health Area/Munster.

10. National Children's Cancer Service at Children's Health Ireland at Crumlin

10.1 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.

10.2 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.

10.3 Development opportunities for 2024-2026

- 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 Haematopoietic Stem Cell Transplantation (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).

11. AYA Cancer Communications

11.1 Highlight of achievements to date

- During 2023, 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.
 - NCCP Communications Workshop and Plan Developed.
 - Interviews on National Radio and the National and Medical Press.
 - Health Matters HSE Publication in 2023.
 - Young Persons Advisory Group (YPAG) Video recorded.
 - Launch of Psychology-oncology Model of Care Sept 2023.
 - Launch of NCCP CAYA Annual Report 2022 on 15th February 2023.
 - Presented NCCP AYA Framework at EU Conferences.
 - Third CAYAS conference took place in September 2023. This event was a collaboration between Childhood Cancer Ireland (formerly CanCare4living & Childhood Cancer 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.

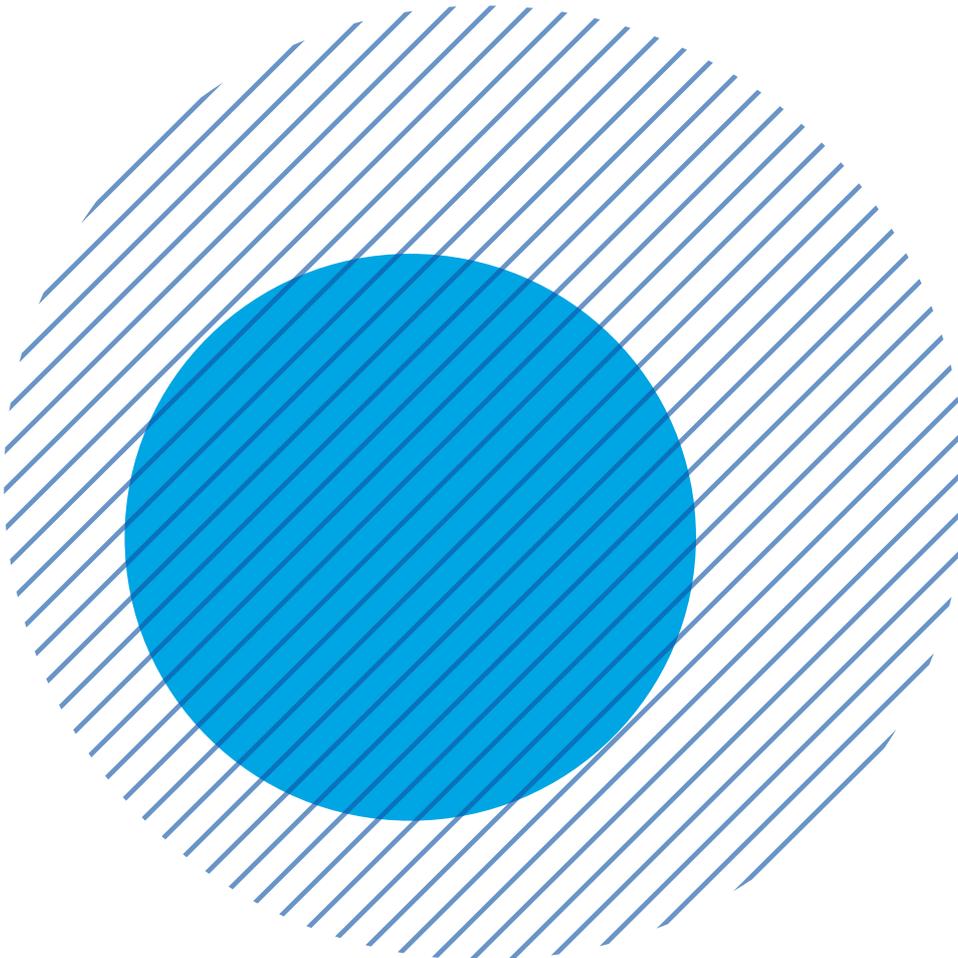


11.2 Work in progress

- 15 Feb 2024 – International Childhood Cancer Awareness Day #ICCD
- 15 Feb 2024 – launch of NCCP CAYAS 2023 Report
- April 2024 – AYA awareness and framework development
- June 2024 – Survivorship awareness
- September 2024 – Childhood Cancer Awareness Month / Light it Up Gold
- Saturday 12th October 2024 – CAYAS Conference
- September 2024– Palliative Care awareness.

11.3 Development opportunities for 2024-2026

- 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 patient and public involvement and engagement
 - Between 2024-2026, 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.



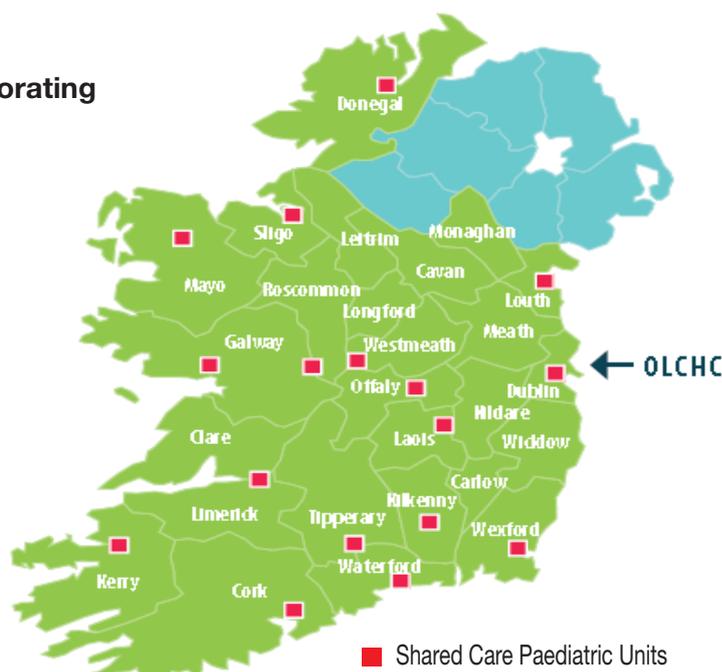
12. Shared Care

12.1 Highlight of achievement to date

The Shared Care Team includes:

- Dr Jane Pears, Consultant Medical Oncologist, CHI at Crumlin
- Ms Fiona O’Loughlin, Shared Care Manager, CHI at Crumlin.
- Access to blood results via Healthlink successfully rolled out to include University Hospital Kerry, just before Christmas. This is in addition to Our Lady of Lourdes Hospital, Drogheda, Mercy University Hospital, Cork, and University Hospital Limerick.
- Vinblastine chemotherapy is offered to our patients in Mayo University Hospital, thanks to the commitment to education sessions by paediatric nursing staff there.
- Resumption of normal service in the Paediatric Department in Wexford General Hospital following the fire there in 2023. Many thanks to the teams in University Hospital Waterford and St Luke’s General Hospital, who stepped in to the breach and helped care for our patients in the interim.
- Well attended Education days took place in the following:
 - Tipperary University Hospital
 - Limerick University Hospital
 - University Hospital Waterford
 - Letterkenny University Hospital
 - Midland Regional Hospital, Tullamore
 - Portiuncula University Hospital
 - University Hospital Kerry, Tralee.
- National Shared Study Day kindly hosted by Barretstown in May, attended by over 60 delegates from around the country.
- Supportive care Guidelines officially celebrated their 10th birthday in 2023. It is hoped to update these in 2024.

Figure 1:
Cancer Service (NCCS) incorporating
the 16 shared care centres

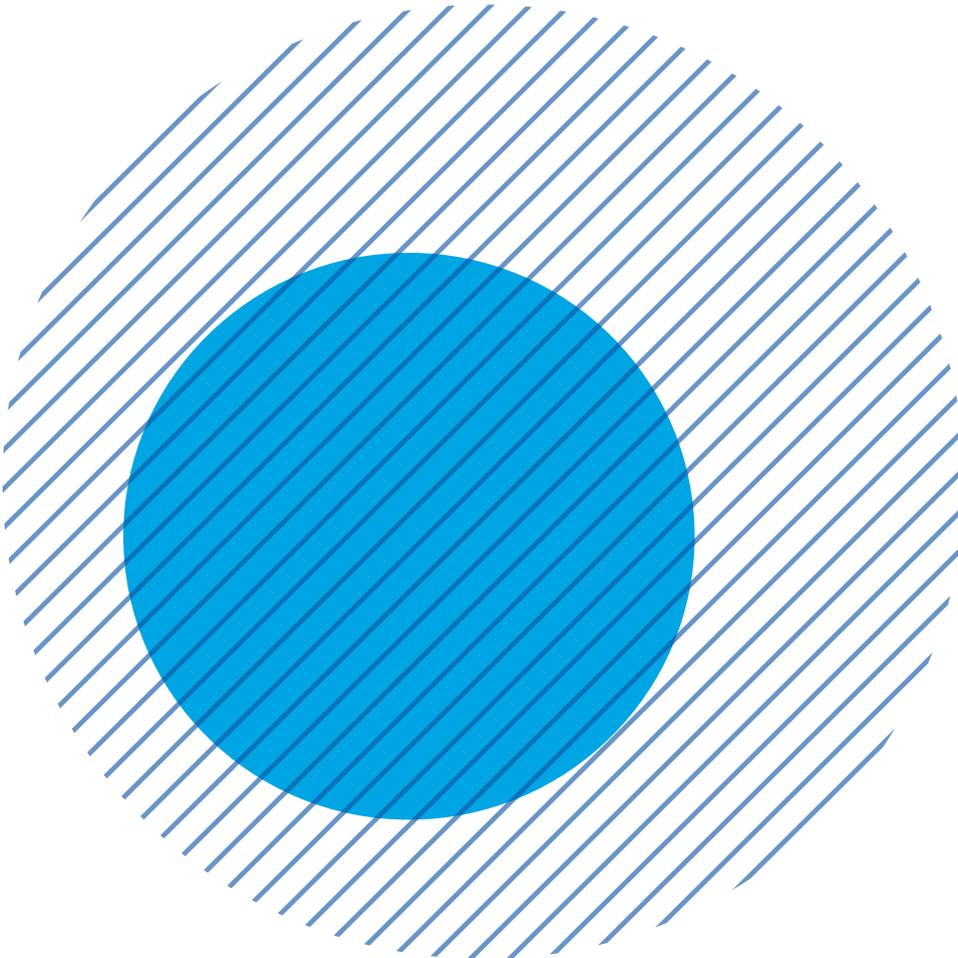


12.2 Work in progress

- Updating of shared care guidelines
- St Luke's General Hospital, University Hospital Waterford, Wexford General Hospital, Tipperary University Hospital, Clonmel are next in line for Healthlink access, with Saolta Group (Galway and Portlincula) to follow.

12.3 Development opportunities for 2024-2026

- Ongoing commitment to education sessions, with next shared care study day planned for Galway in April 2024.
- Consolidate chemotherapy administration in shared care centres.
- Audit of phone call queries from shared care centres to Non-Consultant Hospital Doctor (NCHD) with aim of facilitating improved communication by dedicated shared care phone and/or email.



13. Fertility

13.1 Highlight of achievements to date

- Model of care operational and working very well for sperm and egg freezing at Merrion Fertility Clinic (MFC) for AYA requiring fertility preservation prior to gonadotoxic treatment (gametes stored for 51 boys and 22 girls).
- Assessment clinic and fertility preservation services established for female cancer survivors, extended to include young women up to 26 years.
- Funding provided by MFC 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.
- Public/patient Webinar 'Fertility considerations in AYA Cancer' (April 5th 2023), hosted by Irish Cancer Society, guest speakers from Merrion Fertility Clinic and Children's Health Ireland.
- National Healthcare Professional Study Day 'Fertility preservation services for children, adolescents and young adults in Ireland' (May 29th 2023, National Maternity Hospital).
- Collaborative study between CHI and MFC on 24-month follow-up of female childhood cancer survivor ovarian reserve; manuscript published in Irish Medical Journal (Ir Med J. 2023 Jun 29;116(6):785).
- Cross-sectional survey-based study examining Patient and Parent/Guardian experiences of the CAYA Fertility Service in Merrion Fertility Clinic; manuscript in preparation, abstract accepted for poster presentation at British Fertility Society meeting Edinburgh Jan 2024.

13.2 Work in progress

- Outreach to oncology/haematology AYA healthcare providers at adult hospitals to ensure fertility preservation service offered to all AYA (<18yrs) patients in Ireland.

13.3 Development opportunities for 2024-2026

- Business case for urgent HSE/Department of Health funding of AYA sperm and egg freezing services (previously funded by an Irish Cancer Society grant, expired Dec 2023).
- Care pathway for male survivors of childhood/adolescent cancer.
- Care pathway (fertility assessment and counselling) for post-cancer treatment AYA patients who availed of egg/sperm freezing, as part of continuum of care.
- Development of ovarian and testicular tissue freezing service for pre-pubertal children in Ireland.
- Development of option of surgical sperm retrieval for AYA males unable to produce sample by ejaculation. Collaboration with British Fertility Society, Fertility Preservation Discussion Forum (FPDF).

14. Psycho-Oncology

14.1 Highlight of achievements to date

- The following are core members of the psycho-oncology team:
 - Dr Helen Greally, National Clinical Lead in Psycho-Oncology, NCCP
 - Dr Chiara Besani, Principal Clinical Psychologist at Children’s Health Ireland at Crumlin, CHI at Crumlin
 - Ms Niya Mateeva, National Project Manager for Survivorship and Psycho-Oncology, NCCP.

CAYA:

- The National Cancer Control Programme (NCCP) and Children’s Health Ireland (CHI) at Crumlin were delighted to launch the CAYA Model of Care for Psycho-Oncology services for patients aged 0-24 years and their families on May 17th. The primary aim of the Model of Care is to provide a blueprint for the provision of psychosocial and psychological support services for children, adolescents and young adults (CAYA) with cancer over the lifetime of the current National Cancer Strategy (2017-2026) and beyond. The launch brings to fruition the work that has been developing in CAYA Psycho-Oncology over the past decade by hospitals and charities. While cancer is recognised as a potentially traumatic life event for CAYA, the aim of the MoC is to provide a framework to minimise the psychological, neurocognitive and psychosocial aspects of a cancer diagnosis and contribute to improved long-term quality-of-life for our patients. This Model of Care was presented at national and international conferences by its authors Dr Helen Greally, Dr Chiara Besani and Ms Deirdre Love.
- The AYA Service network has established AYA MDMs and Psycho-Oncology has been an important contributor to these meetings with many consultations taking place over the year.
- Under the auspices of the Psycho-Oncology programme at the NCCP and with the support of Prof Owen Smith, Clinical Lead for CAYA, specific recommendations of the MoC concerned with provision of services for 16 to 18 year olds have been addressed and continue to be reviewed in 2024.

National Paediatric Psycho-Oncology Service:

- The NCCP and CHI launched the National Paediatric Psycho-Oncology Service within the National Children’s Cancer Service (NCCS), CHI at Crumlin on the same day as the launch of the MoC. Over the past decade a motivated group of professionals, led by Dr Chiara Besani and supported by Professor Owen Smith and by Dr Helen Greally, has come together to redefine Psycho-Oncology care in the NCCS. The aim of the National Paediatric Psycho-Oncology (NPPO) is to provide every child and adolescent going through a cancer journey with equity of access to the optimal Psycho-Oncology practice based on international best practice, and in line with the recommendations of the National Cancer Strategy. Significant funding is needed to achieve this aim.
- The Psycho-Oncology team participates regularly at AYA MDMs.
- International Research in CAYA: the NPPO has joined as a local collaborator in the work of Prof Anne-Sophie Darlington and the EORTC Quality of Life group, participating in research, exploring measures to assess quality of life in CAYA.
- The NPPO has commenced the Psychology Maintenance Clinic for children with ALL, collaborating with the medical and nursing maintenance clinic.
- The NPPO is collaborating with the ALLTogether clinical trials group to hopefully open in 2024 in Ireland the “Biomarkers to Reform Approaches to therapy-Induced Neurotoxicity (BRAIN) Sub-study Protocol” and “Interfant-21 (ALL)”. This is dependent on available resources.

14.2 Work in progress

NCCP:

- The Psycho-Oncology programme within the NCCP will continue to collaborate with relevant stakeholders to continue to progress the relevant recommendations from the MoC.

NPPO:

- At present the service is struggling to offer basic care for CAYA with cancer because the HSE embargo has blocked 2 of the 5 permanent post we had secure funding for. These posts were vacant due to staff leaving the service. Once the posts are released we will be able to continue with the development of the NPPO service.

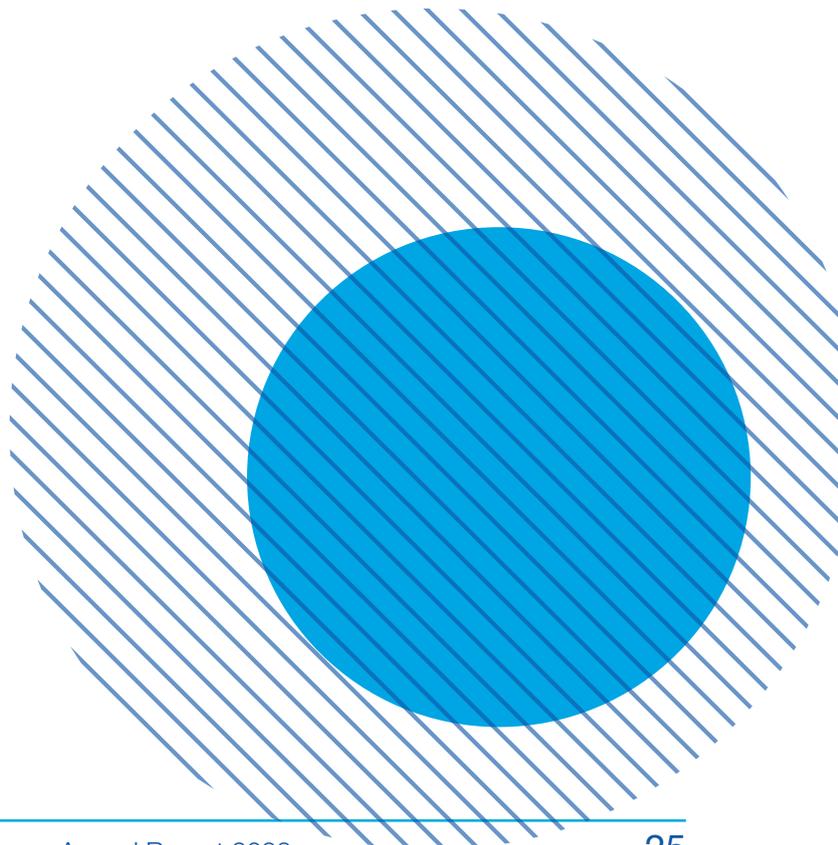
14.3 Development opportunities for 2024-2026

NCCP:

- The NCCP is exploring the possibility of bringing invited guests with expertise and lived experience in the age group of 16 to 18 years to discuss relevant topics of transition within this age cohort.

NPPO:

- International collaboration:
- International clinical research collaboration started in 2023 to seek funds to open in Ireland an “Early Infancy 0-3 clinic” across different type of cancers, offering a systemic and developmental based attachment and neurocognitive assessment and intervention program. Infancy collaboration with St Jude’s Hospital. Depending on securement of funds.



15. Palliative Care

15.1 Highlight of achievements to date

The CAYA palliative care team include the following:

- Dr Fiona McElligott, Consultant in Palliative Care, Temple Street, CHI at Crumlin
 - Dr Hannah Linane, AYA Palliative Medicine Fellow
 - Dr John Allen, Consultant in Palliative Care, CHI at Crumlin
 - Dr Maeve O'Reilly, Consultant in Palliative Care, St Luke's Hospital, St James's Hospital
 - Dr Marie Twomey, Consultant in Palliative Care, CHI at Crumlin
 - Dr Mary Devins, Paediatrician in Paediatric Palliative Medicine CHI at Crumlin.
- Completion of two years by AYA Palliative Medicine Fellow inclusive of Adolescent Health MSc and a placement in Palliative Medicine Service in Princess Margaret Cancer Centre, Toronto to observe local AYA palliative and oncology service.
 - Representation on and advocacy to the HSE National Transition of Care Working Group.
 - Representation on international and national groups focused on the provision of palliative care for the AYA population.
 - Incorporation of KPI 8 within the framework For CAYA palliative care in conjunction with HSE Palliative Care Programme.
 - Collaboration with Steering Group to develop a new Palliative Care Policy for Adults, specifically advocating for AYA palliative care to be an identified component of National Policy for Palliative Care 2023/2024.
 - 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.

15.2 Work in progress

- Ongoing delivery of education on AYA palliative care to paediatric and adult based healthcare services nationally.
- Grant awarded to AYA Palliative Medicine Fellow from The Royal City of Dublin Hospital Trust to support a PHD investigating ways to support provision of palliative care for adolescents and young adults.
- The continued support in the development of a business case and a job description for additional CAYA consultants in palliative medicine as part of the HSE Palliative Care Programme.
- Development and introduction of an adapted palliative care needs assessment within developing AYA cancer service.

15.3 Development opportunities for 2024-2026

- Restructuring of the group in acknowledgement of the need for multi-professional input. Group to reform Q1 2024.
- The Palliative Care subgroup will progress funding applications and continue service development in delivering palliative care to the AYA population, informed by outputs from targeted research investigating ways to support provision of palliative care for adolescents and young adults. This will have a particular emphasis on the appointments required for the initial phase of implementation.
- The Palliative Care subgroup will continue to promote and advocate for further development multidisciplinary palliative care provision within existing and growing paediatric and adult palliative services to cater to the needs of the AYA group.

16. Radiation Oncology

16.1 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.
- Implementation and participation in CAYA psychosocial MDT in St. Luke's Radiation Oncology Network to capture CAYA patients attending for radiotherapy.

16.2 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.

16.3 Development opportunities for 2024-2026

- 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.

17. Adolescent Young Adult (AYA) Education Programme

17.1 Highlights of achievements to date

The AYA Cancer Education day was delivered on 23rd October 2023, hosted by the AYA Programme at Galway University Hospital. The event, sponsored by the Irish Cancer Society, consisted of topics about AYA cancer, adolescence and young adulthood, psycho-social perspectives on the impact of AYA cancer, updates on the psychological oncology model of care for children and AYA cancer in Ireland. The sessions were delivered by a multi-disciplinary line-up. The day concluded with a workshop on communication with AYA's on complex topics.

An enormous thank you to our sponsors, The Irish Cancer Society and Amy Nolan and Claire McCall for their generous effort and contribution in delivering a very successful day.

A huge thank you to wonderful colleagues from Teenage Cancer services in Northern Ireland, who added a great depth of knowledge and expertise; Lisa Callendar, Teenage Cancer Trust Clinical Nurse Specialist at South Eastern Belfast Trust and Simon Darby, Lead social worker at Young Lives Vs Cancer.

The day was also supported by Dr Hannah Linane, AYA palliative care fellow who provided expert knowledge and advice in navigating complex end of life scenarios. Dr Maebh Horan of the Merrion Fertility Clinic also attended to provide support in fertility queries and practicalities.



Attendees at AYA Cancer Education Day 2023

17.2 Work Ongoing at Present

Nursing Education: The AYA Cancer nursing team provided local and national education to peers throughout 2023. Regular contributions to MSc programmes for cancer nursing at Trinity College Dublin (TCD) & SJH and to UCD postgraduate nursing students through CHI at Crumlin.

Multi-disciplinary Education: Dr Scheryll Alken and Ms Niamh O'Sullivan provided education to MSC Survivorship students through SJH and TCD.

Medical Education: NCHD teaching and inclusion in medical orientation to CHI

- Contribution to local teaching and AYA Cancer awareness week for all disciplines.
- AYA Cancer MDM weekly.
- Lecture at MSc survivorship affiliated with TCD and SJH.

AYA Cancer MDM: Weekly AYA Cancer MDM providing discussions around unique AYA cancer complexities. Multi-disciplinary discussion on care planning and delivery.

Monthly research meeting at CHI: A forum to share current, upcoming and potential research on AYA Cancer. Multi-disciplinary in nature and collaborative in process

- 2024 will host another national AYA Cancer education day in quarter four.
- Continue developing AYA Cancer related education across disciplines and within all levels of healthcare training.
- Continue regular education at local and national levels throughout Adolescent Young Adult Cancer Service Network (AYACSN).

17.3 Development opportunities for 2024-2026

- Assess need for further, more in-depth educational day delivery.
- Enhance presence of adolescent specific healthcare information within current and future education forums.

18. Adolescent & Young Adult (AYA) MDM Development

The following are members of the AYA MDM team:

- Ms Ruth McMenamin, AYA Cancer Programme Manager, CHI at Crumlin
- Mrs Sarah Lawrence, AYA Cancer MDM/Data Manager, CHI at Crumlin
- Ms Paula O’Byrne, AYA Cancer MDM/Data Manager, CUH
- Ms Gillian Ferguson, AYA Cancer MDM/Data Manager, UHG
- Ms Louise Kelly, AYA Cancer MDM/Data Manager, St James’s Hospital
- Prof. Owen Smith, CBE, NCCP National Clinical Lead for CAYA Cancers, Consultant Haematologist, CHI at Crumlin
- Dr Scheryll Alken, Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, CHI at Crumlin, SJH
- Dr Peter McCarthy, Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
- Ms Niamh O’Sullivan, Assistant Director of Nursing for AYA Cancer, CHI at Crumlin.

18.1 Achievements to date

Pilot meeting of National AYA Cancer MDM held on 14 March 2023.

Regular meetings then established:

- 30 MDMs held in 2023, discussing 69 cases in total.

Survey & feedback on MDM process conducted in May 2023.

- Moved to alternating meeting days to maximise attendance options (alternating Tuesdays 1pm and Wednesdays 8am).

Campaign to promote MDM undertaken in August 2023, with over 200 documented individual contacts made.

Four AYA Cancer MDM/Data Managers now in post across the AYA Cancer Service Network.

National MDM SOP finalised and issued.

18.2 Work ongoing at present

Integration of National Cancer Information System (NCIS) within the MDM format

Development of local KPIs & associated data collection, and beta testing of KPIs

Continued engagement and partnership with referral centres.

18.3 Development Opportunities for 2024-26

- Formal review of MDM process during 2024.
- Enhance, develop and expand the National AYA MDM to include referrals from all cancer centres in Ireland.
- Expansion of KPIs to a national level.

19. Adolescent Young Adult Cancer Service Network (AYACSN) Programme Team-Programme manager, MDM Co-ordination and Data Management

19.1 Achievements to date

The AYA CSN team members are as follows:

- Ms Ruth McMenamin, AYA Cancer Programme Manager, Children’s Health Ireland (CHI) at Crumlin
- Mrs Sarah Lawrence, CHI at Crumlin
- Ms Paula O’Byrne, Cork University Hospital
- Ms Gillian Ferguson, Galway University Hospital
- Ms Louise Kelly, St James’s Hospital, Dublin.

2023 saw the recruitment of the programme team for the AYA Cancer Service Network (AYACSN).

Four key appointments were made to support the creation, delivery and maintenance of the AYA Cancer Multidisciplinary Team Meeting (AYAC MDM) and AYA Cancer data registry. All team members bring a varied wealth of healthcare, administrative and clinical experience that will enhance the AYACSN.

- Commencement of AYA Cancer MDM.
- Regular AYACSN programme team meetings.
- Representation at domestic steering groups across AYACSN.
- Partnership forming with adjacent services in local regions and throughout Ireland.
- Delivering AYA Cancer Education Day 2023, hosted at Galway University Hospital.

19.2 Work Ongoing at Present

- Creation of AYA Cancer data set.
- Creating mechanism for collecting, reporting and delivering relevant KPIs.
- AYACSN team development processes.
- Active membership of AYA Cancer MDM.
- Attendance at international conference for an International Childhood Cancer Data Partnership.
- Supporting AYA Cancer awareness week.

19.3 Development Opportunities for 2024-2026

- Commencing pilot collection of AYA Cancer data In relation to AYA Cancer framework KPIs.
- Local and national data repository.
- MDM hosting, maintenance and evaluation.

20. Adolescent Young Adult (AYA) Cancer Nursing Update Children's Health Ireland (CHI)

20.1 Highlight of Achievements to Date

The AYA Cancer Nursing Team includes the following:

- Ms Niamh O'Sullivan, Assistant Director of Nursing, CHI at Crumlin & St James's Hospital
- Ms Patricia Gleeson, Clinical Nurse Specialist, Galway University Hospital
- Ms Joy Lewis, Clinical Nurse Specialist, St James's Hospital & CHI at Crumlin
- Ms Joanne O'Mahony, Clinical Nurse Specialist, CHI at Crumlin & St James's Hospital.

Teams across AYACSN:

- Jane Shanahan, Assistant Director of Nursing CUH
- Ellen Wiseman, Assistant Director of Nursing, GUH
- Jane Murphy, Assistant Director of Nursing, St James's Hospital
- Anne Rynne, Assistant Director of Nursing, CHI at Crumlin
- Teresa Slevin, Clinical Nurse Manager III, CHI at Crumlin.

2023 focused on introducing a Clinical Nurse Specialist (CNS) workforce within the AYA Cancer Service Network (AYACSN).

The AYACSN welcomed three new nursing appointments, bringing extensive nursing experience and skill to the care of adolescents and young adults with cancer. CNS appointments in Dublin work in a cross-site capacity with 80:20 split between SJH and CHI.



In Photo from Left to Right:

*Ms Joanne O'Mahony commenced in CHI at Crumlin and St James's,
Ms Patricia Gleeson commenced in Galway University Hospital,
Ms Joy Lewis commenced in St James's and CHI at Crumlin*

- Establishing AYACSN meeting.
- Nursing membership across network steering groups.
- Doubling patient attendance at 'The Hangout' in St James's.
- Creating clinical partnerships with adjacent services at all AYA Cancer centres.
- Presentation at national and international conferences.
- Nursing representation on NCCP steering groups related to AYA Cancer Programme.



20.2 Work in progress

Highlight of Achievements to Date

- Assessment and review and tailored care delivery to AYA Cancer patients in both inpatient and outpatient setting within the AYACSN.
- Provision of expert advice for national AYA Cancer MDM.
- Creation of education pack for AYA cancer patients.
- Establishing clinical and community partnerships focused on the care of AYA cancer patients.
- Active support for clinical teams outside of AYACSN.
- Developing research agenda for AYA Cancer nursing.
- Develop training and education opportunities for AYA Cancer nursing.

20.3 Development opportunities for 2024-2026

- Continue to grow clinical and community network.
- Recruitment of AYA Cancer CNS to the programme team at CUH, Cork.
- Developing national AYA cancer nursing research portfolio.
- Team development across AYACSN.

21. Adolescent Young Adult Cancer Service Network (AYACSN) at Children's Health Ireland (CHI)

21.1 Highlight of Achievements to Date

The AYA Cancer Nursing Team includes the following:

- Ms Niamh O'Sullivan, Assistant Director of Nursing, CHI at Crumlin & St James's Hospital
- Ms Joanne O'Mahony, AYA CNS, CHI at Crumlin and SJH.

21.2 Work in progress Highlight of Achievements to Date

- Assessment and review and tailored care delivery to AYA Cancer patients in both inpatient.

21.3 Development opportunities for 2024-2026

- Continue to grow clinical and community network.

22. Adolescent Young Adult Cancer Service Network (AYACSN) at Children's Health Ireland (CHI)

22.1 Highlight of Achievements to Date

The AYACSN Team includes the following:

- Dr Scheryll Alken, Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, CHI at Crumlin, SJH
- Ms Niamh O'Sullivan ADON AYA Cancer, CHI at Crumlin, SJH
- Dr Peter McCarthy, Consultant Haematologist s.i. AYA Cancer, CHI at Crumlin, SJH
- Ms Ruth McMenamin, Programme Manager, CHI at Crumlin, SJH
- Ms Joanne O'Mahony, AYA CNS, CHI at Crumlin, SJH
- Mrs Sarah Lawrence, Data Manager/MDM Co-ordinator, CHI at Crumlin, SJH
- Ms Cairenn McDonnell, AYA Medical Social Worker, CHI at Crumlin, SJH
- Ms Stephanie O'Toole, Senior clinical psychologist, CHI at Crumlin, SJH
- Ms Chiara Besani, Principal Clinical Psychologist, CHI at Crumlin, SJH.

Workforce additions in 2023 included Ms Joanne O'Mahony, Mrs Sarah Lawrence, Ms Cairenn McDonnell. All team mates bring a wealth of experience and commitment to developing AYA cancer services in nursing, data and MDM coordination and medical social work, respectively.

- Formation of CHI steering group for AYA Cancer.
- Formation on monthly research meeting for AYA Cancer service.
- Relaunch of the multidisciplinary AYA Cancer committee.
- Successful AYA Cancer Awareness Week April 2023.
- Attendance and presentation at the Global AYA Cancer congress.
- Reopening of AYA room on St John's Ward, CHI at Crumlin, SJH.
- Membership of NCCP CAYA groups.



AYA Cancer team members at AYA Cancer Global Accord 2023



Reopening of AYAC room on St John's at CHI Crumlin

22.2 Work in progress Highlight of Achievements to Date

Research: AYA REACH- The study combines a retrospective clinical review to assess the demographic characteristics of 16-24 year olds with cancer, a survey of a representative sample examining the level of marginalisation and quality of cancer care experienced, and a qualitative study of the perceptions of staff working with the population.

MDM: National AYA Cancer MDM established and hosted by CHI weekly

Nursing: AYA cancer CNS, Joanne O'Mahony working with AYA cancer patients in CHI and across site with St James's in 20% capacity.

AYA Research Priorities- 'Exploring research together; Identifying research priorities for adolescent and young adults (AYA) with cancer in Ireland'.

A mixed methods study to ascertain what Irish AYA cancer patients consider to be the top research priorities in the field. This project is in its final stages and will be reporting and disseminating in 2024.

Medical Service: Dr Peter McCarthy, Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin, joined The AYA Cancer Programme at CHI in late 2023 as Consultant haematologist, joining Dr Scheryll Alken; Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, CHI at Crumlin and SJH.

- AYA cancer outpatient clinic commenced in both oncology and haematology.
- AYA inpatient ward round in place weekly.
- The programme has catered for over 40 new cases in AYA oncology and haematology in the last six months of 2023.

22.3 Development opportunities for 2024-2026

- Contribute to the development of transition pathway for AYA cancer patients.
- Develop multidisciplinary research portfolio.
- Continue to develop clinical service at CHI and cross-site working with St James's.
- Deliver, monitor and evaluate national MDM in line with AYACSN colleagues.
- Focus on creation of AYA cancer clinical trials.
- Contributing to national survivorship pathways and services for cancer patients.

23. Neuro-Oncology

23.1 Highlight of achievements to date

The Neuro Oncology AYA team at Beaumont University Hospital include the following:

- Ms Denise Andrews, Neuro Oncology AYA CNS, Beaumont
 - Professor Mark Sherlock, Consultant Endocrinologist, Beaumont
 - Dr Scheryll Alken, Consultant Medical Oncologist with s.i. in Adolescent and Young Adult (AYA) Cancer, SJH, CHI at Crumlin
 - Professor Darrach Crimmins, Consultant Neurosurgeon, Beaumont
 - Mr John Caird, Consultant Neurosurgeon, Beaumont
 - Ms Tafadzwa Mandiwanza, Consultant Neurosurgeon, Beaumont
 - Mr Kieron Sweeney, Consultant Neurosurgeon, Beaumont
 - Mr Stephen McNally, Consultant Neurosurgeon, Beaumont
 - Dr David Fitzpatrick, Consultant Radiation Oncologist, Beaumont
 - Dr Patricia Daly, Consultant Radiation Oncologist, Beaumont
 - Dr Naomi Lavin, Consultant Radiation Oncologist, Beaumont
 - Dr Claudia Carvagal (locum), Consultant Radiation Oncologist, Beaumont
 - Dr Liam Grogan, Medical Oncologist, Beaumont
 - Dr Paddy Morris, Medical Oncologist, Beaumont
 - Ms Lisa McAnea, Consultant Neuro Ophthalmologist, Beaumont.
- The Neuro Oncology AYA Outpatient Service at Beaumont Hospital was established in 2016 by for patients aged 16 to 24 by an Oncology CNS (Ms Eloise Cowe) on foot of demand for a service for adolescents and young adults who have graduated from Paediatric Neuro Oncology Programme at CHI Crumlin and Temple Street.
 - This initiative is at Beaumont Hospital without any additional funding.

23.2 Work in progress

- Patients attending this outpatient service have their imaging arranged either at Beaumont Hospital or at their local hospital. In addition, they have phlebotomy as required in relation to their endocrine status. The clinic is held every two months (six clinics per year).
- In 2022, 57 patients attended the service (18 new patients, 39 review patients).
- In 2023, 75 patients attended the service (19 new patients, 56 review patients), which is a significant increase year on year. We anticipate as the survivorship population continues to expand with current treatments for malignant and benign Paediatric neuro oncology the numbers will continue to grow significantly over time.
- Patients transition from the Paediatric Service oncology team from CHI at Crumlin. There is a Paediatric Neuro-oncology Liaison Nurse.
- Patients who receive radiotherapy as children for brain or spinal cord tumours will continue to attend “Late Effects” clinic even after they have been discharged from Neuro-oncology. This operates as a shared care Programme with physicians in the community regarding the ongoing endocrine care of these patients.
- Fertility issues are address in the context of an endocrine assessment. For neurosurgery, there is a continuum of care from the Paediatric service through into the adult service, working across both sites. Endocrine services transition from the Paediatric service in CHI at Crumlin Beaumont.
- Palliative Care Services are provided generally through the regional palliative care provisions and hospice care in the patient’s locality as required. There is a very active Paediatric palliative care service at CHI at Crumlin and Temple Street.
- The AYA general oncology MDT takes place at St James’s University Hospital. Patients with primary CNS tumours who have transitioned to the adult service are discussed at the Adult Neurooncology MDT with occasional crossover discussions with the Paediatric medical oncology team in CHI at Crumlin.
- Ancillary supports such as the Irish Cancer Society, Barretstown, Canteen Ireland, Childhood Cancer Ireland are coordinated by CNS specialist nurse and medical social work department.

23.3 Development opportunities for 2024-2026

A dedicated AYA Medical Social Worker (MSW) and Psychologist are a priority for the neuro-oncology service.



24. Laura Lynn

LauraLynn 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, as well as supports to their families. Care is provided free of charge to families, from the point of diagnosis through to end-of-life care and bereavement.

24.1 Highlight of achievements to date

- During 2023, 239 families were supported by the LauraLynn Hospice team in their home, hospital, and hospice.
- There were 100 new referrals, of which 12 were for a child/adolescent with cancer.
- Sadly 21 children/ adolescents with a cancer diagnosis cared for by the LauraLynn Hospice team died during the year, of these children/adolescents were cared for at End of Life to die at home.

24.2 Work in progress

- Opening an additional Community LauraLynn team in Ballinasloe to serve the counties of Galway, Roscommon and Mayo, with further plans to expand the Northwest to provide in home nursing care and music therapy to children/adolescents and their families.
- Extension of the Mallow Team to provide care at home to Children/Adolescents in Limerick, South Tipperary and Waterford with the addition of play therapy to the team.
- Currently there are 321 bereaved families within the LauraLynn community.
- A review of the bereavement care pathway is underway.

24.3 Development opportunities for 2024-2026

- Further collaboration with state and voluntary organisations involved in the delivery of care for children/adolescents with cancer and their family unit.



Laura Lynn Hospice

25. Young Persons Advisory Board (YPAG)



The Young Persons Advisory Group (YPAG) are a group of young people who have or had cancer. YPAG volunteer their time to co-design research for children and young people with cancer in Ireland.

YPAG meet a number of times per year and accept submissions from researchers in all disciplines to co-design and advise on research projects and service design and delivery for young people with cancer.

25.1 Highlight of achievements to date

January 2023: Members of YPAG visited System Biology Ireland at UCD.



After some fun, the group met with a number of early researchers and had a tour of the research labs – both wet and dry labs. The group made important contributions in design of many projects and learned lots about how research is conducted behind the scenes. A huge thank you to Professor Jonathan Bond for his partnership in supporting this YPAG session.

May 2023: Sponsored by the Irish Cancer Society (ICS), YPAG met at the ICS HQ. YPAG made valuable contributions to a number of requests, and had fun learning all about music therapy!

Thank you to Amy Nolan and the CAYA team at ICS for their sponsorship and for hosting this fulfilled YPAG session.

Applications are open to meet with YPAG throughout 2024. All information and application details are available at www.ypag.ie. Find YPAG webinar here: <http://tinyurl.com/Ypag-webinar>



25.2 Development opportunities for 2024-2026

- Co-design and develop research and AYA cancer service improvements across Ireland
- Develop and empower YPAG attendees in scientific and research skills

26. Adolescent and Young Adult (AYA) AYA Cancer Research

26.1 Highlight of achievements to date

The AYA Cancer Research team includes the following members:

- Prof. Owen Smith, CBE, NCCP National Clinical Lead for CAYA Cancers, Consultant Haematologist, CHI at Crumlin
- Dr Scheryll Alken, Consultant Medical Oncologist s.i. in Adolescent and Young Adult (AYA) Cancer, CHI at Crumlin
- Dr Peter McCarthy, Consultant Haematologist s.i. in Adolescent and Young Adult (AYA) Cancer, SJH & CHI at Crumlin
- Dr Charlotte O’Sullivan, AYA Cancer Fellow, CHI at Crumlin
- Ms Niamh O’Sullivan, Assistant Director of Nursing for AYA Cancer, CHI Crumlin
- Mrs Sarah Lawrence, AYA Cancer MDM/Data Manager, CHI at Crumlin
- Ms Joanne O’Mahony, Clinical Nurse Specialist, CHI at Crumlin
- Ms Joy Lewis, Clinical Nurse Specialist, St James’s & CHI
- Ms Patricia Gleeson, Clinical Nurse Specialist, GUH
- Ms Rachael Keating, Senior Physiotherapist, CHI at Crumlin,
- Ms Cliona Godwin, Senior dietitian, CHI at Crumlin
- Ms Ruth McMenamin, Programme Manager, CHI at Crumlin
- Ms Chiara Besani, Principal Psychologist, CHI at Crumlin
- Ms Cairenn McDonnell, AYA Cancer Medical Social worker, CHI at Crumlin.

26.2 Work in progress

- Introduction of a monthly AYA Cancer Research Meeting.
- First meeting held April 3rd 2023.
- Completion of ‘A Re-Audit of the Fertility Preservation Practices at CHI at Crumlin Hospital between January 1st and March 31st 2023.

A Quality Improvement project to optimise the discussion and documentation of the fertility risks of cancer treatment and fertility preservation.

AYA Cancer Research Fellow completing MD on ‘AYA Cancer in Ireland’.

Academic Intern completing project on Transition of AYA Cancer patients from Paediatric to Adult Services.

AYA REACH - The study combines a retrospective clinical review to assess the demographic characteristics of 16-24 year olds with cancer, a survey of a representative sample examining the level of marginalisation and quality of cancer care experienced, and a qualitative study of the perceptions of staff working with the population.

AYA Research Priorities - 'Exploring research together; Identifying research priorities for adolescent and young adults (AYA) with cancer in Ireland'.

A mixed methods study to ascertain what Irish AYA cancer patients consider to be the top research priorities in the field. This project is in its final stages and will be reporting and disseminating in 2024.

26.3 Development opportunities for 2024-2026

Development of a teaching resource for healthcare providers involved in the care of adolescents and young adults with cancer to develop the skills required to discuss fertility risks of treatment and fertility preservation procedures.

27. Survivorship

27.1 Highlight of achievement to date

- Publication of Phase 2 report: Childhood Cancer Survivorship Project Assessment of the needs of childhood cancer survivors in Ireland, 2023: healthcare provider perspectives.
- Launch of the NCCS Survivorship Database.
- Presentation of research findings at the PanCare, (Pan-European network for care of childhood and adolescent cancer survivors), annual conference and Digital Health Conference TCD.

The Childhood Cancer Ireland with support from NCCP and the Irish Cancer Society held the 3rd annual CAYAS conference which took place on the 16th of September 2023. The large gathering was held in Croke Park and attended by; survivors, families, clinicians and other healthcare professionals and academics. The conference included an art exhibition and a display of current research and initiatives of interest.

The Conference programme concentrated on two areas.

- The National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults with Cancer.
- How Survivors and their families can be assisted and supported in their return to education and/or work and what improvements can be made.

The CAYAS conference continues to provide valuable opportunities to gather, learn, network and forge partnerships for co-design and service development.

27.2 Work in progress

- Commence populating Survivorship Database with all newly diagnosed patients in the NCCS.
- Commence populating Survivorship Database with retrospective patients treated in the NCCS.
- All patients graduating from the NCCS to receive their medical treatment summary / survivorship care plan.

International collaborative role within the European for Health (EU4H-2021-PJ2) smartCARE grant (project number 101080048). The aim of this grant is to develop a Cancer Survivor Smart Card to improve the quality of life and health status of cancer survivors, in the form of a mobile application, embracing the core attributes of patient-centred care.



28. Research and Innovation

28.1 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.

28.2 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).

28.3 Development opportunities for 2024-2026

- 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.



Irish Cancer Society

29. Irish Cancer Society

29.1 Highlight of achievements to date

- Creative Arts Therapy – we have launched our national service for CAYA cancer survivors and their siblings to avail of free creative arts therapies in their communities.
- Complementary Therapy – The Irish Cancer Society is funding the Julie Wren complementary therapy post in St. John’s Ward.
- CAYA Camps – We funded and co-designed 7 camps this year in partnership with Barretstown, including a pilot of a bereavement camp for families.
- We held two study days for CAYA healthcare professionals – one on CAYA fertility, the other on AYA cancer care.
- The Irish Cancer Society hosted a briefing on the Early Detection of CAYA cancers in Leinster House.



29.2 Work in progress

- A specialist AYA publication is in progress and due for publication in 2024.
- We are co-designing early detection materials for primary healthcare providers with the NCCP.
- To date, our Irish Cancer Society night nurses have provided end of life care to 29 children in their homes in 2023.

29.3 Development opportunities for 2024-2026

- Our research on the cost of cancer for families will continue, with a publication expected in 2024.

Our essential services for the CAYA group and their families are undergoing continuous improvement processes to ensure support is provided when and where they need it.



BARRETSTOWN

a seriousfun camp

30. Barretstown

30.1 Highlight of achievements to date

- Barretstown served over 17,000 children and family members in 2023 through onsite residential programmes and outreach programmes in hospitals and schools across Ireland. Barretstown's core programmes are open to families affected by childhood cancer, and we continue to serve children affected by cancer through our year-round hospital programme and schools' education programme. In 2023 we celebrated the milestone of having served our 100,000th camper since we opened in 1994.
- We also continued our partnership with the Irish Cancer Society by hosting seven disease specific programmes for families and young adults affected by cancer, serving 322 children and family members and 38 young adults through these partner programmes. We also partnered with the ICS to host a weekend programme for families who have lost a parent to cancer. This pilot programme served 69 family members.
- In April of 2023 we hosted the ACORN Research engagement event onsite and in May we hosted the CHI Haematology/Oncology Shared Care Conference, to engage with the wider medical and research community.

30.2 Work in progress

- In 2024 Barretstown will host 47 Residential Programmes throughout the course of the year as well as a number of day programmes. Our goal is to serve over 22,000 children and family members through programmes. These core programmes will continue to serve families affected by childhood cancer.
- We will continue our partnership with the Irish Cancer Society by providing disease specific programmes for families and young adults with cancer. We will also expand our Young Adult Programme to support more young people between the age of 18-24yrs and our priority is to grow awareness of this programme.

30.3 Development opportunities for 2024-2026

- We have ambitious goals for the years ahead and our 2028 Strategic Plan will see us grow our numbers by 95% serving 33,500 campers per year by 2028. We will continue to focus our programmes to provide support to children and families affected by cancer.



31. CanTeen Ireland

31.1 Highlight of achievements to date

CanTeen Ireland is the national support group for young people between the ages of 12 and 25 years who have or have had cancer and for their brothers, sister and friends. Our aims are to support, empower and develop young people with cancer. The philosophy of CanTeen is one of empowerment with a majority of young people on the steering committee.

In 2023 we continued to support our members both in person and online and via telephone and text support. We held 6 residential weekends away and 9 day support meetings. These residential weekends away give our members the opportunity to connect with each other, support each other and learn some very valuable coping skills in these very challenging times. We go to various activity centres throughout Ireland giving our members the opportunity to participate in activities that they would not have engaged in previously.



Group Photo Barretstown 2023

These activities - indoor / outdoor rock climbing, kayaking, team challenges, arts & crafts etc challenge their perceptions of their abilities and help with their self-esteem. It gives them the chance to get away from it all - hospital, treatments and just be a “normal” teenager not the “sick teenager”, away from their parents and spend time with their peers which is hugely important at this stage in their lives. We also give them the opportunity to make lifelong friendships with their peers who understand exactly what they are going through. CanTeen has only one employee so depend heavily on our volunteer leaders - many of whom are survivors of cancer. This gives them the opportunity to give “something back” and helps them develop their skills working with young people.

We held various workshops regularly – weekly / bimonthly – including music, drama, mindfulness, and makeup workshops (with Look Good Feel Better) throughout the year. We also have a weekly online gaming meeting via Discord which gives our members the opportunity to chat and connect with each other.

CAYAS conference 2023:

The third 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 fully in person in Croke Park. This 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 second conference in 2022.

In November 2022 our new Exercise Programme with Ex Well Medical with weekly exercise sessions via Zoom and once a month we met up for an in person exercise class.. This has been a great success so far and we a plan to continue to offer this to our members throughout 2024 and in the future as part of peer support programme.



Group Photo Delphi April 2023

31.2 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.



Canteen Group Photo

32. Childhood Cancer Ireland

32.1 Highlight of achievements to date

Childhood Cancer Ireland continued our work as a charity founded and led by parents of children and young people with cancer and by 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.
- Funding the **Beads of Courage®** Oncology/Haematology Programme in CHI at Crumlin, which will be extended to other designated centres in 2024.
- Continuing to fund treatment room upgrades and equipment for **Shared Care Hospitals** and working with the newly appointed Adolescent and Young Adult Cancer Service Network Sites – particularly Galway University Hospital and Cork University Hospital.

CAYAS conference

The third 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. The conference was fully in person for the first time, with almost 250 in attendance. The delegates are made up of parents, survivors, clinicians, charities and others with a professional interest or involvement in childhood, adolescent and young adult cancer. The conference included exhibition stands from 20 charities and other service providers.

The patient voice continues to be at the centre of the event, as we heard from parents and survivors on a range of topics including psycho-social care and education.

Advocacy

Childhood Cancer Ireland continued to advocate for families, bringing the issue of access to palliative care to the fore in 2023.

Engagement

In 2023, 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 ran monthly coffee mornings and disease-specific events, such as a coffee morning for parents of children and young people with a brain tumour diagnosis.

We were proud to contribute to the Survivorship project conducted by Dr Michael Capra and Katherine Gavin and to provide feedback on the Model of Care for Psycho-Oncology.

Childhood Cancer Ireland provided valuable contributions to the ongoing work of the NCCP through its membership of the NCCP Communications Committee.

Parent Workshops

In response to feedback from parents via surveys and focus groups, we delivered a series of parent workshops in 2023, entitled: Putting the Pieces Back Together: understanding the experience and taking steps forward. Parents report feeling unsupported after treatment, unsure of how to return to normal family life after their experience of trauma and unaware of what services are available to them. Our workshops bring parents together to validate the experience, normalise feelings, provide and facilitate peer support and provide practical strategies to help with self-care and relationships with partners, children and friends.

Awareness

Our **Light It Up Gold Walk**, which took place for the first time in 2013, returned in 2023, bringing families together to shine a light on childhood cancer and to offer an opportunity for families to come together in hope and remembrance.

Childhood Cancer Ireland's **Gold Ribbon Conversations** Podcast grew further in 2023, with 20 episodes released throughout the year exploring 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, siblings, adult survivors, oncologists, psychologists and other experts.

Access to Play Therapy

Childhood Cancer Ireland launch a pilot programme to provide financial support to parents who wish to access play therapy for children who are out of treatment, or for siblings at any stage. We developed a network of qualified and experienced play therapists around the country and are able to refer parents directly and fund the intervention.

Engagement in Europe

In 2023 we continued our policy of facilitating parents, survivors and clinicians to attend European and international conferences, providing an opportunity for networking, shared learning and participation to address topics of importance to their community. In 2023, parents and survivors attended the SIOPE/CCI (Childhood Cancer International) Europe conference and PanCare (focus on survivorship).

- **CCI Europe:** Childhood Cancer Ireland is an active member of CCI Europe and we serve on the Survivorship Pillar.
- We were invited to present at the **SIOPE/CCI Europe** conference in Valencia in May on the importance of collaboration and on the successful merger of Childhood Cancer Foundation and CanCare4Living to become Childhood Cancer Ireland.
- **EU CAYAS NET:** We are involved in this EU-funded project that supports the creation of a Survivors' network in Europe. In 2023, our activities included peer visits to late effects clinics in Utrecht, Barcelona and Vienna, as well as EU CAYAS NET Ambassador training workshops.
- **EU mission on Cancer:** we participated in conferences and workshops to increase collaboration and improve communication between European organisations involved in the CAYAS community (charities and professional organisations).
- **PanCare:** in collaboration with colleagues from Italy, we organised and facilitated the parents workshop at the PanCare meeting in Ghent in May.
- Also assisted with reviewing of the Plain Guidelines (Information on late effects and recommendations for long term follow up) [PLAIN language summaries – PanCare](#).



33. The Gavin Glynn Foundation

33.1 Highlight of achievements to date

The Gavin Glynn Foundation is the only charity supporting families who need to travel overseas for specialist cancer treatment not available in Ireland.

The Gavin Glynn Foundation arrange all logistics and cover all costs associated with:

- Transportation (eg. Flights, Car Hire).
- Transportation to and from the designated Airports.
- Accommodation within, or close to, the designated medical centre.
- Food and living expenses for the duration of the child's treatment while abroad.

We have supported 40 families in 2023 with travel overseas for childhood and independent international 2nd opinions and 244 families to date over the last 8 years.

We conducted a survey of 240 childhood cancer families on early diagnosis/ Referrals which was shared with NCCP and ICS in 2023 to aid the Early Detection and GP Referral Guidelines project.

33.2 Work in progress

Continued support for all CAYA families for specialist cancer treatment not available in Ireland.

Collaborating with NCCP on Early Detection and GP Referral Guidelines, Advocating for improved early-detection of CAYA cancers, including the development of GP referral guidelines & Childhood Cancer public awareness campaigns.

The Gavin Glynn Foundation is affiliated with the Irish Cancer Society and are members of their CAYA stakeholders group to assist and support the delivery of their strategy.

33.3 Development opportunities for 2024-2026

Strengthen links between The Gavin Glynn foundation and international centres of excellence for childhood cancer treatment not available in Ireland.

Continue to work closely with NCCP to promote early detection and GP Referral Guidelines, and the Irish Cancer Society CAYA Steering Committee.

34. CAYA Patient Perspective

34.1 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.

34.2 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.

34.3 Development opportunities for 2024-2026

- 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.

33. 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.

NCRI: The National Cancer Registry.

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.

