

# ADOLESCENT AND YOUNG ADULT WITH CANCER REGIONAL SERVICE MODEL WORKSHOP

The Pavilion, Stormont Estate, Belfast  
Thursday 3 October 2024

Summary Report and Recommendations

Seamus McGoran  
Associate Consultant  
HSC Leadership Centre  
October 2024

## Contents

Purpose.....	2
Background.....	2
Context.....	3
Ministerial Mandate .....	4
Format of the Regional Service Model Workshop .....	5
Recommendations .....	6
Proposed Structure.....	7
Conclusion .....	7
Appendix 1 .....	9
Key priorities for Subgroups.....	9
Appendix 2 .....	11
Table list of Delegates .....	11
Appendix 3 .....	12
Summary of workshop discussions.....	12
Session 1 - How will Northern Ireland progress the development of this Regional Service Model? .....	12
Session 2: What are the challenges and opportunities we need to address to deliver a best practice regional networked model? .....	13
Session 3: What actions need to be taken to implement the best practice regional networked model?.....	15

## Purpose

The specific purpose of the workshop was to:

- identify the key features of an Adolescent and Young Adult (AYA) Regional Networked Service Model
- understand the key challenges to implementation
- agree the actions which will enable this to be achieved

## Background

Within Cancer Services, AYA refers to patients aged 13 to their 25<sup>th</sup> birthday.

The need for improved services for AYA with cancer has been recognised for many years. This distinct group of patients have complex, and specialist needs associated with not only the uniqueness of their cancer biology but also the recognised challenges of this age and life stage.

AYA with cancer interact with many services including haematology, oncology, medical and surgical specialities, psychology, psychiatry, palliative care, social work, youth work and education with wider support from Allied Health Professionals.

Services are delivered across all five Health and Social Care Trusts.

From 2011-2015 scoping exercises took place to identify the number of AYA across the region who had been diagnosed with cancer between their 13<sup>th</sup> and 25<sup>th</sup> birthdays.

Since 2017-2024 there has been ongoing investment from the voluntary sector to enhance psychosocial support, peer support and age-appropriate environments across the region for all AYA with a cancer diagnosis.

The 2022 NI Cancer Strategy recognised the need for reform within AYA Cancer Services and included Action 33:

---

***Review the provision of services for teenage and young adults in Northern Ireland including transition arrangements, age-appropriate environments, psychological support and long-term follow up.***

---

As a result, in 2023 an external review of AYA services (the Cable Report) and benchmark against other services in NHS and ROI was presented to the Cancer Programme Board.

The review made 21 recommendations clearly recognising key pillars to support the continual improvement of the service within NI. These pillars included the need to establish:

- A clear regional framework/model for service delivery, enabling equitable and resilient multiprofessional interagency services across all settings,
- A robust clinical and strategic leadership structure
- Standards of care that are measurable
- A service in which the voice of AYAs is enabled in respect of their own care and service development

Significant work and engagement since the 2023 review has enabled the development of twelve regional standards which set a high-level outcome that:

---

***‘All adolescents or Young Adults (AYA) with cancer will have equitable and timely access to safe, efficient and effective care. This should be compassionate, holistic and person-centred, and delivered by staff with appropriate skills and competencies in settings that are both clinically and developmentally appropriate.’***

---

## Context

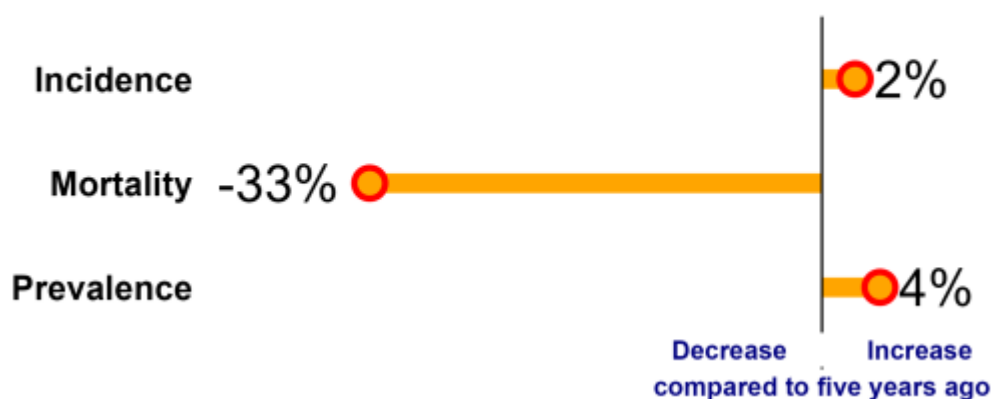
Between 2017 to 2021 each year an average annual incidence of 59 AYA aged between **15 to 24 years** were diagnosed with cancer.

The AYA Service covers **13–24-year-olds** and in 2023 the incidence recorded was 66 cases.

While the five-year survival rate for this age group is 83.4%, with a 33% decrease in mortality rates ,cancer is the most common cause of death from disease in this age group and sadly there continues to be approximately 8-9 deaths each year in Northern Ireland.

### Trends in cancer among young adults

(Cases/deaths: 2017-2021 vs 2012-2016 ; 10-year prevalence: 2021 vs 2016)



Current data demonstrates that around 60% of AYA are treated in Belfast Health and Social Care Trust as their primary centre. This includes those resident in Belfast and those on specialist pathways, for example those with acute leukaemia or brain tumours.

A further 20%, who have primary treatment in other trusts, require additional treatment in the Belfast Trust including radiotherapy, specialist Systematic Anti-Cancer Treatment (SACT) and transplant services.

The remaining 20% are treated in the other four diagnosing trusts (surgery, SACT).

Best practice models which exist within the rest of the United Kingdom and the Republic of Ireland provide an exciting opportunity to create an effective Regional Networked Model for AYA cancers within Northern Ireland.

NHS England has developed service specifications for AYA with cancer services, translating policy into practice. The service specifications are aimed at delivering safe and effective services where adolescents and young adults receive the right care in the right place at the right time. Specifically, the service specifications direct the following:

- Services are delivered via a network with the infrastructure to deliver a range of specialist and sub-specialist expertise to a population
- Designated Principal Treatment Centres (PTC) in both Paediatric and Adult Services
- Designated Hospitals (DH) approved to facilitate aspects of care that are deemed safe to deliver more locally
- Clinical Leadership hosted by PTC's, with operational and strategic leadership at Network level
- Weekly AYA Multi-Disciplinary Meetings (MDM) chaired by Clinical Lead
- Collaboration between Paediatric and Adults services and the voluntary sector within the Network
- All children and young people who use these services should be able to take part in decision making to the fullest extent that is possible.
- Entry of patients to appropriate clinical trials

## **Ministerial Mandate**

The Minister of Health, Mr Mike Nesbitt, in addressing the workshop made it clear that AYA cancer services are an important priority for his department and that the work to date unequivocally provided a clear direction how AYA cancer services should be delivered within Northern Ireland.

It was acknowledged that the development and implementation of a Regional Networked Service Model for Adolescents and Young Adults (AYA) with Cancer

requires meaningful engagement with clinicians, managers, funding charities and with people who have lived experience of cancer.

The NI model will reflect learning from the NHS England service specification and from the model used in the Republic of Ireland.

AYA cancer services in N Ireland will be delivered by a regional, networked service model with Principal Treatment Centres (PTCs) for both Paediatric and Adult services designated at the Belfast trust. The age range for the AYA cancer service is defined as 13th to 25th birthday.

This model is designed to bring the key teams and personnel together that comprise the clinical and holistic components of the pathway of care. The goal of the service model is to enable service users to access the right care in the right place and at the right time, including clinical trials, while benefiting from coordinated holistic and psychosocial support.

This report will provide a summary of the workshop feedback and make recommendations to take forward the implementation of a best practice Regional Networked Model for AYA with cancer.

## **Format of the Regional Service Model Workshop**

The Regional Service Model Workshop was facilitated by Mr Seamus McGoran, Associate Consultant of the HSC Leadership Centre. A background and context of the work was provided by PHA TYA Cancer Service Development Nurse, Bernie McShane.

It was attended by a range of clinical and managerial staff from across the 5 HSC trusts, the Department of Health, the Strategic Planning and Performance Group and the Public Health Agency.

A number of charitable organisations play a key role in the delivery of AYA cancer services. To ensure equality in representation from the voluntary sector, the Department approached the NI Charities Coalition, a group of 33 local and national charities, seeking a nomination to attend the workshop. The nominated voluntary sector representative was the Teenage Cancer Trust (TCT), an invitation for this workshop was extended to TCT. Unfortunately, due to tight timelines, TCT were not able to attend. TCT will continue to be engaged throughout the ongoing development of AYA services.

Nominations were sought for lived experiences representatives from AYA CNS' in all trusts.

Due to education, work and health commitments, we were unable to secure representation on the day from adolescents and young adults.

One parent of an AYA with cancer attended as a representative of those with lived experience. Some parents and young people are interested in contributing, we will continue to engage with them as this work progresses.

A 'Critical Friend' from the Health Service of the Republic of Ireland was also in attendance. A full list of attendees is held at [Appendix 1](#).

Three sessions of table discussions focused on addressing the following key questions:

- 1. How will Northern Ireland progress the development of this Regional Networked Service Model?**
- 2. What are the challenges and opportunities we need to address to deliver a best practice Regional Network Model?**
- 3. What actions need to be taken to implement this best practice Regional Networked Model?**

Each of the three tables identified a scribe to capture the discussion points and nominated someone to present feedback to the wider workshop audience, creating opportunities for further discussion.

A summary of the feedback for each question is outlined at [Appendix 3](#).

## **Recommendations**

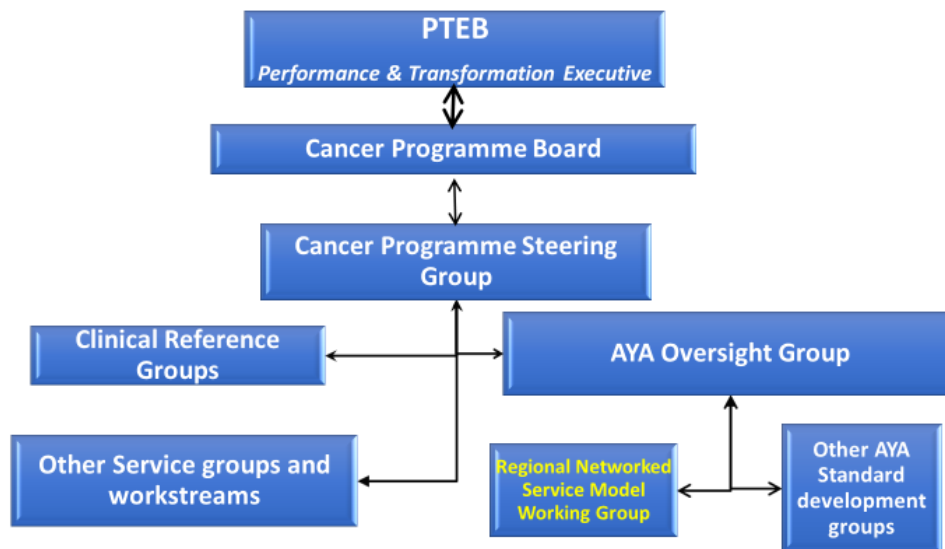
The workshop provided opportunity for positive engaged discussions. Participants provided valuable insights and a commitment to the evolving development of high quality AYA services within NI.

The workshop identified a range of actions which must be taken forward to deliver the new AYA service model which meets the Minimum Standards that have been developed.

The following actions should be prioritised in order to maintain momentum and to ensure timely implementation of the regional network model:

1. The governance and programme structure must include representation at senior level from Belfast Trust. This should be a Lead Director for AYA with cancer to ensure a single point of contact between the Department/SPPG and the Principal Treatment Centre/Network.

## Proposed Structure



2. A Workforce Subgroup should be established to ensure that the Lead Clinician, Lead Nurse and Service Manager posts are recruited as quickly as possible.
3. A Clinical Subgroup, led by the lead clinician and lead nurse (or interim appointments), should be established to ensure that key clinical considerations are addressed throughout this programme of work.
4. An MDM Group, led by the lead clinician and lead nurse (or interim appointments), should be established. This group will be responsible for developing the MDM Terms of Reference, SOP and referral proforma.
5. A Clinical Pathways Subgroup led by the lead clinician and lead nurse (or interim appointments) established to ensure that key clinical considerations are addressed throughout this programme of work.

Key Priorities for each of the above-mentioned Groups are included at [Appendix 1](#)

## Conclusion

Considerable work has been undertaken in recent years in respect of AYA services. It will be important to build on this strong foundation if the region is to see continual improvement and best practice embedded across the AYA service in Northern Ireland.



Acknowledging the invaluable roles of those working in the AYA service and the contribution of all workshop attendees there was a confidence that the advancement of a regional networked model coupled with strong clinical leadership would enable the vision set out by the Minister.

Seamus thanked the attendees for their open and constructive discussions and recognised the high level of enthusiasm for developing a best practice regional networked model for AYA with cancer.

By implementing the above recommendations and by tapping into the ideas, energy and commitment of those working within AYA services the prospects of a successful implementation are extremely high.

## Appendix 1

### Key priorities for Subgroups

<b>Workforce Subgroup</b>
<b>Led By AYA Strategic Oversight Group and Belfast Trust</b>
<b>Key Priorities</b>
<ul style="list-style-type: none"><li>• Recruitment of Lead Clinician</li><li>• Recruitment of Lead Nurse</li><li>• Recruitment of Service Coordinator</li></ul>

<b>Clinical Subgroup</b>
<b>Led by Lead Clinician and Lead Nurse</b>
<b>Key Priorities</b>
<ul style="list-style-type: none"><li>• Planning for clinical changes that will arise from implementation of the network, including the development of new clinical pathways</li><li>• Engaging with Clinical Reference Groups as appropriate when planning service changes</li><li>• Leading the implementation of new ways of working including ambulatory care and the transfer of some care closer to home</li></ul>

<b>MDM Group</b>
<b>Led by Lead Clinician and Lead Nurse</b>
<b>Key Priorities</b>
<ul style="list-style-type: none"><li>• Build on existing work and plan for a new MDM approach which provides holistic clinical and psychosocial care planning for every AYA with cancer.</li><li>• Develop a Terms of reference for the MDM</li><li>• Develop SOP</li><li>• Develop a referral proforma for the AYA service</li></ul>

<b>Clinical Pathways Subgroup</b>
<b>Led by Lead Clinician and Lead Nurse</b>
<b>Key Priorities</b>
<ul style="list-style-type: none"><li>• Identifying an initial tumour group to focus process</li><li>• Planning for clinical changes that will arise from implementation of the network including impact analysis using data on 16–18-year-old diagnosis</li><li>• Engaging with NICA Tumour site Clinical Reference Groups as appropriate when planning service changes</li><li>• Maximising engagement and communication with all patients and professionals</li><li>• Leading, testing and implementing new ways of working including ambulatory care and the transfer of some care closer to home</li></ul>

## Appendix 2

### Table list of Delegates

Name	Position	Organisation
Seamus McGoran	Facilitator	Leadership Centre-HSCNI
Craig Donnachie	Head Of Cancer Projects	DOH
Geraldine Byers	Divisional Nurse Cancer and Specialist Medicine	BHSCT
Matt Mallon	Service Manager	NHSCT
Claire Black	Interim Lead Nurse	SEHSCT
Bernie McShane	AYA Service Improvement Lead	PHA
Jean Frizzell	Interim Cancer Programme Director	SPPG
Ceara Gallagher	Consultant AHP	PHA
Naomi McCay	Cancer Network Manager	SPPG
Lorna Nevin	Nursing Consultant Cancer Adult	PHA
Eilidh McGregor	Nursing Consultant Paediatric	PHA
Heather Monteverde	Cancer Strategy Advisor	DOH
Fiona Reddick	Head of Cancer Services	SHSCT
Nick Cunningham	Haematology	BHSCT
Anthony McCarthy	Consultant Clinician Oncology	RBHSC
Trish McKinney	Interim Co-Director Child Health & NISTAR	RBHSC
Gill Hughes	Divisional Nurse Child Health & NISTAR	RBHSC
Niamh O'Sullivan	Assistant Director of Nursing AYA Cancer	CHI & St James's Hospital, Dublin
Melanie Douglas	AHP Clinical Rep	BHSCT
Gillian Acheson	IG Lead Belfast Trust	BHSCT
Lesley Mitchell	Assistant Director of Nursing, Cancer & Diagnostics	WHSCCT
Susan Starrett	Sarcoma CNS	BHSCT
Paul Brownlees	Specialist services	SPPG
Aileen O'Dwyer	Parent Representative	N/A

## Appendix 3

### Summary of workshop discussions

#### Session 1 - How will Northern Ireland progress the development of this Regional Service Model?

##### 1. Operational Management Group Required

An Operational Management Group should be developed to oversee the Regional Network. The group should have a Lead Clinician and have representation from all trusts and the commissioner. All Multidisciplinary Team professions should also be represented, and it was suggested that it would be appropriate to have a lymphoma representative as this is the largest group of cancers for this age group. Other representatives should include a senior manager from the Belfast trust which will be the Primary Treatment Centre and there should be patient representation. There should also be a clear Terms of Reference for this group with appropriate governance and accountability arrangements also clearly articulated and understood.

##### 2. Develop a regional approach to specific underrepresented cancers e.g. Lymphoma - replicating MDT structure across the region

- Led by trust services
- Linking adult and paediatric/ AYA services around the patient
- **CLINICAL LEADERSHIP**
- Connecting local/site specific MDT with AYA regional MDT
  - What does it look like? This needs to be addressed
  - Ensure connection between treatment as well as holistic/ psychosocial
- Data capture and information sharing - ensuring systems and processes in place. Governance also needs to be addressed

Sustainability and training are critical.

##### 3. Ensure clarity in respect of the MDT Model

- Paediatrics
- Site specific arrangements
- How Adolescents and Young Adults receive holistic care through regional MDT
- Clarity around referral process
- Addressing issues with CAPPS and Encompass

##### 4. Access to clinical trials for all.

## **5. Governance will need to be addressed**

- Clear structures
- Clear accountability
- Effective leadership
- Clarity re systems wide governance and from within the Principal Treatment Centres (AYA services span across 3 different directorates in the Belfast Trust)

## **6. Transition from paediatric to adult services needs to be a priority.**

## **7. Workforce requirements need to be addressed.**

## **8. Clear pathways – treatments are constantly changing, and most treatments will be administered at home in future.**

## **9. New ways of working need to be part of the evolution of care for AYA with cancer.**

- E.g. less sophisticated examinations/procedures like phlebotomy done close to home.

## **10. Data management needs to be addressed, including**

- Recruitment of data managers/administrators
- Data sharing and access across everyone within the care team.

## **11. Leadership will be critical, including clarity around who has the final say.**

Session 2: What are the challenges and opportunities we need to address to deliver a best practice regional networked model?

## **CHALLENGES**

1. Establishing the regional oversight group
  - Governance
  - Time and space to attend
  - Terms of Reference
  - Ensuring regional support to establish the group
2. Culture and relationships

3. Permanent sustainable services
  - Succession planning
  - Future proofing
4. Getting clinical trials to work for AYA further away from Belfast
5. Drugs issues
  - Policy NICE guidelines
  - Age limits
  - Inequity between England and N Ireland
6. Access to clinical trials
7. Workforce challenges
  - Resourcing
  - Releasing time for clinicians
  - Recruitment
  - Job planning
  - 'Cloudy' roles and responsibilities
  - Defining key worker role
  - Training
8. Information governance
9. Defining clear pathways
10. Service issues
  - Phlebotomy
  - Infusion services
  - Protected imaging slots
  - Primary Care's role in the network/pathways

## **OPPORTUNITIES**

1. Learning from well-established, efficient regional services
2. Link CNS's and clinicians across the region to share knowledge and increase skills.
3. Opportunity to focus on mental health and wellbeing of staff delivering these services across the region
4. Scope to build flexibility for different ages/developmental stages
5. Chance to address disparity across the region
6. Opportunity to strengthen and develop the workforce.
7. Encompass - opportunity to automate patient tracking.
8. Opportunity to develop new and better ways of working:
  - Moving care closer to home

- Development of more ambulatory services
  - Establishing a holistic MDT which addresses treatment and psychosocial needs of the patient.
9. Improving quality of care
- Ensuring equitable services are delivered.
  - Benchmarking with other services
  - Creating greater regional accountability for services delivered
  - Pursuing all-island opportunities, particularly in respect of the North West Cancer Centre's radiotherapy services
  - Maximising the opportunities that are created by the further roll-out of Encompass
  - Maximising the opportunities to offer clinical trials for all
  - Take advantage of evidence-based data opportunities
  - Improving tracking of patient pathways
10. Opportunities to build on existing infrastructure and expertise in pursuit of delivering the best care to AYA.

### Session 3: What actions need to be taken to implement the best practice regional networked model?

Workshop attendees were asked to identify prioritise key actions which need to be taken in the short term (3-6 months) and in the medium term (over the next 12 months). The most critical of these actions were as follows:

**1. A structure needs to be established to oversee the implementation of the regional networked model which is:**

- agreed regionally across all trusts
- led by DoH, SPPG and PHA
- Enables engagement with all members, including charitable partners
- supported by a communication strategy

**2. Recruitment of key leadership posts also needs to be taken forward as a matter of urgency. The key posts to be recruited are the following:**

- Clinical Lead
- Lead Nurse
- Data Manager
- Administrative Support

**3. Define/finalise the MDT.**

- Requires focused task and finish group with defined purpose
- Need to highlight the importance of 'selling' it to ensure full buy-in



#### 4. **Pathway mapping**

- Requires a focused task and finish group with defined purpose and appropriate membership

#### 5. **Pursue investment of recurrent funding so that the service is sustainable and charitable funding can supplement service funding.**

#### 6. **Clarify roles and responsibilities within the network:**

- AHP/CNS roles
- Agree job descriptions
- Governance
- Accountability
- Data governance
- Suggestion of a fixed term contract for lead clinician to get the service up and running
- Clarity in respect of the role of the voluntary sector