AYA NI

Cancer Update

Department of Health

www.health-ni.gov.uk

SHAPING THE FUTURE

Health Minister Mike Nesbitt

It is with great pride that I introduce the new Regional Model of Care and Standards for Adolescents and Young Adults with Cancer in Northern Ireland. This vital framework represents a significant step forward on Action 33 of the NI Cancer Strategy 2022-2032 ensuring that young people facing a cancer diagnosis receive the highest standard of care, tailored to their personal medical, psychological and social needs.

Adolescence and young adulthood are times of immense change and development and a cancer diagnosis at this stage of life presents personal challenges. It is crucial that our healthcare system not only provides excellent clinical treatment but also holistic, age-appropriate support that acknowledges the educational, emotional, and social aspects of each young person’s journey.

The regional standards of care have been developed in close collaboration with healthcare professionals, charities and most importantly young people and their families who have first-hand experience of cancer. Their voices have helped shape a person-centred approach that ensures every young person in Northern Ireland has access to equitable, high quality and compassionate care, regardless of where they live.

I want to extend my sincere gratitude to all those who have contributed to this essential work. Together, we are improving healthcare services and providing young people with hope, dignity and the support they need to navigate their cancer journey.

This document is more than a set of guidelines - it is a commitment. A commitment to delivering the best possible care, enhancing better outcomes, and ensuring that no young person in Northern Ireland faces cancer alone.

EMPOWERING CHANGE

We are proud to welcome the Regional Standards of Care for Adolescents and Young Adults (AYA) living with Cancer in Northern Ireland – an essential step in ensuring that young people and their families receive the tailored support they need. The standards reflect the voices, experiences, and dedication of patients, families, healthcare professionals and advocates who have shaped them.

This milestone is a testament to the collective efforts of all stakeholders who have worked tirelessly to improve AYA NI cancer services. From frontline healthcare teams to community organisations and charities, parents and courageous young people facing cancer, every contribution has been vital in driving positive change.

By embracing these standards, we commit to empowering the future of AYA cancer care – ensuring that every young person receives age appropriate, holistic and compassionate support. Together, we celebrate progress, champion innovation, and reaffirm our dedication to transforming outcomes for young people with cancer in Northern Ireland.

Because you said this

Recovery is a long process, even 2 years on I am still recovering.
Young person

I was basically sent a load of information on support groups-you have to do the referral yourself.
Young person

It is good to work with charities-they bring innovation.
Professional Stakeholder

If young people don't know about services, we have failed them.
Professional Stakeholder

It feels as if we are all travelling in the dark.
Health Care Professional

I haven't met any other parents or families.
Parent

Then together we say

High level outcome

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.

A REGIONAL SERVICE

Under this model

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.

13-16

All AYA under the age of 16 at the point of diagnosis will be referred to the Paediatric PTC

16-18

All AYA aged 16-18 years (+364 days) at the point of their diagnosis will be referred to a Principal Treatment Centre (PTC) Multi-Disciplinary Team (MDT) for their cancer treatment.

19-24

All AYA aged 19-24 years (+364 days) at point of their cancer diagnosis will be referred to a PTC MDT and - may be given the choice to be treated at a Designated Hospital (DH) other than in situations where management in a PTC is indicated because of their diagnosis.

AYA services will be informed by and developed:

- In partnership with a regional AYA cancer service user forum
- From information gathered from a regional AYA cancer database with agreed and reportable data fields which include data on disease and outcomes, care and support and operational pathways.

Join us in making a difference: We need more people with recent lived experience to help us on our journey of transformation. Contact us today to find out more

STANDARDS

The regional model is built on the foundations of the following co – produced standard statements bringing together those with lived experience of cancer, healthcare professionals and many other stakeholders to inform its development. Evidence of these should be evolving as the regional model is established.

1 MULTI DISCIPLINARY TEAMS

All AYA aged 13-24 years with cancer have their diagnosis confirmed and their treatment and support agreed and delivered by a Paediatric or cancer site-specific Multidisciplinary team AND an Adolescent and Young Adult Multidisciplinary team.

2 FERTILITY

All AYA with a cancer diagnosis will be assessed for potential future fertility risk and have fertility preservation options discussed and recorded before treatment is started.

3 CLINICAL TRIALS

All AYA with a cancer diagnosis will be offered the opportunity to take part in biobanking, and clinical trials where they are eligible.

4 KEY WORKER

All AYA with a cancer diagnosis will be allocated a named Clinical Nurse Specialist (CNS) as their key worker.

5 DIGITAL HOLISTIC NEEDS ASSESSMENT

All AYA with a cancer diagnosis will be offered access to a developmentally appropriate digital Holistic Needs Assessment (HNA) tool for use at key stages in their pathway.

6 PREHABILITATION AND REHABILITATION

All AYA with a cancer diagnosis will be offered the opportunity to have their prehabilitation/ rehabilitation needs assessed at key points in their care pathway and will receive support based on their identified need including specialist rehabilitation where appropriate.

STANDARDS

7 PSYCHOSOCIAL SUPPORT

All AYA with a cancer diagnosis and those important to them, will be offered the opportunity to have their psychological and social needs assessed at key points in their care pathway and will receive support based on their identified needs.

8 PEER SUPPORT

All AYA with a cancer diagnosis and their families will be signposted to opportunities for peer support facilitated by statutory and third sector organisations across the region.

9 TRANSITION PATHWAYS

A person and family centred care plan will be developed for those AYA identified as requiring transition between paediatric and adult cancer services for treatment or long-term follow-up.

10 PALLIATIVE/END OF LIFE CARE NEEDS

When identified that treatment intent is not curative a timely assessment of palliative/end of life care needs will be carried out by AYA MDT ensuring appropriate referral and engagement with developmentally and age-appropriate primary care and palliative care teams.

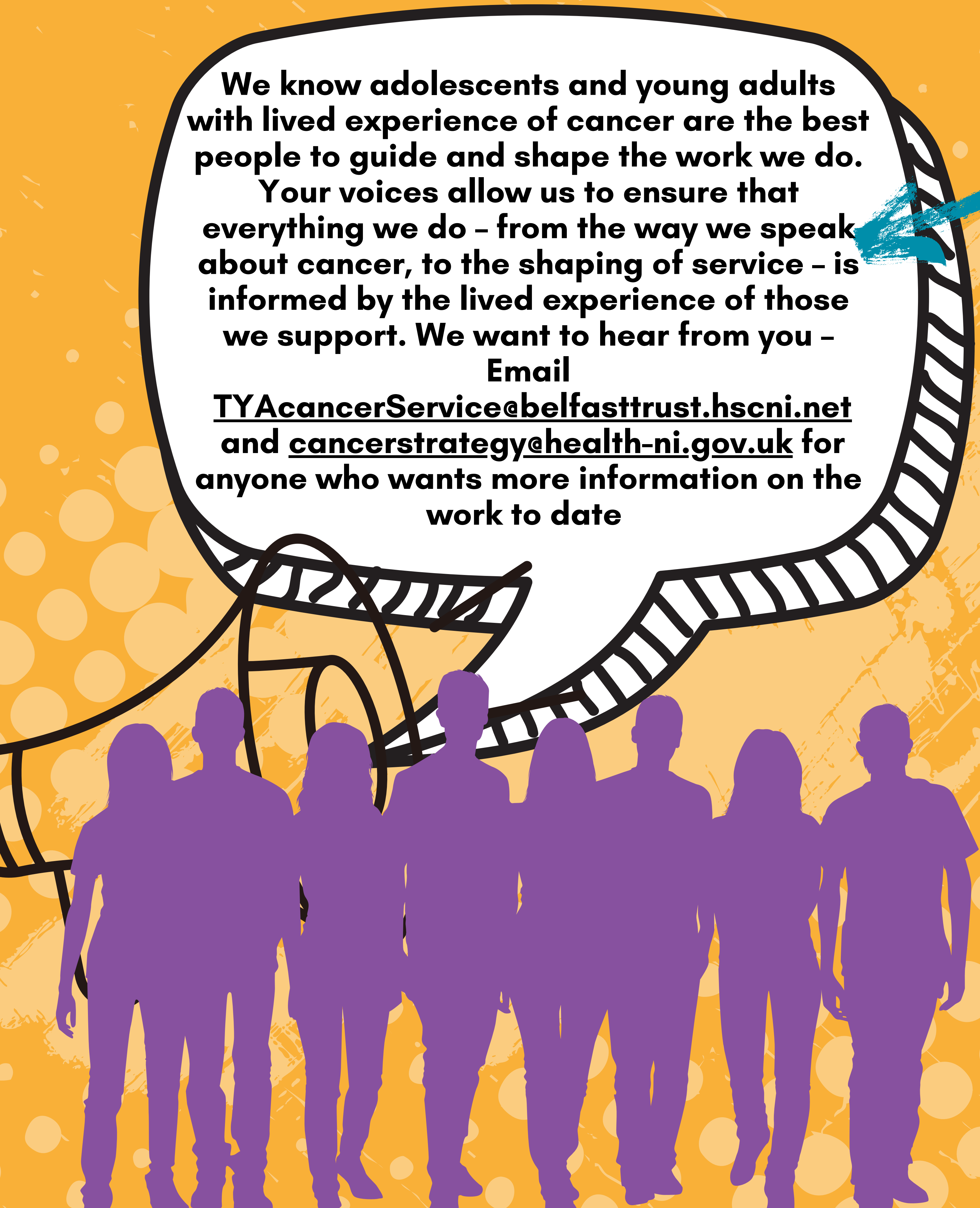
11 END OF TREATMENT

All AYA will receive an end of treatment summary and evidence based long-term follow up plan from their AYA CNS.

12 WORKFORCE AWARENESS & TRAINING

The AYA service will deliver awareness training, in all health and social care settings, of the unique needs of AYA with cancer while also supporting specialist training and education for the AYA MDT

YOUR VOICE



We know adolescents and young adults with lived experience of cancer are the best people to guide and shape the work we do. Your voices allow us to ensure that everything we do – from the way we speak about cancer, to the shaping of service – is informed by the lived experience of those we support. We want to hear from you – Email TYAcancerService@belfasttrust.hscni.net and cancerstrategy@health-ni.gov.uk for anyone who wants more information on the work to date