Department of Health

Northern Ireland

Review of Provision of Cancer Services for Teenagers and Young Adults in Northern Ireland 2023

Review led by Dr Maria Cable

Submitted 20th March 2023

Report delivered to the Northern Ireland Department of Health, Spring 2023

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Acknowledgements

The expert panel for the teenage and young adult cancer service review would like to acknowledge the patients and their families whose experience, expertise and advice has shaped the development of this report.

The review team would like to express thanks to the many health and social care professionals, and support staff who gave of their time during the winter of 2022, amidst winter pressures, to give of their time freely to support the review of services and speak so candidly and honestly about their achievements, frustrations and aspirations.

The commitment, advocacy and support of the many charities who strive to make a difference to the cancer experience of children, teenagers and young adults with cancer in Northern Ireland cannot go unrecognised. We are particularly grateful to those who captured the voices of young people that influenced action 33 of the Northern Ireland cancer strategy. We welcome their skill, passion and desire to have everyone's voices heard.

We recognise the dedication and commitment of the Department of Health staff to make sure this review was carried out following due process, independence and with their project support as much as possible. For this we are extremely grateful.

As the chair of this review, I am grateful to other external expert panel members, Dr Clare Rowntree, Prof Dan Stark and Ms Liz Watt for their expert advice, wise counsel and good humour during this process.

Thank you all, your contribution to this review against the backdrop of experiencing cancer first hand as a young person or for others who strive to support, care for and treat you amidst winter pressures and the fallout from the COVID-19 pandemic, has not gone unnoticed.

Executive Summary

The cancer strategy for Northern Ireland 2022 to 2032 launched in March 2023 and outlines the vision and actions for optimum cancer services for the people of Northern Ireland over a 10-year period. This strategy has been based on co-production, bringing together those with lived experience of cancer, healthcare professionals and many other stakeholders to inform its development. There is a focus on stabilising existing cancer services, supporting and growing the workforce and improving data collection to enable implementation of the 60 actions. The strategy not only included actions relating to all patients but also separately considered the specific needs of teenagers and young adults with cancer (TYAC).

Action 33 specifically focusses on the needs of TYAC for the first time. It recommended that an external review of the provision of services for teenagers and young adults (TYA) in Northern Ireland, including transition arrangements, age-appropriate environments, psychological support, and long-term follow-up was carried out. Whilst this was not a criterion-defined service review, this external review panel aimed to review services and propose recommendations that would support patients and families, as well as a range of other stakeholders delivering or directing care for TYAC in Northern Ireland. The involvement of a range of third sector organisations in this service delivery is compelling, welcomed by many and adds another layer of complexity that can improve the provision of services.

The expert panel, with the support of a diligent team from the Department of Health conducted a mixed methods review of the service. This included stakeholder engagement with a range of professionals, organisations and most importantly TYAC and their supporters. Central to the success of the regional TYAC service that has been operational since 2017 is the dedication and efforts of staff from the health service and charity sector who strive to deliver the best possible care. We hope this collaborative work continues and strengthens.

With a clearer framework to deliver TYAC services, that can be measured, and a more robust leadership structure at strategic and local level, we believe that the TYAC service in Northern Ireland will go from strength to strength. Young people with cancer in Northern Ireland all deserve an equal service offer; the will and desire to deliver this is there and with stronger foundations, all stakeholders in Northern Ireland including TYAC and families can achieve optimum developmentally appropriate cancer care.

This report summarises a review of the provision of current cancer services for TYAC in Northern Ireland which helped identify and characterise the breadth of parallel aspects not considered in the strategy that may well influence milestones being reached.

Dr Maria Cable

Chair of the Expert Panel.

1. Introduction and background to the review

The cancer strategy for Northern Ireland (NI) outlined 4 themes and 60 actions. At least 5 actions (numbers 31, 32, 33, 46 and 56) specifically relate to teenagers and young adults with cancer (TYAC) including environment, transition arrangements, screening, access to staff with specialist knowledge, increased clinical trials and appropriate person-centred care.

The cancer strategy outlined steps required to meet the vision for improving cancer outcomes for the people of NI. The programme of services it outlines are person-centred, comprehensive, and challenging with the ultimate aim of stabilising and improving service provision through innovative, collaborative and inter organisational ways of working. This cancer strategy has recognised the differing needs of teenagers and young adults (TYA) as a distinct group, whose experiences straddle many services, boundaries and organisations.

Much of this strategy relies on having a coordinated regional approach where some progress was made but has stalled and remains challenging in terms of current government stability, commissioning processes and Trust-based delivery structures.

This comes into sharp focus in action 33 in the cancer strategy, which asks that ‘A review of the provision of services for TYA in NI is concluded which includes a focus on transition arrangements, age-appropriate environments, psychological support and long-term follow up.’

2. Purpose and scope of the review

This time and resource bound project aimed to review the provision of current cancer services for TYA in NI with a focus on four key areas to identify potential service delivery improvements. The report proposes recommendations and actions to improve the quality-of-service provision.

An external panel of four experts (MC, CR, DS, LW) from across the UK were appointed to offer impartial advice to the review. They worked in partnership with colleagues from the Department of Health (DOH) who provided project management support and ensured good project governance. It was agreed that that this was not a criterion-defined service review against any agreed standards.

The review team was asked to include:

- the perspectives of TYAC aged 13-25 years old inclusive
- a range of approaches to engage a range of stakeholders such as online focus groups and in-person meetings
- informed discussion of the key specific elements of action 33:
    1. transition arrangements,
    2. age-appropriate environments,
    3. psychological support and
    4. long-term follow-up.

The final report was to be delivered at end March 2023.

3. Approach taken for this Review

A mixed methods approach was taken to understand more about the service that is offered to TYAC in NI. This included:

1. A desk review of pre-existing evaluations of service and data (Appendix 1) that particularly addressed service user feedback, including that from Cancer Fund for Children.

2. A round-table stakeholder event (October 2022) helped identify priorities within Action 33 which helped to focus on parallel issues not considered in the strategy that could influence milestones being reached.

3. Six hospital site visits by the external panel where TYA cancer care is delivered in NI gathered information on systems, processes, approaches to TYA cancer care and resources

4. Online focus group meetings with other stakeholders such as charities, professional groups and service users that focus on addressing action 33.

We caried out 37 meetings, visits, and events in total:

- 8 internal planning meetings (includes 4 Expert Panel Meetings)
- 2 stakeholder events with 104 attendees across the 2 events
- 16 meetings with various individual stakeholders and groups
- 6 site visits
- 8 focus groups with 44 participants

A list of all meeting attended features in Appendix 2.

Terms of reference for this review were defined and agreed at the start by the expert panel and DOH team. All stakeholders which included service providers were informed that they would be expected to engage in this review.

Due diligence, in relation to the process, was followed by the expert panel and the DOH team with an emphasis on presenting unbiased external review findings, documentation of what was observed and heard, and reporting systems.

4. Teenage/Young Adult Cancer Care - why it is different?

What makes TYAC and survivors of cancer distinct from children and older adults with cancer relates to their spectrum of diseases, cancer biology, developmental status, psychosocial needs and long-term complications of their cancer and treatment (Ferrari *et al.*, 2021). They are often poorly served by the different approaches of paediatric and adult oncology services which can impact patient related outcomes (Barr *et al.,* 2017; Osborn *et al.*, 2019). Importantly, survival gains in this patient population have only achieved modest improvement compared with older adults and children with cancer (Fern *et al.*, 2014; Ferrari *et al.*, 2021). Thus, it is important that approaches to service delivery and care provided for this age group, are set against an age or developmentally appropriate and evidence-informed model.

A cancer diagnosis in adolescence or young adulthood is well documented to cause severe disruption during what is a dynamic developmental stage. Young people aged between 12 and 25 years are at greater risk of developing poorer psychological well-being (Smrke *et al.*, 2020; Warner *et al.*, 2016) disruptions to family, peer and romantic relationships (Rabin, 2019; Warner *et al.*, 2016), and can have their educational and vocational plans disrupted (Fardell *et al.*, 2018). Thus, there is a risk of poorer psychosocial outcomes and long-term disruptions. This is particularly worrying as 50- 95% of TYA reportedly experience unmet supportive care needs which can exist for many years beyond the end of active treatment, leading to ongoing distress (Xie *et al.*, 2017).

Cancer in TYAs is different as it is uncommon. There are 2,490 new cases of cancer diagnosed aged 15–24 years[1], and 270 deaths each year (2015-2017) in the UK. Overall, TYA with cancer (TYAC) accounts for 1% of the total cancer population (Cancer Research UK, 2021). There are various types of cancer that occur, including the very rare (that always require specialist treatment in Principal Treatment Centres (PTC), e.g., sarcoma, germ cell tumour, brain tumour), and cancers that are less rare and can often be managed in the PTC or regional hospitals (such as lymphomas and carcinomas).

Each year in NI, approximately 80 TYAs are diagnosed with cancer. There are approximately 7 TYA deaths from cancer each year.

Provision of TYA cancer services are also different because of the balance of charitable and NHS funding. Without collaborative work and substantial funding and lobbying from the third sector, the TYAC specialism, operating within NHS would not have developed. The combined efforts of many dedicated healthcare professionals, researchers, policymakers and charities recognised that because of their age, TYA with cancers' needs were different (Cable and Kelly, 2019; Smith *et al.*, 2016).

The UK charity Teenage Cancer Trust (TCT) started in 1990 by building a specialist ward within a London Hospital and since then, a further 27 specialist wards/units with funding for a variety of specialist TYAC staff, have been opened in UK NHS environments. Other national

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[1] Ages 15-24 here refers to epidemiological data which may differ from those age ranges expressed in service provision guidance.

charities such as Young Lives versus Cancer (YLvC), provide additional support to children TYA and families such as financial and psychosocial support and residential opportunities. Many other local charities across the UK and including NI, support TYAC initiatives to fill gaps not serviced by the public sector.

TYAC care is distinct in having an age-based specification of services in a growing number of UK and international health systems (Ferrari *et al.*, 2021). The UK clinical service provision for TYAC is mandated for a patient range of 15-24 years, with flexibility as to the lower age range to suit local services (National Institute for Health and Clinical Excellence, 2005). This original Improving Outcomes Guidance suggested that TYA should receive treatment and support specific to their developmental and clinical needs. Subsequent data show that this has not been the case for all TYAC (O'Hara *et al.*, 2015). Some but not all TYAC care providers of services in NI are also aware of imminent changes, based upon the consultation upon a draft NHS England TYA cancer service specification which is awaiting final publication at the time of writing. This further specifies patient referral pathways, age-appropriate patient assessment approaches, clinical trials, biological cancer characterisation and clinical networking.

3. Context of current service provision in Northern Ireland

This information was taken from information we gleaned from the desk top review. The NI TYA regional service was in launched in 2017, following a scoping exercise by the NI Cancer Network (NICaN) to ensure equitable service across the region.

Within NI, TYAC are treated across 5 HSC Trusts. Those aged 13 to 15 years old are usually treated within paediatric services. Those aged 16 years and over are usually treated within adult services. Approximately half of TYA in NI will be treated within the Principal Treatment Cancer Centre (PTC), located in Belfast HSC Trust. The remaining TYA patients are usually diagnosed and often treated in one of the regional cancer units throughout NI; Antrim Area Hospital, Northern HSCT, Craigavon Area Hospital, Southern HSCT, Ulster Hospital, South-Eastern HSCT and the Northwest Cancer Centre in the Western HSCT.

Each trust has a site-based haematology team, with provision for outpatient care and inpatient systemic anti-cancer therapy (SACT) for lymphoma. Some TYAs who require very specialist treatments for oncology and haematology will be referred to Belfast Trust for complex cancer care (e.g. specialist regimens for testicular or brain tumours or acute leukaemias, or for bone marrow transplant (BMT)).

Solid tumour oncology services are delivered at NI Cancer Centre in Belfast Trust and NW Cancer Centre at Altnagelvin Hospital in Western Trust. Some regional hospitals (Antrim, Ulster, Altnagelvin and Craigavon) will treat over 16s with cancers such as lymphoma/melanoma/gynaecological /breast, neuroendocrine and thyroid. Patients with other tumour types or requiring treatments may be transferred to the PTC.

Radiotherapy is delivered at NI Cancer Centre in Belfast Trust and NW Cancer Centre at Altnagelvin Hospital in Western Trust sites only.

Most trusts have provision for surgery and surgical follow up for breast, colorectal, gynaecology and dermatology (melanoma) cancer care. Some TYAs will receive that care in those locations. Many receive follow up care in the closest regional hospital.

Visiting oncologists from Belfast run clinics and deliver treatments for adult patients with breast, genitourinary (but not germ cell tumours), lung and colorectal cancers respectively in the Trust cancer units at Southern, South-eastern, and Northern Trusts. This may include occasional TYA. However, there are no oncology in-patient beds for TYA in these units. Those TYAs requiring inpatient care are usually treated in Belfast, or beyond.

All under 16-year-olds diagnosed with cancer are treated at Royal Belfast Hospital for Sick Children which is under the management of Belfast HSC Trust. Unlike some UK services, there is very little planned shared care for patients under 16 yrs. between the regional hospitals and the principal treatment centres (PTC). There have been exceptions to this on a case-by-case basis.

Some highly specialised treatments for children and TYA's are sourced outside NI. TYA's needing Bone Marrow Transplant/Stem Cell Transplant are treated in Belfast, mainland Britain and Dublin. There are pathways to mainland UK, and beyond for proton beam radiotherapy and CAR-T cellular therapy.

In all the referral pathways are complex.

3.1 Leadership, management & governance of TYA cancer regional service

All TYAC services are managed in local trusts within cancer services, where it is expected that there will be an identified TYAC lead clinician and a TYAC CNS. There is a TYA Clinical Reference Group (CRG) within NICaN whose role is to work together to ensure equitable access to high quality, age-appropriate treatment and care, and to ensure the best possible experience and outcome for the TYA patient group, with a cancer diagnosis, and their families. This TYA CRG is also expected to oversee and lead upon the development of a regional cancer service which aims (within current resource constraints) to implement the relevant TYA Service Framework for Cancer Prevention, Treatment and Care, Standards 31 & 32 and the 2005 NICE Improving Outcomes for Children & Young People with Cancer.

This group has a terms of reference document that outlines the scope of their work, core membership along with accountability and reporting responsibilities. The core membership has representation from the regional TYA Cancer services including senior nurses, consultants from paediatrics and adult services, cancer service managers and patients. NICaN administrative support is provided and the current chair of this group is a consultant haematologist. It meets twice per year.

There is also a TYAC Lead Nurse (0.5FTE) for the region based in the NI Cancer Centre in Belfast Trust. There is a regional TYA operational group and a TYA CNS forum.

3.2 TYA Cancer specific Multi-disciplinary Teams

All people with cancer (irrespective of age) in the UK should have their diagnosis and care discussed at a site-specific Multi-disciplinary Team (MDT) meeting which primarily focus on their diagnosis and clinical treatment recommendations. In most services (including in NI) there is an additional regional multi-disciplinary advisory Team (MDaT) meetings specifically for TYAC, where all newly diagnosed patients aged 14-24 years should be discussed and their holistic needs considered. The MDaT occurs twice per month with primarily nurses and social workers in attendance. There is no medical representation at this meeting.

The aim of that Regional TYAC MDaT is to bring together health and social care professionals in paediatric, adult and TYAC settings across all cancer services to enable young people to benefit from the expertise of site-specific and TYAC multi-professional teams, in order to determine a management plan that is realistic for the unique developmental, psychosocial and holistic aspects of the individual TYA. An additional aim of a TYA MDaT should be to clarify whether or not there are any clinical trials that may be available for the young person in addition to the recommendations from the site-specific team. The NI Public Health Agency, Health and the then, Social Care (HSC) Board (now SPPG) and all 5 HSC Trusts endorse that all young patients with cancer age 16-24 years are discussed at this specialist meeting and it follows a specific Standard Operating Procedure, last update in June 2022 (Reid, 2022).

This regional service model is complex and has several funders of TYAC specialist roles (working with the charitable sector). These are portrayed in Appendix 3

3.3 Specialist TYAC Environments

With the exception of low-level embellishments, such as TYA information boards in some hospitals such as the Royal Belfast Children's Hospital, the HSC does not provide any purpose-built in-patient wards, ambulatory care suites or out-patient facilities earmarked specifically for TYA. Unlike elsewhere in the UK, there are no specific TCT 'Units' in Northern Ireland.

Most enhancements of the care environment are provided by the third sector. Teenage Cancer Trust has funded environmental enhancements in all 5 trusts, in outpatient and inpatient settings. Friends of the Cancer Centre have also provided funding for some enhancements. Where spaces or rooms are embellished in adult and paediatric settings, it cannot be guaranteed that TYA with cancer can always access them, owing to the needs of other patients.

3.4 Funding of Specialist Roles

The HSC sector do not fund any of the specialist roles in TYAC services. Examples of these roles include: TYAC Clinical Nurse Specialists (CNS), TYAC Social Workers, TYAC MDaT co-ordinator, and Hospital and Community Support Workers. These roles are all funded by the third sector who seek to work in partnership with the HSC. The key charities are:

- Teenage Cancer Trust
- Young Lives v's Cancer
- Cancer Fund for Children
- Friends of the Cancer Centre
- Children's Cancer Unit Charity

Funding and employment arrangements differ across the region and the charities. Some directly employ specialist staff and others provide funding to HSC for the HSC to employ staff directly.

Appendix 4 outlines the charities funding offer and the funding arrangements.

All patients when introduced to the service get given a pack of information which outlines who their CNS and social worker are along with leaflets from different charities as to what services they offer.

Hospital or Community support roles are integral to any TYAC service. In essence, these roles are modelled on the Youth Support Co-ordinator roles that exist in England, Scotland and Wales, funded by Teenage Cancer Trust. These post-holders provide a service that is central to focussing on the youth element of TYAC' s cancer experience by providing psychosocial support, promoting peer support and often act as a bridge between the patient and clinical teams (Cable *et al.*, 2023).

3.5 Appropriate holistic assessment in TYA Cancer Care

A holistic needs assessment (HNA) is the cornerstone for providing care to patients with cancer; assessment of holistic needs is mandated in UK cancer policy and literature (Johnston *et al*., 2019). The e- Holistic Needs Assessment, as set out by Macmillan (Snowden and Fleming, 2015), is used for adults and often TYAC with cancer in NI, but it does not evaluate the age-specific or developmentally-appropriate needs in this patient population (Farre *et* al., 2016; Rapley *et al.,* 2019) (See Appendix 5). Once the HNA is carried out, a tailored plan of care can be implemented for patients. Identifying and managing distress and other unique psychosocial issues in TYAC can minimise the negative lifelong consequences for psychosocial adjustment and well-being (Cargill *et al*, 2016), therefore identifying age-related needs early is central within TYAC care. No single age or developmentally appropriate assessment tool is used in NI for TYAC. A precis of various adolescent specific health assessment tools is provided in Appendix 6.

3.6 End of Treatment, and Transition as young people get older.

As with all patients with cancer, TYA require information and support in readiness for ending active treatment and reintegration to everyday life. Preparation for the short- and long-term physical, social, and psychological impact of a cancer diagnosis when treatment ends assist in managing this transition. The current NI Cancer Strategy has placed emphasis (Actions 37 & 38) on this period of cancer care, recognising the need for varying approaches to end of treatment care and that TYA's needs are different. Survivorship for individuals who had cancer in childhood or young adulthood has increased significantly over the past few decades. For those aged between 15 and 24 years, the five-year survival rate increased from 79% to 87% in the same two periods. These improvements in survival mean that 80% of children and young adults who had cancer in the early stage of life now survive into adulthood and will require a transfer into adult services. This will include the need to follow-up for screening of late effects of treatment, and education on lifestyle modifications to promote management of late effects of treatment as the burden of late effects is heterogeneous, as is the risk of premature mortality associated with late effects. Thus, the transition into adult services has had heightened awareness in the past decade given that it is a complex and multistage process with multiple stakeholders involved in helping young people negotiate several systems of care such as healthcare, education and social welfare. This transition into adult services can often be troublesome for those going through the process and there are reports of successful generic transition programmes, such as 'Ready, Steady, Go' in the UK (Nagra *et al.*, 2015).

4.Observations and recommendations of the Expert Panel

The panel were made very welcome by every group of people they met including all of the six sites where TYA are treated in NI. Similarly, we were met with enthusiasm by all participants in focus groups and in individual meetings. The staff involved in the delivery of care to young people with cancer in their specialist roles are committed and dedicated to providing distinct and excellent care for young people and their families. Some services are more established than others and could articulate their service offer more readily. We heard from many TYAC and their families that they felt very well cared for and could not fault the HSC or the charities that supported them.

We outline numerous observations in this area. Many are followed by specific recommendations and others have higher level recommendations which aim to capture the essence of needs of the whole service. These links are clearly identified in Appendix 7. We offer anonymised quotations to bring some of these issues to the attention of the reader.

4.1 Organisation of services

Observation 1: None of the sites / trusts were working explicitly to a defined TYA Cancer service specification or set of standards. The more experienced services were familiar with the Improving Outcomes Guidance service specification from 2005, yet the more embryonic services felt that a framework was lacking, and were struggling to articulate the features, the essence and the importance of a strong TYAC service offer. In the absence of a specification, agreement between healthcare providers and commissioners are substantially hampered. Weak clinical governance arrangements contribute towards inequity, professional frustration, and reduced engagement.

> *It feels as if we are all travelling in the dark*
>
> **HCP**

Observation 2: Not every service could clearly articulate their TYAC service level offer, or eligibility criteria for accessing the TYAC cancer service.

Observation 3: Defined pathways for referrals of TYA with cancer within and across the region are not always clearly articulated in terms of disease, treatment, place of care, referral to palliative care, access to the TYAC service and discussion at MDaT. These complex pathways make it difficult for staff or patients to deliver uniform best practice.

Observation 4: We learned from young people and treating teams that some young people had not been referred to the TYA cancer service at all, e.g. those requiring surgery only, such as some with brain, cervical and thyroid tumours and possibly also others.

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

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

1. Develop a co-produced TYAC networked service framework for NI that enables a robust, equitable and resilient multi-professional interagency service across all settings.

2. Set key measurable TYAC care standards and implement an effective review process, including peer review. These should take account of the following (but not exclusively):

- Clinical and referral pathways (including fertility preservation, transition and palliative care)
- Service level offer, eligibility, auditing and governance.
- MDT working locally and regionally and workforce education needs.

- MDaT function
- Approaches to TYAC care in all HSC settings
- Holistic Needs assessment suited to TYAC
- Peer support
- User experience and advocacy
- Psychosocial, mental health and psychological referral systems

Observation 5: We learned that whilst stringent attempts are made to rapidly identify all TYA patients receiving care in the region, most are reliant on the communication between site specific CNS', TYA CNS' and MDaT coordinator, so 100% accuracy could not be guaranteed. Extraneous work of individuals is required to ensure that every patient is known and can access care. When added to inefficient Information Systems, we found that limited information was captured for teams to review and ensure service equity and quality, beyond simply which referrals were made to whom. Since the review commenced, we learned that work has commenced via TYA operational group to develop TYA data capture on the Regional HSC CaPPS (Cancer Patient Pathway Information System Service) aimed to improve data collection, audit and MDaT processes to ensure that all eligible TYAs are referred to the service.

Observation 6: We were not able to determine whether the data captured at MDaT is routinely audited and used to inform and develop services.

Observation 7: We established that participants at MDaT usually include the Lead Nurse at Belfast City Hospital (Chair), the MDaT co-ordinator, TYAC CNS' from all services, social workers* and ward/community specialists*. No clinician is funded to attend and only occasionally do representatives from HSC Allied Health Professionals attend. The co-chair is the Friends of the Cancer Centre funded TYAC Social Worker from Belfast City Hospital.

Observation 8: We found that invitation to and participation at the MDaT of specialist health or social care professionals* (e.g. TYAC social workers, ward/community support specialists) who are employed by charities and directly deliver psychosocial support to TYAC are not afforded equal status at this meeting. A rationale given is that this was because of information governance. We are unsure as to how this best serves the patient, these professionals themselves and the broader MDT. In addition, it is duplicating work for administration teams for meeting participation purposes. This leads to tensions, creates the risk of poor information sharing and potentially leads to inequity of service access and within the regional TYA Cancer team.

Observation 9: We heard that the TYA MDaT meeting is a rich opportunity for exploring shared learning, service development considerations and networking, but mixed views from participants as to whether it fulfilled its role in this way. For some it was felt to primarily function as a registration of new, relapsed, or palliative care patients as well as those transitioning out of the TYAC service with little time given to discuss care in a meaningful way that promoted integrated practice, development of services or generation of new ideas for practice or shared learning.

MDAT has maybe lost its purpose-become a tick box exercise.
Professional Stakeholder

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

3.Ensure that effective TYAC digital data systems are in place and that all required data is captured and audited for accuracy.

4.Review the TYAC MDaT function, in the spirit of good governance and inclusive multidisciplinary working, against mutually agreed aspects including its structure, terms of reference, data presented, members access to patient data.

Observation 10: We also learned that the NI Regional TYA MDaT **should** undertake regular feedback on patient experience of care, though we saw little evidence of this, locally or regionally.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

5.Develop routine mechanisms to capture, review and act upon TYAC experience of cancer treatment and care.

Observation 11: Across the region there is a disparity in how the developmentally or age-appropriate needs of TYA patients are assessed and recorded. Two trusts use Canteen's model (South Eastern and Northern), One uses HEEADSSS (Adult/TYA service in Belfast City Trust) and the remaining sites uses a variation of the Macmillan HNA assessment tool designed for use with older adults. All of the 6 sites expressed an interest in the idea of implementing the digital tool IAM (Cargill, 2016), and two services (South Eastern and Northern Trusts) are actively engaged with TCT as to how to progress this. The implementation of the IAM tool is already referred to in the cancer strategy document, page 73.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

6.Implement a single agreed developmentally appropriate digital holistic needs assessment tool for use across the region.

4.2 Leadership, governance and third sector

Observation 12: We learned that owing to changes within NICaN, the TYAC CRG has not met in recent times due to lack of staffing and changes within the overall structure and function of NICaN, though we understand that this will change in the future.

Observation 13: One haematologist represents TYA at the Regional Clinical Reference Group (CRG) but they have no funding or protected time to commit to this role, which therefore can carry less influence on the delivery of service across the region.

Observation 14: The Lead Nurse post is funded by a charity and employed at Band 7 at Belfast Trust which is commensurate with other CNS roles and not with that of a Lead Nurse. This job description was devised as an extension to an existing TYA CNS role. The role appears to have a strong co-ordination component to it as opposed to a focus upon strategic decision-making about the service that would be expected of a Lead Nurse post, and which is remunerated at Band 8.

The service needs data, a leader, standards to monitor against.

Professional Stakeholder

Observation 15: We saw very little evidence of service development plans, audit or peer review reports that measure any service, though some early work had started via NICaN to measure against the NICE IOG standards. We saw little evidence of clinical pathways or clinical pathway guideline development for TYA with cancer across the cancer trajectory including palliative care.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

7.Develop and implement strategic leadership at a regional level, that takes account of clinical, organisational and nursing leadership.

8. Develop clear local leadership and governance arrangements to ensure equitable services across NI.

We propose that to improve services the following action (s) **should** be carried out:

1.Deliver work that explores pathways to meet the developmentally appropriate healthcare (DAH) palliative care needs of TYAC, linked to action 47-51 of NI cancer strategy.

2.Ensure the unique needs of TYA are reflected in the implementation of the NI Cancer Strategy

We propose that, to improve services, the following action(s) **would** be effective (but may be unlikely to get funding):

1. A review of commissioning and funding arrangements to develop an operationally networked TYAC service.

Observation 16: We learned of the major contribution that many charitable organisations directly provide to the HSC, in relation to the support for service provision for TYAC across NI. Much energy goes into maintaining the relationships between charity and HSC organisations. We learned that these relationships are not always easy in terms of data sharing, referral pathways and contractual arrangements.

Observation 17: We learned that at one time 2 major charities withdrew their service offer in Belfast Trust. It was not the place of this review to understand the detail of this, except to note that these decisions are likely to have negatively impacted care, unlikely to have happened instantaneously, nor without due effort or careful consideration.

> *There is so much experience in the third sector-we are not given respect nor valued for what we can contribute.*
>
> **Professional Stakeholder**

Observation 18: We also heard from several sources, including young people, that there was not equity of meaningful referral to all of the charitable services. Some referrals were too late or too non-specific to support optimal care. This resulted in some young people not having access to peer, financial or practical support, each of which are integral to providing good psychosocial care, and compensating for the limits in what the HSC can provide.

Observation 19: We also learned that integrating specialist workers (such as charity funded social workers or support staff) wholly within the MDaT and healthcare systems was weak in places, resulting in incongruence of services offered across the region, as well as frustration among charity-funded staff not having the opportunity to best serve patients in each treating centre. This was often justified by information governance limitations which is not fully observed across the other 3 UK nations.

Observation 20: We noted that should either HSC or major third sector organisations make strategic business changes, that the impacts on each other were not always realised or factored in which could lead to frustrations. This hampers the progress of services and causes strain on working relationships.

Observation 21: Until recently there was no TYA cancer charitable sector representation at the NICaN board. There is now one nominated charity representative whose role is to represent the breadth of other charities that fund and provide specialist TYAC services regionally.

Observation 22: Another observation was that charity funding arrangements with HSC organisations was complex and often protracted in terms of contractual and governance arrangement which is particularly challenging for the charities when operating their businesses.

> *You can't have a system largely reliant on the third sector which largely excludes the third sector..*
>
> **Professional Stakeholder**

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

9. Develop effective partnership working between HSC and third sector to ensure all young people are afforded equity of access to holistic TYAC care.

Observation 23: We could not see the voice of those with lived experience consistently informing any service development discussion.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

10. Develop a TYAC service user advisor forum that ensures their voices are at the centre of all service developments at strategic and local levels.

4.3 Funding of specialist roles

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

Professional Stakeholder

Observation 24: We learned that without third sector funding most if not all of TYAC specialist services would not exist for patients, peers and families. This is commensurate with what happens in the other 3 UK nations. Heavy reliance on this sector for service development, specific aspects of direct patient care, family/sibling support, residential facilities external to the clinical setting, funding of research and other projects as well as an advocacy role at government level is well documented and, in many ways, NI is no different.

Observation 25: Some key roles such as the TYAC support staff were working to timebound contracts which leads to employment uncertainty for those staff as well as uncertainty to the service in terms of this unique and important service offer to young people.

Observation 26: We also learned of concerns, from some HSC employed staff in the Principal Treatment Centre, about the overreliance of the HSC on third sector funding of key elements of their TYAC service. Whilst we recognise that this can be complex to manage, it is not insurmountable and it is unlikely (for many reasons) that any of the governments of the 4 UK nations would provide funding of these third sector specialist roles from central resources. It is this panel's experience that key to making this work is strong partnership working, good leadership with robust contractual and governance systems that are shared, transparent and worked to.

I don't think we will ever manage without the charities

Young person

Recommendation(s)

<u>We propose that to improve services the following action(s) **must** be carried out:</u>

11. Ensure funding for the provision of the hospital and community support worker continues.

4.3.1 TYA Cancer specific staffing – Nursing and Doctors

Observation 27: We learned that all TYAC CNS were funded by charities. There are several part-time funded CNS posts (all at band 7) based in 5 trusts. One CNS in Belfast Trust (funded by Friends of the Cancer Centre) also acts as Lead Nurse for TYA across the region for 50% of their time and chairs the regional multidisciplinary advisory team meetings (MDaT). The other 50% of their time they work as a CNS TYA, maintain a patient caseload (and work as a peer to the other TYA specialist nurses). It appears that the wider cancer care team defers to the TYAC CNS' to co-ordinate care and manage psychosocial need with little input from the broader healthcare team, who are not equipped or educated to consider developmentally appropriate health needs of TYA in the absence of the CNS.

Observation 28: Many of the sites where TYAs are cared for have a clinician named as lead clinician for TYAC. However, those doctors have no protected time to assume this role and we could not get clarity about the function of this role.

Observation 29: All patients are under the care of consultants with cancer site specific experience, who may not always appreciate TYA specific issues.

Observation 30: Some doctors expressed a desire for better and more accessible access to clinical trials and biobanking for TYAC.

Recommendation(s)

We propose that to improve services the following action(s) **could** be carried out:

1. Progress work to promote better access to clinical trials and biobanking locally and regionally for TYAC.

4.3.2 TYA Cancer specific staffing – MDaT Coordinator/Data Manager

Observation 31: There is a Regional TYA MDaT coordinator and data manager, funded by third sector and employed directly by Belfast Trust. This role is quite different to any other MDT tracker or co-ordinator function yet is integral to reporting of data for the region as regards TYA cancer. Much of this work is protracted and dependant on good working relationships with colleagues across the region with clunky IT systems (not withstanding recent CaPPs changes).

4.3.3 TYA Cancer specific staffing – Social Work and Ward/Community Specialists

Observation 32: We learned that the charity funded TYAC workers (TYAC Social Workers and Ward/Community Support Workers) provide a unique offer of psychosocial care not seen in adolescent healthcare generally. As well as providing traditional young-persons social work around personal skills development and safeguarding, these TYAC social workers offered peer support initiatives during and after treatments, social activities, exercise programmes and 'moving-on after cancer' programmes. These workers also create networking opportunities for TYAC by signposting them to social re-integration events that are delivered by other external (UK-wide) charities such as the Ellen Mc Arthur Trust. They emphasise youth resilience and independence through the treatment experience and beyond. They are integral to the specialist TYA psychosocial team in NI. The social workers worked with the TYA CNS, ward, and community specialist to facilitate this type of care.

Observation 33: We understand that if the TYAC social worker is off on long term absence from Belfast Trust, the internal generic oncology SW team pick up this work so access to specialist TYAC SW is absent.

Observation 34: Referrals to these specialist services can be made by health care professionals or can be made directly by the patient themselves. We found that there was wide variation in the referral rates to a specialist TYA social worker by trusts across NI. We heard from some young people that they were not made aware of the services that some charities could have provided such as much needed financial assistance and peer support thus highlighting inequities in the service offer.

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

4.4 Specialist TYAC environments

Observation 35: The review team established that for the most part when younger people with cancer were treated in all centres they were in the minority in terms of their age and it was often the case that they did not meet other young people with cancer during their own treatment.

Observation 36: We observed attempts by some hospital sites to bring young people together for treatments, which occurred mainly in outpatients. Given the low numbers across the regions, there often are no more than single figure patients having treatment at any one time. This makes developing cancer peer relationships difficult for both young patients and their families, particularly parents. Securing these environments for the sole use of TYAC patients when they need them (rather than when they happen to be available) has proven problematic during hospital bed-space and staffing pressures.

Observation 37: All clinical areas had made attempts with charity funding to make adjustments to the physical environment of in-patient and outpatient care, to have identified spaces for TYAC where they could be treated together and have access to specific information, suitably decorated treatment spaces and where possible have access to specific social spaces.

Observation 38: We heard from some young people that they were cared for on adult wards where the environment was not enhanced in any way for them and they were one of few young people, they felt isolated and sometimes obtrusive to staff and older patients, because of their young age.

> *As parents we felt quite isolated and not in the picture.*
>
> **Parent**

Observation 39: We heard from some young people and parents that a facility where young people could be treated together such as TCT units would be welcomed.

Observation 40: We learned that sometimes TYAC and families/siblings often meet no others having a similar experience. Whilst the charity funded SW and specialist support staff made attempts to create peer support opportunities for patients within and away from clinical environments, not every young person we met had insight into those potential experiences. Parents told us that they had find peer connections via social media outlets.

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

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

12.Develop a framework which ensures that young people and their supporters can access peer support across their cancer experience no matter where they are treated.

We propose that to improve services the following action(s) **should** be carried out:

3.Develop a provision for signposting supporters and siblings of TYAC.

Observation 41: We often heard that the knowledge of newly employed TYAC specialist staff and the wider health care team working in these settings' on meeting the needs of these younger patients was lacking. There are few opportunities for formal or informal learning currently.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

13. Develop and implement a TYAC workforce education plan to raise awareness in both the general and specialist workforce linked to actions 52 & 53 of NI cancer strategy.

4.5 Psychological and psychosocial support

> *I would like to see a more structured approach for the TYA psychology service.*
>
> **Professional stakeholder**

Observation 42: We observed that there is no regional approach to psychology services to adults with cancer across NI let alone young people with cancer. Those that are treated in the children's hospital in Belfast have access to clinical psychology services up to 16 years old – but we heard that this team is very depleted. Those aged 16-17 with cancer do not have a clear pathway to accessing psycho-oncology support. Young people in NI with cancer who have psychological need can be referred to the general CAMHS service or general psychology for which there can be very long wait lists. It is not likely that those working in CAMHS or adult psychology will understand the unique needs of TYA with cancer. For those regions and hospitals that do offer clinical psychology services, relationships with some of the TYA cancer specialist staff are developed such that rapid access is available however, this cannot be said for all sites where TYAC are seen.

Observation 43: We also heard from two psychologists in the focus group that there is a special interest group for those working with TYA with cancer though this is an informal meeting.

Observation 44: We were not clear on the different routes to psychosocial, mental health and psychology services for TYAC and their families/supporters.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

14. Develop clear pathways for access to psychosocial, mental health and psychology for all TYAC in any location, inpatient or outpatient, that aligns with actions 40 and 42 in the NI Cancer Strategy

4.6 End of treatment

Observation 45: We ascertained that there is variation in practice as to who takes the lead in creating end of treatment summaries for TYAC across the region. Where this works well, there is collaboration between the site-specific team and the TYAC team, who together take account of age-related needs (by undertaking a HEEADSSS assessment for example) at this point in the cancer experience. Actions of 37 and 38 of the NI cancer strategy 2022 refer to the need for treatment summary records and risk stratified follow-up pathways.

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

Observation 46: We learned that there is an open-door policy for young people to contact the TYA service after treatment has finished, so in effect they stay in the service. We believe this to be not to the advantage of the TYA or the service. It is developmentally important for TYA to be prepared to take responsibility for their lives and negotiate their healthcare needs in adult settings as they progress into adulthood.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

15. Provide all TYAC with end of treatment summaries: incorporating a developmentally appropriate based assessment building on action 36 of the NI Cancer Strategy.

4.7 Transition as young people get older.

Observation 47: We heard some work has started within the TYA team (by way of a draft policy document) about transition for young people with cancer. This includes transition from the children's service to TYA, and later from TYA to adult services.

Observation 48: Much more collaboration exists for care transition from service to service, and less to the transition from a child to a youth service or on to an adult's service. No transition framework for children or teenagers into adult services is in NI, although some experts were aware of pre-existing models such as Ready-Steady-Go.

Recommendation(s)

We propose that to improve services the following action(s) **must** be carried out:

16. Develop and implement pathways for TYA transitioning into and out of the TYAC service.

5. Conclusion

In conclusion, we have provided a list of observations based on what we read, were told and observed. We do not wish to ignore the fact that many patients and families told us that they could not fault the care that they received and were grateful to the HSC and the charities that cared from them. Some recommendations will require financial investment and others require system reviews and quality improvement approaches that should be supported and monitored using existing NI health service improvement methodologies. We have highlighted some further unique needs of TYA with cancer and those of their families that are not yet seen in NI. Whilst we heard from TYAC, parents and some professionals that one or two TCT units would be an advantage to patients, we do not feel that we can justify making this a recommendation at this point.

We hope that this independent review has been helpful and recognises the good work that has been done already by both HSC and third sector organisations whose solitary and combined aims are to improve the lives and experiences of TYAC. With greater partnership working, this has the possibility to have a synergistic effect and will require innovation and commitment to achieve greater things and a more equal service for this unique patient population across NI. We hope that in implementing the NI cancer strategy that the unique needs of TYAC are considered beyond what was asked of us in reporting on action 33.

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Appendix 1 Desk based papers reviewed.

- Regional report of Service User Experience of TYA service in NI 2021/2 (Mills and Donaghy)
- NICaN TYAC Project 2017
- NICaN Scoping Exercise of current Provision for TYAC in NI March 2015
- NI Regional TYAC Multi-Disciplinary Team Meeting SOP (Updated 2022)
- Transition Best Practice Statement TYAC v6 HSC
- TYAC Information Governance document

Information from Cancer Fund for Children

  - Tell it like it is Survey report Oct 2019
  - Cancer Strategy- TYA feedback Nov 2019
  - Tell It Like It Is Survey – June-July 2022

Appendix 2 List of stakeholder meetings/opportunities.

Focus Groups with:

Lead Cancer Nurses and Managers across NI

The TYAC social work and specialist support teams in NI

Senior Charity Representatives

TYAC CNS' across NI

Clinical Psychologists

Additional meetings /opportunities

We held individual meetings with other key health care professionals such as Consultants and Lead Nurses where we felt further information would be helpful, or where they felt they had insights to offer us that were not heard previously.

We offered to meet other members of staff separately if they had any questions.

We opened a separate email address for people to contact us in confidence- we received one email to this from a healthcare professional.

Hearing from those with lived experience

We heard from three young people at the stakeholder meeting on 6th October 2022.

Three young people formed part of the stakeholder advisory group.

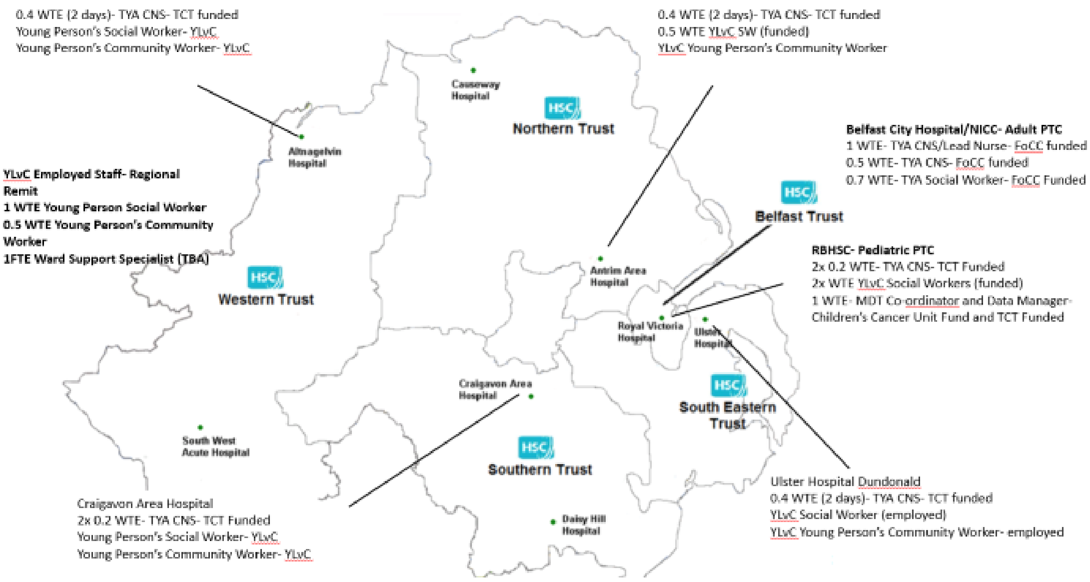
We held 2 focus groups for Young People (Dec 2022) which were opened up to all and were identified by TYA CNS' and SW. 4 attended, there others did not attend on the allocated to times.

We were introduced to two young survivors from Antrim Hospital (Male) and the Ulster Hospital (Female) in Nov 2022.

Parents of 3 young people attended both the stakeholder events (October 2022 and Feb 2023) and parents of 6 young people attended a separate online focus group in December 2022.

Appendix 3 Regional model- geography, specialist staffing and funders

At start of review



0.4 WTE (2 days)- TYA CNS- TCT funded
Young Person's Social Worker- YLvC
Young Person's Community Worker- YLvC

0.4 WTE (2 days)- TYA CNS- TCT funded
0.5 WTE YLvC SW (funded)
YLvC Young Person's Community Worker

Belfast City Hospital/NICC- Adult PTC
1 WTE- TYA CNS/Lead Nurse- FoCC funded
0.5 WTE- TYA CNS- FoCC funded
0.7 WTE- TYA Social Worker- FoCC Funded

YLvC Employed Staff- Regional Remit
1 WTE Young Person Social Worker
0.5 WTE Young Person's Community Worker
1FTE Ward Support Specialist (TBA)

RBHSC- Pediatric PTC
2x 0.2 WTE- TYA CNS- TCT Funded
2x WTE YLvC Social Workers (funded)
1 WTE- MDT Co-ordinator and Data Manager-
Children's Cancer Unit Fund and TCT Funded

Craigavon Area Hospital
2x 0.2 WTE- TYA CNS- TCT Funded
Young Person's Social Worker- YLvC
Young Person's Community Worker- YLvC

Ulster Hospital Dundonald
0.4 WTE (2 days)- TYA CNS- TCT funded
YLvC Social Worker (employed)
YLvC Young Person's Community Worker- employed

Appendix 4 Charities and their funding offer

As of start of review

Young Lives vs Cancer fund:

2 Paediatric Social Workers,

0.5FTE Social Worker in Antrim Area Hospital

1FTE Social Work Team Leader*,

0.5FTE Young People's Community Worker

0.5FTE Social Worker in Craigavon Area Hospital.

These post holders are directly employed and line-managed by this charity.

Jointly fund (50%) with Cancer Fund for Children (CFC) Ward Support Specialists for the regional hospitals. Post holder line managed by CFC.

In addition, this charity fund two project posts:

0.6 FTE **Clinical Psychologist-** funded until Jan 2024 (funded through Community Foundation NI) The clinical psychologist is project based, so doesn't see young people as part of their role. They provide reflective practice sessions to the Social Care Staff and TYA Nursing staff for 4 hours a month. They are also designing a digital resilience program for young people to use when on treatment which will be completed by Jan 2024. This programme will be piloted this year and young people will access it. They have not been recruited to deliver clinical psychology hours to young people.

0.5 FTE **Project Research Officer**- funded until Jan 2024 (funded through Community Foundation NI)

Cancer Fund for Children fund:

A 1.0FTE Ward Support Specialist for the Belfast Trust (who covers both paediatrics and adults).

Their post holder is directly employed and line-managed by this charity.

Part fund (50%) Ward Support Specialists for the regional hospitals. Jointly funded by Young Lives v's Cancer

Teenage Cancer Trust fund:

Part-time Clinical Nurse Specialists (0.4FTE full time equivalent for each of 5 posts) in each of the four regional trusts (Western Trust, South Eastern Trust, Southern Trust, Northern Trust, and the Royal Belfast Hospital for Sick Children at Belfast

This funding is provided to each trust who then employ and line manage these staff members.

Children's Cancer Unit Charity (CCUC)

They fund:

An MDaT Coordinator/Data Manager, based in Belfast Trust.

Their funding is provided to Belfast Trust who then employ and line manage this staff member.

A Play Specialist employed and funded directly by CCUC.

Friends of the Cancer Centre (part of the Belfast City Hospital fund)

They fund:

1.0 FTE Lead Nurse/TYA CNS,

0.5FTE TYA CNS.

0.7FTE Social Worker

This funding is provided to the trust, who then directly employ and line manage these staff members.

Appendix 5 Developmentally Appropriate Healthcare

Whilst the entry and exit from TYA cancer care are often driven pragmatically by chronological age, a more contemporary approach to meeting the needs of this patient group would be to adopt the principles of developmentally appropriate healthcare (Farre et al., 2016; Farre et al., 2015; Rapley et al., 2019) which are outlined in Box 1

Box 1. The five dimensions of developmentally appropriate healthcare (DAH) for young people

(Farre et al., 2015; Rapley et al., 2019)

1. **Biopsychosocial development and holistic care:** a focus on biopsychosocial development rather than chronological age, with routine biopsychosocial developmental assessment and approach to the young person adjusted accordingly.
2. **Acknowledgement of young people as a distinct group:** the recognition that their specific needs—in terms of informational resources, services, spaces, pathways and required competencies of staff—are distinctly different to those of younger children and older adults as a result of their developmental status.
3. **Adjustment of care as the young person develops:** the need for flexibility to acknowledge the biopsychosocial developmental changes over time and the potential for regression in relapsing health conditions.
4. **Empowerment of the young person by embedding health education and health promotion:** that knowledge and skills training for young people is embedded into routine clinical practice to enable them to gradually become more autonomous with respect to the care of their own health as they grow up. Services need to be designed so as to nurture and support such skill development.
5. **Interdisciplinary and interorganisational work:** a focus on continuity of care, coordination, consistency and communication across agencies. Connecting health, education, employment, social, voluntary agencies at a clinical and system level.

Appendix 6 Assessment tools used in TYA Cancer

A long-standing paper based generic assessment tool already exists for the psychosocial needs of adolescents (in general not necessarily in illness). The HEEADSSS encourages professionals to consider Home, Education & employment, Eating, Drugs, Sex & sexuality, Safety & risk-taking and Suicide & depression, (Goldenring and Cohen, 1988). All of those are specifically significant factors for TYA much more than younger children or older adults.

CanTeen, the Australian charity supporting TYAC has validated and implemented a paper-based psychosocial screening tool (Adolescent and Young Adult Psycho-Oncology Screening Tool AYA-POST). An evaluation described an appropriate tool for screening of AYAs with cancer for problems, improving the identification of psychological distress and specific concerns. It is therefore of utility in triaging and tailoring care for young cancer patients (Patterson et al., 2022).

IAM (Integrated Assessment Map) is a web application that assesses holistic needs in TYA with cancer in the UK (Cargill, 2016). This digital tool has been rolled out across many of the TYA Cancer services in the UK, was developed by Macmillan and is now funded by Teenage Cancer Trust. Patients are invited to self-assess against 12 areas in their life that may be affected by cancer such as - where am I now; physical well-being; friends', family and relationships; education and work; housing transport and finance; interest and social life; lifestyle; sex sexuality and fertility; thoughts and feelings, and faith spirituality and culture.

Importantly the IAM functions to;

- self-assess how they are doing, in relation to the domains
- areas of concern are flagged automatically to the TYA Cancer team to follow up with the patient directly and if appropriate raise at the TYAC MDaT
- inform discussion of individual's psychosocial needs during an MDaT, and identify remedial actions as a team
- Capture data, integrated with NHS patient records, which is monitored, audited and used to improve service design and direct capacity.
- Sign-post TYA to local, national and regional support services and information.

  Given that IAM is a digital tool that is not part of routine health service IT structures, it requires significant negotiation and integration with HSC or NHS Information Technology systems and as such specific digital resources and project management should be allocated to any sector wishing to explore its use and implement it..

Appendix 7 Recommendations linked to observations.

Number	Recommendation	Linked to observation number(s)
Must Do:		
1.	Develop a co-produced TYAC networked service framework for NI that enables a robust, equitable and resilient multi-professional interagency service across all settings.	1-4, 28-29
2.	Set key measurable TYAC care standards and implement an effective review process, including peer review. These should take account of the following (but not exclusively): • Clinical and referral pathways (including fertility preservation, transition and palliative care) • Service level offer, eligibility, auditing and governance. • MDT working locally and regionally and workforce education needs. • MDaT function • Approaches to TYAC care in all HSC settings • Holistic Needs assessment suited to TYAC • Peer support • User experience and advocacy • Psychosocial, mental health and psychological referral systems	1-4
3.	Ensure that effective TYAC digital data systems are in place and that all required data is captured and audited for accuracy.	5-6
4.	Review the TYAC MDaT function, in the spirit of good governance and inclusive multidisciplinary working, against mutually agreed aspects including its structure, terms of reference, data presented, members access to patient data.	7-9, 31
5.	Develop routine mechanisms to capture, review and act upon TYAC experience of cancer treatment and care.	10
6.	Implement a single agreed developmentally appropriate digital holistic needs assessment tool for use across the region.	11
7.	Develop and implement strategic leadership at a regional level that takes account of clinical, organisational and nursing leadership.	12-14
8.	Develop clear local leadership and governance arrangements to ensure equitable services across NI.	15, 17
9.	Develop effective partnership working between HSC and third sector to ensure all young people are afforded equity of access to holistic TYAC care.	1, 15-22,24-27
10.	Develop a TYAC service user advisor forum that ensures their voices are at the centre of all service developments at strategic and local levels.	1, 22

11.	Ensure funding for the provision of the hospital or community support worker continues.	24, 34
12.	Develop a framework which ensures that young people and their supporters can access peer support across their cancer experience no matter where they are treated.	32 -40
13.	Develop and implement a TYAC workforce education plan to raise awareness in both the general and specialist workforce linked to actions 52 & 53 of NI cancer strategy.	1, 3, 9, 38, 41
14.	Develop clear pathways for access to psychosocial, mental health and psychology for all TYAC in any location, inpatient or outpatient, that aligns with actions 40 and 42 in the NI Cancer Strategy	42-44
15.	Provide all TYAC with end of treatment summaries: incorporating a developmentally appropriate based assessment building on action 36 of the NI Cancer Strategy.	45-46
16.	Develop and implement pathways for TYA transitioning into and out of the TYAC service.	47-48

Should do:		
1.	Progress work to explore pathways that reflect the DAH palliative care needs of TYAC linked to action 47-51 of NI cancer strategy.	9,15
2.	Ensure the unique needs of TYA are reflected in the implementation of the NI Cancer Strategy	
3.	Develop a provision for signposting supporters and siblings of TYAC.	40

Could do:		
1.	Progress work to promote better access to clinical trials and biobanking locally and regionally for TYAC.	30

Would do:		
1.	A review of commissioning and funding arrangements to develop a operational networked TYAC service.	All