

MSN Children & Young People with Cancer



Annual Report 2022/23



Foreword	2
Introduction	2
Background	3
Vision	3
Children and Young People Cancer Strategy: 2022/23 Delivery Successes	4
Governance Arrangements	12
Patient, Family and Third Sector Involvement	14
Looking Forward – MSN CYPC 2023/34 Workplan	15
Appendices:	
Appendix 1 – MSN CYPC Foundations	17
Appendix 2 – MDT Meetings and Frequency	18
Appendix 3 – End of Treatment Summary Poster	20
Appendix 4 – MSN Staffing	21

Foreword

2022-23 has been a busy year for the MSN as we continue to recover cancer services for children and young people in Scotland from the impact of COVID-19. A large focus for this year has been on developing the new MSN Executive team; with new co-Clinical Directors and a National Network Manager now in post. This has enabled us to refocus our efforts on delivering NHS Scotland's Collaborative and Compassionate Cancer Care: cancer strategy for children and young people 2021–2026.

Of particular note this year is the progress we have made in developing age appropriate services, including our participation in the BRIGHTLIGHT 2021 study for young people (a UK wide study exploring whether specialist services add value for teenagers and young adults) as well as the implementation of e-holistic needs assessments for the same age group. None of these would have been achieved without the hard work of the MSN's TYA Lead Nurse, Liz Watt, who left her MSN post at the end of this financial year. We would like to thank Liz for her valued contributions.

I look forward to going into the new financial year with many exciting projects on the horizon to successfully deliver the ambitions within the children and young people with cancer (CYPC) strategy.

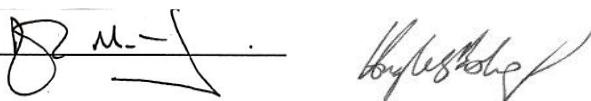


Dr Andrew Murray
MSN CYPC Chair

Introduction

Collaborative and Compassionate Cancer Care marks an exciting time for children and young people's cancer services as the first strategy for this age group. The strategy's emphasis on improving services nationally and supporting a consistent application of care and treatment across the country is really crucial to our ambition as a service network. We're pleased to have an MSN Clinical Leadership team from a broad geographical spectrum across NHS Scotland. We look forward to working with colleagues across the country to build on what is already happening to set out a new course for better services in the future.

We were also pleased to host our first in person education event in March 2023, with great attendance from many specialties and geographies. Coming together to learn and share is really crucial to our vision as a single service for children and young people with cancer. We look forward to seeing colleagues at more of these in the coming year.



Dr Dermot Murphy and Dr Hugh Bishop
MSN CYPC National Clinical Directors

Background

The Managed Service Network for Children and Young People with Cancer (MSN CYPC) was officially launched in 2011 to ensure a single sustainable model of service delivery for children, teenagers, and young adults with cancer across Scotland. Its aim is to ensure patients get the right diagnosis and the right treatment with the right team in the right place. To achieve this, the MSN works collaboratively with all staff involved in the delivery of children and young people's cancer services across Scotland and works with patients, carers and third sector organisations (charities).

Every year in Scotland, around 180 children up to the age of 16 and 200 teenagers and young adults (TYAs) between the ages of 16-25 are diagnosed with cancer. The types of cancers seen in children and young people are different from those in adults and are more treatable. Over 80% of children diagnosed with cancer before the age of 15 years can expect to survive more than five years after the diagnosis. For those between the ages of 15-24 years that rises to more than 90%.

Vision

The MSN CYPC is responsible for delivering the Scottish Government's vision for cancer services.

**Collaborative and
Compassionate Cancer Care:
The Cancer Strategy for
Children and Young People in
Scotland 2021-26:**

Vision: *A once for Scotland,
specialist, multidisciplinary and
age-appropriate service for all
children and young people who
are living with and beyond cancer*

Aim: *A National service that
strives to improve clinical
outcomes, psychosocial care, and
patient experience.*

**Our Ten
Ambitions
between
2021 – 2026**

Our Vision

A once for Scotland,
specialist, multidisciplinary
and age appropriate
service for all children and
young people who are
living with and beyond
cancer

Our Aim

A national service that
strives to improve clinical
outcomes, psychosocial
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experience

The MSN CYPC foundations, that help drive the development of a single service and foster national collaboration, are contained in **Appendix 1**.

Children and Young People Cancer Strategy: 2022/23 Delivery Successes

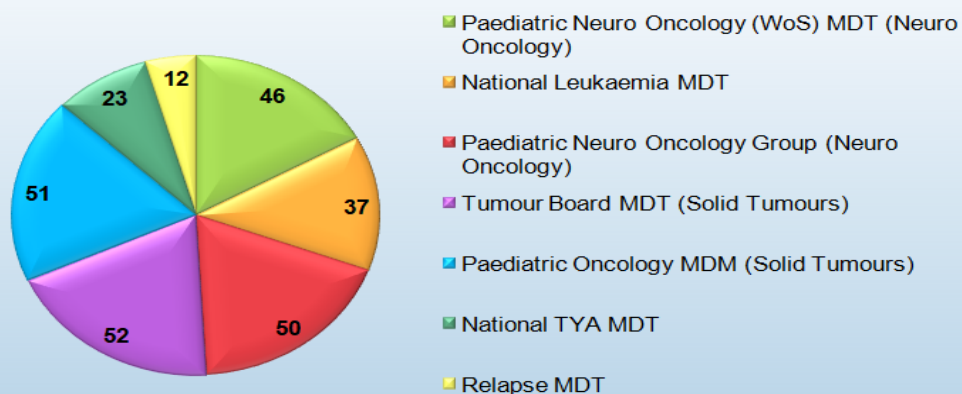
The MSN CYPC has been working with colleagues who deliver cancer services for children and young people (CYP) across Scotland to drive forward the ambitions, and deliver the actions contained within the CYPC strategy. In the absence of an annual workplan for 2022/23, please see below a 'spotlight on success' for each of the ten ambitions.



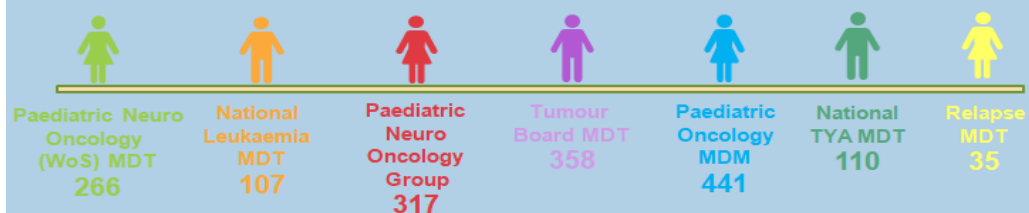
Ambition 1: Enhancing and Improving Outcomes Multi-Disciplinary Team (MDT) Meetings

Strategy Objective	An integrated, multidisciplinary team approach to treatment decisions for all children and young people, to ensure early and precise diagnosis and treatment decisions are made evidence based.
Strategy Action	All patients discussed at regional and/or national MDTs to ensure access to innovative treatments and appropriate clinical trials.
2022/23 Progress	The MSN facilitates up to 7 weekly MDT meetings to enable health professionals to work across Scotland to deliver the best care and improve outcomes.

There were 270 MDTs in 2022-23



There were 1634 case discussions in 2022-23



Information on the MDT meetings are contained in **Appendix 2**.

2023/24 Priorities	To ensure meetings are effective and with the new clinical leadership, a rapid review of the MDT's will take place to identify where improvements can be made. This will include updating the Standard Operating Procedures to improve standardisation.
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Ambition 2: Equity of Access Data Collection

Strategy Objective	Maximising health outcomes by ensuring that no child or young person is disadvantaged from accessing high quality treatment due to socially or environmentally determined circumstances.
Strategy Action	Continued 'Once for Scotland' approach to the collection of high-quality data and review using the Enhanced Cancer Registry, further developing to include an analytics function to provide dashboard reporting.
2022/23 Progress	The MSN has established a data short life working group to review its current indicators and review the added value of the Enhanced Cancer Registry. The group has concluded that further support is needed to improve data quality and consistency. Although further work is needed on regular audits, it was agreed that the original performance indicators are still appropriate (see further performance indicators section).
2023/24 Priorities	<ul style="list-style-type: none"> • To produce a data definitions manual for the Enhanced Cancer Registry. • To produce quarterly reporting against the performance indicators via MSN Board. • To review potential additional aftercare, AHP and palliative care data indicators with national clinical leads.




Ambition 3: Incorporated Supportive Care and Services Embedding psychological support as a core service

Strategy Objective	Ensuring enabling approaches are used, including reablement and rehabilitation, with psychologically informed approaches to support self management, resilience and mental health in individuals and communities.
Strategy Action	Substantive funding provided by the Scottish Government, directly to Health Boards, to ensure equitable access to specialist, age appropriate psychological and neuropsychological assessment and evidenced based interventions during each stage of the cancer pathway, delivered in paediatric and TYA settings.
2022/23 Progress	<p>At a round table hosted by Teenage Cancer Trust and the MSN CYPC TYA Team in March 2022, the Cabinet Secretary for Health and other members of the Scottish Government heard from young people diagnosed with cancer about how important dedicated psychology support was to their patient journey.</p> <p>The accompanying report concluded that there was currently insufficient psychology, physiotherapy and dietetics resource to meet the needs of TYA patients in Scotland in a fair and equitable manner and included a series of recommendations to expand the service.</p> <p>In December 2022, the Cabinet Secretary for Health confirmed recurring funding for the existing TYA psychology posts (the only TYA psychology, physiotherapy and dietetic posts currently filled at the time of the review of the report).</p>
2023/24 Priorities	<ul style="list-style-type: none"> • To complete a wider MSN workforce mapping to understand capacity to expand services using existing budget allocation. • To continue to work with Scottish Government to obtain recurring funding for other services.



Ambition 4: Service Improvement and Patient Safety

Strategy Objective	Ensuring safe and high quality cancer care.
Strategy Action	Continued investment in annual national Mortality and Morbidity (M&M) meetings to ensure learning from adverse events.
2022/23 Progress	<p>This year we held our first face to face event (covering national M&M sessions and educational presentations). Each centre was invited to present a case and 8 learning cases studies were discussed in total.</p> <p>The group discussions, hosted by our Paediatrics and TYA Clinical Lead colleagues, identified the following reflections:</p> <div style="border: 1px solid #00aaff; border-radius: 15px; padding: 10px; margin: 10px 0;"> <ol style="list-style-type: none"> 1. Standardise data; nationally via MSN 2. Communication – the need for a unified system 3. Enhanced focus on improving End of Life Care 4. Lack of equitable/specialist access to all AHP support across Scotland 5. Need for better signposting and understanding of guidelines for all staff. </div>
	
2023/24 Priorities	<ul style="list-style-type: none"> • To develop a planning sub group with clinical representation for future meetings. • Consider different ways to facilitate smaller group discussions so that all learning can be shared and applied across paediatrics and TYA services.



Ambition 5: Continuing care when treatment completes

Strategy Objective	Providing equitable aftercare including health surveillance, psychosocial support, identification of psychological and neuropsychological needs, health education and transition services.																				
Strategy Action	Ensure every survivor has an End of Treatment Summary and have at least one Holistic Needs Assessment completed.																				
2022/23 Progress	<p>Two Aftercare Clinical Nurse Specialists (based in NHS Greater Glasgow & Clyde and NHS Lothian but employed by the MSN) take a lead role operationally, clinically and strategically, in working with multi-professional teams, principal treatment centres and shared care centres across Scotland to ensure the development of best practice in the care of survivors of childhood cancer. They have provided a patient-facing service to patients across Scotland, and supported a number of professionals in providing aftercare support. A key focus has been on supporting the completion of End of Treatment Summaries (EOTS).</p> <p>A small project team was established to define a project to understand the low completion rate for End of Treatment Summaries. From the feedback received, most people recognised the benefits of an end of treatment summary but awareness needed to improve and a streamlining of processes. A copy of the project poster can be found in Appendix 3.</p>																				
<div data-bbox="172 1137 746 1563"> <p>Breakdown of Aftercare Clinical Nurse Specialist's Case Load by Health Board & Tumour Type in 2022-23</p> <table border="1"> <thead> <tr> <th>Health Board</th> <th>Number of Cases</th> </tr> </thead> <tbody> <tr><td>Ayrshire & Arran</td><td>6</td></tr> <tr><td>Borders</td><td>1</td></tr> <tr><td>Dumfries & Galloway</td><td>3</td></tr> <tr><td>Fife</td><td>8</td></tr> <tr><td>Forth Valley</td><td>15</td></tr> <tr><td>Greater Glasgow & Clyde</td><td>44</td></tr> <tr><td>Lanarkshire</td><td>14</td></tr> <tr><td>Lothian</td><td>16</td></tr> <tr><td>Tayside</td><td>2</td></tr> </tbody> </table> <p>Total number of cases = 110 Haematology (47) / Oncology (63)</p> </div> <div data-bbox="778 1137 1513 1563"> <p><i>'We had a patient who had completed treatment for Acute Lymphoblastic Leukaemia in June 2022. In the November, the patient presented to the GP with a variety of symptoms.....and the results showed likely relapseI found the discharge letter written by Ali (Aftercare CNS) which detailed very clearly the aftercare plan from time of discharge and her contact details very helpful. It was amazingly helpful that Ali was able to arrange admission and plans for further assessment so quickly, which meant that when the patient was advised of the abnormal blood results we were immediately able to advise that a plan had been made, therefore avoiding any unnecessary delay and distress to the patient'</i></p> <p>GP, Glasgow</p> </div> <div data-bbox="172 1585 1513 1809"> <p><i>'Your involvement has been crucial in assisting (patient X) in his return to school/education, ongoing support throughout his settling back in period and... indeed even more so as (patient X) was transitioning from Primary into Secondary education which is a stressful enough time without any medical issuesall of which has been invaluable as we would have had no idea where to begin nor who to contact...Having someone there to liaise with the school to make it as seamless and easy as possible is vital.....as is the knowledge that someone is there (out with the family) to check up on their well-being and for them to turn to.'</i></p> <p>Parent, Edinburgh</p> </div>		Health Board	Number of Cases	Ayrshire & Arran	6	Borders	1	Dumfries & Galloway	3	Fife	8	Forth Valley	15	Greater Glasgow & Clyde	44	Lanarkshire	14	Lothian	16	Tayside	2
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2023/24 Priorities	<ul style="list-style-type: none"> • Establish an aftercare group to develop a national aftercare model and approach. • Implement findings from End of Treatment Summaries project. 																				















Ambition 6: Integrated Palliative and End of Life Services

Strategy Objective	Developing equitable and earlier access to 24/7 integrated specialist palliative care services nationally.
Strategy Action	Undertake a national audit to inform the national strategic service development for the provision of end of life care to TYAs and their families.
2022/23 Progress	<p>Work was undertaken to identify the essential baseline data to inform and develop the understanding about the palliative and end of life care needs of this population. Key data identified included:</p> <ul style="list-style-type: none"> • Symptoms in the last 7 days of life • Referral offer to palliative care services • Outcome of referral (and how long before death it was accepted) • Presence of an anticipatory care plan • Presence of a multidisciplinary team at end of life • Place of death (and whether it was preferred place of death) • In receipt of high intensity treatment prior to death <p>A process was identified to collate the data and approval sought via the Public Benefit and Privacy Panel for Health and Social Care. The audit has been paused to review data collection arrangements and to align with the work of the data SLWG (see ambition 2).</p>
2023/24 Priorities	Completion of audit.



Ambition 7: Collaborative, compassionate & inclusive leadership

Strategy Objective	Strong leadership with the capacity and capability to drive innovation and the delivery of high quality, sustainable and responsive services.				
Strategy Action	Scottish Government funding provided to the MSN CYPC for the appointment of a National Clinical Lead for Paediatrics.				
2022/23 Progress	<p>The Scottish Government has provided funding to the MSN CYPC for the appointments of the following posts. This will ensure strong leadership with the capacity and capability to drive innovation and the delivery of high quality, sustainable and responsive services.</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; padding: 5px;"> <p style="text-align: center;">Dr Nick Heaney TYA Clinical Lead</p> <p>Working with Dietetic, Psychology, and Physiotherapy colleagues to secure recurring funding and expand the TYA services.</p>  </td> <td style="width: 25%; padding: 5px;"> <p style="text-align: center;">Dr Lesley Simpson Paediatric Clinical Lead</p> <p>Implementing a single national radiotherapy service for children. This is a key priority within the MSN CYPC strategy.</p>  </td> <td style="width: 25%; padding: 5px;"> <p style="text-align: center;">Dr Mark Brougham Aftercare Clinical Lead</p> <p>Focusing on the development of a national aftercare model for children and young people.</p>  </td> <td style="width: 25%; padding: 5px;"> <p style="text-align: center;">Dr Diana McIntosh Palliative Care Clinical Lead</p> <p>Develop & implement a national audit for the provision of end-of-life care to TYAs and their families.</p>  </td> </tr> </table>	<p style="text-align: center;">Dr Nick Heaney TYA Clinical Lead</p> <p>Working with Dietetic, Psychology, and Physiotherapy colleagues to secure recurring funding and expand the TYA services.</p> 	<p style="text-align: center;">Dr Lesley Simpson Paediatric Clinical Lead</p> <p>Implementing a single national radiotherapy service for children. This is a key priority within the MSN CYPC strategy.</p> 	<p style="text-align: center;">Dr Mark Brougham Aftercare Clinical Lead</p> <p>Focusing on the development of a national aftercare model for children and young people.</p> 	<p style="text-align: center;">Dr Diana McIntosh Palliative Care Clinical Lead</p> <p>Develop & implement a national audit for the provision of end-of-life care to TYAs and their families.</p> 
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2023/24 Priorities	Ongoing organisational development input to support clinical and professional leadership within the MSN CYPC.				



Ambition 8: Education, Training and Staff Support

Strategy Objective	Creating a learning culture and opportunities for greater inter-professional and integrated education.
Strategy Action	Developing further education and learning opportunities to improve referrals and ensure timely diagnosis.
2022/23 Progress	We held our first Education Event since the pandemic; this was combined with our Morbidity & Mortality Day and feedback (from the 62 attendees), indicated it was a great success. There were various discussion topics and presentations including <i>Febrile Neutropenia Management</i> (Dr Bob Philips, Consultant in Paediatric and TYA Oncology, Leeds Teaching Hospital, NHS Trust) and <i>TYA & Paediatric collaboration across Scotland</i> (Camille Goetz, Director of Programmes, Tessa Jowell Brain Cancer Mission).



Comments from the day

The M&M learning was very relevant and demonstrates the need to keep learning and communicating in this particular health sector

Good balance between the M&M presentations and Education session


Very interesting speakers and lots of information shared to develop knowledge

2023/24 Priorities

- Further education sessions.
- Engagement with Scottish Primary Care Cancer Group to review referral approaches.

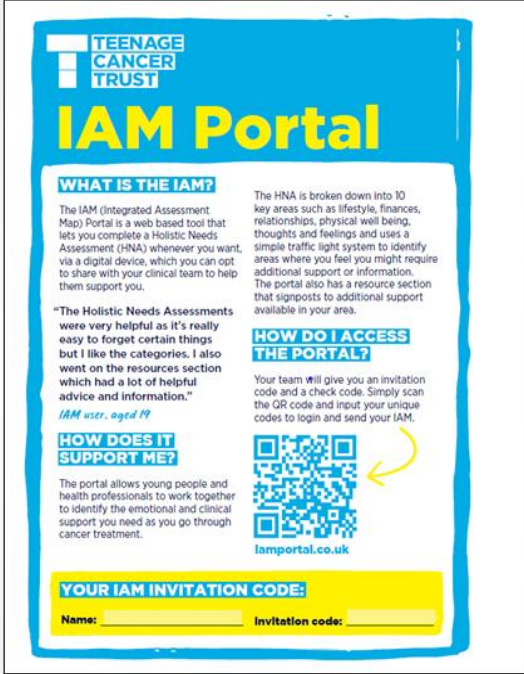


Ambition 9: Specialist and sustainable workforce

Strategy Objective	Continuing to develop and support a clear multidisciplinary approach to working that is based on the needs of the population.
Strategy Action	Undertaking a wider MSN CYPC workforce review to ensure the appropriate staffing model to deliver on the strategic actions in the cancer strategy.
2022/23 Progress	<p>With a new Executive team in place, the workforce review has focused initially on those employed directly by the MSN CYPC. A Workforce Plan using the 6 Steps Methodology has been developed to ensure the MSN has the right workforce with the right skills and competencies deployed in the right place at the right time to deliver our key objectives now and in the future. MSN Board in February 2023 endorsed the recommendations within the plan.</p>  <p>The Six Steps Methodology to integrated workplace planning</p> <ol style="list-style-type: none"> 1. Define the plan Identify the purpose and scope of the plan and establish ownership and responsibilities. Steps 2, 3, and 4 are all inter-related so will need to be approached in synergy. 2. Map the service change Identify the benefits of change, drivers and barriers. Option potential working models. 3. Define the required workforce Map the new service activities, identify the skills needed and the types & numbers of staff required. 4. Understand workforce availability Map out the current workforce in terms of existing skills, demographics and supply options. Consider revising steps 2 and 3 based on availability or shortage of staff with required skills. 5. Develop an action plan Develop a plan to deliver the right staff with the right skills in the right place, and manage any changes. Determine the most effective way to deliver the redesigned service against time and resources. 6. Implement, monitor, and revise Now it's time to make your plan a reality. Be sure to measure the progress of the plan against targets. Revisit the six steps periodically to reflect any unplanned changes.
2023/24 Priorities	<p>Implement the recommendations including:</p> <ul style="list-style-type: none"> Recognising the need for an over-arching network to support the delivery of a virtual single service for children and young people's cancer services, the MSN should retain a national service delivery function and work closely with territorial Health Boards to set out a clear framework for delivery as well as monitoring and reporting arrangements. Recognising the gaps in its current operational delivery model, the MSN should implement a robust optimisation plan focusing on three delivery areas: governance and structure (introduction of annual strategy implementation plan and individual workplans); credibility and accountability (confirmation of activity and finance reporting to Scottish Government) and relationships and engagement (confirm service delivery expectations with Health Boards and optimise national/regional multidisciplinary team meetings). Recruit to priority posts (including project management roles and nursing leader).



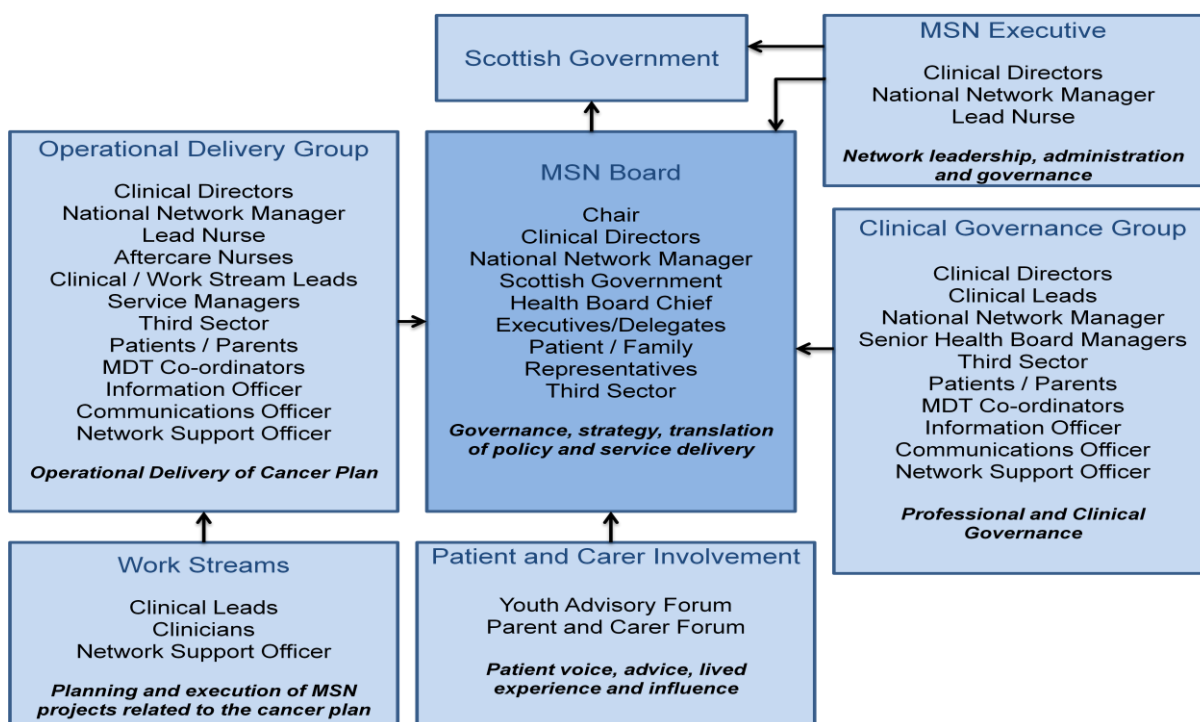
Ambition 10: Age appropriate services and effective transitions

Strategy Objective	Ensuring all young people aged between 16-25 years old have equitable access to comprehensive and personalised age appropriate care.	
Strategy Action	A single TYA specific e-holistic needs assessment (the IAM) will be implemented for use at the national TYA cancer MDT and adopted as the standard approach.	
2022/23 Progress	<p>The IAM Portal (Integrated Assessments Mapping Portal) is an electronic Holistic Needs Assessment (e-HNA) tool that uses a traffic light system to identify areas the young person feels they require additional support/information such as - lifestyle; finances; relationships; physical wellbeing; and feelings. The IAM portal aids the facilitation of MDT discussions and allows the young person's voice to be heard.</p> <p>Since launching in September 2022 until March 2023, 120 young people across Scotland have been given a code to access to the IAM portal and 19 e-HNA's have been submitted.</p>	
2023/24 Priorities	A process for auditing and evaluating the use of the system will continue to be reviewed in 2023 to ensure optimum results from the portal.	

Governance Arrangements

MSN structure

With almost all roles now filled, the MSN CYPC is focusing on re-establishing the governance structure to support delivery of the CYPC strategy, ensuring regular and meaningful engagement with all key stakeholders (including territorial Health Boards, charities and patients, parents and carers).



The MSN staffing structure is contained in **Appendix 4**.

Funding and Resourcing

Funding for the MSN CYPC is provided by the Scottish Government. The 2022/23 budget allocation was £1.272 million (with £772k in recurring allocation and a £500k TYA non-recurring allocation). With a large proportion of the budget allocated to staff costs, and with substantial vacancies in the first half of the financial year, the MSN did not request the full allocation from Scottish Government. It is anticipated that, with the focus on workforce planning and recruitment, the full budget allocation will be required in subsequent years.

Additional funding was provided by Teenage Cancer Trust to support strategic delivery of national TYA projects, and this was used to fund 50% of the TYA Lead Nurse post and 50% of the Holistic MDT Co-ordinator (totalling around £75,000).

Performance Indicators

Identified as a priority area in the previous Cancer Plan (2016-19), the MSN CYPC developed five Quality Performance Indicators (QPIs) to measure performance and in collaboration with NHS National Services Scotland, an Enhanced Cancer Registry (ECR) was developed as a centralised data storage system, collecting the appropriate data to report on the performance indicators. High quality cancer data and intelligence will bring about benefits for the entire cancer journey. The ability to have regular standard reports on incidence of cases, how and where patients are treated, survival, patient safety, mortality and morbidity outcomes, will form an integral part of clinical governance.

To date, reporting from the ECR has been minimal and there are known data quality and completion issues. The table below provides the performance summary against the current indicators in the 12 months to 31st March 2023. The outcomes indicate performance below expectations, but as noted, this is likely due to data completeness rather than a reflection of current practice. However, in the interests of transparency, they have been included for review. The MSN Board has committed to ensuring the quality of the data reaches the required level and to work with Health Boards ensure the correct structure is in place to report and address any performance issue for FY23/24.

MSN Performance Indicators 1 st April 2022 to 31 st March 2023					
		Numerator	Denominator	Target	Performance
QPI No.1	Patients should not wait more than 21 days between being referred to hospital and a primary diagnosis being made	95	133	95%	71.4%
QPI No. 2	Patients should not wait more than 14 days between primary diagnosis and start of treatment	101	133	95%	75.9%
QPI No. 3	All eligible newly diagnosed patients should be offered participation in an available clinical trial:				
a)	Child Interventional Trial	13	115	50%	11.3%
b)	Child Translational Trial	5	115	10%	4.3%
c)	TYA Interventional Trial	1	18	30%	5.6%
d)	TYA Translational Trial	1	18	10%	5.6%
QPI No. 4	All children with cancer should be discussed at a regional and/or national multi-disciplinary team within 14 days of diagnosis	50	133	95%	37.6%
QPI No. 5	An End of Treatment Summary must be completed for every patient within 6 months of treatment ending	6	44	100%	13.6%

The resolution of any performance and/or reporting issues is an area of priority for the MSN Board. To safeguard future reporting, a short life working group was set up to review the function of the ECR, the performance indicators and the current data collection processes. Ambiguities in data definitions have been identified, highlighting the need for standardisation and the benefit of a data definitions manual. To provide assurances we will continue to monitor and review the indicators on a regular basis. This will be shared routinely with key stakeholders and monitored through the quarterly MSN Board meetings.

Patient, Family and Third Sector Involvement

As a result of the COVID-19 pandemic and change in MSN staffing, it has been difficult to sustain the **Parent and Family Forum** (aimed at obtained engagement from those accessing paediatric cancer services) however efforts are underway to re-engage the group with a plan to meet early in 2023/24 to refresh the aims and recruit new members. Person-centred care is at the heart of what we do and must be informed by patient and family feedback.

The National Youth Advisory Forum (YAF) consists of 14 members across Scotland who have accessed teenager and young adult cancer services. It has continued to meet virtually during and after the pandemic with 5 meetings held this year. Despite the impact on their lives, the YAF remained engaged with the MSN CYPC and motivated to contribute to the development of the MSN services for TYA with cancer, including;

- Developing the model for the Buddy Support System (Action 55 of the cancer strategy) and implementing a peer-to-peer support network for young people with cancer.
- Meeting with the Cabinet Secretary for Health to discuss the benefits of accessing psychology, physiotherapy and dietetic support when diagnosed with cancer as a young person.

We have recently re-engaged with our **Third Sector** partners; Teenage Cancer Trust, Children's Cancer and Leukaemia Group, Young Lives Vs Cancer, Cancer Research UK, Tessa Jowell Brain Cancer Mission and Macmillan Cancer Support for a sharing and collaboration discussion on research, data and pathways in early summer. Through this, the MSN aims to develop a patient and carer involvement and engagement strategy.

Looking Forward: MSN 2023/24 Workplan

Develop a national aftercare model for CYPC:

- End Of Treatment Summaries project recommendations roll-out and monitor impact of service improvements
- Project Board to scope and develop a national aftercare model
- Report on service delivery from aftercare nurse specialist and review ways of working to obtain national coverage
- AHP cancer aftercare pathway

End of life care is delivered in the appropriate and preferred location of the patient and family through the safe delivery of a bespoke management plan:

- Audit the end of life care service provision to TYAs and their families
- Updated guidance documentation on palliative care principles for those working with CYPC
- Palliative care training needs assessment and deliver a training event
- Update NHS Inform Directory of Services to reflect the relevant CYP palliative cancer services

Work in partnership with local Health Boards to complete a national workforce mapping exercise:

- Develop mapping template
- Conduct mapping
- Share results with local Health Boards

Complete and implement the MSN workforce action plan:

- Production of workforce plan using 6 steps methodology
- Recruit to agreed vacant posts
- Implementation of optimisation programme

Invest in annual national M&M meetings to ensure learning from adverse events:

- Delivery of M&M event with learning across Paediatrics and TYA services

Report against MSN performance indicators to understand and improve service delivery:

- Consensus on national indicators
- Mapping with adult cancer services performance indicators
- Development of ECR to support data collection and reporting
- Production of data definitions manual to improve consistency

Develop and Implement a Transition Framework:

- Implement a Transition Framework to ensure every survivor has an individualised transition programme

A co-ordinated and strategic approach to patient, parent and carer involvement across the MSN:

- Map existing patient experience
- Conduct a workshop with third sector partners
- Opportunities to extract data from the adult cancer services patient experience survey
- A national peer support system for TYAs with cancer
- Ongoing facilitation of Youth Advisory Forum
- Re-establish paediatrics parent/carer involvement approach

Implement a single site national radiotherapy service for children within Scotland:

- Buy-in from clinical and health service managerial colleagues
- Update the business case to reflect any emerging evidence and research
- A service specification with agreed patient pathways and clearly defined local Board responsibilities Vs those of a national service
- Business case for consideration as national designated service via NSD commissioning team

Ensure effective multidisciplinary team working through review of MDT Standard Operating Procedures to ensure access to innovative treatments and appropriate clinical trials:

- Develop and implement improvement plans for each MDT supported by the MSN (including the development of consistent operating procedures)
- Agree and undertake consistent annual reporting of the MDTs

Re-establish the clinical governance structure to support national ways of working and robust identification, escalation and resolution of risk:

- Operational Delivery Group (with Health Board representation) to support strategy implementation
- Clinical Governance Group to support national escalation of clinical risk and provide SACT governance
- Formation of Paediatrics Clinical Advisory Group
- Review TYA Clinical Advisory Group Terms of Reference

Appendix 1 – MSN CYPC Foundations

- Develop a single, sustainable and cohesive service for Scotland providing guidance on service development, supported by robust shared care arrangements and multidisciplinary ways of working on treatment and beyond.
- Develop and embed governance frameworks that support the work of the MSN CYPC to ensure the safety of children and young people.
- Ensure that all children and young people in Scotland have had the opportunity to be included in an appropriate clinical trial.
- Develop and monitor patient pathways, standards and supporting systems to ensure consistent data standards, collection and management.
- Develop and implement best practice frameworks for multidisciplinary teams.
- Develop sub-specialisation, agreeing referral guidelines and advising on strategic workforce issues including key appointments.
- Lead on the establishment of a robust e-Health strategy, supporting the functioning of multidisciplinary teams and the delivery of services.
- Facilitate mutual support arrangements between units when required.
- Lead on national education and training issues, research, and the establishment of a national academic resource.
- Promote the early detection of cancer in children and young people.
- Ensure that the work of the MSN CYPC is widely communicated to all stakeholders.
- Ensure patient involvement at all levels including network activities and monitor patient satisfaction.

Appendix 2 – MDT Meetings and Frequency

MDT	Geography	Frequency	Attended by
Leukaemia	National	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow and Inverness
Relapse	National	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow, Newcastle and Belfast
Neuro-Oncology	Regional	Weekly	Aberdeen, Dundee and Edinburgh
			Glasgow and Inverness
Solid Tumour	Regional	Weekly	Dundee and Edinburgh
			Aberdeen and Glasgow
TYA	National	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow and Inverness

Paediatric Oncology/Haematology

These contribute to the diagnostic and treatment decisions for each patient and are attended by specialities including Oncology, Haematology, Clinical Oncology, Surgical teams, Radiology, Pathology, Nursing, Research Team, Geneticist, AHPs (allied health professionals) and administrative staff.


Regional Relapse Discussion Panel (RRDP)

This MDT ensures all suitable patients with relapse or refractory disease are offered entry into an appropriate clinical trial. Clinical specialists from all the main treatment centres in Scotland (Aberdeen, Dundee, Edinburgh, Glasgow and Inverness) attend this meeting as well as colleagues from Belfast and Newcastle.

Teenage and Young Adults MDT

Focused more on the holistic needs of the patient, this MDT considers options for fertility preservation, recommendation of clinical trials, an assessment of psychosocial needs, as well as assigning a Key Worker and single point of contact.

Appendix 3 – End of Treatment Summary Poster



NHS
Education
for
Scotland

End of Treatment Summaries for Children and Young People with Cancer

Joanna Macfadyen, Information Officer, MSN for Children & Young People with Cancer

The service identified that improved communication of cancer information provided to patients/families and between healthcare providers may contribute to greater engagement in follow up programmes, raise awareness of potential late effects amongst survivors and enable clinicians to diagnose and treat late effects earlier.

Aim

By March 2023, 75% of children who have had cancer under the age of 16, treated in RHC Glasgow, will have an end of treatment summary completed within 6 months of their treatment ending, this is in alignment with The Cancer Strategy for Children & Young People in Scotland 2021 – 2026.



Method

- Project team established
- Process Map was used to identify problem areas
- Consultation with key stakeholders aided development of a driver diagram and proposed change ideas
- Change ideas were tested in PDSA cycles



Process Changes

Feedback from stakeholder questionnaire provided change ideas to make completion of the EoTS document easier and to develop educational/awareness sessions on EoTS processes.

AIM	PRIMARY DRIVER	SECONDARY DRIVER	CHANGE IDEAS
By March 2023, 75% of children who have had a diagnosis of cancer under the age of 16, treated in the RHC Glasgow, will have an End of Treatment Summary completed within 6 months of their treatment ending. This is in alignment with The Cancer Strategy for Children and Young People in Scotland 2021 – 2026.	Timely completion of End of Treatment Summary	Engagement with key stakeholders on process of End of Treatment Summaries	Communications to key stakeholders on End of Treatment Summaries/Process
	Reduce data collection / information overloading	Monthly report on patients who have completed treatment	Developing reporting guidelines of completion of end of treatment document
	Registry updated with key end of treatment dates	End of Treatment Summary completed by medical teams involved in patient care	Avoid end of treatment document with drop down details by near completion
		Registry updated with key end of treatment dates	Develop way of updating end of treatment document with patient demographics
			Develop educational sessions on End of Treatment Summary processes

Achievements

- Main achievements for project and self:
- ✓ Increased awareness of end of treatment process
 - ✓ Multidisciplinary approach to end of treatment process
 - ✓ Increased my confidence in using quality improvement tools
 - ✓ Greater confidence in myself as a leader to promote and encourage change

Key References:



Results



Conclusions

From feedback received, most people recognised the benefits of patients and families having an end of treatment summary, unfortunately we didn't have enough data to highlight if there was a sustained change in practice, however the MSN has endorsed this and will continue to monitor through their performance indicators.



Key Learning Points

- Don't make project too big, scale it down and start off small
- Have the right people involved from the beginning
- Displaying data helps inform decision making
- Ensure data collection is robust and timely
- Don't underestimate the effect of human factors
- Support from fellow ScIL colleagues is invaluable
- Never give up!

Next Steps

Develop awareness sessions in other treatment centres and seek feedback and involvement with patient's GP's

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ScIL
Scottish Improvement Leader

Appendix 4 – MSN Staffing

Job Title	Employer	WTE	Band
MSN Co-Chairs	SLA (<i>currently NHS Forth Valley</i>) Vacant	0.2 0.2	
National Clinical Director	SLA (<i>currently NHS Grampian & NHSGGC</i>)	2 PAs 2 PAs	
National Network Manager	NHS Tayside	1	8b
Holistic MDT Co-ordinator (part-funded by TCT)	NHS Tayside	1	5
Paediatrics MDT Co-ordinator	SLA (<i>currently NHS GGC</i>)	1	5
Network Support Officer	NHS Tayside (<i>currently vacant</i>)	1	4
Pharmacy Lead	SLA arrangement (<i>currently vacant</i>)	0.6	8c
AHP Lead	SLA arrangement (<i>currently vacant</i>)	0.4	8a
Information Officer	NHS Tayside	1	5
Communications Officer	NHS Tayside	0.8	5
National Lead Nurse	NHS Tayside (<i>currently vacant</i>)	1	8b
National Aftercare Clinical Lead	SLA arrangement (<i>currently NHS Lothian</i>)	1 PA	
National Paediatrics Clinical Lead	SLA arrangement (<i>currently NHS Lothian</i>)	2 PAs	
Palliative Care Clinical Lead	SLA arrangement (<i>currently NHS GGC</i>)	1 PA	
Aftercare Clinical Nurse Specialist	SLA arrangement (<i>currently NHS GGC & NHS Lothian</i>)	2 x 0.8	7



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