Managed Service Network for Children and Young People with Cancer

NHS
SCOTLAND

Annual Report 2024/25

MSN
For Children & Young People
with Cancer

FOREWORD

The Managed Service Network for Children and Young People with Cancer (MSN CYPC) has made significant progress towards achieving our goals during 2024/25 and the Network continues to grow and improve across Scotland. I am extremely proud of the impact that our organisation has had on cancer services for children and young people and the hard work and dedication that has gone into another successful year.

We bade farewell to two of our longest-serving and most influential clinicians this year, with Dr Dermot Murphy retiring out to the Middle East and Dr Hugh Bishop moving into the role of National Clinical Lead for the Scottish Cancer Network before being appointed as Executive Medical Director for NHS Grampian. As joint National Clinical Directors for the MSN CYPC, both were instrumental in shaping the organisation as it stands today, and their clinical and strategic leadership ensured that Scotland continues to provide the best possible service to our patients, no matter where their treatment is delivered. We wish them all the best in their new ventures.

The MSN CYPC welcomed Jamie Cargill to the position of National Nurse Consultant at the end of the reporting period. Jamie trained in Scotland before embarking on a career in Children and Young Adults Cancer Services in NHS England which spanned almost 25 years. Jamie brings to Scotland a wealth of knowledge and experience and we are very excited to work with him in this new leadership role.

Our next 12 months is critical. We will continue to deliver on the current Cancer Strategy whilst also preparing for the long-term future by preparing an updated strategy that will take us to the end of the decade and perhaps beyond. Exciting times lie ahead, and we are very much looking forward to them!

Dr Andrew Murray
MSN CYPC Chair

CONTENTS

INTRODUCTION

We are proud to present the Annual Report for the Managed Service Network for Children and Young People with Cancer (MSN CYPC) in Scotland. This report reflects the collective efforts, challenges, and progress made throughout the year in delivering high-quality, equitable cancer care to children and young people across the country.

Our network brings together clinicians, nurses, psychologists, allied health professionals, service managers, voluntary sector partners, and patients and their families to ensure that every young person affected by cancer receives timely, compassionate, and effective care, no matter where they live in Scotland. Through this collaborative approach, we continue to strengthen national standards, improve patient outcomes, and support the emotional, physical, and psychological needs of our patients and their families, with some of our achievements detailed below

- After many years of hard work and collaboration across the country, the MSN CYPC has succeeded in commissioning a single-site paediatric photon beam radiotherapy service in NHS Greater Glasgow and Clyde. This is a truly ground-breaking initiative and will enhance the quality of service-provision for our young people.
- The MSN CYPC continues to work extremely closely with our young people to learn about their experiences with the aim of improving our pathways. We are extremely proud of the work that the Youth Advisory Forum (YAF) has done during the past 12 months, and they have an exciting forecast of initiatives lined up during 2025/26. We have also reengaged with our 3rd Sector Partners and the renewed Parent, Carer and Families Forum will ensure that we are able to understand the whole picture when it comes to the wider patient and families experience.

We extend our sincere gratitude to all those who contribute to the network — from frontline staff to strategic partners — and most importantly, to the young people and families who inspire and inform everything we do. Their courage and voices continue to shape our services for the better. Together, we strive toward a future where every child and young person with cancer in Scotland receives the best possible care and support.

This year, we have faced both familiar and new challenges, but we remain committed to learning, adapting, and improving. Our focus on person-centred care, early diagnosis, access to specialist treatment, and support through survivorship or end-of-life care remains unwavering. The MSN has children and young people with cancer and their families at the heart of all it does. This uniquely vulnerable group deserves world class services, and the MSN CYPC continues to support health care professionals across the country, to provide care we can all be proud of.

MSN CYPC Executive

BACKGROUND

The Managed Service Network for Children and Young People with Cancer (MSN CYPC) was officially formed in 2011 to develop 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 CYPC 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 16-24 are diagnosed with cancer. The types of cancers seen in children and young people are different from those in adults and are often 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 16-24 years that rises to more than 90%

VISION

The MSN CYPC remains unwaivered in our Vision to coordinate the delivery of the Scottish Government's vision for cancer services and progress through the ambitions set out in the Cancer Strategy 2021-26. To steer these ambitions, our national workstreams and their leadership continue to focus on the design and delivery of services, creation of the evidence base for improving practice and governance. 2024/25 saw significant progress towards delivery of these workstreams as we enter the final year of the current strategy.

WORKSTREAMS

- Data Collection and Reporting
- Single Site Radiotherapy
- MDTs
- Aftercare
- Transition
- Palliative Care
- TYA Services
- Workforce
- Patient Experience and Public Involvement

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 care and patient experience

WORKSTREAM DELIVERY SUCCESS

NATIONAL YOUTH ADVISORY FORUM

Julie Cain, National Lead Nurse, Teenage Cancer Trust

2024/25 has been a hugely successful year for the National Youth Advisory Forum in Scotland. The forum has increased its number of members to fifteen and has participated in several National initiatives.

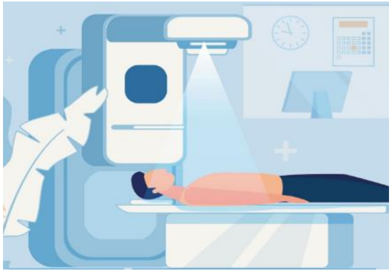
In May 2024, Dr. Gillian Horne, TYA Haematology Consultant, NHS GG&C, led a workshop focused on enhancing access to clinical trials for young people. The forum explored ways to improve how clinical trial information is communicated and how to make trials more accessible to this age group. The work has been progressing well, and a follow-up workshop is scheduled for August 2025. The upcoming sessions will concentrate on improving the communication of clinical trials through digital technology, and equality, diversity, and inclusion in clinical trials.

The TYA team has been working with Health Improvement Scotland to develop a TYA information app which will be hosted on the ***Right Decision Service*** platform. The youth advisory forum has played an integral role in shaping the app and will be involved in testing the working model once it is ready.

The TYA team in Glasgow has launched a new initiative, funded by the Beatson Cancer Charity, to support young people newly diagnosed with cancer. Every patient will receive a tote bag containing essential and comfort items to help them through the early stages of their diagnosis and treatment. The Youth Advisory Forum played a key role in selecting the contents of the bags and one forum member wrote a heartfelt letter to be included in each bag, adding a personal and compassionate touch to the initiative.

The successful implementation of the peer support network represents a major milestone. Although the idea had been under discussion since 2017, various challenges had delayed its progress. In 2024, the project moved forward with the successful training of 12 mentors, several of whom have already been matched with mentees. The Youth Advisory Forum played an important role in shaping the initiative, contributing to the design of promotional flyers and leaflets. We are very grateful to the Arnold Clark Community Fund for their generous grant, which helps cover the cost of refreshments for in-person mentor / mentee meetings. In February 2025, a formal evaluation of the Youth Advisory Forum was conducted. The feedback received was overwhelmingly positive, highlighting the forum's value and impact.

"It's been an amazing opportunity to be a part of the forum – thank you to everyone for creating such a safe and valuable space"



SINGLE SITE RADIOTHERAPY

Dr Lesley Simpson, National Paediatric Clinical Lead, MSN CYPC
Dr Ben Fulton, Consultant Clinical Oncologist, NHS GG&C

Single site radiotherapy service for children was a priority action within the Scottish Government's Cancer Strategy for Children and Young People in Scotland (2021-2026): Collaborative and Compassionate Cancer Care. The aim of developing a single site radiotherapy service was to deliver improved outcomes and experience for children requiring radiotherapy by ensuring equity of access to age-appropriate services and treatment, delivered in line with national quality standards within a sustainable, suitably qualified workforce.

The single site radiotherapy service aims to provide a comprehensive service for all children with cancer who would benefit from radiotherapy as part of their treatment plan. This is estimated (from cancer incidence and current service taxonomy in Scotland) to be around 60-70 patients per year. The national provision of radiotherapy for children includes photon radiotherapy delivered in Scotland (estimated around 40-50 patients per year) and proton beam therapy (estimated around 20-30 patients per year) delivered in NHS England via the UK highly specialised commissioning guidelines.

As well as meeting the requirements of Realistic Medicine, the evidence on the effectiveness of centralised specialist treatment for cancer in children is clear and well known (e.g. Selby et al, 1996). The proposal for centralisation of radiotherapy services in Scotland aligns with proposed service models adopted within NHS England and EORTC centres across Europe. This model strives to ensure every child has equitable high quality radiotherapy treatment and, where possible, delivery within contemporary cutting-edge radiotherapy clinical trials. The single site radiotherapy service ensures children in Scotland receive equitable high-quality radiotherapy delivered within a national centre of excellence, whilst ensuring Scotland maintains a resilient service for the future.

Subsequent modelling around a single site radiotherapy service included comprehensive consultation, needs assessment and options appraisal, undertaken to ensure the service equitably meets the needs of every child and family in Scotland. This comprehensive review process unanimously identified an optimal model involving establishment of a single site radiotherapy service model hosted by the Beatson West of Scotland Cancer Centre and NHS Greater Glasgow and Clyde. This service delivery model was submitted to the National Services Division (NSD) in August 2023 for assessment, supported by the Managed Service Network for Children and Young People with Cancer. The service delivery model aims to provide over-arching provision of children's radiotherapy within a single site radiotherapy service but ensuring that appropriate steps in the patient pathway continue to be delivered locally where possible. This ensures children and their families' best interests remain at the heart of the service model. This proposed model was agreed by multi-disciplinary meeting held in April in Edinburgh with representation from across NHS Scotland paediatric oncology treatment centres, to ensure specific needs of each geographical health board were considered and met.

NSD and the Scottish Government confirmed in March 2025 the proposed single site radiotherapy service application was successful. Planning to implement the single site radiotherapy service commenced in collaboration with all territorial health boards in NHS Scotland and close working between existing radiotherapy centres in NHS Lothian and NHS Greater Glasgow and Clyde to ensure smooth transition process. The service undertook soft launch of some patients requiring complex radiotherapy within clinical trials in the months leading to service designation of national service, providing an opportunity to optimise the patient pathway prior to formal roll out.

The single site radiotherapy service for children officially launched on 1st April 2025, with the first child treated on the 3rd of April 2025. Throughout the implementation of this complex service, it has been of paramount importance to ensure it addresses the needs of children and families. The single site radiotherapy service will collate and present prospective data on performance metrics alongside patient, family and primary referrer feedback of the service. This will allow the service to ensure it equitably meets the patients and service users across NHS Scotland and provides a platform for continued learning and service development, based on the unique needs of the children and families it serves.

EDUCATION EVENTS

Victoria Sanderson, Communications Officer, MSN CYPC

2024 was a successful year for MSN CYPC education events, with our annual Morbidity & Mortality Day, Education Day and a Neuro-Oncology Study Day.

Morbidity & Mortality – Friday 3rd May 2024 – Apex Hotel, Dundee

Hosted by Dr Quentin Campbell-Hewson, Consultant Paediatric Oncologist, Newcastle Foundation Trust, the aim of this event was to facilitate discussion by examining a series of clinical scenarios/cases through a culture of openness and sharing of experiences, in an attempt to identify areas to improve patient care.

Over fifty-four professionals attended the day, with eight case studies presented – two paediatric cases and six TYA cases. There was also a guest presentation from Dr Dawn Penman, Consultant Paediatric and Perinatal Pathologist/Histopathology, NHS GG&C, titled ***'My Retinoblastoma'***.

Feedback comments included.

- *Such a worthy day especially seeing people from other centres – hugely beneficial*
- *Highlights the importance of MDT working*
- *Excellent pathology presentation (many comments praising Dr Penman)*
- *Opportunity to reflect on practice*
- *Good structure of the programme and common themes –illustrates need for more psychology support*

Education Day, *Symptom Management at End of Life* – Friday 6th September 2024 – The Studio, Glasgow

Hosted by Dr Diana McIntosh, Palliative Care Clinical Lead, MSN CYPC, the aim of this education day was to share experience and increase knowledge ensuring we are alleviating suffering by providing all children in Scotland with excellent symptom control.

Overall, fifty-eight health care professionals attended the day. Dr Diana McIntosh delivered a thought-provoking and varied programme which included Psychological Distress on Both Sides, Terminal Agitation and Delirium, GI Symptoms, Complex Pain and Dyspnoea and Respiratory Symptoms. With a mixture of workshops, presentations and guest speakers, the day was well-attended and was a great success.

Feedback comments included.

- *Excellent order of presentations, with the last one being interactive…*
- *Mentimetre analysis was really useful to offer comments*
- *Insightful information to take back to colleagues*
- *Good interaction with other delegates and group work sessions*

Neuro-Oncology Study Day – Friday 1st November 2024 – The Edinburgh Training and Conference Venue

Hosted by Dr Lesley Simpson, Paediatric Clinical Lead, MSN CYPC and Dr Mark Brougham, Aftercare Clinical Lead, MSN CYPC, the aim of the study day was to improve the understanding of recent advances in the field of Paediatric Neuro-Oncology from an MDT perspective and to facilitate and encourage Scotland-wide networking amongst professionals with an interest in Paediatric Neuro Oncology.

Fifty-four registered to attend, with nine presentations including; *Environmental Impact, Protons Vs Photons, Loneliness, Late Effects and Sonodynamic Therapy* and were joined via live link up to Dr George Jallo, Johns Hopkins University, Baltimore, as a guest speaker, who presented on ‘Advances in Paediatric Neurosurgery Brain Tumour Surgery’.

Feedback comments included.

- *Great variety of speakers who were all very clear and knowledgeable*
- *More of the same please, and to continue on a regular basis*
- *Privilege to work in a network with such experiences, passionate and knowledgeable professionals*

WORKSTREAM UPDATES

RAG Status chart

🟩	Progressing as planned
🟨	Progressing with minor delays/ concern
🟥	Not on track / issues / unable to progress/deliver
🟦	Complete

STATUS

🟩

AMBITION
2. Equity of access

ACTION
7: 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.

DATA COLLECTION AND REPORTING

Joanna Macfadyen, Information Officer, MSN CYPC (Lead)
Jamie Cargill, National Nurse Consultant, MSN CYPC

Deliverables achieved

- Regular reporting against the paediatric performance indicators has been implemented, and processes are now in place to gather information required to report on completion of End of Treatment Summaries.
- Performance measures have been reviewed and amended to reflect TYA services and will be fully implemented from April 2025.
- Additional performance measures on Fertility Preservation and End of Life Care have been agreed. One has already been implemented (End of Life Care) and the criteria for Fertility Preservation is in development.
- Aftercare service reporting is embedded and will be reported later in 2025.

Biggest success

The biggest success and output of this workstream is that the MSN is now able to provide regular reports of the performance measures, following validation of the data. This has piqued interest from colleagues working in children and young people's cancer services and how data can be used to help improve services.

Summary

Good progress has been made within this workstream, steadily working through the objectives and deliverables. Next steps are to continue with the 'Once for Scotland' approach to data collection with a further review of the Definitions Manual, and guidance document for the Scottish Enhanced Cancer Registry.

STATUS

🟦

AMBITION
Equity of Access

ACTION
8: Implementation of a single national radiotherapy service for children within Scotland

SINGLE SITE RADIOTHERAPY

Dr Lesley Simpson, Paediatric Clinical Lead, MSN CYPC (Lead)
Dr Ben Fulton, Clinical Oncologist, NHS GG&C (Lead)

The main effort for this workstream this year has been the finalisation of the formal proposal for this new service which was presented to the Cabinet Secretary for Health and Social Care, Mr Neil Gray, fellow MSPs and National NHS colleagues in September. After a period of reflection and consultation, funding arrangements were agreed between NHS GG&C and the National Services Division (NSD) and the proposal was approved.

A go-live for the provision of radiotherapy for paediatrics patients across Scotland delivered by NHS GG&C planned for 1st April 2025 and formal communications were sent to Chief Executives of all health boards in Scotland.

STATUS

🟩

AMBITION
1: Enhancing and improving outcomes

ACTION
4: All patients will be discussed at regional and/or national MDTs to ensure access to innovative treatments and appropriate clinical trials

5: All children and young people should be enrolled on a clinical trial when possible

AMBITION
10: Age-appropriate services and effective transitions

ACTION
50: All TYAs will be referred to the national TYA MDT

MULTI-DISCIPLINARY TEAMS

Kirsten Henderson, Holistic MDT Coordinator, MSN CYPC (Lead)
Pamela Gibson, MDT Coordinator, MSN CYPC (Lead)
Dr Nick Heaney, National Clinical Director, MSN CYPC
Dr Lesley Simpson, Paediatric Clinical Lead, MSN CYPC
Jamie Cargill, National Nurse Consultant, MSN CYPC

Deliverables achieved

- The team reviewed current ways of working of existing MDTs, and improved efficiency of the MDTs by standardising processes & documentation.
- Developed a Terms of Reference and Standard Operating Procedures for all Paediatric MDTs.

Biggest Success

The main priority for this workstream has been to ensure that a Terms of Reference (ToR) and Standard Operating Procedure (SOP) is in place for all the MDTs supported by the MSN CYPC.

Work has also commenced on procuring a suitable IT system to coordinate, manage and capture outcomes for each MDT, as currently this is undertaken manually. Having a functional MDT system will not only improve the MDTs it will also allow for better real time data gathering and data extraction. A full options appraisal, on three viable options is to be undertaken in 2025.

The two MDT coordinators posts are now fully funded by the MSN CYPC, following a cessation of funding from the Teenage Cancer Trust for one of these roles. This necessitated a full review, to ensure greater resilience in the coordination and management of all MDTs facilitated by the MSN CYPC. Re-named MSN CYPC National MDT coordinators, it is envisaged that this will allow shared learning and a more sustainable approach to MDT management and coordination.

Summary

Overall, this workstream has made good process this year and the RAG status has now progressed from amber to green.

STATUS

🟩

AMBITION
5: Continuing care when treatment completes

ACTION
23: Ensure every survivor has an aftercare nurse specialist/key worker who can act as a conduit to other services. This key worker

AFTERCARE

Dr Mark Brougham, Aftercare Clinical Lead, MSN CYPC (Lead)
Ali Hall, Aftercare Clinical Nurse Specialist, MSN CYPC
Bernadine Wilkie, Aftercare Clinical Nurse Specialist, MSN CYPC

Deliverables achieved

- Developed monthly reporting template for service
- Undertook a survey on patient/carer experience
- Implemented performance reporting

will have contact with the survivor at key points in their growth and development for example starting school, transition to secondary school and TYA, Primary Care or Adult Services as well as at individual times of need in relation to their cancer aftercare issues.

25: Ensure every survivor has an End of Treatment Summary and have at least one Holistic Needs Assessment completed.

27: Establish a Project Board to scope and develop a national aftercare model for children and young people, including 16–25-year-olds within adult practice.

- Disease Surveillance: Review undertaken of evidence base and recommendation document developed in consultation with Aftercare Project Board
- Nutritional Issues in Aftercare: Review undertaken of evidence base and recommendation document developed in consultation with Aftercare Project Board and wider Dietetic community
- Fertility Preservation: Promotion of Fertility Preservation services awareness by inclusion in MSN CYPC Newsletter and SharePoint site.

Biggest success

The biggest success of this workstream has been the bringing together different health care professionals from different geographical areas to work together in improving and raising awareness of facets of aftercare services. The group meet every four months and explore different topics such as disease surveillance and nutritional issues in aftercare, develop recommendations and share these to the wider community.

Summary

Good progress has been made within this workstream, steadily working through the objectives and deliverables. Raising awareness and developing recommendations for colleagues across Scotland has played an important role in the wider group. The workstream strives to instil the message that "aftercare begins at diagnosis". However, there are concerns regarding the resilience and provision of a specialist aftercare service for TYA patients, especially for patients transitioned from paediatric services.

STATUS

🟩

AMBITION

Continuing care when treatment completes

ACTION

29: Every survivor should have an individualised transition programme, thus preparing, educating and empowering them to take responsibility for their own health and health promotion/prevention prior to their move to TYA, Primary and Secondary Care.

5: All children and young people should be enrolled on a clinical trial when possible.

TRANSITION

Julie Cain, TYA Lead Nurse, Teenage Cancer Trust (Lead)
Jamie Cargill, National Nurse Consultant, MSN CYPC

Deliverables achieved

- Completion of self-assessment tool by all 7 centres (5 adult centres, 2 children's hospitals) involved in transition across Scotland
- Thematic analysis of data completed and gaps in service provision identified
- Transition framework implemented across Scotland
- Engaged with Aftercare workstream to consider an aftercare model for young people (16-24 years) within adult services

Biggest Success

The biggest success of this workstream has been the implementation of the Transition Framework. This work was started in 2019, paused during the pandemic, and the work progressed again in 2022.

Summary

Good progress has been made within this workstream, achieving most of the objectives and deliverables. Work has started on defining what a gold standard for transition to aftercare for TYA patients in Scotland would be. To align with this, we aim to identify the transition pathways for children and young people with cancer in Scotland. This will include the newly appointed MSN CYPC AHP National Lead, given the need to identify and align with AHP provision in TYA and adult cancer services.

STATUS

🟩

AMBITION
6: Integrated Palliative Care and End of Life Care Services

ACTION
30: Develop equitable 24/7 access to specialist palliative care nationally thus facilitating choice regarding preferred place of care at end of life. This will be undertaken in collaboration with the Paediatric End of Life Care Network (PELiCaN) and third sector organisations.

31: Provide high quality symptom management achieved through anticipatory prescribing using Just in Case boxes and the development of personalised symptom management plans communicated and delivered through local and national teams.

32: Undertake a national audit to inform the national strategic service development for the provision of end-of-life care to TYAs and their families.

33: Provide Paediatric Palliative Care educational opportunities through ongoing collaboration between the Paediatric Palliative Medicine Education Network and Project ECHO team.

34: Promote the NHS Inform Directory of Services, working with NHS24 to ensure the content reflects the available children and young people's palliative cancer care services.

PALLIATIVE CARE

Dr Diana Mckintosh, Palliative Care Clinical Lead, MSN CYCP (Lead)
Jamie Cargill, National Nurse Consultant, MSN CYPC

Deliverables achieved

- Refreshed awareness within the MSN CYPC current guidelines for use of Just in Case boxes for haematology/oncology patients aged 0-18 years.
- Delivery of a Palliative Care Education Event in September 2024, hosted by the MSN CYPC.
- Continued engagement with Paediatric End of Life Care Network (PELiCAN).
- Development of rationale, evidence, criteria and definition of a new standard that all CYPC should achieve preferred place of death.

Biggest success

The biggest success of this workstream has been the delivery of the Palliative Care Education Event entitled 'Symptom Management at End of Life' on 6 September 2024 at The Studio, Glasgow.

Summary

The implementation of the MSN CYPC Key Performance Indicator which states *that all children and young people with cancer should achieve their chosen place of death* has been welcomed. This data will be captured in all MDTs and will provide meaningful and in-depth information to aid service provision and development going forward.

A further key development also underway in 2024-25 is the pilot of a CHAS/NHS Clinical Advisory Service aligned with a weekly MDT. The pilot provides the local clinical team delivering care to patients aged 0-16 years who are approaching end of life, as well as 17–18-year-olds who still access paediatric services and 0–21-year-old in the care of CHAS and resident in a children's hospice, access to a 24/7 specialist Paediatric Palliative Medicine advice service. This supports the overarching aim of the workstream, which is to ensure that end of life care for children and young people with cancer is provided in the most appropriate and preferred location for the patient and family, through the safe delivery of a bespoke management plan.

STATUS

🟩

AMBITION
10: Age-appropriate services and effective transitions

TYA SERVICES

Dr Nick Heaney, National Clinical Director, MSN CYPC (Lead)
Julie Cain, TYA Lead Nurse, Teenage Cancer Trust (Lead)

ACTION
53: 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.

56: Scotland's TYA cancer services will collaborate with the National Institute for Health and Care Research (NIHR) and the University College London Hospitals (UCLH) Centre for Nuse, Midwife and AHP Research to implement BRIGHTLIGHT 2021.

Deliverables achieved

- Worked collaboratively with transition workstream (6) to ensure completion of self-assessment audit tool by paediatric and TYA teams and to operationalise transition framework
- Collated and analysed data from National TYA MDT
- Implemented a quarterly TYA M&M meeting
- Implementation of IAM portal/ Electronic Holistic Needs Assessment (eHNA)to facilitate discussions within National TYA MDT
- Implemented quarterly reporting via TYA MDT on numbers of IAMs/eHNA completed versus numbers eligible
- Work with Health Improvement Scotland to develop an age-appropriate information resource app for TYA, hosted on the Right Decision Services platform

Biggest success
The biggest success of this workstream has been embedding the IAM/ eHNA into the National TYA MDT. This had previously been hindered by only a limited number of non-clinical staff having access. In addition, the development of the information app is close to completion. This has been a large project with multi-professional input from across Scotland. The Youth Advisory Forum have been advising at time points throughout the project and will be involved in user testing when the working model is available.

Summary
The workstream has been overall successful except for being able to implement the recommendations from the TYA Psychology, Physiotherapy and Dietetics workforce planning report. This remains outstanding as there has been no additional financial resource from Scottish Government to allow this to progress. It remains a priority for this workstream.

STATUS

🟩

AMBITION
4: Service improvement and patient safety

ACTION
22: Continued investment in annual national mortality and morbidity meetings to ensure learning from adverse events.

AMBITION
9: Specialist and sustainable workforce

ACTION
41: National workforce mapping exercise to be undertaken across NHS Scotland for children and young people's cancer

WORKFORCE

Robbie Grieve, National Network Manager, MSN CYPC (Lead)
Victoria Sanderson, Communications Officer, MSN CYPC

Deliverables achieved

- Host annual Morbidity & Mortality Day – delivered on 3rd May 2024 in Dundee to approximately 60 colleagues from across Scotland.
- Host national Education Event with a Palliative Care theme, delivered on 6th September 2024 in Glasgow to approximately 50 colleagues from across Scotland.
- Quarterly M&M meetings within TYA service implemented to share learning
- Recruit to key vacant MSN CYPC posts;
  - Network Support Officer – May 24
  - National Nurse Consultant – Feb 25
  - National AHP Lead – Apr 25

services to support local Health Board workforce planning processes.

43: Undertake a wider MSN CYPC workforce review to ensure the appropriate staffing model to deliver on the strategic actions of the cancer strategy.

- Confirm financial and activity reporting with Scottish Government – MSN CYPC Budget updates are now provided to the MSN CYPC Board on a quarterly basis
- Optimise multidisciplinary team working through national/MSN CYPC MDT structures (aligned to workstream 4)
- Production of patient involvement strategy for the MSN CYPC (aligned to workstream 10)
- Establish formal and informal communication channels with MSN CYPC staff
- Undertake further assessment of communications functions

Biggest success

The MSN CYPC has recruited Jamie Cargill (National Nurse Consultant) and Gillian Matheson (National AHP Lead) during this financial year and in doing so has added two extremely talented and experienced individuals to the Executive Leadership Team. As we move towards the development of the next Cancer Strategy post-2026, Jamie and Gillian will bring their experience and leadership to the group and ensure that we are able generate an exciting and ambitious plan going forward.

Summary

Good progress has been made within this workstream, with many of the deliverables having been met and robust plans are in place to deliver the remaining aspects within the desired timeframe.

STATUS

🟩

AMBITION

10: Age-appropriate services and effective transitions

ACTION

51: Data extraction to be undertaken for patients between 16-25 years of age to inform the development of an age-appropriate patient experience survey for young people in adult cancer services in partnership with the Scottish Cancer Patient Experience Survey team.

55: Establish a Project Board to implement a national peer support system for TYAs with cancer.

PATIENT EXPERIENCE, PUBLIC ENGAGEMENT

Robbie Grieve, National Network Manager, MSN CYPC (Lead)
Julie Cain, TYA Lead Nurse, Teenage Cancer Trust (Lead)
Victoria Sanderson, Communications Officer, MSN CYPC

Deliverables achieved

- Mapped existing patient experience/feedback mechanisms available to the MSN CYPC
- Drafted survey for patient experience questionnaire, with input from TYA and paediatric CAGs, and 3rd sector group
- Third Sector national group re-introduced
- Implementation of national peer support system for TYAs with cancer
- Finalised information booklets for TYAs
- Re-establish paediatrics parent/carer involvement group

Biggest success

The implementation of the peer support network has been a huge achievement. This project was first started in 2017, but for multiple reasons was never implemented. 12 mentors have been trained, some of whom have been matched with mentees. The success of the project will be monitored over the 2025/26 using the mentor and mentee evaluations. We were fortunate to be awarded a grant from Arnold Clark Community Fund to support the costs of ‘refreshments’ for the mentors and mentees if they were meeting face to face.

	Summary The workstream has been overall successful and has achieved most of the objectives and deliverables. The completion of these has led to new objectives for 2025. A priority for this workstream is to gather patient and family experiences through a national questionnaire. Contribution from the youth advisory forum and the parent and carer forum will assist with this. All the PPI groups have been re-established, with broad and diverse representation.

GOVERNANCE AND FUNDING

The MSN CYPC, hosted by NHS Tayside, is funded by the Scottish Government with a budget allocation of approximately £1.32m during 2024/25. In keeping with previous years, the MSN CYPC's underspend has been primarily attributed to vacant staff roles, with the delayed recruitment of a National Nurse Consultant and National AHP Lead as well as our National Clinical Director posts being vacated during this financial year, all contributing to a significant decrease in spending. However, all these positions have been recruited to for 2025/26 and with only 1 remaining vacancy, we stand in good stead to meet our financial targets for the next financial year.

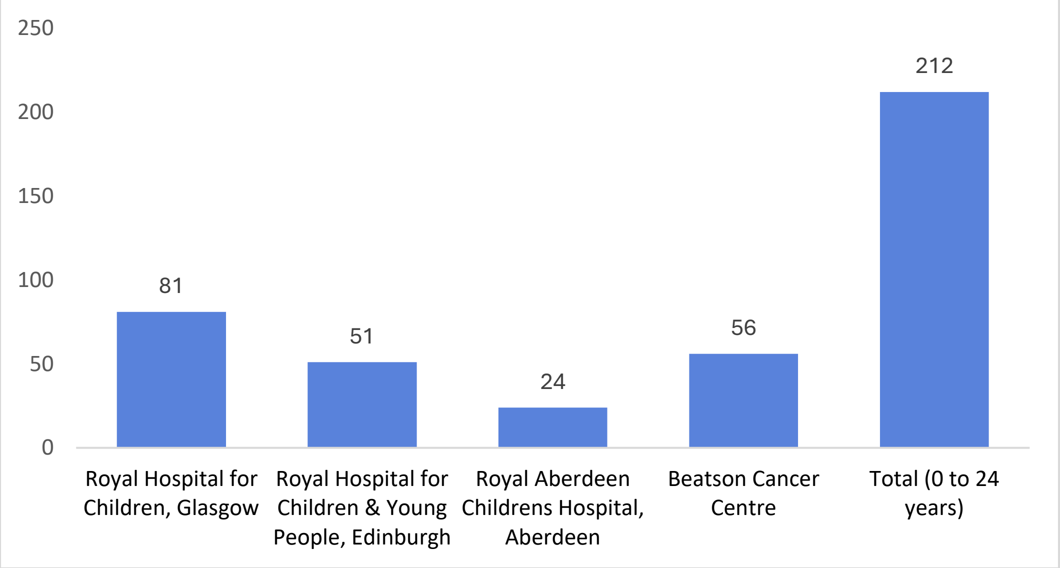
As with all organisations across the NHS in Scotland, we have not been immune to the financial pressures and there will be a requirement to reduce our spending during 25/26. We have already been informed that the Teenage Cancer Trust will be withdrawing funding for the TYA MDT Co-ordinator role from 1st June 2025 and we are planning solutions to further potential budget reductions that are anticipated to come our way. Nevertheless, we will continue to work hard to ensure that the MSN CYPC maintains focused towards the delivery of our goals, regardless of the hurdles that appear in front of us.

Robbie Grieve
National Network Manager
MSN CYPC Executive

DATA PERFORMANCE MEASURES 2024/25

Table 1: New Cancer Registrations by hospital of registration
01/04/2024 to 31/03/2025

(Data Source: Scottish Enhanced Cancer Registry)



(note: patients registered by the Beatson Cancer Centre, represent patients discussed at the Teenagers & Young Adult (TYA) Multi-Disciplinary Advisory Team Meeting (MDaT))

Table 2. New Cancer Registrations for children and young people treated in a Paediatric Principal Treatment Centre, by diagnostic category
01/04/2024 to 31/03/2025

(Data Source: Scottish Enhanced Cancer Registry)

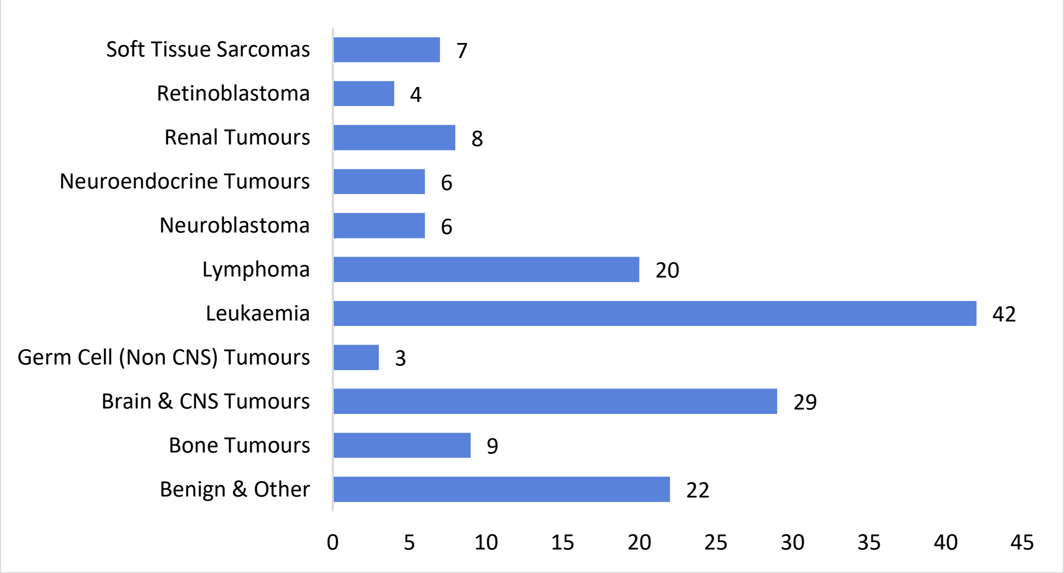


Table 3. New Cancer Registrations in TYA by diagnostic category 01/04/2024 to 31/03/2025

(Data Source: TYA MDaT / Scottish Enhanced Cancer Registry)

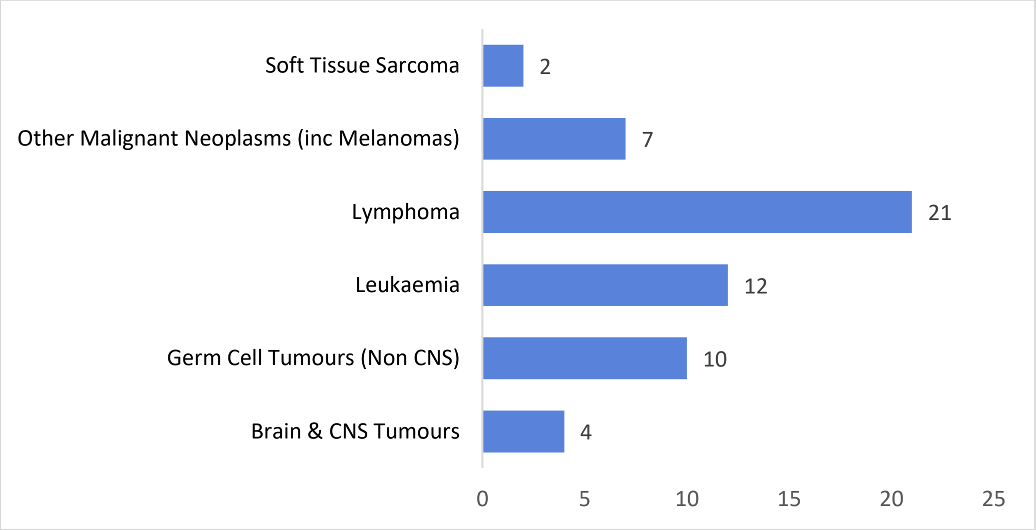


Table 4: Key Performance Indicators for Paediatric Principal Treatment Centres

MSN CYPC Performance Indicators 1st April 2024 to 31st March 2025

		Numerator	Denominator	Target	Performance	Compared to 2024
KPI No 1.	Patients should not wait more than 21 days between being referred to hospital and a primary diagnosis being made	148	156	95%	95%	▲
KPI No 2.	Patients should not wait more than 14 days between primary diagnosis and start of treatment	118	156	95%	76%	▼
QPI No 3.	All eligible newly diagnosed patients should be offered participation in an available clinical trial:					
a)	Child Interventional Trial	40	60	50%	67%	▼
b)	Child Translational Trial	13	60	10%	22%	▲
QPI No 4.	All children with cancer should be discussed at a regional and/or national multi-disciplinary team within 14 days of diagnosis	109	156	95%	70%	▲
QPI No 5.	An End of Treatment Summary must be completed for every patient within 6 months of treatment ending	18	42	100%	43%	▲

LOOKING FORWARD 2025/26

WORKSTREAM 2 – DATA COLLECTING & REPORTING

- Implement regular reporting against current MSN CYPC performance indicators 2024/25
- Further scoping and planning for extended MSN CYPC key performance indicators
- Review, and improve, the effectiveness of the Enhanced Cancer Registry (ECR) support routine data collection and reporting 2024/25
- Develop Data Strategy

WORKSTREAM 4 – MULTI-DISCIPLINARY TEAMS (MDTs)

- Look at ways to increase the efficiency of the MDTs by standardising processes, documentation and shared learning
- Identify data requirements and consensus around content of national IT support system for all MDTs
- Agree and undertake consistent annual reporting of the MDTs
- Streamlining of MDT Coordinators' roles

WORKSTREAM 5 – AFTERCARE

Develop a national aftercare model for children and young people through:

- Produce impact report on service delivery from current aftercare nurse specialist posts and review ways of
- working to obtain national coverage (where possible) (action 28)
- Develop national guidelines on prevention/protection of cardiotoxicity
- Develop national guidelines on prevention/protection of ototoxicity
- Re-immunisation boosters after treatment / standard methods of referral
- Ensure all patients have an individual transition programme
- Raise awareness of importance of Aftercare starting from diagnosis

WORKSTREAM 6 – TRANSITION

- Work collaboratively with the aftercare workstream to align the transition framework with the aftercare service model (ambition 5)

WORKSTREAM 7 – PALLIATIVE CARE

- Undertake an audit of end-of-life care service provision to TYAs and their families

WORKSTREAM 8 – TYA SERVICES

- Work with Health Improvement Scotland to develop an age-appropriate information resource app for TYA, to be hosted on the Right Decision Services platform
- Implement recommendations from TYA Psychology, Physiotherapy and Dietetics workforce planning report

WORKSTREAM 9 – WORKFORCE

- Workforce Planning

WORKSTREAM 10 – PATIENT EXPERIENCE / PUBLIC INVOLVEMENT

- Map existing patient experience/feedback mechanisms available to the MSN CYPC
- Re-establish paediatrics parent/carer involvement approach

WORKSTREAM 11 – ALLIED HEALTH PROFESSIONALS

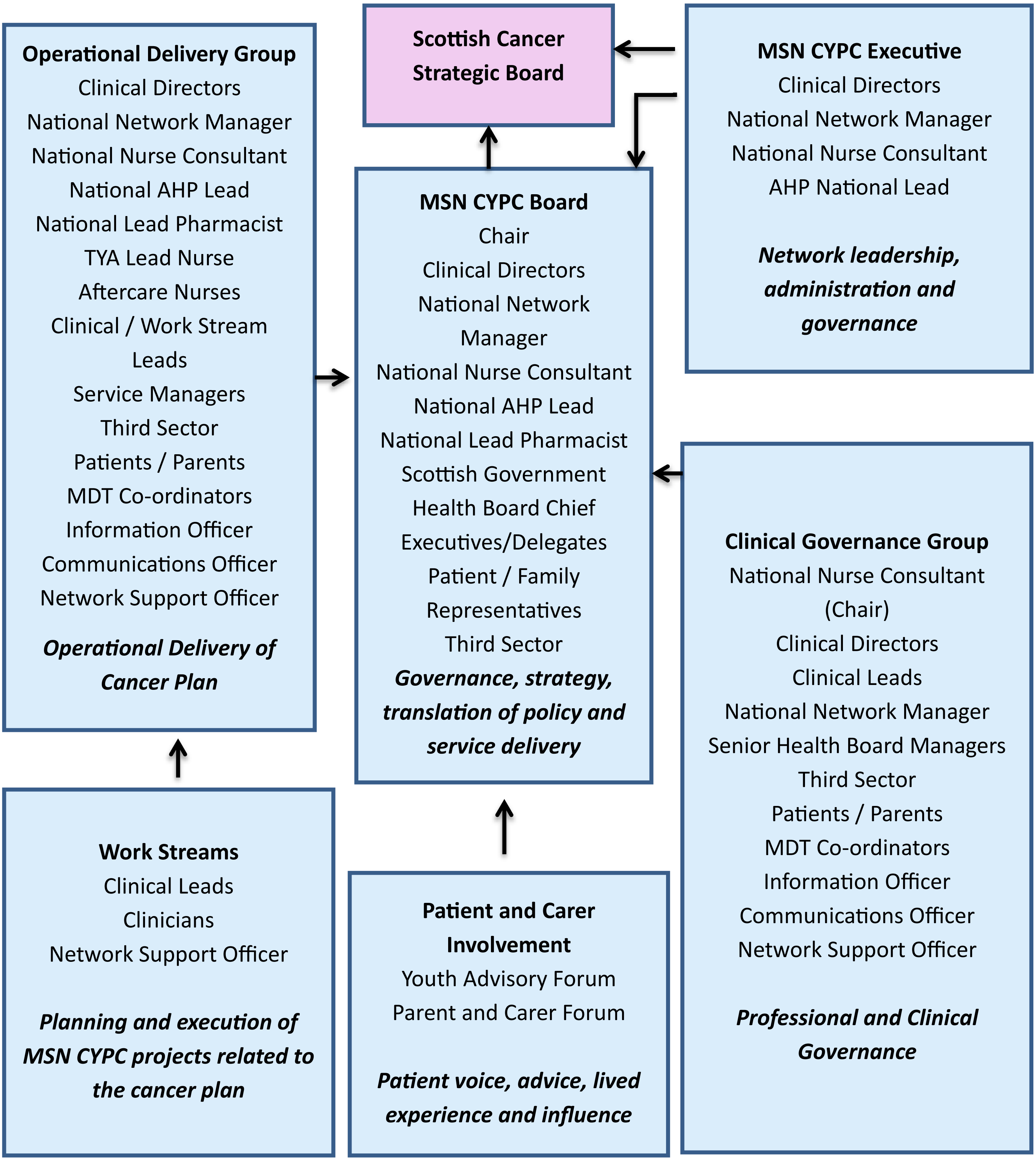
This is a new workstream for 2025/26:

- Support Health Boards to ensure equitable and timely access to specialist AHP assessment and intervention at all stages of the cancer journey, regardless of age, stage of treatment or geographical location (Action 11)
- Evaluate the needs of CYP and their families in relation to current AHP service provision for cancer services (Action 13)
- Develop and implement a national AHP resource package which all CYP will receive at diagnosis and at End of treatment which can be audited to ensure it meets the holistic needs of service users (Action 14)
- Develop a cancer aftercare pathway to establish clear routes to referral (Action 26)
- Develop a competency framework for AHP's working with CYP affected by cancer across Scotland based on the results of an educational/training needs analysis exercise (Action 15)
- Support the recruitment of specialist AHP's across all treatment centres, based on the recommendations of a workforce scoping analysis (Action 10)

MSN CYPC WORKFORCE

Job Title	**Employer**	**WTE**	**Band**
Chair	SLA *(NHS Forth Valley*)	0.2	Consultant
National Clinical Director	SLA *(NHS GGC) – vacant March 2025*	2 x PA	Consultant
National Network Manager	NHS Tayside	1.0	8b
National Nurse Consultant	NHS Tayside	1.0	8b
National AHP Lead	SLA arrangement *(vacant)*	0.4	8a
National Aftercare Clinical Lead	SLA arrangement *(NHS Lothian)*	1 x PA	Consultant
National Paediatric Clinical Lead	SLA arrangement *(NHS Lothian)*	2 x PA	Consultant
National Palliative Care Clinical Lead	SLA arrangement *(NHS GGC)*	1 x PA	Consultant
National TYA Clinical Lead	SLA arrangement (NHS GGC)	2 x PA	Consultant
TYA Clinical Lead	SLA arrangement (NHS GGC, Lothian, Tayside & Grampian)	4 x 0.5 PA	Consultant
TYA Lead Nurse (funded by Teenage Cancer Trust)	SLA arrangement (NHS GGC)	1.0	8A
Project Manager	SLA arrangement (PgMS)	0.8	7
Holistic MDT Co-ordinator	NHS Tayside	1.0	5
Paediatric MDT Co-ordinator	SLA (*NHS GGC)*	1.0	5
Information Officer	NHS Tayside	1.0	5
Communications Officer	NHS Tayside	0.8	5
Network Support Officer	NHS Tayside	1.0	4
Pharmacy Lead	SLA arrangement *(vacant)*	0.6	8c
Aftercare Clinical Nurse Specialist	SLA arrangement *(NHS GGC & Lothian)*	2 x 0.8	7

MSN CYPC STRUCTURE



Scottish Cancer Strategic Board

MSN CYPC Executive
Clinical Directors
National Network Manager
National Nurse Consultant
AHP National Lead

Network leadership, administration and governance

Operational Delivery Group
Clinical Directors
National Network Manager
National Nurse Consultant
National AHP Lead
National Lead Pharmacist
TYA Lead Nurse
Aftercare Nurses
Clinical / Work Stream Leads
Service Managers
Third Sector
Patients / Parents
MDT Co-ordinators
Information Officer
Communications Officer
Network Support Officer

Operational Delivery of Cancer Plan

MSN CYPC Board
Chair
Clinical Directors
National Network Manager
National Nurse Consultant
National AHP Lead
National Lead Pharmacist
Scottish Government
Health Board Chief Executives/Delegates
Patient / Family Representatives
Third Sector

Governance, strategy, translation of policy and service delivery

Clinical Governance Group
National Nurse Consultant (Chair)
Clinical Directors
Clinical Leads
National Network Manager
Senior Health Board Managers
Third Sector
Patients / Parents
MDT Co-ordinators
Information Officer
Communications Officer
Network Support Officer

Professional and Clinical Governance

Work Streams
Clinical Leads
Clinicians
Network Support Officer

Planning and execution of MSN CYPC projects related to the cancer plan

Patient and Carer Involvement
Youth Advisory Forum
Parent and Carer Forum

Patient voice, advice, lived experience and influence

Managed Service Network for

Children & Young People with Cancer

Kings Cross Hospital

Clepington Road

DUNDEE, DD3 8EA

tay.msncypc@nhs.scot

www.msncypc.nhs.scot