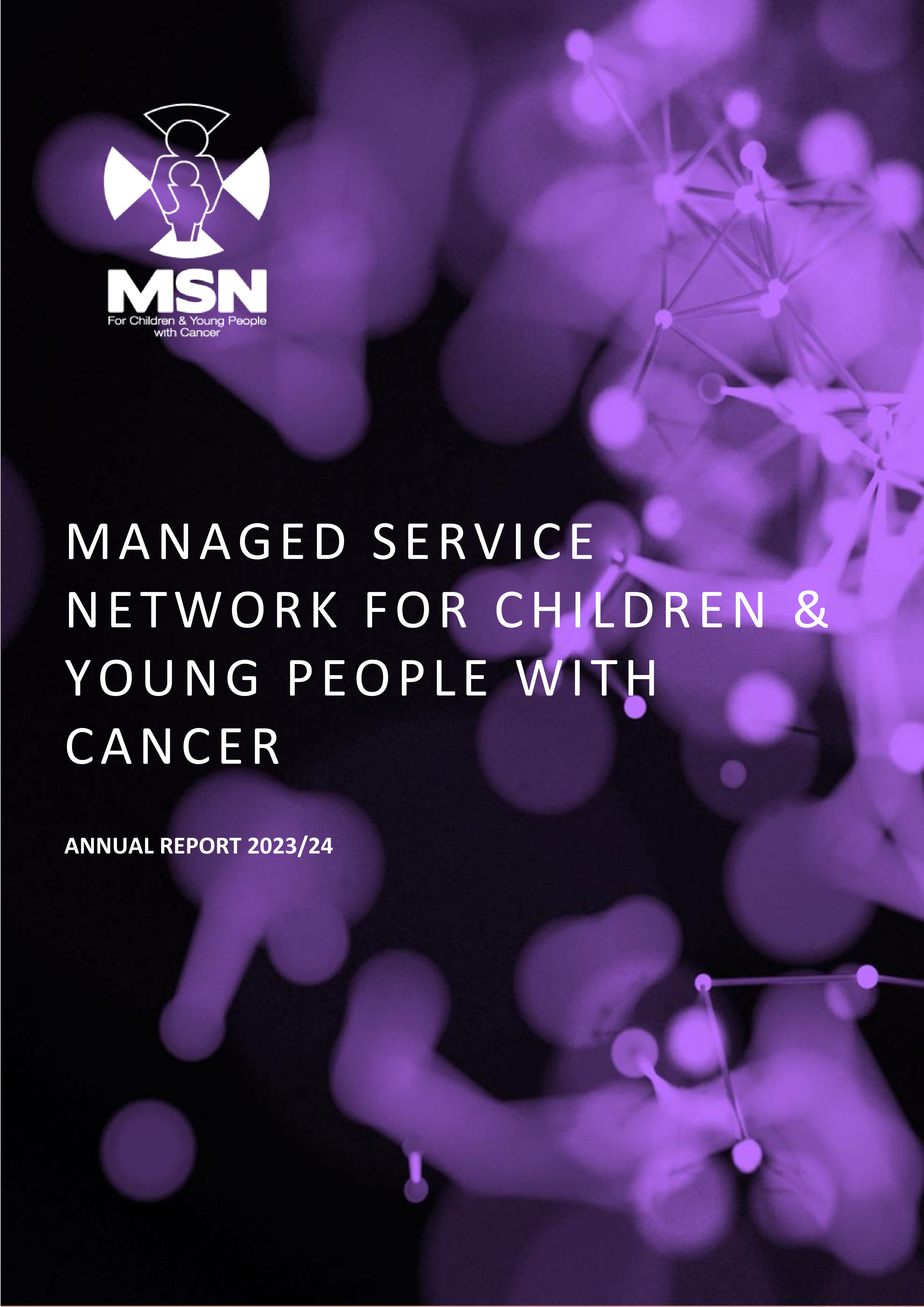

MSN
For Children & Young People
with Cancer

MANAGED SERVICE NETWORK FOR CHILDREN & YOUNG PEOPLE WITH CANCER

ANNUAL REPORT 2023/24

FOREWORD

Building on a busy 2022-23 of post-COVID-19 recovery, 2023-24 has seen a sizeable turnover of personnel within the MSN Team as we continue to focus on delivering our Cancer Strategy for Children and Young People 2021-2026 work plan. Our changes in leadership positions have provided a new energy, fresh ideas and an opportunity to drive forward and achieve our goals.

We now have a new Network Manager in post and would like to thank Marion O'Neill, who left the MSN in August, for all her hard work and support. Marion has passed the baton onto Robbie Grieve, who is continuing to build on the foundations that have been set in place. Julie Cain has been appointed as Teenage and Young Adult Lead Nurse, succeeding Liz Watt who left in April 2023. Julie has over 30 years of experience within the Children and Young People with Cancer service, and we are delighted to welcome her into her new role.

The coming year promises to be an exciting and productive year and I am very much looking forward to working with the Network to ensure we deliver for our patients across Scotland.

Dr Andrew Murray
MSN CYPC Chair

Governance

Appendices

INTRODUCTION

The Managed Service Network 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 help health care professionals across the country, to provide care we can all be proud of.

The very strong relationships that have been built with colleagues in the Scottish Government and across Health Boards have allowed the voice of the community to be heard and we have been able to clearly demonstrate what we have achieved and what the gaps in the service are. We are grateful to colleagues in Information Services Division (ISD) who were instrumental in helping us launch the Scottish Enhanced Cancer Registry for Children and Young People, providing a reliable, population-based register, which will allow us to robustly define our population, critical outcomes, and performance measures.

The Scottish Molecular Radiotherapy Service (SMaRT Kids) continues to provide innovative therapies to Scottish Children and is in the process of opening 2 new therapeutic options, in conjunction with colleagues in Scandinavia (LUDO-N) and the USA (MINT) which will allow Scottish children and their families to access revolutionary therapies without leaving Scotland.

All 3 Principal Treatment Centres applied for Tessa Jowell Brain Cancer Mission Centre of Excellence status. The process was rigorous and only 5 UK centres were recognised. The Scottish bids were very well received, and we have been asked to re-apply after making some minor improvements.

Cancer Genomics is revolutionising diagnostics and treatment of childhood, teenage and young adult cancers. Lack of cancer genomics infrastructure is a major health care issue for Scotland and we are encouraged that the Scottish Government recognises that a national solution needs to be found. The MSN CYPC is an important stakeholder in determining what is necessary to provide this service and we have been extensively consulted as a strong partner in advocating for a Scottish solution.

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 coordinating 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 ten new national workstreams and their leadership will focus on the design and delivery of services, creation of the evidence base for improving practice and educational governance. 2023/34 saw the MSN CYPC drive these workstreams forward.

Workstreams

1. **Governance**
2. **Data Collection and Reporting**
3. **Single Site Radiotherapy**
4. **MDTs**
5. **Aftercare**
6. **Transition**
7. **Palliative Care**
8. **TYA Services**
9. **Workforce**
10. **Patient Experience and Public Involvement**

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 UPDATES

The progression of each workstream is marked with a RAG Status:

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

STATUS

🟦

AMBITION

Overall CYPC Strategy

ACTION

All actions

1. GOVERNANCE

Aim of workstream: To develop a robust governance structure with re-establishment/ formation of key Governance groups and establish a 'Once for Scotland' paediatric Systemic Anti-Cancer Treatment (SACT) governance process to enable efficient and effective MDT working and support a future national paediatric Chemotherapy Electronic Prescribing and Administration systems (CEPAS).

Deliverables achieved 2023/24:

1. **Re-establish Operational Delivery Group as part of national (clinical) governance structure**

2. **Re-establish Clinical Governance Group to support national escalation of clinical risk and provide SACT governance**

3. **Formation of Paediatrics Clinical Advisory Group**

4. **Review TYA Clinical Advisory Group Terms of Reference**

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

2. DATA COLLECTING & REPORTING

Aim of workstream: To improve CYPC audit processes to support continuous quality improvement and address variations in treatment and outcomes. Develop a consistent approach to data collection to improve performance management reporting and service planning for CYPC services.

Deliverables achieved 2023/24:

developing to include an analytics function to provide dashboard reporting.

1. Implement regular reporting against current MSN performance indicators

3. Review, and improve, the effectiveness of the Enhanced Cancer Registry as a mechanism to support routine data collection and reporting

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STATUS

🟨

AMBITION

Equity of Access

ACTION

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

3. SINGLE SITE RADIOTHERAPY

Aim of workstream: Implementation of a single national radiotherapy service for children within Scotland

<u>Deliverables achieved 2023/24:</u>

1. Secure buy-in from clinical and health service managerial colleagues across Scotland

2. Update the business case to reflect any emerging evidence and research

3. Elicit patient feedback from existing national engagement mechanisms

4. Develop detailed service specification with agreed patient pathways and clearly defined local Board responsibilities versus those of a national service

5. Support NHSGGC with submission of business case for consideration as national designated service via NSD commissioning team

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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

4. MULTI-DISCIPLINARY TEAMS

Aim of workstream: To review and document current processes, identify areas for development, devise an improvement plan and if necessary, implement the recommended changes. The MSN CYPC MDT coordinators currently support and facilitate the National TYA MDT, National Leukaemia MDT, Paediatric Neuro-Oncology (WoS) MDT (Glasgow & Grampian), Paediatric Neuro-Oncology Group (Lothian & Grampian)), Tumour Board MDT (Glasgow & Grampian), National Relapse/Refractory Discussion Panel and Paediatric Oncology MDT (Lothian).

<u>Deliverables achieved 2023/24:</u>

1. Secure buy in from MDT Chairs to support review process
1.1. MSN Clinical Director engage with MDT Chairs to advise of review with rationale for change and invite comments
1.2. Meeting with Chairs to discuss review and what this will involve

2. Review current ways of working
2.1. Clarify purpose and objectives of the MDT review
2.2. Breakdown of current processes and the disparity between the MDT meetings for discussion/review at session

4. Identify data requirements and consensus around content of national IT support system for all MDTs
4.1. Active involvement in Data SLWG

4.2. Provide Information Officer with breakdown of real time patient diagnosis to assist with compiling data definition manual
4.3. Review ECR and performance indicator data with the data that is collected from MDTs to understand better alignment and/or streamlining for reporting and audit purposes

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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 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.

5. AFTERCARE

Aim of workstream: Develop a good understanding of how aftercare cancer services are delivered locally across Paediatric and TYA populations and make recommendations for a national aftercare model for children and young people, including 16–25-year-olds within adult practice.

Deliverables achieved 2023/24:

1. Develop a national aftercare model for children and young people through:
1.1. Establish a project board with appropriate geographical and professional membership including primary care
1.1.1. Questionnaire issued to invite interest to join Board
1.1.2. Invite potential members to join Board
1.1.3. First meeting of board
1.1.4. Ratification of objectives and deliverables at board

1.2. Conduct survey to understand current delivery models (including discharge and age criteria)
1.2.1. Develop template for first board meeting
1.2.2. Undertake survey

2. Produce impact report on service delivery from current aftercare nurse specialist posts and review ways of working to obtain national coverage (where possible)
2.1. Develop reporting summary of 21/22 service provision for inclusion in MSN 21/22 Annual Report

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STATUS

🟨

AMBITION

Continuing care when treatment completes

ACTION

29: Every survivor should have an individualised transition programme, thus preparing, educating and empowering

6. TRANSITION

Aim of workstream: To implement a transition framework which supports the delivery of equitable, high quality transitional care to young people wherever they live in Scotland and to ensure every survivor has an individualised transition programme.

Deliverables achieved in 2023/24:

2. Operationalise transition framework

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.

2.1. Completed framework presented to MSN board for ratification and approval
2.2. Circulate framework and assessment tool to TYA CAG and discuss implementation Plan

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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.

7. PALLIATIVE CARE

Aim of workstream: To ensure that 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

Deliverables achieved in 2023/24:

2. Undertake an audit of end-of-life care service provision to TYAs and their families
2.1. Undertake review of data already gathered
2.2. Decision on whether data to proceed with appropriate approval and audit completion (via TYA CAG and MSN Board)
2.3. Questionnaire for clinicians (Paeds & TYA) following patient death to gather data on place of death, was preferred option achieved, barriers, services involved, etc.

3. Increase use of Just in case boxes and personalised symptom management plans (including in TYA services)
3.3. Develop and implement questionnaire in collaboration with PELiCaN to POONs/Lead Clinician providing end of life care

4. Develop the skills and confidence across the wider MSN community around palliative care principles and practice
4.1. Map existing palliative care training opportunities (topics include communication training, symptoms management training, prescribing, CYPADM training, post- mortem conversations, bereavement support)
4.3. Develop and complete palliative care training needs assessment (either separately or as part of wider MSN training questionnaire)

5. Review and update NHS Inform Directory of Services to ensure it reflects the relevant CYP palliative cancer services
5.1. Map existing services contained in the Directory (confirming services are still up and running and contact details are correct)
5.2. Scope additional services to be included in the Directory
5.3. Share proposed revisions with NHS Inform 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.

STATUS

🟩

AMBITION

10: Age-appropriate services and effective transitions

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.

8. TYA SERVICES

Aim of workstream: The TYA Services workstream is a multidisciplinary group of professionals, with representation from all Scotland, who meet regularly as the TYA Clinical Advisory Group. The aim of the group is to ensure high quality and equitable care for TYA with cancer throughout Scotland.

Deliverables achieved in 2023/24:

1. Review of TYA CAG and ensuring collaborative links with other workstreams

1.1. Invitation of new members to TYA CAG

1.2. Attendance at Aftercare workstream

1.3. Attendance at Paediatric CAG

2. TYA National MDT: Support and attendance, data collection and review and implementation of IAM

2.3. Collate feedback from other services and develop recommendations on how to increase engagement (including Beatson TYA psychology services)

2.4. Review current access arrangements and opportunities to develop more nurse-led approach

2.5. Review added value of discussing IAMs as part of TYA MDT meetings

3. Collaborate with the National Institute for Health and Care Research (NIHR) and the University College London Hospitals (UCLH) Centre for Nurse, Midwife and AHP Research to implement BRIGHTLIGHT 2021 during its analysis stage

3.1. Maintain regular contact with Scotland Lead PI to support any further developments

3.2. Maintain regular contact with BRIGHTLIGHT National team

3.3. Review final BRIGHTLIGHT report following publication

3.4. Disseminate relevant findings and recommendations via MSN governance channels (including relevant education days)

4. Work with Health Improvement Scotland to develop an age-appropriate information resource app for TYA, to be hosted on the Right Decision Services platform

4.1. Submit application for development of app to eHealth

5. Implement recommendations from TYA Psychology, Physiotherapy and Dietetics workforce planning report

5.1. Understand and address barriers to recruitment to current Dietetic post configuration

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 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.

9. WORKFORCE

Aim of workstream: Education, training, recruitment, implementation, work force mapping

<u>Deliverables achieved 2023/24:</u>

1. Workforce Development
1.1. Delivery of M&M event with learning across Paediatrics and TYA services
1.1.1. Confirm date of national mortality and morbidity event at ODG
1.1.2. Plan and organise M&M
1.1.3. Finalise and agree template for data collection for M&M audit with TYA Clinical Lead, Paediatric Clinical Lead and Information Officer
1.1.4. Agree responsible person to collate data for each centre using data collection
1.1.5. Host M&M Event

1.2. Delivery of MSN Education events
1.2.1. Confirm date of education event at ODG

2. Workforce Planning
2.1. Recruit to agreed vacant posts
2.1.1. Agree nursing leadership configuration with Teenage Cancer Trust
2.1.2. Advertise and recruit to Nurse Lead post(s)
2.1.3. Advertise and recruit to Network Support Officer post
2.1.4. Recruit fixed term Project Manager post to support embedding of project management principles

2.2. Implementation of optimisation programme
2.2.1. Governance: Review Executive membership
2.2.2. Governance: Develop Annual Implementation Plan
2.2.3. Governance: Share workplans across the Network
2.2.5. Accountability: Implement revised governance framework and confirm reporting arrangements *(aligned to workstream 1)*

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

10. PATIENT EXPERIENCE / PUBLIC INVOLVEMENT

Aim of workstream: To engage with children, young people and their families, and use their experiences and feedback to inform and improve age-appropriate cancer services.

<u>Deliverables in 2023/24:</u>

3. Development of national peer support system for TYAs with cancer
3.1. Finalise information booklets

4. Ongoing facilitation of Youth Advisory Forum
4.1. Introduction meeting to Clinical Director and Network Manager
4.2. Establish at least quarterly meetings
4.3. Elicit feedback on accessing services away from home

Cancer Patient Experience Survey team. 55: Establish a Project Board to implement a national peer support system for TYAs with cancer.	4.5. Establish workplan **5. Re-establish paediatrics parent/carer involvement approach** 5.1. Review meeting with current members 5.2. Engagement exercise on accessing care away from home to support single site radiotherapy application

GOVERNANCE

FUNDING AND RESCOURCING

Funding for the MSN CYPC is provided by the Scottish Government. The 2023/24 budget allocation was £1.285 million (with £859k in recurring allocation and a £426k TYA non-recurring allocation). Staff costs continue to account for the majority of spending each financial year, although several vacancies remain from the previous FY, resulting in an overall underspend. Teenage Cancer Trust continues to provide funding to support strategic delivery of national TYA projects, contributing 100% of the TYA Lead Nurse post and 50% of the Holistic MDT Co-ordinator (totalling around £81,000).

The MSN has recruited a new Network Manager, who joined the team in January 2024, alongside the new TYA Lead Nurse who started at the same time.

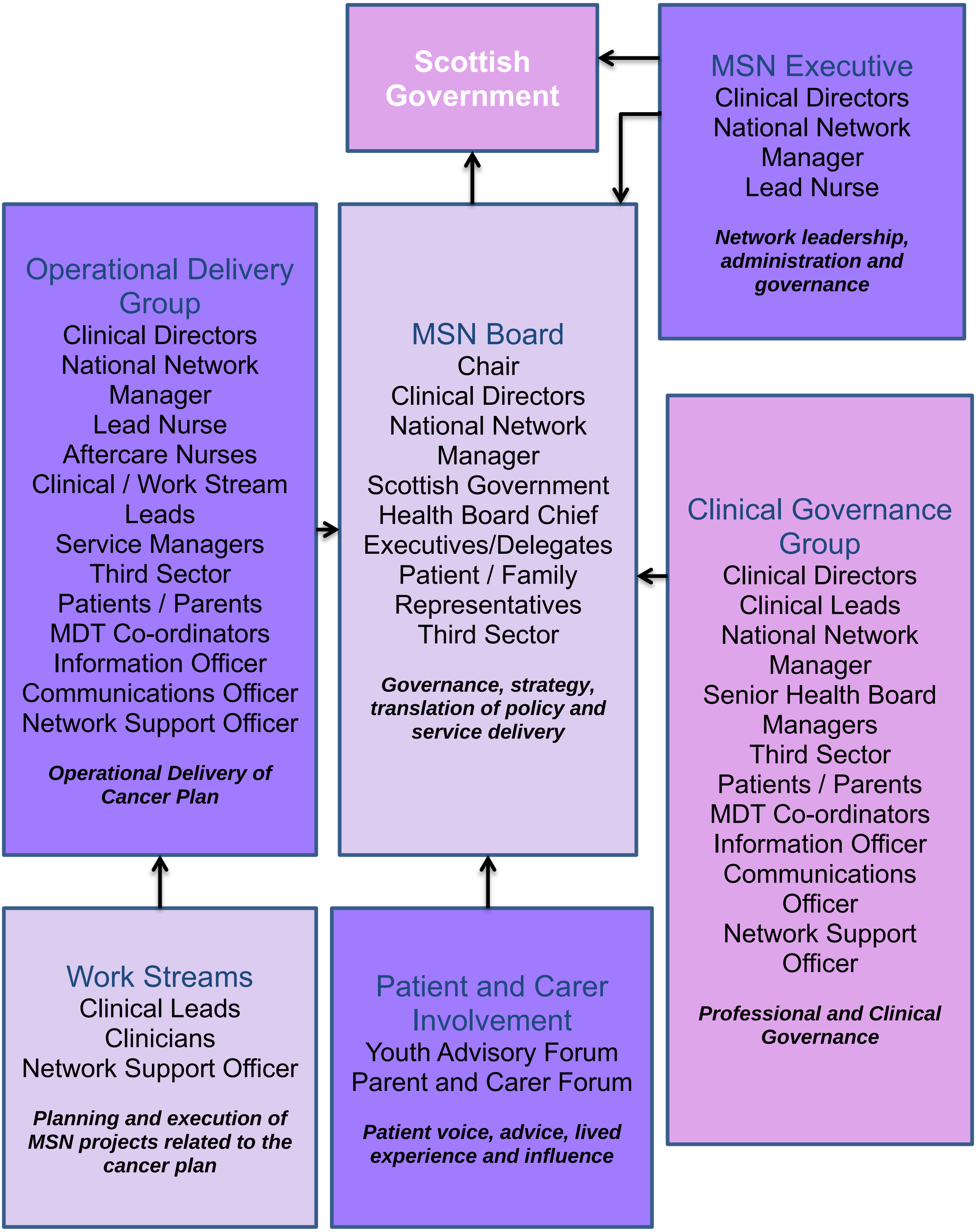
DATA PERFORMANCE INDICATORS

DATA REPORT: APRIL 2023 TO MARCH 2024 - MSN FOR CHILDREN & YOUNG PEOPLE WITH CANCER

NUMBER OF NEW CANCER REGISTRATIONS = 151

PI	Performance Indicator Description	Denominator	Numerator	Target	Performance	Compared to 2022/23
No. 1	Patients should not wait more than 21 days between being referred to hospital and primary diagnosis being made	151	136	95%	90%	▲
No. 2	Patients should not wait more than 14 days between primary diagnosis and start of treatment	151	129	95%	85%	▼
No. 3	All eligible newly diagnosed patients should be offered participation in an available clinical trial					
a)	Child Interventional Trial	72	59	50%	82%	▲
b)	Child Translational Trial	72	5	10%	7%	▲
No. 4	All children with cancer should be discussed at a regional and /or national multi-disciplinary team meeting within 14 days of diagnosis	151	101	95%	66%	▲
No. 5	An end of treatment summary must be completed for every patient within 6 months of treatment ending	37	4	100%	11%	N/A

MSN CYPC STRUCTURE



Scottish Government

MSN Executive
Clinical Directors
National Network Manager
Lead Nurse

Network leadership, administration and governance

Operational Delivery Group
Clinical Directors
National Network Manager
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 Board
Chair
Clinical Directors
National Network Manager
Scottish Government
Health Board Chief Executives/Delegates
Patient / Family Representatives
Third Sector

Governance, strategy, translation of policy and service delivery

Clinical Governance Group
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 projects related to the cancer plan

Patient and Carer Involvement
Youth Advisory Forum
Parent and Carer Forum

Patient voice, advice, lived experience and influence

LOOKING FORWARD

WORKPLAN 2024/25

WORKSTREAM 2 – DATA COLLECTING & REPORTING

2. Further scoping and planning for extended MSN key performance indicators

2.1. Support aftercare workstream to review alternatives/additions to End of Treatment Summary performance indicator as appropriate measures for aftercare services.

2.2. Develop a reporting framework to support the development of consistent routine (at least annual) reporting for services funded through the MSN including aftercare nursing, TYA psychology and physiotherapy services.

2.3. Support the Palliative Care Clinical Lead to develop recommendations for palliative care reporting indicator (identified as a gap from the data SLWG)

2.4. Support the TYA Clinical Lead to develop recommendations for holistic care reporting indicator (identified as a gap from the data SLWG/Scottish Government)

2.5. Develop recommendations for introducing and measuring the new performance indicators referenced in the Cancer Strategy

WORKSTREAM 3 – SINGLE SITE RADIOTHERAPY

1. To implement a single site radiotherapy service, the MSN CYPC will need to;

1.1. Develop implementation plan

1.2. Implement service in a phased approach

1.3. Aim to have service fully implemented 2025/26

WORKSTREAM 5 – AFTERCARE

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

1.2. Conduct survey to understand current delivery models (including discharge and age criteria)

1.3. Review evidence and/or key clinical guidelines.

1.4. Consider preventative strategies at diagnosis including development of national guidelines on prevention/protection of cardiotoxicity.

1.5. Consider preventative strategies at diagnosis including development of national guidelines on prevention/protection of gonadotoxicity and ensuring equal access to fertility preservation service provision.

1.6. Consider post-treatment strategies including national framework to improve increased uptake in completion and use of End of Treatment Summaries.

1.7. Consider post-treatment strategies including national framework to implement national approach to disease surveillance with paediatrics and TYA services.

1.8. Ensure aftercare strategies are embedded within the national transition framework for children and young people with cancer.

1.9. Presenting model for implementation of aftercare services to MSN Board.

2. Produce impact report on service delivery from current aftercare nurse specialist posts and review ways of working to obtain national coverage (where possible)

2.2. Map existing service specification (referral criteria, service interventions: type and frequency, exit points).

2.3. Develop monthly reporting template for service.

2.4. Implement monthly reporting.

WORKSTREAM 6 – TRANSITION

2. Operationalise transition framework

2.3. Identify key people at each site to complete assessment tool

2.4. Agree timescales for completion of assessment tool

2.5. Present data to MSN

2.6. Develop and agree a regular review process

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

3.1. Engage with project board to consider an aftercare model for young people (16-25 years) within adult services (action 27)
3.2. Gather information through transition framework self-assessment tool
3.3. Collate data from transition framework self-assessment tool
3.4. Engage with Aftercare project board to develop a business case for provision of aftercare nurse specialists within TYA services in adult centres (action 28)

WORKSTREAM 7 – PALLIATIVE CARE

1. Map existing palliative care feedback mechanisms for families who have had a bereavement of a child or young adult with cancer (thirds sector colleagues, service feedback questionnaires, academic surveys)
1.1. Develop feedback form for clinicians to go through with families at Consultant-led bereavement visit
1.2. Commence feedback project (with aim to gather feedback over one year period)
1.3. Review, and if required extend, membership of existing Youth Advisory Forum/Patient and Carer Forum to assess whether the MSN can access experiences of end-of-life service provision and/or use these groups to gain insights into future service development
2. Undertake an audit of end-of-life care service provision to TYAs and their families
2.4. Collect data
2.5. Analyse data
2.6. Present draft report at M&M
2.7. Final report
3. Increase use of Just in case boxes and personalised symptom management plans (including in TYA services)
3.1. Contribute to PELiCaN working group to ensure cancer service requirements are reflected in national service developments
3.2. Refresh awareness within the MSN around current guidelines for use of just in case boxes for oncology patients
3.4. Commence feedback project (with aim to gather feedback over one year period) and produce 6-month summary report
4. Develop the skills and confidence across the wider MSN community around palliative care principles and practice
4.2. Representation at MSN Workforce Development and Planning working group to ensure palliative care needs are considered as part of any wider MSN training needs assessment work
4.4. Plan a palliative care training event to take place in Dying Matters Week (May 2024)
6. Engage and influence nationally to ensure palliative care and end of life needs of CYP patients are reflected in national service developments and guidelines emerging from the PELiCaN network and Scottish Government's national strategy
6.1. Engage with PELiCaN to explore development of joint guidelines and service development (including representation on relevant governance groups)
6.2. Engage with Scottish Government about national strategy and how the MSN can be involved

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WORKSTREAM 8 – TYA SERVICES

1. Review of TYA CAG and ensuring collaborative links with other workstreams
1.4. Work collaboratively with transition workstream (6) to ensure completion of self-assessment audit tool by paediatric and TYA teams and to operationalise transition framework
2. TYA National MDT: Support and attendance, data collection and review and implementation of IAM
2.1. Annual data review from National TYA MDT (data from 2023)
2.2. Implement quarterly reporting via TYA MDT on numbers of IAMs completed versus numbers eligible
3. Implementation of IAM
3.7. Agree process for scheduling re-discussion of individual IAM at TYA MDT
4. Work with Health Improvement Scotland to develop an age-appropriate information resource app for TYA, to be hosted on the Right Decision Services platform
4.2. Establish a project team to assist with the building of the app
4.3. Collate resources for inclusion in the app
4.4. Work with MSN and relevant staff groups to promote the use of the app
5. Implement recommendations from TYA Psychology, Physiotherapy and Dietetics workforce planning report
5.2. Develop more detailed business case for dietetic service ensuring a good understanding of how additional resource requested could meet any existing unmet need

5.3. Develop more detailed business case for psychology service, ensuring a good understanding of how additional resource requested could meet any existing unmet need
5.4. Develop more detailed business case for physiotherapy service ensuring a good understanding of how additional resource requested could meet any existing unmet need
5.5. Develop a consistent approach to (at least) annual reporting to the MSN for TYA psychology, physiotherapy and dietetics services including overall patient numbers, health board residence, type of intervention and outcomes/impact.

WORKSTREAM 9 – WORKFORCE

1. Workforce Development
1.1. Delivery of M&M event with learning across Paediatrics and TYA services
1.2. Delivery of MSN Education events
2. Workforce Planning
2.2. Implementation of optimisation programme
3. Wider Workforce Mapping: Complete a national workforce mapping exercise
3.1. Seek Health Boards' requirement for workforce data collection under Healthcare Staffing Act
3.2. Define data fields required for mapping e.g. which specialties; age profile of staff; WTE; permanent posts, seconded posts
3.3. Develop mapping template
3.4. Presentation/Feedback from ODG and Board on template
3.5. Conduct national workforce mapping
3.6. Analysis of workforce mapping
3.7. Share results within MSN governance structure

WORKSTREAM 10 – PATIENT EXPERIENCE / PUBLIC INVOLVEMENT

1. Map existing patient experience/feedback mechanisms available to the MSN
1.1. Review opportunities to extract data from the adult cancer services patient experience survey
1.2. Presentation from NHS England on U16 Cancer Patient Experience Survey to Board and/or ODG
1.3. Collate data from Care Opinion Survey
2. Engage third sector partners to develop an evidence-based approach to engagement
2.1. Initial scoping meeting with third sector partners to discuss mechanisms
2.2. Collation of third sector patient engagement strategies
3. Development of national peer support system for TYAs with cancer
3.2. Recruit to buddy roles
3.3. Identify key facilitators and address any support needs
3.4. Training for buddies
3.5. Advertise service
3.6. Match buddies to patients
3.7. Establish review framework
4. Ongoing facilitation of Youth Advisory Forum
4.4. Elicit final feedback on Peer Support information documents
5. Re-establish paediatrics parent/carer involvement approach
5.1. Further review meeting with current members
5.3. Recruit new Chair
5.4. Collate case studies/stories of current members
5.5. Identify MSN governance groups that would benefit from parent/patient representation
5.6. Identify programmes of work that would benefit from parent/patient representation

APPENDICES

APPENDIX 1 – 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 - Staffing chart

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

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