Collaborative and Compassionate Cancer Care

The Cancer Strategy for Children and Young People in Scotland 2021–2026

September 2021

Scottish Government
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The Cancer Strategy for Children and Young People in Scotland 2021–2026

The Scottish Government, Edinburgh 2021

NHS
SCOTLAND

MSN
For Children & Young People with Cancer

The Scottish Government
Riaghaltas na h-Alba

The Scottish Government and the Managed Service Network for Children and Young People with Cancer would like to extend its grateful thanks to all stakeholders who supported the development of this strategy and to those who provided the data displayed. All information and data contained in this strategy were accurate and up to date as of August 2021. Extended thanks are also provided to Dr Lorna Fern of the University College London Hospitals NHS Foundation Trust for providing helpful insights to inform the content regarding clinical trials and diagnostic delays

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Foreword

Cancer can affect anyone at any age and touches not only the person receiving the diagnosis, but also their friends and family. Receiving a cancer diagnosis at any point in an individual's life is never easy, but receiving one at such a young age is especially difficult. We know that diagnosis has come a long way, with survival rates remaining stable for children and young people. However there is still more that we can do to support this age group to live long, healthy and happy lives.

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. This strategy emphasises the Scottish Government's commitment to improving services nationally and supporting a consistent application of care and treatment across the country. I recognise that the COVID-19 pandemic has incurred a period of unprecedented challenge and change to health care services; however throughout this NHS Scotland has continued to prioritise its children and young people's cancer services. The strategy builds from what is already happening to set out a new course for better services in the future.

Collaborative and Compassionate Cancer Care strives to address the challenges of demographic change and the rising demands on the health service. The strategy sets out a direction and focus for those working within children and young people's cancer services. It has been developed in collaboration with clinicians themselves, partners and patients, past and present. It is the Scottish Government's strong belief that service users should have a voice in how services are developed. Members of the public have played a significant role in determining the strategic direction and I hope that this is evident throughout the strategy. It is underpinned by a guiding aim – 'a national service that strives to improve clinical outcomes, psychosocial care and patient experience'.

We have already achieved great success through the development of the national Managed Service Network for Children and Young People with Cancer. In the last decade the network has provided an opportunity for those working within and alongside children and young people's oncology and haematology services to work to collective priorities which are consistent across Scotland. Although these services operate at a national level, by undertaking a Scotland-wide perspective, we can support equity of service provision and quality.

This vision is to provide – 'a national, specialist, multidisciplinary and age appropriate service for children and young people who are living with and beyond cancer'. We want this strategy to ensure children and young people are firmly at the centre of care with shared decision making at the core; supported by expertly resourced teams. The ambitions, objectives and actions within this strategy will provide real and tangible benefits for individuals, their families and carers.

Enabling approaches, including reablement, rehabilitation and supported self-management will be pivotal to underpinning the delivery of children and young people’s cancer care. The achievement of this will depend largely on both practitioners and the people who use these services; their families and carers working together and employing strategies to support children and young people to live healthy and fulfilling lives.

The strategy connects with our current policy for children and young people, recognising the use of ‘Getting it Right for Every Child’ and contributions to emerging national work such as the National Cancer Plan for adult cancer services. The service developments already happening, or that have happened, for children and young people with cancer are also reflected in the strategy. This builds for a strong foundation in the future design and delivery of services.

However, the success of this strategy cannot be delivered in isolation or solely by the Managed Service Network. It will require strong leadership across NHS Scotland, utilising the clinical expertise available. This leadership will be essential to drive innovation and the delivery of high quality, effective, efficient, timely and responsive services that are developed around the needs of children, young people and their families. Furthermore, success will require strong partnership working and collaboration across agencies.

I would like to thank all of those involved in the creation of this strategy and those involved in the delivery of children and young people’s cancer services. The Managed Service Network will continue to be dedicated to the needs of patients, influenced by their families. It will support the delivery of services to children and young people with cancer, informed by the work of the multidisciplinary teams and will optimise the outcomes for children in Scotland who have a diagnosis of cancer through age-appropriate, safe and effective services; provided as local as possible and as specialised as necessary.

My thanks go to the huge number of people who have helped set and deliver this excellent vision.

H. Yousaf

Humza Yousaf, MSP
Cabinet Secretary for Health and Social Care

Executive Summary

On behalf of the Managed Service Network for Children and Young People with Cancer (MSN CYPC) Board I am pleased to provide the Executive Summary for this ambitious strategy. Its development has resulted from extensive consultation, which has paved the way for this publication. The strategy celebrates our achievements to date as well as emphasising the improvements that we know are still needed and we believe can be achieved over the coming 5 years.

This is firstly due to the excellent work undertaken by our national and multi-professional Cancer Strategy Oversight Group, but of course this success is not due to one person or group. Whilst this strategy is focused on the delivery of NHS Scotland services, we recognise that we cannot make improvements to care and treatment alone. This strategy results from a real team effort across health care professions and specialties in Scotland; including close working with our young people, their parents and carers, third sector and charitable organisations, institutes and academia. All have shown a real commitment to delivering a strategy which allows the MSN CYPC to strive to achieve our collective goals and improve the lives of the communities in which we serve. It is recognised that there are many important areas of focus which could have been included within this strategy; however the ambitions, objectives and actions provided have been developed through feedback from children, young people, their families and carers as what matters most to them.

In developing our vision for the next 5 years, the MSN CYPC has been afforded the opportunity to look back at our achievements to date as we mark our 10th year of existence. I am pleased to see that the strategy is not only a celebration of this, but also an opportunity for recognition of the continued hard work children and young people's cancer services provide every day. From doctors, nurses, psychologists, allied health professionals, to admin and support staff, alongside our key partners, patients and their families; it is people who are at the heart of the MSN CYPC. The strategy reminds us of how privileged we are to work alongside such creative and innovative individuals, collectively focused on improving the delivery of health care.

This year has seen significant changes for NHS Scotland due to the COVID-19 pandemic; however staff continue to go above and beyond to maintain services during this difficult period in our health care history. Throughout it all the commitment has remained to deliver this strategy. From what we know of the spirit of the MSN CYPC family, I have every confidence that our dedicated and committed workforce will welcome this new publication and will continue to do their utmost to deliver its outputs over the coming years to the benefit of our population.

Dr Andrew Murray
Chair of the Managed Service Network for Children and Young People with Cancer

Introduction

Collaborative and Compassionate Cancer Care, Our Cancer Strategy for Children and Young People in Scotland 2021-2026, is the first NHS Scotland children and young people's cancer strategy which has been clinically led and is underpinned by science. This strategy builds upon the earlier successes of our children and young people's cancer plans in 2012 and 2016; harnessing the enthusiasm and expertise of the multi-professional teams working within the MSN CYPC, 10 years since its conception.

Grounded in the principles of Realistic Medicine, this strategy affords the children and young people of Scotland with the opportunity to receive world class cancer care, using precision medicine, close to home for the majority of their care and in national centres of excellence for the most specialised elements of treatment.

Much has been achieved through the first two cancer plans, from the adoption of national and regional multidisciplinary teams, through investments in specialist teenager and young adult teams and aftercare nursing, to the creation of an early phase clinical trial network comprising Scotland, Northern Ireland and the North East of England. Our existing state of the art National Bone Marrow Transplantation service will continue to be supported and developed in addition with an aspiration to expand Chimeric Antigen Receptor T-Cell therapy (CAR-T) to the teenagers and young adults patient group; both providing exciting opportunities for the next five years.

To support territorial Health Boards in the delivery of this strategy, the MSN CYPC leadership model is evolving to include national lead positions for Doctors, Nurses, Pharmacists and Allied Health Professionals (AHPs); incorporating those who care for children, teenagers and young adult patients. Recognising the complexity of the landscape, the senior leadership team will use the core pillars of systems leadership; Complex Systems Insight, Coalition-Building and Advocacy Tactics and Collaborative Leadership Skills to facilitate change and further harmonise and improve cancer care for our children and young people. Furthermore, to mirror the established and highly successful teenagers and young adults Clinical Advisory Group (CAG), a paediatric CAG will be commissioned, led by a new national Clinical Lead for paediatrics.

Specific clinical developments supported in this cancer strategy are the commissioning of a national molecular radiotherapy service for children, the move to permanent funding for a dedicated teenagers and young adults workforce (devolved to the territorial Health Boards for delivery), raising the profile of supported care services and holistic care, the evolution of a single site expert centre for the delivering of curative radiotherapy for children and a commitment to work towards the substantive funding of the required infrastructure for molecular characterisation of cancer at diagnosis and relapse, to enable access to modern personalised target treatments.

This strategy places the importance of high quality care for those who cannot be cured and equitable access to ongoing care for those who are cured and experiencing long term impacts from their treatment, at its heart, explicitly calling for parity of these parts of the cancer journey with all others.

Collaborative and Compassionate Cancer Care is our ambitious strategy for the next five years, with measurable actions, which when delivered, will enhance the achievements of the last decade; providing world class cancer care for the children and young people of Scotland.

Dr Nicholas Heaney
Children and Young People's Cancer Strategy Oversight Group Chair

Background and Context

The Managed Service Network for Children and Young People with Cancer aims to make a positive difference for children and young people with cancer, their families and carers, by sharing knowledge, skills and experience. The MSN CYPC has led the development of a single national cancer service for Scotland, comprising of Principal Treatment and Shared Care Centres. *Collaborative and Compassionate Cancer Care*, our new cancer strategy, showcases our expectations for high quality cancer care over the next five years.

Every year in Scotland, approximately 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. Recent data on cancer outcomes is encouraging. The types of cancers seen in children and young people are different from those in adults and generally more treatable. Over 80% of children diagnosed with cancer before the age of 15 years can expect to be alive more than five years after the diagnosis. For those between the ages of 15-24 years that rises to more than 90%. These high rates of cure result from many decades of clinical research. The MSN CYPC will continue to contribute to national and international research projects which aim to maximise cure for those with the highest risk disease and minimise treatment burden for those who are already curable.

This cancer strategy is divided into six interlocking sections:

1. Reflections on our development as a national network to date
2. Providing the evidence and data to demonstrate the current landscape
3. Focusing on patient pathways that are developed and informed by outcome measures that ensure quality of care
4. Confirming our methods to measure our success against our objectives
5. Confirming the process undertaken to deliver this strategy
6. Collective actions required to achieve success

Our second cancer plan for children and young people with cancer (2016-2019) set out its vision to deliver a world class national service (Scottish Government, 2016a). The MSN CYPC was charged with delivering this vision and ensuring that all young cancer patients received the *right diagnosis, the right treatment, by the right team and in the right place*. The MSN CYPC has successfully accomplished a wide ranging and varied programme of activity during this time period, recognising that a number of projects are still to be completed; however it is intended that the majority of these will be carried forward into this new strategy. All will involve partnership working between the MSN CYPC, NHS Scotland Health Boards, front line clinical staff, the third sector and service users to deliver high quality cancer care that is driven by evidence and best practice; with all aiming to provide assurance on the quality of cancer care for children and young people and to inform evidence based planning, management and policy development.

In preparing this new strategy, we consulted widely with stakeholders including NHS Scotland health professionals, patients, families and our colleagues within the third sector. Their valued contributions have shaped its development and our future.

Section 1

Our Story so Far

The MSN CYPC was officially launched in 2011 to ensure a single sustainable model of service delivery for children, teenagers and young adults with cancer. It was recognised that adopting a network approach could support services to further improve outcomes. The creation of a pan Scotland co-ordinated network supported all relevant clinicians operating across the NHS Scotland children and young people's main cancer centres to work collectively in accordance with national standards and guidelines. Cancer plans were published in 2012 and 2016 and have driven the development of a single service and fostered national collaboration, aiming to deliver a world class service for our children and young people.

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
- Ensure patient involvement at all levels including network activities and monitor patient satisfaction
- Develop sub-specialisation, agreeing referral guidelines and advising on strategic workforce issues including key appointments
- Lead on the establishment of a robust eHealth 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
- Develop and implement best practice frameworks for multidisciplinary teams

Governance and Structure

The MSN CYPC works in partnership with the 14 territorial Health Boards and frontline clinical staff. National multidisciplinary working is pivotal to delivering our vision, promoting consistency and equity of care. The MSN CYPC, while not a legal entity, holds accountability for the delivery of the NHS Scotland Children and Young People's Cancer plans, and this new strategy, with the operational delivery of services lying directly with each territorial Health Board. Key to delivering a single national service is collaboration, networking and communication; this is supported by the MSN CYPC's organisational operating structure (Appendix 1).

National Multidisciplinary Teams

Multidisciplinary working with regards to treatment is widely accepted as the ‘gold standard’ of cancer care delivery across the world. Throughout the UK, health departments have obligated multidisciplinary team (MDT) working in order to ensure reliable and equitable delivery of safe and high quality care that is necessary to improve patient outcomes. In addition to delivering safe management plans for patients, the national MDTs maximise expertise, facilitate data collection, support cancer registration and audit, provide educational value, guide patient pathways and provide reassurance to patients and families that high quality care is being delivered.

Cancer multidisciplinary teams meet regularly in multidisciplinary meetings (MDMs) to discuss and agree treatment recommendations for individual patients. Members include oncologists, surgeons, radiologists, pathologists, palliative care clinicians, pharmacists, specialist cancer nurses, social workers[1], clinical psychologists, clinical geneticists, dietitians, occupational therapists and physiotherapists. They also have a governance role to ensure the quality and safety of care, by overseeing and monitoring the impact of treatment decisions. Table 1 demonstrates the current MDTs that exist within Scotland for children and young people’s cancer services to ensure joint assessment of all new cases of children and young people with a diagnosis of cancer and agreement upon their ongoing treatment and management. For teenagers and young adults, all patients are discussed at a national TYA MDT that works alongside the traditional site specific MDTs which have responsibility for treatment recommendations.

Table 1 – NHS Scotland Paediatric, Teenager and Young Adults Cancer MDTs

MDT	Geography	Frequency	Attended by
Palliative Care	National	Weekly / Monthly	Aberdeen, Dundee, Edinburgh, Glasgow and CHAS[2]
Leukaemia	National[3]	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow and Inverness
Relapse	National	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow, Newcastle and Belfast
UK National Advisory Panels	National	Varies	All UK Children and Young People’s Cancer Centres
Neuro-Oncology	Regional	Weekly	Aberdeen, Dundee and Edinburgh
			Glasgow and Inverness
Solid Tumour[4]	Regional	Weekly	Dundee and Edinburgh
			Aberdeen and Glasgow
Sarcoma	Local	Weekly	Edinburgh
	National	Weekly	Aberdeen, Dundee, Edinburgh, Inverness and Glasgow
TYA[5]	National	Weekly	Aberdeen, Dundee, Edinburgh, Glasgow and Inverness

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[1] Young Lives vs Cancer Social Workers

[2] Children’s Hospices Across Scotland

[3] In addition there is a fortnightly UK National Leukaemia MDT

[4] TYAs treated in the adult sector are discussed at tumour site specific local, regional and national MDTs

[5] Psychosocial focused MDT

Section 2

The Current Landscape

Within Scotland when a child or young person is diagnosed with cancer or a condition which may lead to cancer, healthcare staff record details regarding the diagnosis and the treatments received. This information is then recorded within the national Scottish Cancer Registry. This service is provided by Public Health Scotland. By collecting information nationally, health care services can plan and improve care for patients in the future. National cancer incidence statistics are published annually, with the next report to be published later in September 2021.

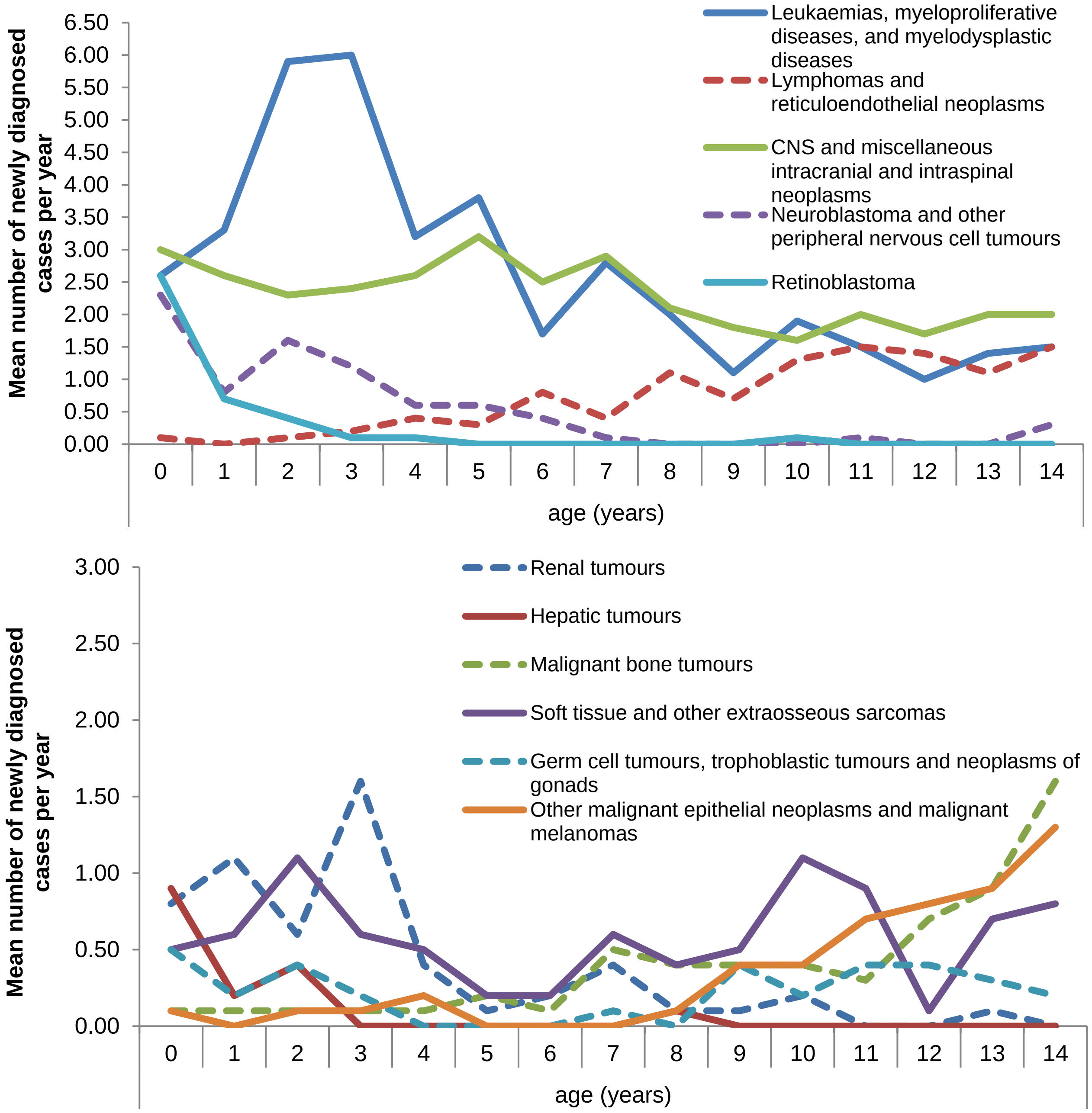
Whereas the Scottish Cancer Registry regularly publishes data on cancer at all ages, the classification used (the 10th edition of the International Classification of Diseases or ICD-10) is more suited to adult cancers. These cancers are classified primarily by the part of the body where the cancer is located; whereas cancers in children and young people are more appropriately classified by the type of tumour (i.e. which cell types are involved). Therefore to ensure appropriate reporting and recording for children and young people the MSN CYPC and NHS National Services Scotland in partnership began publishing annual reports based on the type of tumour and also developed an ‘Enhanced Cancer Registry’ to support the appropriate recording of childhood related cancers.

In February 2019 the first jointly produced 10 year report (2007-2016) on occurrence and outcomes of cancer in children (0-14 years) and young people (15-24 years) in Scotland was published (NHS National Services, 2019). The most recent report, published in September 2020, demonstrates that cancer in children and young people is rare, accounting for <1.5% of the cancer burden. In the ten year period 2009-2018, 1,298 children (ages 0-14, 53% male) were diagnosed with some form of cancer. Amongst 15-24 year olds 1,996 (51% female) were diagnosed with some form of cancer. The most common cancer diagnoses in children were leukaemia (31%) and central nervous system tumours (27%), while in the older group lymphomas (19%), melanomas and skin cancers (14%) predominate; with all carcinomas combined forming the largest group (22%). One year survival rates have remained fairly stable, with the most recent figures (patients diagnosed between 2013 and 2017) at around 93.6% for children and 96.7% for young people. Scotland has over 5,000 children and young people who have survived a diagnosis of cancer after 1999 (Public Health Scotland, 2020). Their ongoing health care needs form part of this strategy.

Stepwise improvements in treatments mean that most children and adolescents can be cured of their disease, with five year survival around 88% in children and 92% in young people for those diagnosed in 2013-2017. For teenagers and young adults, carcinomas continue to lag behind successes in haematological malignancies and germ cell tumours. With around 41 deaths each year (stable), cancer remains the leading cause of disease related death in children and young people in Scotland (Royal College of Paediatrics and Child Health, 2020). Our outcomes are comparable to England and our data was part of the first UK report published in 2021 on cancer outcomes for children and young people (Public Health England, 2021).

The following data presented have been provided by Public Health Scotland and provides information relating to cancer incidence and survival rates for children and young people within Scotland. Cancer registration is a dynamic process therefore the data presented may be subject to future change.

Figures 1 and 2 – Children Aged 0-14: Mean Number of Cancer[6] Diagnoses per Year by Age and Diagnostic Grouping[7], Scotland, 2009-2018



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6 Cancer is defined as: ICD-10 C00-C96 (C97 is not used by the Scottish Cancer Registry), D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5. All malignant neoplasms including non-melanoma skin cancer: ICD-10 C00-C96 (C97 is not used by the Scottish Cancer Registry). Benign and uncertain behaviour tumours of the brain and central nervous system (CNS): ICD-10 D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5

7 Cancers in Children are classified according to ICCC diagnostic groupings as based on the Steliarova-Foucher methodology (ICCC Third Edition)

Figure 3 – Young People Aged 15-24: Mean Number of Cancer[6] Diagnoses per Year by Age and Diagnostic Grouping[8], Scotland, 2009-2018

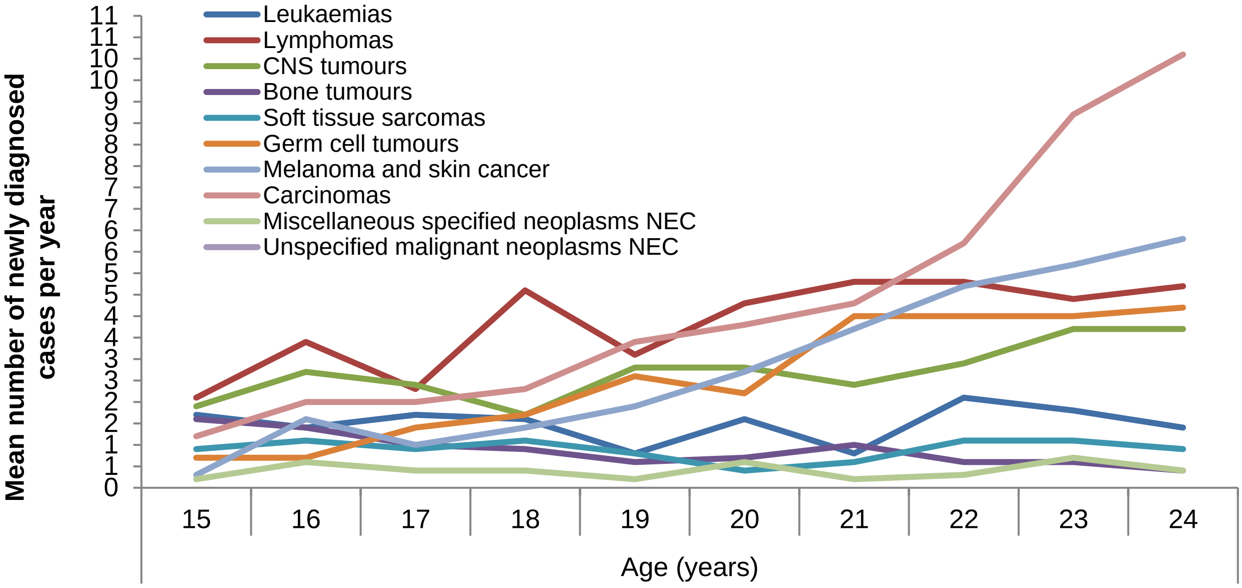


Figure 4 – Children Aged 0-14: Microscopically Verified Cancer[6] Diagnosis by Year of Diagnosis, Scotland, 2009-2018 (*Males and Females combined*)

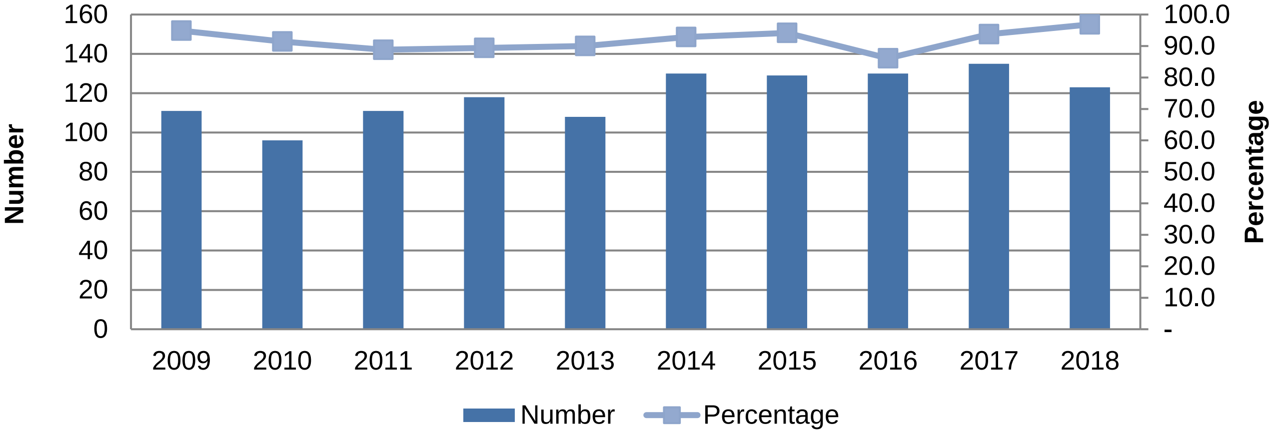
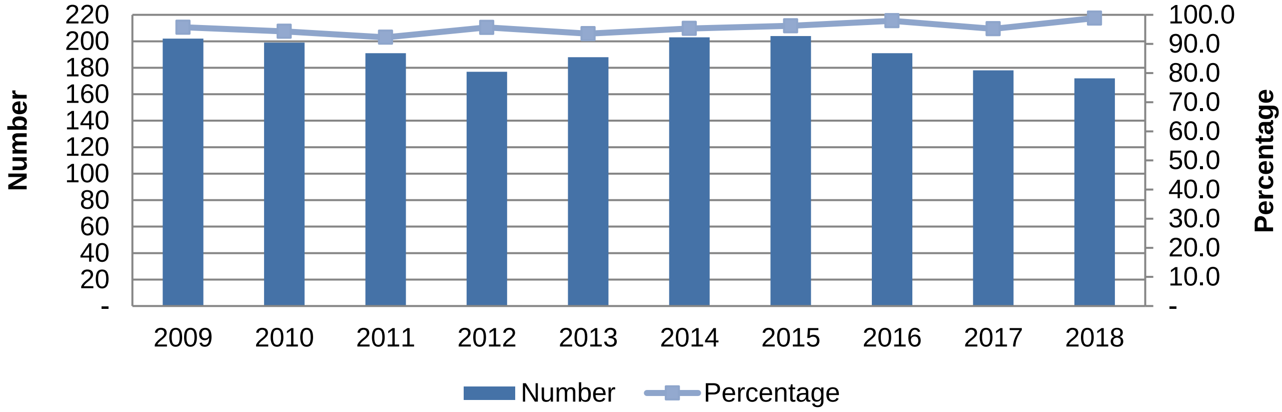


Figure 5 – Young People Aged 15-24: Microscopically Verified Cancer[6] Diagnosis by Year of Diagnosis, Scotland, 2009-2018 (*Males and Females combined*)



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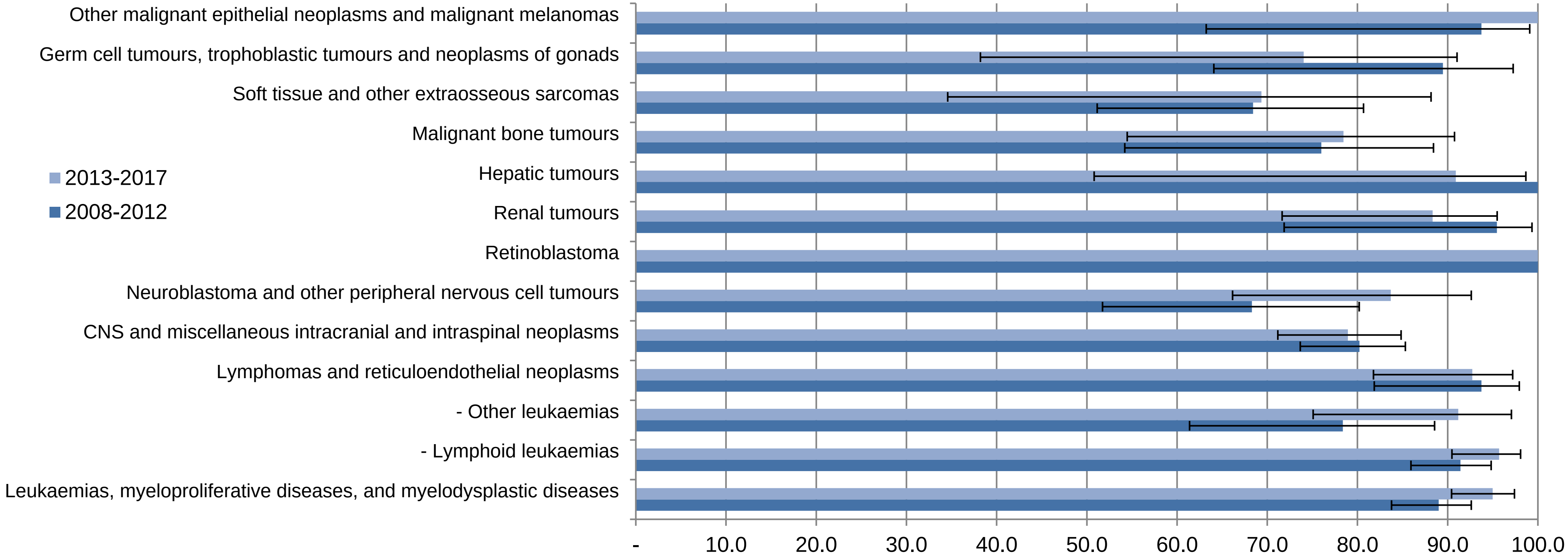
[8] Cancers in Young People are classified according to Birch-Alston diagnostic groupings

Figure 6 – Children Aged 0-14: Cancer[6] survival[9] by Diagnostic Grouping[7,10,11] and Period of Diagnosis, Scotland, 2008-2017[12] (*Observed (Kaplan-Meier) survival (%) at 5 years following diagnosis[13], with 95% confidence intervals[14] and result of chi-squared test for trend by year of diagnosis*



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9 Observed (crude) survival is the overall survival based on deaths from all causes and is calculated using Kaplan-Meier (K-M) method, which does not take into account competing risks

10 Separate information is not shown for 'Other and unspecified malignant tumours'

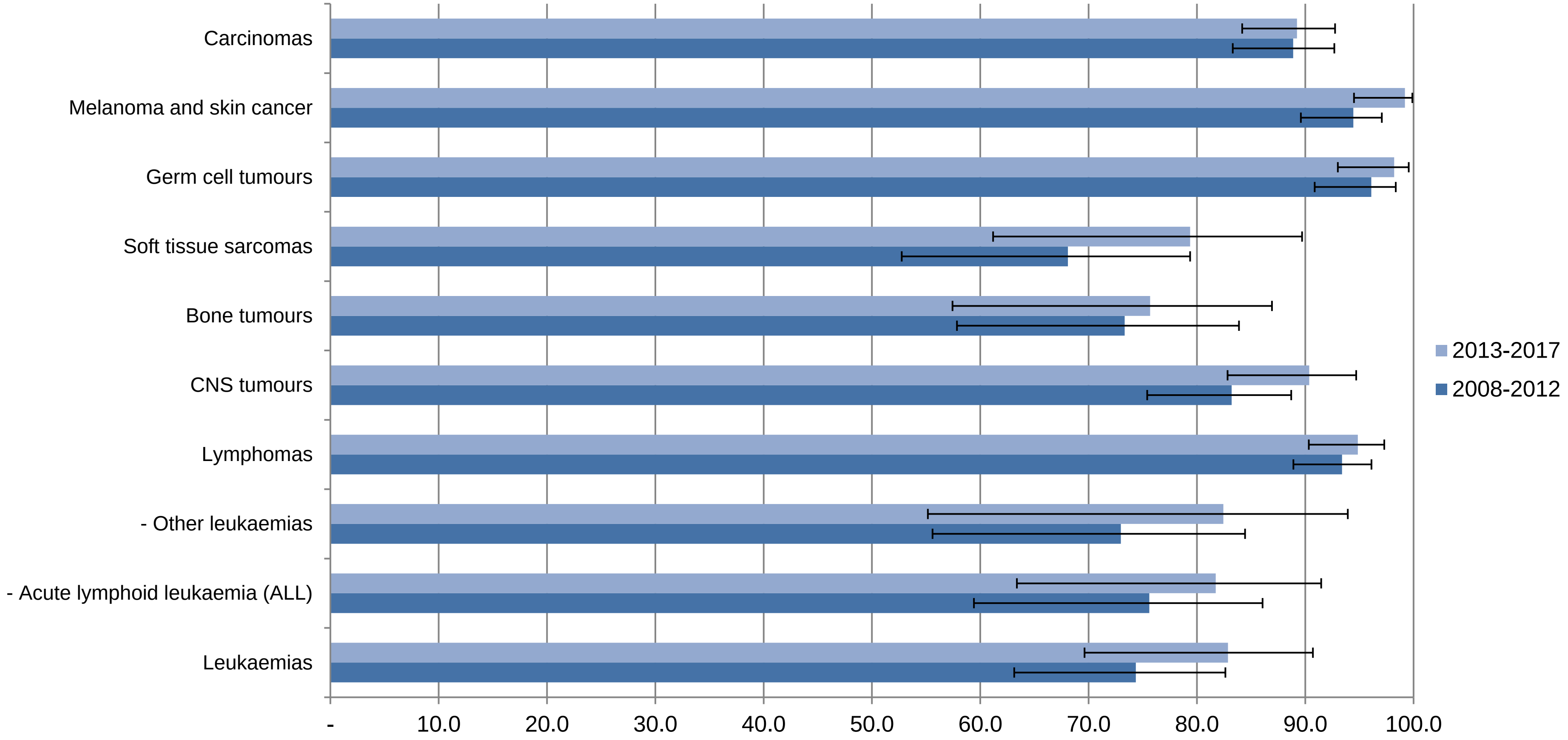
11 Only cancers that are the first malignant tumour for a patient in a diagnostic grouping are selected for survival analysis

12 Survival is censored at 31 December 2018. Therefore, cases diagnosed in 2014-2017 do not have a full 5 years' follow-up

13 Survival probabilities are not calculated where there are fewer than 10 cases

14 95% confidence intervals (CIs) are calculated using the method detailed in Hosmer and Lemeshow (Applied Survival Analysis, 1999, Wiley). This method is based on a transformation of intervals for the log-minus-log (LML) survival function, or log cumulative hazard function. This method works well in small samples

Figure 7 – Young People Aged 15-24: Cancer[6] survival[9] by Diagnostic Grouping[8,15,11] and Period of Diagnosis, Scotland, 2008-2017[12] (*Observed (Kaplan-Meier) survival (%) at 5 years following diagnosis, with 95% confidence intervals[14] and result of chi-squared test for trend by year of diagnosis*)



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15 Separate information is not shown for 'Miscellaneous Specified and Unspecified Neoplasms Not Elsewhere Classified'

> “I would like to say thank you for the amount of time that has gone into creating this, the fact that the Youth Advisory Forum is being heard and is going to make a difference. It is incredibly rewarding and I am honoured to be able to be a part of it. With this new strategy I have hopefully been able to make a difference for future young people going through cancer”

MSN CYPC Youth Advisory Forum Member

Section 3

The Way Forward

This cancer strategy embraces change and is founded on the principles within the Scottish Government's 'Realistic Medicine' movement[16] and the core components of 'Getting It Right for Every Child (GIRFEC)[17]'. Our previous cancer plan highlighted the need to ensure our efforts fully embraced the principles of GIRFEC and this approach has again underpinned our future policy direction. The strategy provides the foundations and structure for planning, monitoring and sustainability and, in adopting this third publication for children and young people's cancer, we will support practitioners to have the confidence and skills to drive forward improvement for better outcomes for their patients and the communities we serve.

In December 2020, the Cabinet Secretary for Health and Sport announced the publication of a National Cancer Plan 'Recovery and Redesign: An Action Plan for Cancer Services' (Scottish Government, 2020b). The plan will drive a 'Once for Scotland' approach to cancer service delivery and aims for equitable access to care and treatment across Scotland. To support the Plan's implementation, the Scottish Government has created a national Scottish Cancer Network which will work towards all existing national cancer networks, including the MSN CYPC, becoming part of this new approach. The Scottish Cancer Network will drive improvements as well as supporting common pathways, expectations and experiences for patients. In addition, the new national Centre for Sustainable Delivery (CfSD) will develop new innovative improvement programmes to support our approach to COVID-19 recovery focusing on cancer performance and early diagnosis. The MSN CYPC will ensure our cancer services are fit for purpose as part of the national '*redesign for recovery*' of NHS Scotland.

Our Ten Ambitions

At the core of our ten ambitions are fundamental requirements to ensure collaborative learning and a commitment to service improvement. It is envisaged that by aligning all involved in cancer care to similar values, this strategy will bring benefit to our children and young people. To drive these ambitions, our 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. Whilst the principles of each ambition span across all age ranges, ambitions one to nine are focused on both paediatric and TYA services; with ten aimed specifically at TYAs in adult services to ensure appropriate representation of this age group.

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[16] Scottish Government, 'Realistic Medicine'
[17] Scottish Government, 'Getting it Right for Every Child'

Enhancing and Improving Outcomes

Incorporated supportive care services

Specialist and sustainable Workforce

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

Age appropriate services and effective transitions

Collaborative, compassionate and inclusive leadership

Integrated palliative and end of life care services

Service improvement and patient safety

Education, Training and Staff Support

Equity of access

Continuing care when treatment completes

Ambition 1 – Enhancing and Improving Outcomes

OBJECTIVE

An integrated multidisciplinary team approach to treatment decisions for all children and young people to ensure the most precise diagnosis is made as early as possible and treatment decisions are made that are evidence based

A cancer diagnosis is now made with a high degree of precision, as a consequence of rapid evolution in the knowledge of molecular genetics. Such diagnoses are increasingly complex and require the correct tissue, consistent laboratory processes, expert pathologists and multidisciplinary cancer teams. In support of this, it remains an objective of the MSN CYPC that cancer services have the correct infrastructure and appropriate funding to ensure all patients have the right diagnosis made as early as possible.

Research is integral to all aspects of cancer care. Improving outcomes is not just achieved through single breakthroughs, but more often progress is dependent on incremental advances in multiple areas. This includes precise diagnostics and prognostic assessments, which will enable more appropriate selection of treatment protocols and identification of those at risk of treatment toxicity; enabling a better balance to be made between treatment and quality of life.

All children and young people with cancer should have the genetic and molecular profile of their tumour characterised. This enables appropriate new treatments to be offered and facilitates future drug development. The achievement of this basic standard of modern personalised medicine is contingent on the funding of the Scottish Genetic Laboratory Consortium ten prioritised molecular pathways.

Tumour banking allows for potential future drug target screening and other research. Such banking is standard practice within paediatrics using the Children’s Cancer and Leukaemia Group[18] (CCLG) facility. This is less utilised within the TYA population. The CCLG tissue bank is a resource available to TYAs and its use is encouraged by the MSN CYPC. National and multidisciplinary working with our MDTs, supported by data collection, is essential to deliver this. MDTs are an essential part of integrating complex diagnostic and prognostic information, thus agreeing an appropriate treatment plan. The MSN CYPC has successfully introduced local, regional and national MDT working for a number of patient groups.

The gold standard for clinical research is the randomised clinical trial (RCT). Within paediatric oncology the RCT is considered to be the standard of care. We intend that children and young people are offered the benefits of being in trials. Where case numbers are small, this approach is vital if we are to generate the evidence to treat cancer better in children and young people.

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[18] Children’s Cancer and Leukaemia Group

For children, pathways for diagnostic biopsies in paediatric cancer centres are well established with diagnoses made by paediatric pathology, haematopathology, sarcoma and neuro-pathology and involving specialist adult pathology teams when required. Treatment decisions for TYA patients continue to be made at adult site specific MDTs with holistic care considered at the weekly national TYA MDT. One of the MSN CYPC's previous performance indicators is that all patients will have national MDT agreed diagnoses and treatment plans. Management plans for children with central nervous system tumours and solid tumours are made at weekly regional MDT meetings hosted by Glasgow and Edinburgh.

Children from Aberdeen with a central nervous system tumour or solid tumours are discussed at the Edinburgh and Glasgow MDTs respectively. The arrangement for shared care with Dundee is provided in partnership with Edinburgh. It should be noted the MSN CYPC recognises that due to increasing service demand, shared care services are now being provided by other district general hospitals (Appendix 2). The MSN CYPC will work with these Health Boards to support the paediatric haematology oncology inpatient care work which is being delivered, ensuring that arrangements are formalised, recognised and appropriate pathways developed.

The MSN CYPC will promote and monitor access of children and young people to clinical trials. Treatment within a clinical trial is considered to provide a high standard of care, often providing access to new therapies or by trialling new methods of delivering tested medicines. Stepwise improvement in cancer survival rates have been seen as a result of clinical trials. The Scottish Government recommends that all children, teenagers and young adults with cancer participate in clinical trials.

However data collected by the MSN CYPC has demonstrated that many children and young people, particularly those in the TYA group, are not treated on clinical trials. A lack of available front-line clinical trials for common cancer within this age group is the main factor. There are situations where inequitable access to a clinical trial is seen within Scotland. MDTs serve to highlight such discrepancies. In addition it is clear that there has been an affect of the COVID-19 pandemic on clinical trial entry, with many trials closing to recruitment for periods of time. Reluctance to travel or being away from home has also impacted.

Fewer TYAs are recruited to trials and have seen less improvement in survival over time. To explore the barriers to participation in cancer trials amongst TYA patients, caregivers and health professionals and the representatives of the MSN CYPC have been working in collaboration with Edinburgh University, funded by the Chief Scientist Office (CSO). Initial findings have indicated there are few relevant trials for this age group, competing pressures for opening trials and delays in regulatory processes in opening trials.

There is an increasing population of young adults living with and beyond cancer, many of whom who are at increased risk of ill-health due to long term side effects of cancer therapy. We need to support clinical research studies to allow these young people to enrol so that we can learn together which of them requires more intensive surveillance and which can be more strongly reassured and directed to support for life after cancer, as highlighted within Ambition 5.

For patients with relapsed or refractory diseases, molecular profiling may facilitate access to clinical trials where new treatments are offered. It is a priority for the MSN CYPC to ensure clinical trials are offered within Scotland. For this, networking and national collaboration are essential. This may be done within the context of the MSN CYPC Relapsed Disease MDT.

ACTIONS

1. Ensure all children and young people have access to tumour banking for precision medicine, to guide current and future treatment
2. Work closely with the Scottish Government to source funding for future allocation to support the Scottish Genetic Laboratory Consortium ten prioritised molecular pathways
3. Advocating for and supporting the enrolment of children and young people to the national childhood cancer diagnostic study, up to 18 years old
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
6. Continuation of support and expanding the number of early phase clinical trials available within the network, when possible, currently provided in partnership with Newcastle and Northern Ireland for children and teenagers

Ambition 2 – Equity of Access

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

It is of concern that there may be variation in the provision of health care across Scotland for children and young people with cancer. The MSN CYPC will examine this to understand the nature of any disparities with the aim of ensuring equitable care for all.

This will require data collection to measure compliance with expected outcomes. The MSN CYPC developed, in partnership with NHS National Services Scotland, an Enhanced Cancer Registry as part of the national Scottish Cancer Registry in 2016 to collect an enhanced diagnostic, staging, treatment and prognostic dataset to inform clinical and research outcomes and drive improvement in services for children and young people. Therefore the use of the Enhanced Cancer Registry as a single data collection system will continue to be required. Such data will be collected through the MDTs with the support of the MSN CYPC MDT Co-ordinators and individual Health Board Data Managers.

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 all form an integral part of our clinical governance role.

Radiotherapy provision for Adults (including 16-25 year olds) is available in all five Scottish Cancer Centres and is managed and delivered by the relevant site specialist team. Children in Scotland requiring external beam radiotherapy as part of their treatment are currently referred to either Edinburgh or Glasgow where discussions and decisions occur about the most appropriate treatment modality.

Since 2008, children and adults who require a form of radiotherapy called proton beam therapy (PBT), have accessed treatment through the NHS England proton overseas programme (NHSE POP) and are treated at The Christie in Manchester or, in the past, the United States, Germany and Switzerland. A further centre is due to open at University College London Hospital in 2021. It is anticipated these two UK centres will become fully operational and absorb all UK PBT provision by late 2021 or early 2022.

Children in Scotland receiving photon radiotherapy currently receive treatment in Edinburgh or Glasgow. Anticipated photon radiotherapy activity figures published in 2019 expect 60% of paediatric radiotherapy will be delivered using PBT within 2 years. This will inevitably lead to a reduction in the number of children requiring photon radiotherapy delivered in Scotland.

In light of this, the provision of paediatric radiotherapy in Scotland has been reviewed by the MSN CYPC and regional Health Boards with a view to developing a single site national service for Scottish paediatric radiotherapy. This is currently under early stage submission to NHS National Services Division for commissioning.

The National Allograft Stem Cell Transplant Service for Scotland is located in Glasgow and provides all allograft activity for children, young people and adults. The policy of the MSN CYPC is that all stem cell transplants should be performed in JACIE (Joint Accreditation Committee International Society for Cell and Gene Therapy Europe and European Society for Blood and Marrow Transplantation) accredited units.

Table 2 – JACIE Accreditation Status

Name of Centre	Status	
	Children	**TYA**
Aberdeen	No service	Application in Progress
Dumfries and Galloway	No service	No service
Dundee	No service	No service
Edinburgh	Not accredited	Accredited
Glasgow	Accredited	Accredited
Inverness	No service	No service

Molecular radiotherapy with metaiodobenzylguanidine (MIBG) for a selection of neuroblastoma paediatric patients is currently provided at the University College London Hospital (UCLH). The physical infrastructure for such a service was included in the building of the Royal Hospital for Children in Glasgow.

The Scotland Molecular Radiotherapy Service (SMaRT) is based in Glasgow and offers targeted radiotherapy services to children and young adults with malignancy in particular neuroblastoma and thyroid cancer. The Autograft required post high dose molecular radiotherapy will be carried out at the National Transplant Centre.

ACTIONS

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
8. Implementation of a single national radiotherapy service for children within Scotland
9. Commissioning of a national meta-iodobenzylguanidine (mIBG) paediatric service for Scotland

Ambition 3 – Incorporated Supportive Care Services

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

The delivery of a high quality cancer service for children and young people, whilst supporting the holistic needs of patients, remains a priority for the MSN CYPC. Services such as Allied Health Professionals (AHPs) and Psychology work alongside other disciplines to ensure integrated and holistic care which should be in line with clearly defined pathways that incorporate proven screening and assessment tools as standard, at key intervals along the patient's pathway. The MSN CYPC will continue to prioritise supportive care and health promotion. Our AHPs and psychologists will be central to delivering this.

AHPs are highly skilled professionals and are uniquely placed to offer holistic assessments of needs when a child or young person is diagnosed with cancer. They endeavour to provide individualised support across the whole pathway from diagnosis, through active treatment, to living with and beyond cancer; inclusive of palliative and end of life care. They help children and young people to live healthy, active and independent lives, helping them to achieve what matters most to them.

In addition, AHPs support people of all ages and their families during their cancer journey. AHPs aim to maximise participation and independence within activities of daily living to improve the child or young person's physical, emotional and mental wellbeing (inclusive of regaining movement and mobility), maximising nutritional status, improving communication and life choices and restoring confidence in everyday living skills. Timely, supportive and personalised goals aim to build resilience during the cancer journey, enhancing the child or young person's quality of life, even when faced with life limiting conditions.

More specifically, nutritional support is an important part of supportive care in children and young people throughout their cancer journey to prevent both under and over nutrition. Ensuring children and young people are adequately nourished is essential during treatment to help maximise treatment tolerance and outcome, reduce complications and improve quality of life whilst aiming to achieve appropriate growth and development. On completion of treatment nutrition can continue to play an important role as being a modifiable factor in helping to reduce long term health problems (Cohen et al, 2020). To achieve this aim, children and young people require to be assessed and advised by a paediatric trained dietitian specialising in haematology and oncology (NICE, 2005).

A recent AHP cancer workforce scoping exercise has highlighted concerning gaps in both paediatric and TYA trained specialist AHPs dedicated to cancer services; across all treatment centres in Scotland. Equity of access to support services is a key ambition for the MSN CYPC.

To deliver this high standard of supportive care, it is essential that the MSN CYPC ensure there is a sustainable and highly skilled AHP workforce across Scotland. In 2020, the MSN CYPC held a number of workshops involving service users and health care professionals working within NHS Scotland cancer services. It was highlighted that there were gaps in supportive care and a clear request for nutritional and exercise advice after cancer treatment; two modifiable factors which can help reduce long term side effects and toxicity of treatment along with reducing the future burden on the NHS.

The evidence is growing to support the role of physical activity during and after cancer treatment. Keeping active throughout the Cancer journey can preserve or improve physical function and psychological well being, reducing the negative impact of some cancer related side effects. Regular physical activity also has a potential role in reducing risk of cancer recurrence and increasing survival. The MSN CYPC recognises the importance of integrating evidence based promotion of physical activity into patient care along the cancer care pathway (Macmillan, 2012).

For Paediatrics, physical activity will be informed by the Children’s Cancer and Leukaemia Group publication ‘Keeping Active During and After Treatment’ (CCLG, 2017) and the World Health Organisation ‘Guidelines on Physical Activity and Sedentary Behaviour’ (WHO, 2020). For TYAs, physical activity will be informed by the Macmillan guidance on interventions to promote physical activity for people living with and beyond cancer and the Teenagers and Young Adults with Cancer best practice statement for physical activity and exercise (TYAC, 2016). This will be supported through a universal and targeted approach. A number of specialist health professionals will have a key role in delivering this; however we also recognise the valuable contribution of our wider community services.

Furthermore, the MSN CYPC recognises and aims to ensure that appropriate and timely information is provided to children and young people throughout their treatment. To achieve this, despite the gaps in AHP resources, the MSN CYPC proposes using a tiered model of service provision for children, young people and their families. This is based on a continuum of universal, targeted and specialist support (Scottish Government, 2016b) delivered by the wider (community teams) and specialist (primary and shared care treatment centres) workforce; working together and supported by a platform of training and development (competencies and learning packages).

In doing so, the MSN CYPC will provide targeted, age appropriate and quality assured information and resources. The AHPs will collaborate to develop an educational resource package which will be utilised at diagnosis as pre-habiltiation and at the end of treatment to improve outcomes, quality of life and to build resilience; empowering parents, carers and young people. It will cover key evidence based information; for example, the importance of optimising nutritional status, the benefits of physical activity and keeping active, promoting participation in daily tasks and how to support communication skills.

With this resource in place, AHPs will be enabled to provide early identification and intervention to those at higher risk, through the implementation of screening tools and more intensive input during cancer treatment. There is also an identified need to develop aftercare pathways to ensure children, young people and their families can access AHP services as close to home as possible (Scottish Government, 2017a). Currently there is no dedicated AHP service embedded within aftercare.

To support this and the co-ordination of high quality, timely and person centred AHP services across Scotland that meets the needs of children, young people and their families; the MSN CYPC will create a national AHP professional leadership position. This new role will engage with medical, nursing, psychology and other colleagues including partners, communities, integrated joint boards and third sector organisations to ensure AHPs are integral to the development and implementation of evidence based clinical pathways. Thus ensuring consistency of provision and appropriate resource allocation nationally. The position will be key to informing plans for the future development of children and young people’s cancer services, raising the profile of AHPs and demonstrating the integral contribution that AHPs can make to these services. Furthermore, the role will provide professional and expert clinical opinion in this area of healthcare.

Alongside AHPs, the MSN CYPC recognises and supports the important contribution that Health Play Specialists make to the MDT and children and young people. Using play as a tool, Health Play Specialists input can assist children and young people to make sense of what is happening to them, work through their concerns and worries and assist in their coping.

The MSN CYPC also recognises the importance of and the requirement for further support in relation to mental health and psychological wellbeing, as highlighted regularly by young people and their families. There is widespread acceptance that the relationship between physical and mental health is such that poor mental health is linked with a higher risk of physical health difficulties. In addition, poor physical health is linked with poor mental health. Psychologists have a key role in supporting mental health and wellbeing as well as helping children, young people and families to engage with other rehabilitation specialities.

A ‘parity of esteem’ approach enables services to provide a holistic, ‘whole person’ response to each young person and their family, with their physical and mental health needs being treated equally. The Scottish Government’s Mental Health Strategy (2017-2027) sets out the importance of “preventing and treating mental health problems with the same commitment, passion and drive as we do with physical health problems”. The strategy highlights the importance of prevention, early intervention and equitable access to integrated, multidisciplinary care (Scottish Government, 2017b).

The psychological and emotional impact of living with and beyond cancer is well documented and can range from “normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety and panic” (National Comprehensive Cancer Network, 2020). Recent evidence also indicates that the COVID-19 pandemic has had a significant adverse impact on the mental health of young people (Young Minds, 2021).

This adds to the well documented experience of stress and distress among patients and staff within oncology services throughout the pandemic (British Psychological Society, 2020).

Positive mental health is essential to the overall health of children and young people, therefore the MSN CYPC will look beyond clinical outcomes to ensure that psychologically informed care and mental wellbeing are at the heart of practice within our services. In doing so, the MSN CYPC will support age appropriate programmes of training and education which are specifically focused on equipping staff with the skills and knowledge they require to recognise the symptoms of distress and poor mental health and to signpost to appropriate services.

For paediatrics this approach will be informed by the NHS Education for Scotland (NES) Competency Framework for Psychological Approaches and Interventions in Multidisciplinary Paediatric Healthcare Settings (NES and University College London, 2018) and the accompanying Training in Psychological Skills – Paediatric Healthcare portfolio (NES, 2018). For TYAs this will be informed by the West of Scotland Cancer Network (WoSCAN) Psychological Therapies and Support Framework (WoSCAN, 2017) and the accompanying NES Psychological Skills in Physical Healthcare portfolio (NES, 2019).

The MSN CYPC acknowledges the valuable contribution of specialist clinical psychology input in our paediatric and TYA populations to enhance the delivery of psychologically informed care. The National Institute for Health and Care Excellence (NICE) recommends that the core components of a Principle Treatment Centre includes "designated lead psychological services on site" and that a "psychological services professional" be part of the core medical team, both during treatment and aftercare (NICE, 2005). In addition, the quality standard suggests that children and young people and their families should have access to expert psychological support with clear routes of referral in all settings. While all team members have a role in the delivery of psychological and emotional support with appropriate training, education and support to do so, this should be delivered alongside an identified psychologist with expertise in the care of children and young people with cancer who can support and implement the following key tasks:

- a structured psychological assessment at significant points in their care pathway (including diagnosis, on treatment, end of treatment, during long term follow up, at relapse, during palliative care and at bereavement and evidenced based psychological intervention to address any difficulties identified
- assessment of family needs and coping skills and supports put in place to address;
- assessment of the psychological needs of siblings and supports put in place to address;
- access to neuropsychological services for cognitive assessment, particularly those with central nervous system tumours and also to guide schooling and career decisions
- availability of specialist neuro-rehabilitation services, including neuropsychological diagnosis and intervention when required
- encouragement of peer support groups, sibling and family support groups

Whilst the MSN CYPC will provide a new leadership position for AHPs as part of the delivery of this strategy, it is recognised that strategic leadership will be required to support the future direction of psychological therapies within children and young people's cancer services. At present this strategy focuses on ensuring and delivering equity across age related clinical psychology services; however the MSN CYPC will make a commitment to work towards delivering a psychology leadership role as part of our future direction.

ACTIONS

10. Substantive funding provided by the Scottish Government, directly to Health Boards, to support the recruitment of specialist AHPs across all treatment centres that provide care to children and young people with cancer based on the recommendations of a workforce scoping analysis
11. Health Boards will ensure equitable and timely access to specialist AHP assessment and interventions at all stages of the cancer journey, regardless of age, stage of treatment or geographical location
12. Substantive funding and appointment of national AHP Lead within the MSN CYPC to ensure strategic service delivery across Scotland
13. Evaluate the needs of children, young people and their families in relation to current AHP service provision for cancer services
14. Develop and implement a national AHP resource package which all children and young people will receive at diagnosis and at the end of treatment, which can be audited to ensure it meets the holistic needs of service users
15. Develop a competency framework for AHPs working with children and young people affected by cancer across Scotland based on the results of an educational / training needs analysis exercise
16. 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
17. Support psychological health by the implementation of national emotional wellbeing training packages, provided by NHS Education for Scotland, with peer support groups initiated to support learning into practice

Ambition 4 – Service Improvement and Patient Safety

OBJECTIVE
Ensuring safe and high quality cancer care

Cancer treatment should be delivered in a consistent and safe way. Consistency through Scotland ensures that there is no inequity of care with patient safety ensured through a national governance framework. This therefore supports the delivery of nationally agreed Systemic Anti-Cancer Therapy (SACT) protocols. For the majority of treatment protocols, the MSN CYPC will align with UK National recommendations such as those from the Children's Cancer and Leukaemia Group. Treatment decisions will be supported through regional, Scotland wide and UK national MDTs.

The delivery of safe SACT is subject to national standards. These include the use of chemotherapy electronic prescribing and administration systems (CEPAS). The Scottish Government has provided a governance framework for the safe delivery of SACT for children, young people and adults undergoing medical treatment for cancer as set out in the SACT Chief Executive Letters (CEL) 21 (Scottish Government, 2009a) and CEL 30 (Scottish Government, 2012a). In 2021, the Scottish Government convened a short life working group to review the current CEL 30 (2012) guidance to ensure the guidance on the safe delivery of SACT accounts for recent innovations in medicines, digital transformation and COVID-19 service changes. Representatives of the MSN CYPC have joined the membership of this group to ensure the guidance reflects the needs of children and young people's cancer services.

In 2019, the MSN CYPC commissioned a national scoping exercise to determine any variability of working practices across Scotland and the feasibility of implementing a shared CEPAS. This work concluded that a national approach would enable the introduction of standardised practices and processes. Therefore the MSN CYPC will work towards implementing a national CEPAS and will join the national CEPAS oversight group to support a collective governance approach to future implementation. It is recognised that significant resource will be required to achieve a national CEPAS for the MSN CYPC.

The MSN CYPC will produce a national business case to determine the allocation required to ensure successful delivery. We will ensure dedicated pharmacy leadership is provided to navigate the MSN CYPC to success in this area whilst continuing to support the safe delivery of SACT, demonstrating compliance with standards. Our intended pharmacy leadership will establish a national MSN CYPC SACT governance group whilst ensuring collaborative working across age specific services.

Mortality and Morbidity review meetings form an established part of the provision of high quality clinical care. These meetings provide an opportunity for clinicians to review and discuss clinical cases, supporting children and young people's cancer services to identify lessons to be learned and changes that require to be made. The MSN CYPC and Healthcare Improvement Scotland (HIS)[19] regards these reviews as an essential element of clinical governance and a key component of continued service improvement and shared learning.

Furthermore, the MSN CYPC welcomes the Queen Elizabeth University Hospital / NHS Greater Glasgow and Clyde Oversight Board Final Report (Scottish Government, 2021) led by Professor Mike Stevens which investigated 118 episodes of serious bacterial infection in children and young people who received treatment at the Royal Hospital for Children. The shared learning from this report has informed the current and future format of our revised national Clinical Governance and Assurance Group. This group is responsible for setting the national clinical governance priorities based on learning and feedback as well as providing a forum where members can inform, share and learn from each other regarding areas of good practice, local improvements and changes to practice. The group forms part of the wider NHS Scotland Health Board's local clinical governance mechanisms which are responsible locally for ensuring there are effective clinical governance arrangements in place.

The MSN CYPC will review the role and remit of the group, ensuring senior clinical representation from across all Health Boards. The group will take ownership of reviewing local adverse events and activities to inform planning for each Mortality and Morbidity day to ensure national dissemination of learning. A sub group will specifically concentrate on SACT governance, led by the MSN CYPC Lead Pharmacist, across the children's cancer care units, including shared care centres, on a 'once for Scotland' basis with wider benefits to TYA patients being treated within adult centres.

ACTIONS

18. Funding provided for the appointment of a substantive Lead Pharmacist within the MSN CYPC to lead national CEPAS and SACT programmes of work
19. Establish a 'Once for Scotland' paediatric SACT governance process to enable efficient and effective MDT working and support a future national paediatric CEPAS
20. Develop a national business case to determine the allocation required to ensure successful delivery of a paediatric CEPAS across NHS Scotland
21. Participation in the national procurement and tendering process for CEPAS, preparing for the future implementation of a paediatric CEPAS across NHS Scotland
22. Continued investment in annual national mortality and morbidity meetings to ensure learning from adverse events

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[19] Healthcare Improvement Scotland

Ambition 5 – Continuing Care when Treatment Completes

OBJECTIVE

Providing equitable aftercare including health surveillance, psychosocial support, identification of psychological and neuropsychological needs, health education and transition services

Today over 80% of children and young people with a cancer diagnosis will enter into children and young people's Aftercare services following which they are transitioned into teenage and young adult services or Primary Care. There is a wealth of evidence which highlights the multifaceted challenges which young people and their families face following treatment.

To deliver a comprehensive and equitable service for this patient group we require an appropriately trained workforce who, through co-ordinating with the wider MDT, can provide a comprehensive aftercare service, linked with education, to support the detection and treatment of late effects, offering health surveillance advice alongside psychosocial support and health education.

Recent focus groups have provided insight into the many and diverse needs of these survivors. They reported a lack of:

- education and awareness of the risks of late effects, particularly fertility issues
- understanding of the needs and benefits for long term follow up
- peer support and access to psychosocial support

In 2021 the MSN CYPC held a 'late effects of cancer treatment' workshop involving healthcare specialists and patients. This highlighted insufficient / inadequate advice regarding nutrition, physical exercise, and support with readjustment into society, school, university and the workplace. Children and young people can experience both psychological and neuropsychological difficulties long after treatment completes, with some difficulties not manifesting until several years later.

Due to growing numbers of cancer survivors, there is a considerable body of research highlighting that survivors of childhood cancer are at increased risk of anxiety, post-traumatic stress symptoms, internalising behaviours and lowered self-esteem. In addition, to the NICE Cancer Quality Guideline (2005) which specifies continuing access to psychology throughout aftercare, 'The National Cancer Survivorship Initiative' in England has made a number of recommendations which emphasise the importance of holistic needs assessments and access to psychological support throughout aftercare (Jenkins et al, 2013).

In Scotland, guidance for aftercare emphasises the importance of the need for regular review and assessment of psychological function, educational achievement and overall adjustment, for all survivors of childhood cancer (Healthcare Improvement Scotland, 2014).

The MSN CYPC believes that for Aftercare services to meet these concerns, to develop, be sustainable and equitable across Scotland, a MDT approach is required alongside increased aftercare nurse specialist time. A MDT approach is recognised as essential in the treatment phase and should continue into, at least, their early follow up phase; if not into longer term follow up. Ideally children and young people should have access to specialist psychology and neuro-rehabilitation for as long as necessary. This team would include the aftercare clinical nurse specialists as well as funding for wellbeing practitioners, AHPs and psychologists with specialist knowledge in children and young people's cancer in each Principal Treatment Centre, thus ensuring an equitable service. By preference, this would also include access to those with specific expertise in neuro-rehabilitation (e.g. neuro-oncologists, AHPs, psychologists, neuropsychologists, aftercare).

In this way, the MSN CYPC proposes an Aftercare model where AHPs and psychologists can follow the child or young person throughout their cancer journey, supporting them in their transition to adult services, preventing the child or young person having to re-tell their story multiple times; helping them to reach their full potential. AHPs and psychologists are ideally placed to help meet their needs at this key transition phase.

The model, as it stands offers 1.6 whole time equivalent (WTE)[20] nurses to meet the need of Scotland's entire paediatric aftercare services. This is split 0.8WTE between NHS Lothian and NHS Greater Glasgow and Clyde. There is no funding for AHPs for aftercare and limited term psychology services.

No dedicated funding for AHPs for aftercare results in a direct referral to community services as soon as they finish treatment; often whilst still in the acute recovery phase. These patients are seen by individuals who are specialist in their field, but often with no knowledge or experience of working with a child or young person who has had cancer treatment.

In reality many children and young people do not access local community based support services and local services are not equipped with the specialist knowledge and experience of cancer late effects to meet the needs of this population. Specialist cancer AHPs are able to pick up, predict and pro-actively treat future challenges; improving outcomes and decreasing the future burden on adult services within the NHS. However there is an identified need to develop appropriate pathways to access AHP and psychology services, signposting to ensure families, children and young people are aware of, and know how to, obtain support and information for physical activity, nutrition, psychological and neuropsychological difficulties.

The value of this continuity of care is evident in the work of the Lothian paediatric neuro-oncology nurse specialist who is able to follow the neuro-oncology cohort through treatment and beyond, working alongside the aftercare nurse specialist enabling patients to attain their best rehabilitation. NHS Greater Glasgow and Clyde hopes to welcome an equivalent post in the near future.

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[20] Whole Time Equivalent (WTE) – anyone who works a minimum of 37.5 hours per week counts as 1.0WTE

TYAs who have completed their cancer treatment are managed and followed up within adult services. Some will have transitioned from paediatric services and others will have had all their treatment within the adult sector. A national model for this service does not currently exist and needs to be developed to ensure all people who have completed their cancer treatment have the support and care they require. This will ensure an equitable and sustainable provision across Scotland which meets the requirements of TYAs.

Delivery of this service will involve dedicated posts to allow both direct clinical contact and outreach support for staff and young people, and the development of protocols. This service model will be aligned with the MSN CYPC National Transition Framework to allow seamless care. Every TYA cancer survivor should have access to a TYA Aftercare Nurse Specialist who will act as a key worker in adult cancer services. The Aftercare Nurse Specialist will oversee and co-ordinate aftercare / late effects services; personalising the cancer pathway for individual patients to meet the complex information and support needs of patients and their carers and referring on to other services as needs are identified.

Furthermore, our previous cancer strategy recommended the development of a national, integrated, risk stratified approach to cancer follow up. The Pan European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare EU)[21] has achieved this via an International Guideline Harmonisation Group (IGHG). The IGHG have reviewed and harmonised the recommendations for follow up by the Children's Cancer and Leukaemia Group, Children's Oncology Group, Dutch Childhood Oncology Group and the Scottish Intercollegiate Guidelines Network (SIGN) Guideline Long Term Follow Up; creating 24 evidence based guideline panels, 8 of which are ready for publication. We hope to adopt these guidelines rather than repeating this work.

The IGHG has evidenced the reality that cure is not enough for the 1 in 1000 European citizens who are survivors (van Kalsbeek et al, 2021). This translates into more than 7000 children and young people in Scotland as survivors of cancer, of whom around 6000 were diagnosed more than 5 years ago (Scottish Government, 2012b). Two thirds will have at least one physical or psychological problem affecting their health and well-being and around a quarter have a severe or life threatening late complication of therapy. Compared to their peers all survivors face a fivefold increase in their chance of a secondary cancer diagnosis by middle age. For some specific cancers there is a thirtyfold increase in incidence (PanCare EU, 2021). By 2030 it is projected that this population will be in the region of 1 in every 100 of the young adult population.

Long term follow up services must be flexible enough to accommodate the needs of young survivors as they grow older. Improved education of survivors and care providers alongside good communication is imperative to this approach. End of Treatment summaries that the survivor can take with them on their forward journey are essential and are already embedded in the MSN CYPC vision; however there are challenges in ensuring continued compliance.

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[21] PanCare EU – Pan-European Network for Care of Survivors After Childhood and Adolescent Cancer

Therefore it is becoming increasingly apparent that Scotland requires a multidisciplinary workforce with the necessary skills and one that holds the capacity and knowledge of late effects to provide the specialist advice and needs sought by young cancer survivors and their families after treatment.

ACTIONS

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
24. Ensure every survivor has access to specialised care including, but not exclusively, Dietetics, Medical, Nursing, Occupational Therapy, Psychology, Neuropsychology, Physiotherapy and Social Work
25. Ensure every survivor has an End of Treatment Summary and have at least one Holistic Needs Assessment completed
26. Develop an AHP cancer aftercare pathway to establish clear routes to referral
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
28. Substantive funding provided by the Scottish Government, directly to Health Boards, for equitable aftercare nurse specialists in the Principal Treatment Centres and within TYA services in adult cancer centres
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 or Secondary Care

Ambition 6 - Integrated Palliative and End of Life Care Services

OBJECTIVE

Developing equitable and earlier access to 24/7 integrated specialist palliative care services nationally

Cancer is the most common cause of disease related death in children and young people. In Scotland around 40 children and young people die from cancer each year generally occurring at the end of a prolonged and intense period of treatment aimed at cure or participation in early phase clinical trials. Referral to specialist palliative care is usually later in the disease trajectory even though symptom burden is often complex requiring specialist management with significant emotional, psychological, spiritual and existential suffering experienced by the patient and family. There is a need for ongoing services to provide support not only before and during the end of life phase but also in the time after death.

The MSN CYPC advocates strongly that end of life care should be delivered in the appropriate and preferred location of the patient and family with the vast majority of children and young people choosing the community setting. This often requires co-ordination of highly complex care between interdisciplinary and interagency services to ensure safe delivery of a bespoke management plan. True choice cannot not always be offered throughout Scotland currently as there is significant geographical variability in local service provision and access to 24/7 specialist support. The MSN CYPC is committed to addressing this inequality of access to end of life care by collaboration with key stakeholders to develop a specialist national nursing and medical model which can complement the local services available and includes Paediatric Oncology Outreach Nurse Specialists, Adult Community Hospices, Community Children's Nurses, District Nurses, Primary Care and Children's Hospices Across Scotland (CHAS). The MSN CYPC also recognises the need for ongoing research into the role of specialist paediatric palliative care and medicine for children and young people with cancer and remains passionate about leading and collaborating on studies in this field.

The MSN CYPC Palliative Care group implemented the National Paediatric Anticipatory Care Plan and has developed guidance for prescribing anticipatory medications through the use of 'Just in Case' boxes. These contain standardised medications which are often required to provide safe and effective management for symptoms commonly encountered at the end of life. Specific needs and symptoms are addressed by the development of individualised Symptom Management Plans (SMPs). Multidisciplinary collaboration and communication of Anticipatory Care Plans, SMPs, anticipatory prescribing and recording of ceilings of care discussions between all professionals and agencies involved in end of life care is essential to ensure safe and effective care delivery. Furthermore, the MSN CYPC Palliative Care Group developed a national paediatric MDT to support a clearer definition of patient pathways and provide specialist advice. This has been superseded by weekly / monthly local palliative care MDT meetings, but plans are underway to develop a National Specialist Paediatric Palliative Care Medicine service.

In addition a training programme is being developed to support RCPCH accredited Paediatric Palliative Care Medicine subspecialty training in Scotland. The educational component of the monthly MSN CYPC MDT was extremely well received; it has expanded and developed into a highly successful monthly educational platform in collaboration with the Project ECHO (Extension of Community Healthcare Outcomes) based in CHAS. This Paediatric Palliative Medicine Education Network now has up to 100 attendees from across the UK and Europe with national and international speakers delivering educational sessions.

Teenagers and young adults with cancer represent a unique group; their palliative care needs are often under reported and under recognised (Murray, Pettitt and Tomas, 2020). Access to specialist palliative care services for this population is variable across the UK, as they fall between paediatric and adult palliative care services. There is growing recognition of the need for specific palliative care services and for clear pathways, to ensure equitable access to appropriately trained multidisciplinary professionals (Ngwenya et al, 2017; Kenten et al, 2019). As well as nursing and medical professions, this should include AHPs and psychology. To inform the development of palliative care for this population a national audit, measuring care against the objectives of the Strategic Framework for Palliative care and Healthcare Improvement Scotland indictors, will be conducted. The work proposed would support the growing evidence base and provide a unique insight into the population in Scotland.

It should be noted that there are currently no paediatric palliative care pharmacists within NHS Scotland. Whilst palliative care services are not specific to children and young people with cancer, the MSN CYPC supports this as a vital resource, being able to improve safety and the quality of services being provided, particularly during end of life care across our children’s cancer centres.

ACTIONS

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[22]) 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 NHS 24 to ensure the content reflects the available children and young people’s palliative cancer care services
35. Provide equitable access to pharmacy services for palliative care patients

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[22] Paediatric End of Life Care Network (PELiCAN)

Ambition 7 – Collaborative, Compassionate and Inclusive Leadership

OBJECTIVE

Strong leadership with the capacity and capability to drive innovation and the delivery of high quality, sustainable and responsive services

Effective leadership is essential to promote the aims of the MSN CYPC to enable and sustain service improvement. Leadership should be inclusive and collaborative if it is to effectively influence, in particular where a change to new and existing services may be required. Such leadership is required at all levels of our children and young people's cancer services.

Effective staff development is vital to meeting future goals and ambitions. The MSN CYPC will investment in the people who deliver services through enhanced workforce development and effective leadership. We will provide leadership development opportunities to support continuing professional development and facilitate future succession planning for staff working within our services. We will initiate a new leadership development network which will provide a platform for staff to discuss and learn from emerging topics such as advanced practice developments. Through this we aim to deliver our ambitions and objectives. There will be national specific multidisciplinary workstreams to support leadership and ensure a Scotland wide contribution to innovation, with Quality Improvement at the core, supported by an Improvement Advisor. To further support this model, the MSN CYPC will ensure its leadership operates in a co-ordinated manner, working collaboratively across existing professional Health Board structures (Appendix 3).

Furthermore the MSN CYPC is aware of the significant improvements made within TYA services following the introduction of the MSN CYPC TYA Lead Nurse position, delivered in partnership with Teenage Cancer Trust. This role, in partnership with the TYA Clinical Lead, has supported the planning, implementation and improvement of excellence in clinical care for young people and their families across Scotland. The MSN CYPC recognises that by adopting a similar structure for paediatric oncology in the form of a National Clinical Lead and substantive Lead Nurse for paediatrics, we can ensure the continued clinical development across all age ranges. These roles will work alongside the TYA leads and in partnership with our new leadership roles for AHPs and Pharmacy.

ACTIONS

36. Ongoing organisational development input to support clinical and professional leadership development to MSN CYPC via current hosting arrangements
37. Scottish Government funding provided to the MSN CYPC for the appointment of a National Clinical Lead and substantive Lead Nurse for paediatrics
38. Scottish Government funding provided to the MSN CYPC for the fixed term appointment (23 months) of a national Improvement Advisor to support a quality improvement approach to the initial delivery of national workstreams

Ambition 8 – Education, Training and Staff Support

OBJECTIVE
Creating a learning culture and opportunities for greater inter-professional and integrated education

The MSN CYPC requires an appropriately skilled and staffed workforce throughout the country to deliver a high quality integrated service and to achieve the best possible outcomes for patients. A skilled workforce requires education, training and support. These skills should be shared across Scotland, in particular where staff are relatively few in number; to ensure there is no inequity of access for patients. In addition, skills should be shared in the form of sub-speciality education and training.

It is recognised that the COVID-19 pandemic has dramatically changed our approach to national working, with a move to online platforms and virtual teams. A historical challenge within the MSN CYPC has been the geographical separation of patients and clinical teams. New technology provides the opportunity for more regular collaboration between regions, enabling specialist team members to offer input into the care of patient wherever they are treated.

In order to ensure the most effective workforce, the MSN CYPC places education and development at its heart. Annual meetings such as our Educational Development and Morbidity and Mortality days are very well received by our staff as these bring everyone together and provide an opportunity for learning, sharing best practice and improving care. Reviews of patient care reflect the complex pathways through which a patients progress from time of first symptom to definitive treatment. There is risk for potential delay at many different steps either within primary or secondary care. The MSN CYPC seeks to reduce the potential delays leading to more timely diagnosis with the aim of improving outcomes.

We recognise that in order to continue to build upon the current available knowledge of children and young people’s cancer across the wider health service, we require to build and foster closer working relationships with our colleagues in academia and primary care. In order to do so, the MSN CYPC will work with our academic partners to influence the current health curriculums to support a broader clinical exposure to our services and bridge the information gap.

The MSN CYPC values the mental health and wellbeing of all staff working within paediatric and TYA oncology services, recognising that enhanced staff wellbeing is not only fundamental to its duty of care to staff, but also central to the delivery of exceptional care, patient experience and improved outcomes for children, young people and their families. The impact of COVID-19 on staff wellbeing in oncology settings is well documented, with health care professionals reporting higher levels of psychological distress and stress (British Psychological Society, 2020). Health Boards across Scotland have been responsive to this need and instrumental in delivering a number of staff wellbeing initiatives examples of which include, but are not limited to, staff wellbeing hubs, the delivery of Psychological First Aid and the inclusion of designated psychology posts within Occupational Health departments.

However, the MSN CYPC recognises that the wellbeing needs of staff existed prior to COVID-19 and therefore requires long term attention and commitment. Staff working in oncology settings frequently report symptoms characteristic of burnout, compassion fatigue and moral injury. In 2013 a survey of multidisciplinary staff working in each of the 19 UK Principal Treatment Centres highlighted three key findings:

1. Differences between Principal Treatment Centres in the range of staff support and wellbeing practices offered
2. Differences among professional groups in the types of staff support and wellbeing practices available and
3. One-off as opposed to ongoing support interventions being more readily available

Alongside the measures implemented within Health Boards, the MSN CYPC acknowledges the need for a range of staff support and wellbeing practices to be available and embedded within oncology services, while recognising that 'one size does not fit all'.

The MSN CYPC is committed to undertaking a scoping exercise with a view to better understand the wellbeing needs and preferences of all staff working within paediatric and TYA oncology services. This will include the identification of existing wellbeing practices and the extent to which these are embedded within routine practice as well as highlighting gaps in current provision. The MSN CYPC recognises the importance of delivering and evaluating a range of evidence based wellbeing practices such as Values Based Reflective Practice (VBRP), psychological support following significant / distressing events and opportunities for informal supervision to ensure a high standard of delivery across all services.

Furthermore, the MSN CYPC also recognises the importance of raising the profile of children and young people's cancer. This is particularly important in supporting medical trainees across NHS Scotland to enhance their learning and development in understanding children and young people with haematological and oncological conditions. We currently support education sessions led and facilitated by clinical colleagues which are recorded and shared via our YouTube channel. We will continue to utilise social media and other platforms to provide education and training opportunities with the aim of increasing knowledge and understanding of this speciality.

ACTIONS

39. Developing further education and learning opportunities to improve referrals and ensure timely diagnosis, including implementation of national programmes such as Headsmart[23]
40. Undertake a national staff wellbeing scoping exercise to explore opportunities to improve the psychological and emotional wellbeing of oncology staff

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[23] Headsmart

Ambition 9 – Specialist and Sustainable Workforce

OBJECTIVE

Continuing to develop and support a clear multidisciplinary approach to working that is based on the needs of the population

Maintaining an appropriately skilled and available workforce is critical to delivering a quality integrated service and achieving the best possible outcomes for patients. Networked care by multiple teams across the country with different skill-sets, delivering different aspects of patient care requires collaboration, excellent communication and adequate training and education opportunities to ensure staff are trained to deliver the best treatments.

Paediatrics Workforce

Specialist children's services are often accessed by relatively small numbers of patients, but require highly specialised and scarce clinical skills. The challenge of delivering high quality, accessible and sustainable services to children and young people in the context of the size and distribution of the Scottish population was recognised in the National Framework for Service Change 'Building a Health Service Fit for the Future' (Scottish Government, 2005). Historically many of these services have evolved in their different regions with a measure of independence which has resulted in variable patterns of service, inefficient use of scarce resources and growing problems of sustainability particularly in regard to workforce issues and the requirements of clinical governance.

By way of response, 'Better Health, Better Care – National Delivery Plan for Children and Young People's Specialist Services in Scotland' (Scottish Government, 2009b) highlighted the need for much more robust arrangements for the planning, commissioning and delivery of specialist paediatric services within Scotland. The National Delivery Plan ensured substantial investment was directed to resource the children's cancer Principal Treatment Centres and to effectively support local shared care services in other centres to reflect local demand and service configuration whilst maximising appropriate opportunities for local care. However it remains clear that the balance of investment within paediatric services should be kept under review as rising demands on health and social care services, as well changes in patient needs, emerge over time.

Although the National Delivery Plan ensured substantial investment in the children's cancer Principal Treatment Centres, there remains inequity within the AHP workforce. Not all Principal Treatment Centres and TYA units have paediatric trained AHPs with dedicated time; either in the cancer services or in the shared care centres. To allow equitable care for all our children and young people in Scotland these gaps need to be addressed. This will also allow better provision of care nearer to home. With the increasing number of children and young people surviving their cancer treatment there is an added increase in demand for access to AHPs to support in the health and wellbeing of these individuals.

This need was highlighted by children and young people in our stakeholder workshops undertaken in 2020, as aforementioned. We have already highlighted the lack of dedicated time AHP time to support the Aftercare services with patients being seen by the acute team or by AHPs not trained in cancer services. In order to support the children and young people after treatment, pathways need to be developed allowing access to AHPs with dedicated time within their roles and with adequate training to provide this service.

In comparison, within pharmacy, ensuring the safe and efficient delivery of SACT and associated supportive treatment to children and young people with cancer is complex. Pharmacy services are provided via clinical pharmacists and technicians within inpatient, outpatient and day care services. They also require support from other pharmacy services including dispensing, aseptic dispensing, clinical trials, CEPAS, medicines management, stores and distribution, medicines information and homecare. The constitution of services and duties will vary between Health Boards. A mapping and benchmarking exercise is required to identify workforce capacity and gaps in service provision. Furthermore, as stated within Ambition 4, implementation and maintenance of a national CEPAS for children will require significant resource alongside a robust business plan to ensure successful delivery.

The MSN CYPC also recognises the important role of nursing in the successful delivery of this strategy. Using their expertise and skills to offer the best care and support to their patients across diverse settings and specialties, nurses are often the most frequent line of contact with people of all backgrounds and experiences. Accounting for 42% of the workforce (NES, 2021), nurses represent the largest staff group in NHS Scotland.

The MSN CYPC recognises the cornerstone for the profession over the coming years is the Nursing 2030 Vision (Scottish Government, 2017). The vision focuses on preparing a nursing workforce that will be ready and able to meet people’s needs moving towards 2030. It reflects the national policy drivers in Scotland, which includes putting people at the centre of health and social care services, delivering the right care, in the right place, at the right time and ensuring quality is at the heart of service delivery.

Fundamental to achieving the 2030 vision of delivering a nurse-led compassionate, person centred and rights based service, where nurses are prepared for increasingly technological environments, is the recognition that there must be strong foundations for future nurses which reflect their new responsibilities. Values reflected in the 2030 vision, shared by the MSN CYPC, are the need for nurses to be educated and prepared in the right numbers to meet population needs and take on transformed roles; both through initial academic training and on-going professional and education support.

Work on this has already started, through the Transforming Roles programme, to review the clinical nurse specialist / advanced clinical nurse specialist role. This work aims to build national consistency, through the development of a clear education and career pathway, to maximise the contribution of the clinical nurse specialist to meet the future needs of Scotland’s health care system.

The MSN CYPC further recognises that paediatric haematology oncology nursing is a highly specialist area with only three dedicated wards in Scotland; therefore the pool of experienced nurses in this field is limited. Any movement within the nursing workforce for example, to a different speciality or through promotion, most frequently entails replacement by nurses new to the field. This causes consistent pressures on the nurses responsible for education; providing up skilling for new nurses to ensure safe staffing numbers on every shift to ensure the specialised supportive care this patient group requires. There must be adequate SACT trained nurses on every shift in each Principal Treatment Centre and Shared Care setting, in order for this to be delivered safely. This is challenging in non-dedicated speciality wards and Shared Care settings where SACT trained nurses are fewer in number and where delivering SACT may be a small part of the nurses overall role. In this setting, retaining highly skilled staff is even more challenging. This is also reflected within the medical workforce and there is a need for highly trained medical staff in both Principal Treatment Centres and Shared Care settings. Close working is required between centres to ensure all substantive posts are occupied by highly trained doctors or that there is a training plan in place for those in departments that are developing formal shared care roles.

As this strategy is implemented, the MSN CYPC will continue to recognise the future influence the Nursing 2030 Vision and Transforming Nursing programme will have on both paediatric and TYA cancer nursing.

In relation to paediatric psychology, these services typically see children, young people and their families from the age of 0-18 years. A diagnosis of cancer is typically a period of great shock and worry. Along with treatment, it provides a sense of vulnerability, fear and sadness for patients and their families; usually causing a great deal of distress. A diagnosis of cancer meets the criteria for a traumatic stressor because it involves ‘actual or threatened death or serious injury, or a threat to the physical integrity of self or others’. Studies have shown that around 33-40% of patients report clinically significant levels of distress at diagnosis (Zabora et al, 2001) which can have a negative impact on satisfaction with care (Von Essen et al, 2002), health related quality of life (Shim, Kelly & Hornik, 2007) and self management after treatment (Santacroce & Lee, 2006). In addition, distress can worsen disability, prolong hospital stays, increase medication non-adherence and reduce survival rates (Kennard et al, 2004).

In the United States, the Children’s Oncology Group looked at rates of anxiety, depression and behavioural change after a diagnosis of Acute Lymphoblastic Leukaemia (ALL) in ages 2-9 years. The findings suggest that depression and anxiety scores at one month after diagnosis significantly predicted persistence of symptoms throughout the first year of therapy for children. These results highlight the importance of early identification of distressed children and early intervention to avoid long term issues (Myers et al, 2014).

Perhaps unsurprisingly, parents of children with paediatric cancer report high levels of psychological stress such as post-traumatic stress symptoms (PTSS), anxiety and depression. Although many of these families adjust well over time a significant number of them report long term psychological difficulties, with subgroups of parents who maintain a high level of distress throughout their child’s illness.

Children of parents who had less support, either as a result of relationship status or lack of wider social supports, were typically found to have more difficulties with their mood (Myers et al, 2014). However research has demonstrated that psychological interventions work well with parents and that they, in turn, can pass on this education to their children (Cernvall et al, 2015).

Scottish Government guidelines clearly recommend that psychological services should be considered as an integral part of children's medical health care (Scottish Government, 2009b). It is increasingly recognised that psychological factors have an impact on the outcome and quality (actual and perceived) of health care. There is also a growing evidence base to support the clinical effectiveness of psychological interventions, such as Cognitive Behavioural Therapy (CBT), Motivational Interviewing and Family Therapy for a number of medical conditions (British Psychological Society, 2015; NES, 2015).

The MSN CYPC previously conducted a survey of paediatric clinical psychology and neuropsychology provision to paediatric Principal Treatment Centres across the UK in August 2016 which identified a significant discrepancy between the psychological provision to children in Scotland versus the rest of the UK and a discrepancy in provision within Scottish centres.

Therefore the MSN CYPC supports the requirement for all children and young people aged 0-18 years in paediatric services to have access to the expertise of AHPs, nurses, psychologists and pharmacists who can provide both direct and indirect care to children, young people, their families and the professional network.

As the MSN CYPC continues to embed and progress our earlier workforce modelling, and with the implementation of this national strategy, we will become better informed about any workforce challenges, gaps and inefficiencies within our services and how these should be addressed. We will undertake a national workforce scoping exercise to develop a national map of the current profile of our services to support individual Health Boards in their own local workforce planning. Furthermore, the MSN CYPC will undertake a conceptualisation and cost analysis of the clinical workforce required for the future.

The MSN CYPC will also undertake a workforce review to facilitate future service delivery and outcomes that align with the strategic direction from this strategy. A workforce realignment will afford the MSN CYPC the opportunity to enhance national working whilst ensuring we continue to deliver a shared governance model.

ACTIONS

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
42. Future workforce cost analysis to be undertaken to inform the Scottish Government of future associated costs
43. Undertake a wider MSN CYPC workforce review to ensure the appropriate staffing model to deliver on the strategic actions of the cancer strategy

Teenagers and Young Adults Workforce

A key ambition for the MSN CYPC has been to ensure that any future strategy developed for TYAs with cancer is consistent with approaches adopted in other UK countries (Scottish Government, 2012b). In line with this, pan-Scotland TYA cancer specific services have been developed in adult cancer practice to meet the complex clinical, psychological, and social issues experienced by young cancer patients.

The provision of specialist age-appropriate cancer services for TYAs in adult cancer services is delivered through the development of a national TYA cancer network model of care (Appendix 4). This encompasses TYA cancer hubs established across the five adult regional cancer centres and nominated geographical regions. These collaborate to deliver personalised age-appropriate care and create smoother, more effective patient pathways. Each hub is supported by clinical leadership and a specialist workforce, knowledgeable of the biomedical and psychosocial issues specific to TYAs with cancer, who advocate locally and nationally for their interests.

Whilst the development of the national TYA cancer model of care has been successful, there remain areas for improvement. A workforce census in March 2021 (Appendix 5) demonstrated gaps in specialist TYA Clinical Psychology provision in three TYA hubs, a gap in AHP provision in four hubs and no dedicated provision for aftercare support available to TYA in any of the five TYA hubs in adult care.

Scottish Government investment is fundamental to the development of age-appropriate TYA cancer services and the implementation of a national model of care. Current investment has included non-recurring funding from the Adult Cancer Strategy, made available to specifically address the identified disparities between paediatric cancer provision and provision for TYA in adult cancer services. This facilitated a number of temporary clinical appointments which support the delivery of specialist and age appropriate services for TYA within adult cancer practice. Further substantive funding is required to sustain these clinical posts and expand the TYA workforce. This is necessary to progress the TYA model of care and deliver the actions of this strategy.

Teenage Cancer Trust has made significant investment in the TYA model in Scotland, committing substantive funding for TYA Clinical Nurse Specialists and Youth Support posts; this includes youth support activities / events and maintenance of the four TCT units. The MSN CYPC values its close partnership working with TCT and will continue to work closely with the charity to deliver a high quality service within NHS Scotland for TYAs. The benefits of continued investment in TYA cancer services will be experienced by TYA, their families, and carers through the delivery of a national service model which drives equity and consistency of care across patient pathways; is designed to meet the unique needs of this patient group (Teenage Cancer Trust, 2016), addresses priorities TYAs have identified and is delivered by a workforce who are skilled in the care and support of this age group (Aldiss, Fern and Gibson, 2018).

The psychological impact of cancer throughout the cancer pathway is well documented (WoSCAN, 2017) along with widespread agreement that the psychological needs of TYAs with cancer are distinct from both their paediatric and adult counterparts (National Institute for Health and Care Excellence, 2005; Barnett et al, 2016). TYAs experience significant and rapid social, cognitive, emotional and physical change. This can increase their vulnerability to experiencing mental health difficulties; three quarters of lifetime psychiatric diagnoses will have their onset prior to reaching the age of 24 (Mental Health Foundation, 2015).

The onset of cancer during this vulnerable period and accompanying psychosocial sequelae will often interrupt ‘normal’ development, increasing the likelihood of psychological morbidity. For many TYAs this represents a ‘dual crisis’ which can have long-lasting consequences (Teenage Cancer Trust, 2016). If left untreated this can lead to poor treatment adherence and potentially prognosis, reduced quality of life and a legacy of mental ill-health (Zebrack et al, 2010). TYAs consistently report the importance of their psychological well-being and highlight difficulties accessing specialist care (Aldiss et al, 2018; Young Lives vs Cancer, 2017). Recent evidence also indicates that the COVID-19 pandemic has had a significantly adverse impact on the mental health of many young people (Young Minds, 2021); further increasing the need for access to specialist and evidence-based psychological assessment and intervention.

NICE recognises the requirement of and added value of specialist, age-appropriate Clinical Psychology during all stages of the cancer pathway (NICE, 2014). NICE recommends that “all young people with cancer have their psychological needs assessed at key points during their cancer pathway… and have access to expert psychological support with clear routes of referral in Principal Treatment Centres and other treatment settings”. WoSCAN (2017) also emphasises the requirement for equitable and timely access to specialist psychological care at key points in the cancer pathway.

In addition to providing direct support to young people and families, NICE (2004) recognises the vital role of Clinical Psychologists in enhancing psychologically informed multi-disciplinary care by offering training, support and consultation to other team members. This is particularly important in relation to treatment decisions, fertility preservation, end of treatment, and palliative care decisions. Clinical psychologists should also have a key role in providing staff support; for example, evidence based psychological debriefs following significant events and attendance at key meetings as part of routine practice. Consequently, the MSN CYPC supports the continued integration and expansion of specialist TYA Clinical Psychologists within the TYA MDT.

The MSN CYPC supports the requirement for all TYAs in adult cancer services to have access to the expertise of specialist TYA Clinical Psychologists who can provide both direct and indirect care to TYAs, their families, and the professional network. The MSN CYPC will continue to provide long term investment, provided by the Scottish Government and directly aligned to Health Boards, which includes the substantive funding of existing TYA Clinical Psychology posts.

The MSN CYPC workforce review will also provide an opportunity for recommendations to be made to determine future service provision and reduce inequity of access to specialist psychological care.

Specialist TYA cancer care in the adult cancer setting is delivered by small number of highly trained staff who should be experienced, skilled and have a high level of competence in the field (Teenage Cancer Trust, 2016). To achieve expert level of practice in the field, all TYA specialist staff working in adult cancer services are expected to undertake TYA cancer focused education, such as formally accredited opportunities, with an expectation of TYA focused continuing professional development during an appraisal cycle.

The TYA cancer competency framework for nurses, which is a practical tool to assist nurses from Band 5 to Band 8 in developing their practice, should be used for self-assessment and as part of a CPD process for nurses who work in the TYA cancer field. We want to ensure that TYA specialist care continues to grow and develop by promoting education for all professional groups, particularly as care for young people with cancer can be delivered in a variety of health care settings and by a number of health professional groups who are non-specialists in the field. Training packages specific to TYA cancer care for non-specialist staff are not readily available or accessible.

ACTIONS

44. Substantive funding provided by the Scottish Government, directly to Health Boards, for existing TYA clinical posts
45. Substantive funding provided by the Scottish Government, directly to Health Boards, to expand the TYA workforce as per workforce analysis
46. Substantive funding provided by the Scottish Government, directly to Health Boards, for existing specialist TYA Clinical Psychologists
47. Substantive funding to be provided by the Scottish Government, directly to Health Boards, for increasing specialist TYA Clinical Psychology services to ensure equity of access across all TYA cancer hubs
48. Mapping exercise to be undertaken to determine the educational requirements of TYA specialist staff
49. Partnership working to be undertaken with NES to develop TYA cancer specific information for non-specialist staff

Ambition 10 – Age Appropriate Services and Effective Transitions

OBJECTIVE
Ensuring all young people aged between 16-25 years old have equitable access to comprehensive and personalised age appropriate care

The national TYA MDT is an essential component in providing high quality care to TYAs with cancer. It has a key role in working with the cancer site-specific and other teams involved in the patient's care to ensure a holistic and coordinated approach across pathways and throughout their care. Discussion of a young person's care at the MDT will ensure consideration of 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. The MSN CYPC is committed to ensuring that all TYAs with cancer benefit from having their care discussed at the national TYA MDT.

The MSN CYPC wants every TYA to have an excellent experience of care; however there are currently no consistent ways of capturing patient experience for this age group. It is known that poorer experiences of care compared to those of adults have been consistently reported in the English National Cancer Patient Experience Survey (Furness et al, 2017). Given that 16-25 year olds are not included in a bespoke survey for children and young adults in Scotland, it would inform TYA patient experience if the Scottish Cancer Patient Experience Survey (SCPES) could be broken down into the 16–25 years age group. Development of an age-appropriate patient experience survey for 16–25 year olds would also identify priority areas for improvement in TYA cancer services at a national level.

The SCPES has highlighted the need for more information to be available in some areas for patients. Although specific information from the survey was not available about the information needs of the 16–25 years age group, we do know that providing age-appropriate information is one of the quality criteria for young people's services (Department of Health England, 2011). Existing cancer information is often tailored to older adults or children's cancers and does not include the issues relevant and important to young people (Lea et al, 2018; Lea et al, 2019). To ensure young people receive the information they need to make health care decisions we will work with young people in adult cancer services to develop age-appropriate information about what standards of care they can expect in NHS Scotland.

To support the assessment, care planning and delivery of person-centred care for young people, the Teenage Cancer Trust digital portal and application, the 'IAM' (Integrated Assessment Mapping) will be implemented in Scotland. The IAM enables partnership working by providing a structure to support professionals and young people in holistically assessing needs for information and support at any point in the pathway. To support the IAMs implementation, the MSN CYPC will review and redevelop the TYA MDT Co-ordinator role.

The opportunity to spend time with others who are on or have completed treatment helps to facilitate the adjustment and continued personal development of young cancer patients who may be unable to access their normal social environments (Matsui et al, 2020). The MSN CYPC National Youth Advisory Forum identified the need for the development of a peer to peer support network. Although many of the members had met other young people with cancer they could see a gap for a formalised support system; where the person being “buddied” could ask questions they may not feel comfortable asking in an informal peer relationship. Through a process of co-design and collaboration between the forum and health professionals, a national framework for delivering peer support has been developed. The “Buddy System” will enable TYAs, wherever they live, to meet and benefit from peer support. This requires implementation across Scotland.

Although new models and pathways of TYA cancer care have been widely implemented across the UK there has been limited research to evidence these service models. The recent national evaluation of TYA services across England demonstrated that young people receiving all their care in a specialist TYA service (Principal Treatment Centre) experienced faster improvements in quality of life over three years compared with those who had no care in a specialist centre. In addition those in the specialist centre were more likely to have documentation of fertility discussion, molecular diagnostics where relevant and access to the wider appropriate team (Taylor et al, 2020). Questions remain as how to configure services and pathways for TYAs with cancer. We will contribute to the international evidence base and examine outcomes associated with TYA cancer specialist services in Scotland by participating in the UK wide study BRIGHTLIGHT 2021. The primary outcome measure is quality of life, secondary outcomes include survival and experiences of cancer care for young people.

TYAs with cancer have to navigate complex and varied patient pathways. Their sometimes transient lifestyle, influenced by educational, family, and social factors, can mean that TYAs move between a number of different care settings and across geographical locations. The purpose of the TYA element of the MSN CYPC is to navigate these challenges; ensuring optimal, effective and efficient TYA cancer services which deliver excellent patient experience. This will be achieved through the effective coordination of patient pathways between providers and within the network’s geographical area, and sometimes beyond.

We want to ensure that all patient pathways are considered and aim to develop processes and services which meet the needs of this patient group. The MSN CYPC will also seek to address identified disparities in the TYA group specific to clinical trial recruitment and time and route to diagnosis.

The MSN CYPC recognises that preparing young people for the move from children’s health services to adult health services is critical to ensure good health and outcomes for young people (Royal College of Physicians of Edinburgh, 2008; NICE, 2016). Young people are especially challenged by changes in their care and need to be well informed on how this will be provided (London South Bank University and Great Ormond Street Hospital for Children, 2014).

There is also growing recognition that young adults require additional support during a time of transition from TYA to adult healthcare services. Therefore, it is vital that barriers to patient-centred and joined-up care for young adults are removed (Mulder et al, 2016).

To support the multidisciplinary teams who are core to the successful transition of young people from children's cancer services to adult services, and to ensure that young people are central in transition assessment and planning, the MSN CYPC has developed a national framework for transition. The 'Once for Scotland' framework and five outcome focused standards were developed following a review of existing evidence on transition, with the objective of supporting the delivery of high quality transitional care to young people wherever they live in Scotland. We will work with clinicians across Scotland to implement the framework into practice.

TYAs with cancer are reported to have long and complex journeys to cancer diagnosis (Herbert et al, 2018 and Dommett et al, 2019). Presenting symptoms are often multiple, vague and non-specific (Koo et al, 2020). Although specific studies exploring route to diagnosis and time to diagnosis are limited, timely diagnosis is a major concern for young people and their families (Fern et al, 2013). Recent unpublished data also demonstrates that for TYAs longer diagnostic and treatment intervals are associated with a higher risk of impaired quality of life, clinical anxiety and clinical depression six months after diagnosis (Foster et al, TBC).

The inclusion of TYAs into clinical trials is paramount to future advances for TYA survival and quality of life. Although survival for many TYA cancers is high, long term treatment related morbidity is significant with increased risks of secondary cancers, cardiovascular and neurological events (Henson et al, 2016; Bright et al, 2017; Bright et al, 2019). Therefore the MSN CYPC wants to continue to ensure TYAs have the opportunity to enter trials of new and less toxic therapies. The five A's describe a process to maximise opportunities for inclusion in trials:

1. Trials must be **A**vailable in the cancer types occurring in TYAs
2. **A**ppropriate eligibility criteria should be applied to allow TYA inclusion
3. Studies should be **A**ccessible to TYAs through their treatment centre and entry facilitated by professionals
4. Both professionals and TYAs need to be **A**ware of trials which are available and the importance of trial entry
5. The trial design and question must be **A**pplicable to both TYAs and the treatment team (Fern et al, 2014)

Finally, continuing with education and employment during treatment can be challenging for TYAs and is not infrequently disrupted by treatment toxicities and hospitalisation. None the less, TYAs place a high importance in being able to achieve education and employment goals as this quote from a member of the Youth Advisory Forum illustrates:

"One service I feel is missing from this is careers / education advice. When I finished treatment, it was challenging to define and consider my options to restart my "normal" life"

Returning to education and employment was also identified as a top ten research priority for TYAs contributing to the James Lind Alliance work (Aldiss et al, 2019). However resource to enable TYAs to achieve employment and educational goals are not consistently or comprehensively supported across TYA cancer services in Scotland, and access can be dependent on geographical location. The MSN CYPC recognises the importance of this area to young people and aims to identify what resource is available and where there are gaps. The MSN CYPC will also work with young people to undertake a needs analysis.

ACTIONS

50. All TYAs will be referred to the national TYA MDT
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
52. In partnership with the MSN CYPC Youth Advisory Forum, information will be developed for young people with cancer on what standards of care to expect from NHS Scotland
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
54. Redevelopment of the TYA MDT Co-ordinator role to focus on holistic MDT delivery
55. Establish a Project Board to implement a national peer support system for TYAs with cancer
56. Scotland’s TYA cancer services will collaborate with the National Institute for Research (NHIR) and the University College London Hospitals (UCLH) Centre for Nurse, Midwife and AHP Research to implement BRIGHLIGHT 2021
57. Establish a Project Board to support implementation of the national children and young people’s cancer transition framework across Scotland
58. Develop and implement individual transition care plans
59. Monitoring the development of the Early Cancer Diagnostic Centres (ECDCs) Programme, linking with it where appropriate for the TYA community
60. Ensure TYAs are included in the national diagnosis audit and diagnosis is not grouped inappropriately i.e. 15-49 years
61. Ensure open trials are available to all TYAs in the TYA Principle Treatment Centres
62. Undertake a needs analysis to identify what resources are available and any gaps in the achievement of employment and educational goals for TYAs

“I am very pleased to see the focus on shared decision making. My daughter and I, together with our Oncologist, have always been at the very heart of shared decision making. Because of this she is living her best teenage life every single day”

MSN CYPC Parent / Carer Group Member

Section 4

Making Change Happen

‘Collaborative and Compassionate Cancer Care’ will see the MSN CYPC strengthen collaborations and partnerships with our adult cancer colleagues and with external partners such as Education, Health and Social Care Partnerships and third sector organisations. These third sector organisations include, but are not exclusive to, Maggie’s[24], Children’s Hospices Across Scotland[25], Teenage Cancer Trust[26], Young Lives vs Cancer[27] and Macmillan[28].

Overall we all want to maintain the delivery of excellent cancer care and this strategy sets out the way in which by 2026 we can not only demonstrate that quality, but also develop upon it in terms of the science, staff development, patient involvement and public understanding. Our core approach is starting the cancer journey at the right point with diagnosis and negotiating that entire terrain with expert guidance from the MDTs. Our wider approach is to support the infrastructure to improve that core activity, through research, audit and workforce development. Our Executive and Operational Delivery Groups will monitor ongoing review of progress towards achieving the strategies ambitions. These groups will ensure that activities are kept within the parameters of the agreed strategic objectives and actions, whilst ensuring that their delivery is consistent with our vision, aim and the values of NHS Scotland.

Measuring Success

This strategy seeks to improve survival and patient experience whilst reducing variance and ensuring safe, effective, efficient, timely and person centred care. It aims to ensure that this is provided in the right place, by staff who have the appropriate training and expertise. Taking into account the ambitions of the Healthcare Quality Strategy (Scottish Government, 2010) for NHS Scotland (safe, person-centred, effective, efficient and timely); the objectives and actions within this strategy have been drawn from current guidance, good practice documents, medical expertise and experience. We will continue to implement our performance indicators from our previous cancer plan with two additions. These will be reviewed regularly and will continue to be responsive to changes in clinical practice and emerging evidence. We will audit our services against these where appropriate.

1. Time between referral and diagnosis
2. Time between diagnosis and start of treatment
3. Proportion of patients with cancer who are offered a clinical trial
4. Management plans made by a properly constituted multidisciplinary team
5. End of treatment summary completed and access to after services offered
6. Tumour banking for all patients
7. Molecular characterisation of malignant disease

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[24] Maggie’s
[25] Children’s Hospices Across Scotland
[26] Teenage Cancer Trust
[27] Young Lives vs Cancer
[28] Macmillan Cancer Support

Section 5

Development of the Strategy

An evaluation of our previous cancer plan was undertaken in 2019 by the MSN CYPC National Clinical Director. The evaluation was to review progress against the actions detailed within the last cancer plan, but also to highlight examples of good practice. Consultation was also undertaken with service users, parents / carers, partner organisations and NHS Scotland staff, held over a twelve week period from February 2020, to gain valuable insight and also to help inform the content of this strategy.

National virtual workshops were held across the summer in 2020, with representation from all cancer specialities, service managers, partner organisations and service users to debate and determine the required focus within the cancer strategy. This provided evidence of strong support from across the children and young people's cancer community for the strategy.

The MSN CYPC National Clinical Director developed an initial draft strategy and following this a Cancer Strategy Oversight Group was initiated to review and finalise; incorporating the wide feedback received. The group consisted of representatives from each of the associated professions aligned to children and young people's cancer services, including appropriate geographical representation (Appendix 6). A further consultation period was held regarding the content of the updated draft strategy between the 1st and 15th August 2021. Feedback from members of our MSN CYPC Youth Advisory Forum and Parent / Carer Group ensured that the service user's voice was represented prior to moving to final publication. This collaborative approach has paved the way for the development of this ambitious new cancer strategy to ensure that all children and young people with cancer in Scotland receive high quality care throughout their journey.

Section 6

Summary of Actions

The following list of actions reflects the order in which they are presented within this strategy, rather than the required priority. The MSN CYPC will produce an annual workplan detailing the actions to be delivered within that specific phase of strategy implementation, liaising closely with Health Boards.

Action No	Action	Services	Responsible
1	Ensure all children and young people have access to tumour banking for precision medicine, to guide current and future treatment	Paediatrics and TYA	NHS Board Medical Directors
2	Work closely with the Scottish Government to source funding for future allocation to support the Scottish Genetic Laboratory Consortium ten prioritised molecular pathways	Paediatrics and TYA	MSN CYPC
3	Advocating for and supporting the enrolment of children and young people to the national childhood cancer diagnostic study, up to 18 years old	Paediatrics and TYA	NHS Board Medical Directors
4	All patients will be discussed at regional and / or national MDTs to ensure access to innovative treatments and appropriate clinical trials	Paediatrics and TYA	NHS Board Medical Directors
5	All children and young people should be enrolled on a clinical trial when possible	Paediatrics and TYA	NHS Board Medical Directors
6	Continuation of support and expanding the number of early phase clinical trials available within the network, when possible, currently provided in partnership with Newcastle and Northern Ireland for children and teenagers	Paediatrics and TYA	MSN CYPC
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	Paediatrics and TYA	MSN CYPC / Public Health Scotland
8	Implementation of a single national radiotherapy service for children within Scotland	Paediatrics	NHS National Services Scotland
9	Commissioning of a national metaiodobenzylguanidine (MIBG) paediatric service for Scotland	Paediatrics and TYA	Scottish Government

Action No	Action	Services	Responsible
10	Substantive funding provided by the Scottish Government, directly to Health Boards, to support the recruitment of specialist AHPs across all treatment centres that provide care to children and young people with cancer based on the recommendations of a workforce scoping analysis	Paediatrics and TYA	MSN CYPC / Scottish Government / NHS Board AHP Directors
11	Health Boards will ensure equitable and timely access to specialist AHP assessment and interventions at all stages of the cancer journey, regardless of age, stage of treatment or geographical location	Paediatrics and TYA	NHS Board AHP Directors
12	Substantive funding and appointment of national AHP Lead within the MSN CYPC to ensure strategic service delivery across Scotland	Paediatrics and TYA	Scottish Government / MSN CYPC
13	Evaluate the needs of children, young people and their families in relation to current AHP service provision for cancer services	Paediatrics and TYA	MSN CYPC AHP Lead
14	Develop and implement a national AHP resource package which all children and young people will receive at diagnosis and at the end of treatment, which can be audited to ensure it meets the holistic needs of service users	Paediatrics and TYA	MSN CYPC AHP Lead
15	Develop a competency framework for AHPs working with children and young people affected by cancer across Scotland based on the results of an educational / training needs analysis exercise	Paediatrics and TYA	MSN CYPC AHP Lead
16	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	Paediatrics and TYA	Scottish Government / NHS Board Psychology Directors
17	Support psychological health by the implementation of national emotional wellbeing training packages, provided by NHS Education for Scotland, with peer support groups initiated to support learning into practice	Paediatrics and TYA	NHS Board AHP, Nurse and Psychology Directors

Action No	Action	Services	Responsible
18	Funding provided for the appointment of a substantive Lead Pharmacist within the MSN CYPC to lead national CEPAS and SACT programmes of work	Paediatrics and TYA	Scottish Government / MSN CYPC
19	Establish a 'Once for Scotland' paediatric SACT governance process to enable efficient and effective MDT working and support a future national paediatric CEPAS	Paediatrics	MSN CYPC Lead Pharmacist
20	Develop a national business case to determine the allocation required to ensure successful delivery of a paediatric CEPAS across NHS Scotland	Paediatrics	MSN CYPC Lead Pharmacist
21	Participation in the national procurement and tendering process for CEPAS, preparing for the future implementation of a paediatric CEPAS across NHS Scotland	Paediatrics	MSN CYPC
22	Continued investment in annual national morbidity and mortality meetings to ensure learning from all adverse events	Paediatrics and TYA	MSN CYPC
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	Paediatrics and TYA	NHS Board Nurse Directors
24	Ensure every survivor has access to specialised care including, but not exclusively, Dietetics, Medical, Nursing, Occupational Therapy, Psychology, Physiotherapy and Social Work	Paediatrics and TYA	NHS Board AHP, Nurse and Psychology Directors
25	Ensure every survivor has an End of Treatment Summary and have at least one Holistic Needs Assessment completed	Paediatrics and TYA	NHS Board Medical and Nurse Directors
26	Develop an AHP cancer aftercare pathway to establish clear routes to referral	Paediatrics and TYA	MSN CYPC AHP Lead
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	TYA	MSN CYPC Lead Nurses

Action No	Action	Services	Responsible
28	Substantive funding provided by the Scottish Government, directly to Health Boards, for equitable aftercare nurse specialists in the Principal Treatment Centres and within TYA services in adult cancer centres	TYA	Scottish Government / NHS Board Nurse Directors
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 or Secondary Care	TYA	MSN CYPC Clinical Leads / MSN CYPC Lead Nurses
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	Paediatrics and TYA	MSN CYPC Clinical Leads / MSN CYPC Lead Nurses / MSN CYPC AHP Lead
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	Paediatrics and TYA	MSN CYPC Clinical Leads / MSN CYPC Lead Nurses / MSN CYPC AHP Lead
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	TYA	MSN CYPC Clinical Leads / MSN CYPC TYA Lead Nurse
33	Provide Paediatric Palliative Care educational opportunities through ongoing collaboration between the Paediatric Palliative Medicine Education Network and Project ECHO team	Paediatrics	MSN CYPC Clinical Leads / MSN CYPC Lead Nurses / MSN CYPC AHP Lead

Action No	Action	Services	Responsible
34	Promote the NHS Inform Directory of Services, working with NHS 24 to ensure the content reflects the available children and young people's palliative cancer care services	Paediatrics and TYA	MSN CYPC Clinical Leads / MSN CYPC Information Officer
35	Provide equitable access to pharmacy services for palliative care patients	Paediatrics and TYA	NHS Board Directors of Pharmacy / MSN CYPC Lead Pharmacist
36	Ongoing organisational development input to support clinical and professional leadership development to MSN CYPC via current hosting arrangements	Paediatrics and TYA	MSN CYPC National Network Manager
37	Scottish Government funding provided to the MSN CYPC for the appointment of a National Clinical Lead and substantive Lead Nurse for paediatrics	Paediatrics	Scottish Government / MSN CYPC
38	Scottish Government funding provided to the MSN CYPC for the fixed term appointment (23 months) of a national Improvement Advisor to support a quality improvement approach to the initial delivery of national workstreams	Paediatrics and TYA	Scottish Government / MSN CYPC National Network Manager
39	Developing further education and learning opportunities to improve referrals and ensure timely diagnosis, including implementation of national programmes such as Headsmart	Paediatrics and TYA	MSN CYPC
40	Undertake a national staff wellbeing scoping exercise to explore opportunities to improve the psychological and emotional wellbeing of oncology staff	Paediatrics and TYA	MSN CYPC
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	Paediatrics and TYA	MSN CYPC

Action No	Action	Services	Responsible
42	Future workforce cost analysis to be undertaken to inform the Scottish Government of future associated costs	Paediatrics and TYA	MSN CYPC
43	Undertake a wider MSN CYPC workforce review to ensure the appropriate staffing model to deliver on the strategic actions of the cancer strategy	Paediatrics and TYA	Scottish Government / NHS National Services Scotland
44	Substantive funding provided by the Scottish Government, directly to Health Boards, for existing TYA clinical posts	TYA	Scottish Government
45	Substantive funding provided by the Scottish Government, directly to Health Boards, to expand the TYA workforce as per workforce analysis	TYA	Scottish Government
46	Substantive funding provided by the Scottish Government, directly to Health Boards, for existing specialist TYA Clinical Psychologists	TYA	Scottish Government
47	Substantive funding to be provided by the Scottish Government, directly to Health Boards, for increasing specialist TYA Clinical Psychology services to ensure equity of access across all TYA cancer hubs	TYA	Scottish Government
48	Mapping exercise to be undertaken to determine the educational requirements of TYA specialist staff	TYA	MSN CYPC TYA Clinical Lead, TYA Lead Nurse and AHP Lead
49	Partnership working to be undertaken with NES to develop TYA cancer specific information for non-specialist staff	TYA	MSN CYPC TYA Clinical Lead, TYA Lead Nurse and AHP Lead

Action No	Action	Services	Responsible
50	All TYAs will be referred to the national TYA MDT	TYA	NHS Board Medical Directors
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	TYA	MSN CYPC TYA Lead Nurse / MSN CYPC Holistic MDT Co-ordinator
52	In partnership with the MSN CYPC Youth Advisory Forum, information will be developed for young people with cancer on what standards of care to expect from NHS Scotland	TYA	MSN CYPC TYA Lead Nurse
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	TYA	MSN CYPC TYA Clinical Lead / MSN CYPC TYA Lead Nurse
54	Redevelopment of the TYA MDT Co-ordinator role to focus on holistic MDT delivery	TYA	MSN CYPC National Network Manager
55	Establish a Project Board to implement a national peer support system for TYAs with cancer	TYA	MSN CYPC TYA Lead Nurse
56	Scotland's TYA cancer services will collaborate with the National Institute for Research (NHIR) and the University College London Hospitals (UCLH) Centre for Nurse, Midwife and AHP Research to implement BRIGHLIGHT 2021	TYA	MSN CYPC TYA Clinical Lead / MSN CYPC TYA Lead Nurse
57	Establish a Project Board to support implementation of the national children and young people's cancer transition framework across Scotland	TYA	MSN CYPC TYA Lead Nurse

Action No	Action	Services	Responsible
58	Develop and implement individual transition care plans	TYA	MSN CYPC TYA Lead Nurse
59	Monitoring the development of the Early Cancer Diagnostic Centres (ECDCs) Programme, linking with it where appropriate for the TYA community	TYA	MSN CYPC TYA Clinical Lead / MSN CYPC TYA Lead Nurse
60	Ensure TYAs are included in the national diagnosis audit and diagnosis is not grouped inappropriately i.e. 15-49 years	TYA	MSN CYPC TYA Lead Nurse
61	Ensure open trials are available to all TYAs in the TYA Principle Treatment Centres	TYA	NHS Board Medical Directors
62	Undertake a needs analysis to identify what resources are available and any gaps in the achievement of employment and educational goals for TYAs	TYA	MSN CYPC TYA Lead Nurse / MSN CYPC AHP Lead

Glossary

Term	Description
Allied Health Professionals (AHP)	An umbrella term for a collective group of 12 distinct professions, each with its own scope of practice and unique body of knowledge. These include Arts Therapy, Diagnostic Radiography, Nutrition and Dietetics, Occupational Therapy, Orthoptics, Orthotics, Paramedics, Physiotherapy, Podiatry, Prosthetics, Speech and Language Therapy and Therapeutic Radiography
Assessment	The work that staff do to understand how to treat, care for and support someone
Biopsy	A procedure to remove a piece of tissue (collection of cells) from the body for analysis in the laboratory to establish the diagnosis. For all children, and most teenagers and young adults, this will be performed under general anaesthetic
Birch-Alston Category	For young people (ages 15-24) cancers are described using the Birch-Alston classification. It groups cancers by their cell types rather than by the anatomical site of the cancer (which is used to group most adult cancers)
Cancer	A term for diseases in which abnormal cells divide and grow uncontrollably and can invade nearby tissues. Cancer cells that have the ability to spread to other parts of the body through the blood and lymph nodes is a malignant cancer
Cancer Registry	The Scottish Cancer Registry is responsible for the collection of information on all new cases of cancer arising in residents of Scotland. More detailed information is available on the ISD website here
Chemotherapy	Cancer treatment that uses one or more anti-cancer drugs in combination to kill cancer cells. The drugs can be given into a vein (intravenous chemotherapy), or as tablets or liquid (oral chemotherapy) or into the spinal fluid (intrathecal chemotherapy)
Clinical Governance	Defined as corporate accountability for clinical performance. It is an initiative to assure and improve clinical standards at a local level and throughout the NHS

Clinical Trial	A carefully designed research study looking at the effects of a procedure or treatment. All new treatments are tested through a series of clinical trial phases to assess if the treatments are safe and whether they work
Confidence Level	The interval or range of values that is likely to contain the true value of a parameter
Curative Treatment	This refers to treatment that is given with the goal of achieving a complete remission and preventing the recurrence of cancer
Diagnostic Investigation	People with suspected cancer will undergo a series of medical tests to establish the diagnosis. These may include blood tests, urine tests, scans (such as MRI or CT scans), and biopsy
ICCC-3	For children (ages 0-14), cancers are described using the third edition of the International Classification of Childhood Cancer (ICCC-3). It groups cancers with more emphasis on the cell type rather than the anatomical site (which is used to group most adult cancers)
ICD-10	The 10th revision of the International Statistical Classification of Diseases and Related Health Problems produced by the World Health Organisation (WHO). It assigns codes to particular diseases and conditions, not only for cancer but for all diseases.
Incidence	Incidence refers to the number of new cases of a condition in a defined population during a defined period, and is typically expressed as the number of new cases per million person-years at risk (or other suitable units)
Molecular Genetics	Molecular diagnostics are tests that detect genetic material, proteins or related molecules to provide information about the molecular changes in the cancer. This will give a more precise diagnosis to guide treatment
Multidisciplinary Teams (MDTs)	A group of health care professionals with expertise in cancer who work together to make decisions regarding recommended treatment of individual patients
Multidisciplinary Team Meetings (MDM)	Deliberate, regular meetings (either face-to-face or virtual) at which health professionals with expertise in a range of different specialties discuss the options for a patient’s treatment and care prospectively

Oncology	Area of medicine dealing with the prevention, diagnosis and treatment of cancer
Palliative Care	Palliative and end of life care are integral aspects of the care provided by health or social care professionals to people living with and dying from any advanced, progressive and incurable condition
Pathology	Area of medicine which studies the cause and effect of diseases and injuries; the bridge between science and medicine
Patient Pathway	The route that a patient will take from their first contact when referred for treatment through to completion
Primary Care	Usually the first resource / point of access for health care including general practice, community pharmacy, dental and optometry (eye health) services
Secondary Care	Services provided by specialists focusing on a specific area of the body, condition or disease following referral by a primary care physician
Staging	Patients will undergo a series of tests to assess how much the cancer has grown and spread (metastases). This helps direct treatment and prognosis
Radiotherapy	A type of anti-cancer treatment using radiation (such as X-rays, gamma rays, protons) to kill cancer cells and shrink the tumour. This may be ionizing photon (x-rays or gamma rays) or charged particle radiotherapy – proton radiotherapy
Service Level Agreements	A commitment / contract between two or more parties against specific and measurable aspects in the delivery of a service
Tertiary Care	Services providing a higher level of speciality care, equipment, expertise and complex procedures
Third Sector	An umbrella term referring to different organisations that do not sit under public or private sector. Often referred to as voluntary, non-government and non-profit organisations
Tumour Banking	Tissue (e.g. tumour or blood) is collected during diagnostic or therapeutic procedures which can then be frozen and stored for future use, either directly for patient benefit or for scientific researchers with the aim of improving diagnosis and treatment

TYA	Teenagers and Young Adults. For the purposes of the Cancer Strategy the age bracket is 16-24

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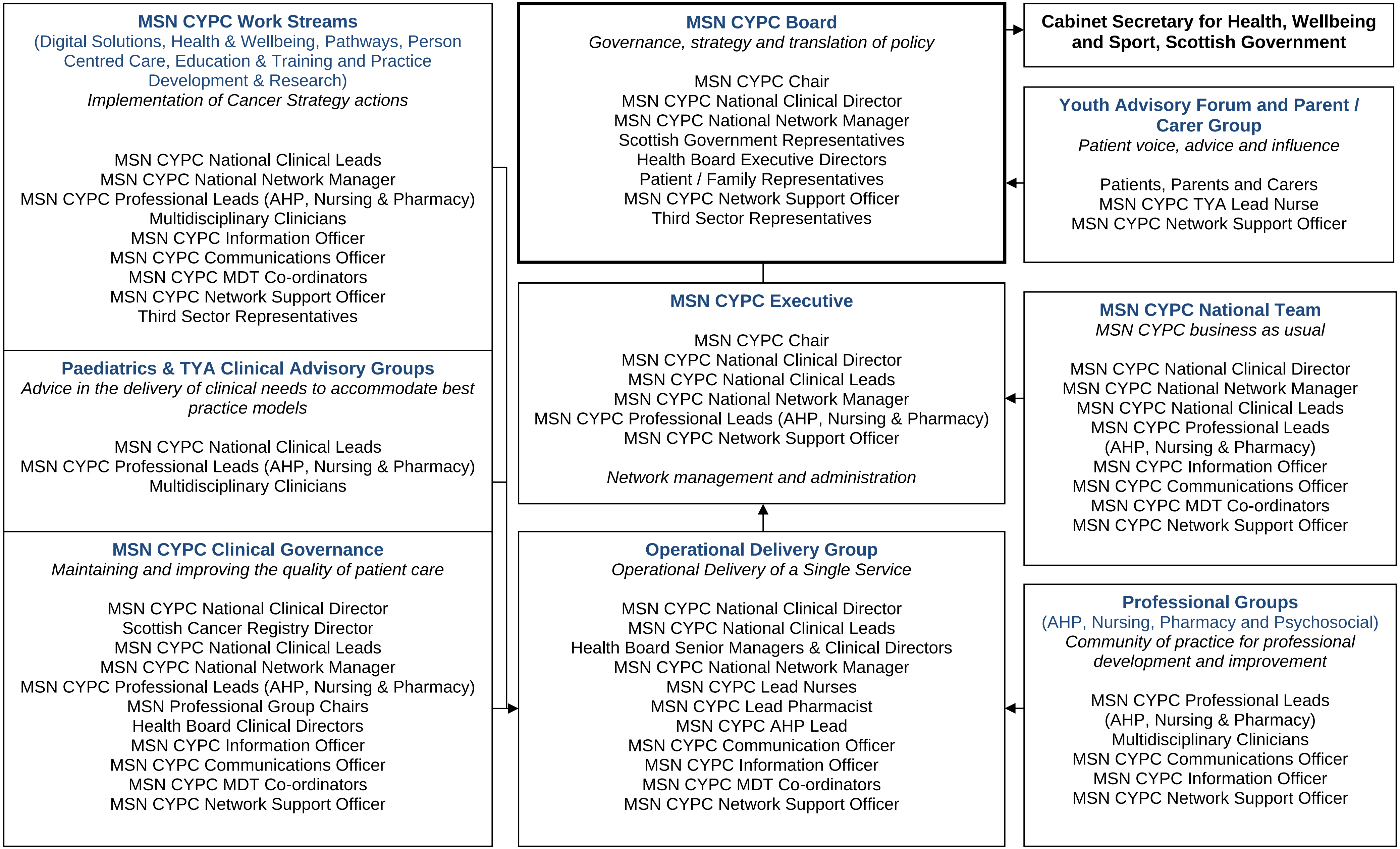
Appendix 1 – MSN CYPC Organigram



MSN CYPC Work Streams
(Digital Solutions, Health & Wellbeing, Pathways, Person Centred Care, Education & Training and Practice Development & Research)
Implementation of Cancer Strategy actions

MSN CYPC National Clinical Leads
MSN CYPC National Network Manager
MSN CYPC Professional Leads (AHP, Nursing & Pharmacy)
Multidisciplinary Clinicians
MSN CYPC Information Officer
MSN CYPC Communications Officer
MSN CYPC MDT Co-ordinators
MSN CYPC Network Support Officer
Third Sector Representatives

Paediatrics & TYA Clinical Advisory Groups
Advice in the delivery of clinical needs to accommodate best practice models

MSN CYPC National Clinical Leads
MSN CYPC Professional Leads (AHP, Nursing & Pharmacy)
Multidisciplinary Clinicians

MSN CYPC Clinical Governance
Maintaining and improving the quality of patient care

MSN CYPC National Clinical Director
Scottish Cancer Registry Director
MSN CYPC National Clinical Leads
MSN CYPC National Network Manager
MSN CYPC Professional Leads (AHP, Nursing & Pharmacy)
MSN Professional Group Chairs
Health Board Clinical Directors
MSN CYPC Information Officer
MSN CYPC Communications Officer
MSN CYPC MDT Co-ordinators
MSN CYPC Network Support Officer

MSN CYPC Board
Governance, strategy and translation of policy

MSN CYPC Chair
MSN CYPC National Clinical Director
MSN CYPC National Network Manager
Scottish Government Representatives
Health Board Executive Directors
Patient / Family Representatives
MSN CYPC Network Support Officer
Third Sector Representatives

MSN CYPC Executive

MSN CYPC Chair
MSN CYPC National Clinical Director
MSN CYPC National Clinical Leads
MSN CYPC National Network Manager
MSN CYPC Professional Leads (AHP, Nursing & Pharmacy)
MSN CYPC Network Support Officer

Network management and administration

Operational Delivery Group
Operational Delivery of a Single Service

MSN CYPC National Clinical Director
MSN CYPC National Clinical Leads
Health Board Senior Managers & Clinical Directors
MSN CYPC National Network Manager
MSN CYPC Lead Nurses
MSN CYPC Lead Pharmacist
MSN CYPC AHP Lead
MSN CYPC Communication Officer
MSN CYPC Information Officer
MSN CYPC MDT Co-ordinators
MSN CYPC Network Support Officer

Cabinet Secretary for Health, Wellbeing and Sport, Scottish Government

Youth Advisory Forum and Parent / Carer Group
Patient voice, advice and influence

Patients, Parents and Carers
MSN CYPC TYA Lead Nurse
MSN CYPC Network Support Officer

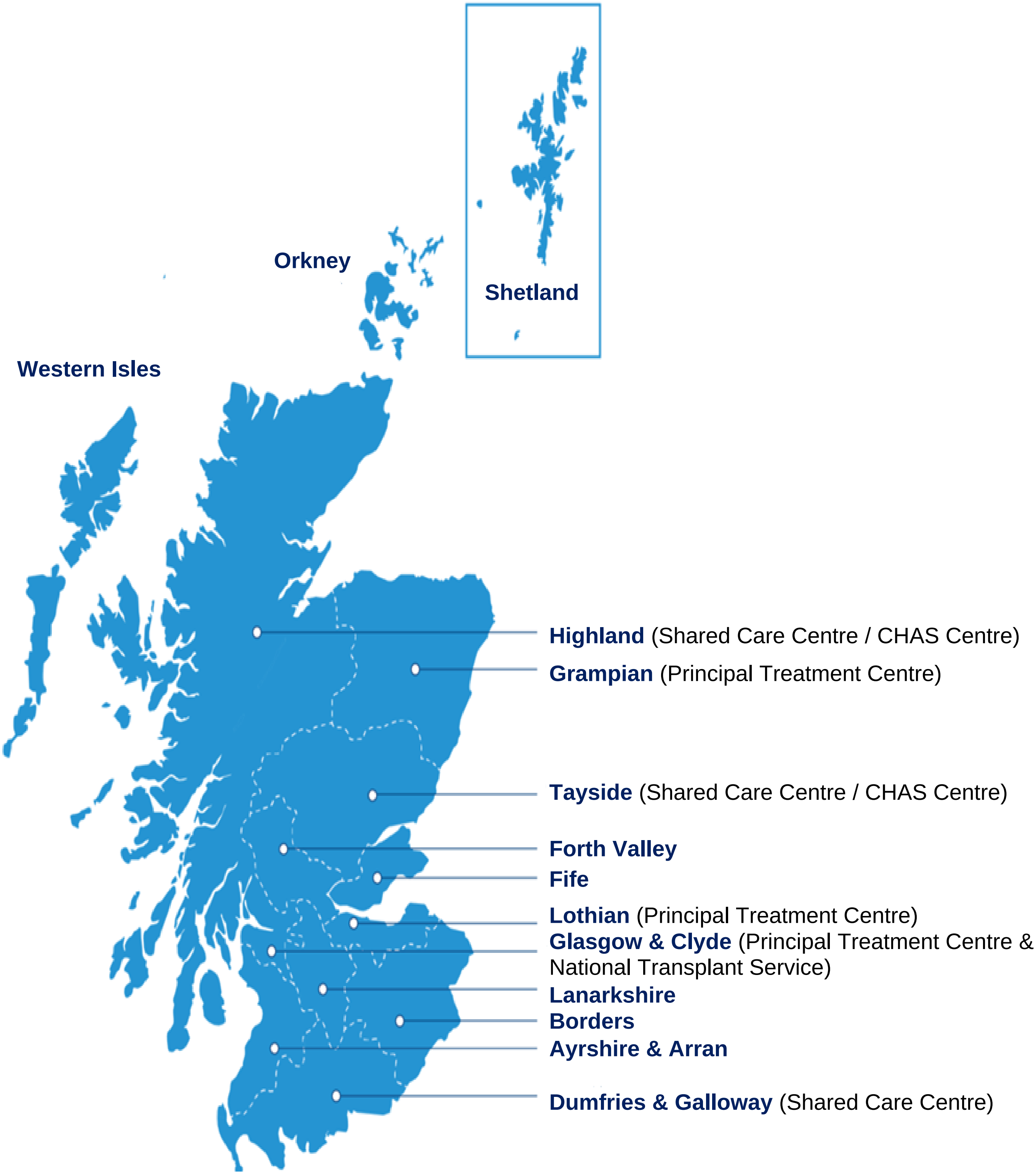
MSN CYPC National Team
MSN CYPC business as usual

MSN CYPC National Clinical Director
MSN CYPC National Network Manager
MSN CYPC National Clinical Leads
MSN CYPC Professional Leads
(AHP, Nursing & Pharmacy)
MSN CYPC Information Officer
MSN CYPC Communications Officer
MSN CYPC MDT Co-ordinators
MSN CYPC Network Support Officer

Professional Groups
(AHP, Nursing, Pharmacy and Psychosocial)
Community of practice for professional development and improvement

MSN CYPC Professional Leads
(AHP, Nursing & Pharmacy)
Multidisciplinary Clinicians
MSN CYPC Communications Officer
MSN CYPC Information Officer
MSN CYPC Network Support Officer

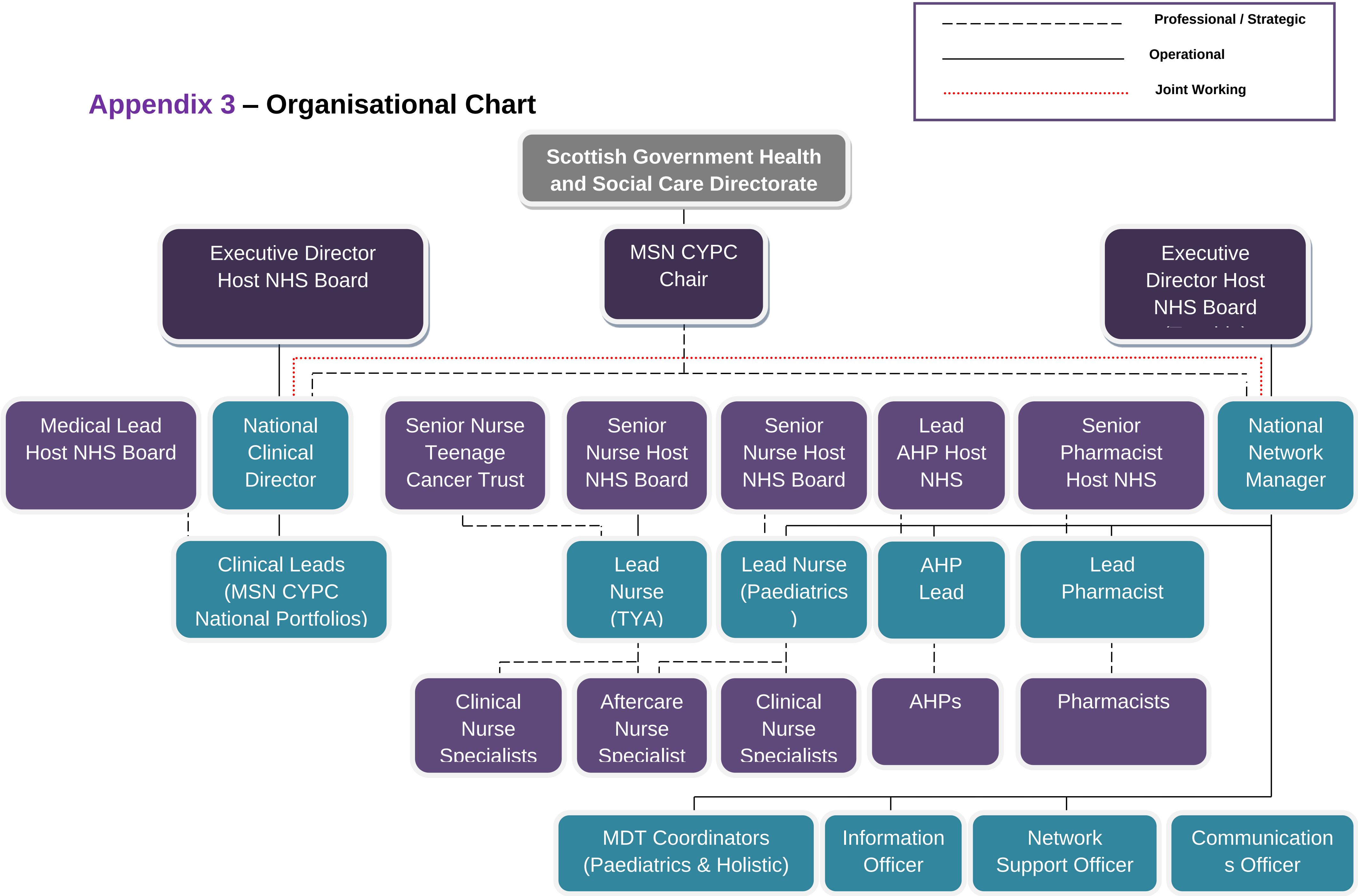
Appendix 2 – NHS Scotland Paediatric Principal Treatment and Shared Care Centres Map



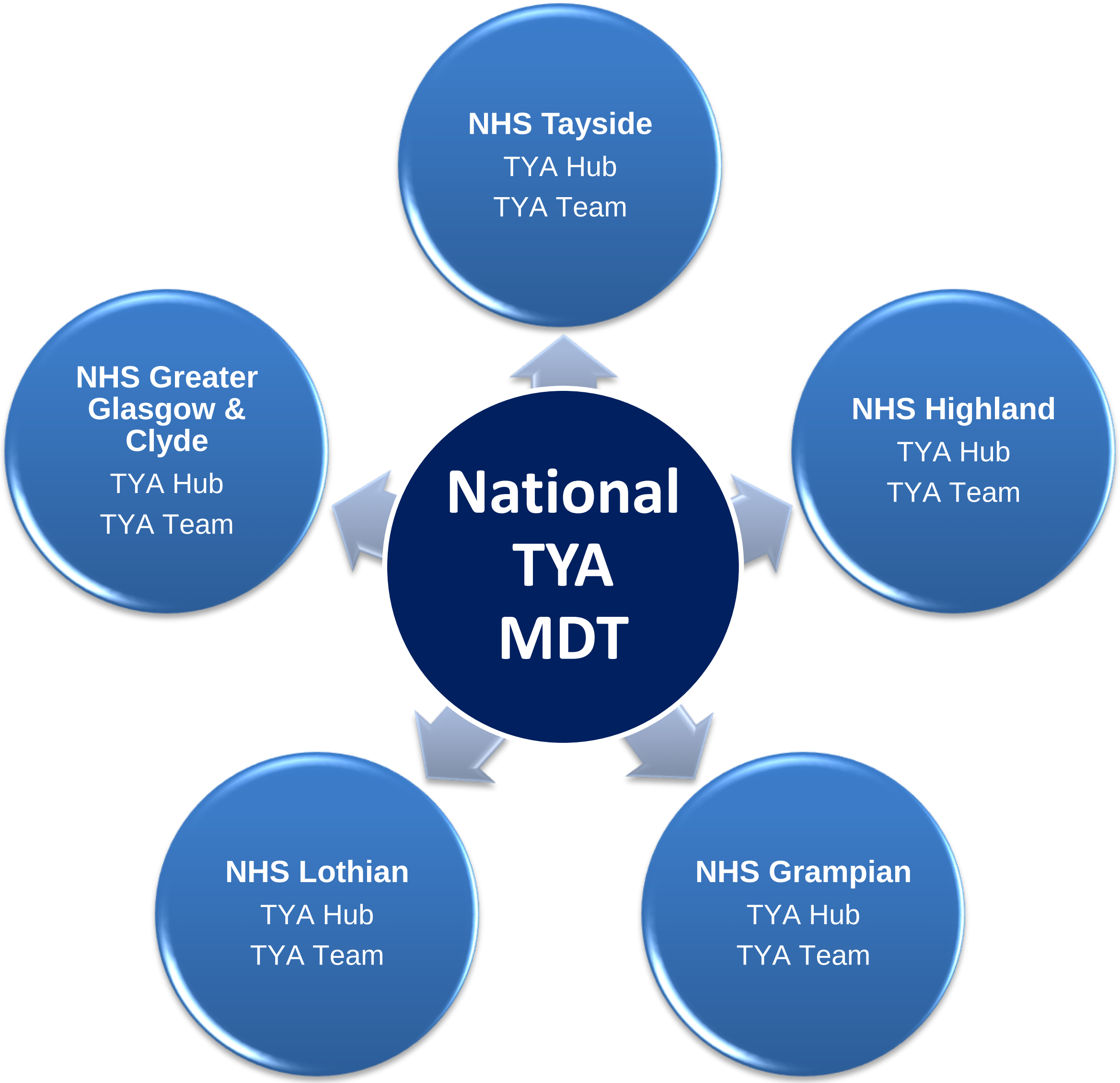
NB

- Specialist Services i.e. Proton Beam Therapy – Delivered in USA or Europe
- Respite, Hospice, Palliative and End of Life Care – Delivered by Children's Hospices across Scotland (CHAS) in Rachel House, Kinross or Robin House, Balloch. CHAS At Home services also provided
- Map reflects current recognised paediatric Principal Treatment and Shared Care Centres. As per Ambition 1, the MSN CYPC will work with Health Boards which are now providing shared care services in addition to the above to ensure recognition and formalisation of pathways

Appendix 3 – Organisational Chart



Appendix 4 – TYA Model of Care



National TYA MDT

NHS Tayside
TYA Hub
TYA Team

NHS Highland
TYA Hub
TYA Team

NHS Grampian
TYA Hub
TYA Team

NHS Lothian
TYA Hub
TYA Team

NHS Greater Glasgow & Clyde
TYA Hub
TYA Team

Appendix 5 – TYA Cancer Specialist Workforce – Census March 2021

Funding Body	Post	Base	Hours	WTE
MSN CYPC & Teenage Cancer Trust (TCT)	TYA National Lead Nurse	National	37.5	1.0
MSN CYPC	TYA National Clinical Lead		8	2 PAs[29]
MSN CYPC & TCT	TYA National MDT Co-ordinator		37.5	1.0[30]
TCT	Clinical Nurse Specialist	NHS Highland (Raigmore Hospital)	18.75	0.5
Young Lives vs Cancer	Social Worker		17.5	0.5
MSN CYPC	TYA Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Tayside (Ninewells Hospital)	37.75	1.0
Young Lives vs Cancer	Social Worker		10	0.29
MSN CYPC	Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Grampian (Aberdeen Royal Infirmary)	25	0.67
Young Lives vs Cancer	Social Worker		10	0.29
MSN CYPC	Principal Clinical Psychologist		18.75	0.5
MSN CYPC	Clinical Lead		4	1 PA
TCT	Clinical Nurse Specialist	NHS Lothian (Western General Hospital)	37.5	1.0
NHS Lothian	Clinical Nurse Specialist[31]		34	0.91
TCT	Youth Support Co-ordinator[32]		37.5	1.0
Young Lives vs Cancer	Social Worker		30	0.86
MSN CYPC	Clinical Lead		4	1 PA
TCT	Youth Support Co-ordinator	NHS Greater Glasgow & Clyde (Beatson West of Scotland Cancer Centre)	37.5	1
NHS Greater Glasgow & Clyde	Clinical Nurse Specialist[31]		37.5	1.0
	Clinical Nurse Specialist[33]		37.5	1.0
Young Lives vs Cancer	Social Worker		35	1.0
MSN CYPC	Principal Clinical Psychologist		18.75	0.5
MSN CYPC	Physiotherapist		18.75	0.5
MSN CYPC	Dietitian		7.5	0.2

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[29] PAs - Programmed activities or hours treated as whole time (10 PAs per week = 40 hours

[30] Post vacant since February 2020, cover provided by the MSN CYPC Network Support Officer

[31] TCT adopted post

[32] TCT fund additional 2.0WTE Youth Support Co-ordinators, working within the paediatric hospitals. These posts work with children and young people beyond 16 years. These are not TYA specific, therefore have not been included within the above data

[33] Macmillan Cancer Support pump primed

Appendix 6 – Cancer Strategy Oversight Group Membership

Name	Designation	Health Board	Area of Representation
Dr Hugh Bishop	Clinical Director / Consultant Paediatric Oncologist	NHS Grampian	Paediatric Oncology
Julie Cain	Clinical Nurse Specialist	NHS Greater Glasgow and Clyde	TYA Nursing
Dr Fiona Cowie	Consultant Clinical Oncologist	NHS Greater Glasgow and Clyde	Adult Oncology / Paediatric Radiotherapy
Fiona Dawson	Clinical Nurse Specialist	NHS Lothian	TYA Nursing
Dr Ben Fulton	Consultant Clinical Oncologist	NHS Greater Glasgow and Clyde	Adult Oncology / Paediatric Radiotherapy
Emma Gallagher	Senior Physiotherapist	NHS Lothian	Physiotherapy
Alison Gillies	Senior Dietitian	NHS Lothian	Nutrition and Dietetics
Ali Hall	Aftercare Nurse Clinical Specialist	NHS Greater Glasgow and Clyde	Aftercare Services and MSN CYPC Nurses Group
Dr Nicholas Heaney (Chair)	MSN CYPC TYA Clinical Lead / Consultant Haematologist	NHS Greater Glasgow and Clyde	Haematology / TYA
Gillian Matheson	Senior Occupational Therapist	NHS Greater Glasgow and Clyde	Occupational Therapy
Karon McDowall	Lead Pharmacist	NHS Greater Glasgow and Clyde	Pharmacy
Lesley-Ann McGregor	MSN CYPC National Network Manager	NHS Tayside	MSN CYPC
Dr Nicola Miller	Principal Clinical Psychologist	NHS Greater Glasgow and Clyde	Psychological Therapies
Dr Diana McIntosh	Consultant Paediatric Oncologist	NHS Greater Glasgow and Clyde	Palliative Care
Dr Dermot Murphy	Consultant Paediatric Oncologist	NHS Greater Glasgow and Clyde	Paediatric Oncology / Epidemiology
Neil Richardson	Lead Pharmacist	NHS Lothian	Pharmacy
Jill Scott	Senior Radiographer	NHS Greater Glasgow and Clyde	Radiography
Professor Hamish Wallace	Consultant Paediatric Oncologist	NHS Lothian	Paediatric Oncology
Liz Watt	MSN CYPC TYA Lead Nurse	NHS Greater Glasgow and Clyde	TYA Nursing

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