Right Diagnosis, Right Treatment,
Right Team, Right Place;

The Cancer Plan
for Children and Young People in Scotland
2016 – 2019

Managed Service Network for Children and Young People with Cancer

Right diagnosis, right treatment, right team, right place; The cancer plan for children and young people in Scotland 2016 – 2019

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Foreword

When the then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon introduced the first Cancer Plan for Children and Young People in 2012, she highlighted the need for health services to work together to deliver a world class service for children and young people with a diagnosis of cancer.

That vision for our children and young people remains constant.

Since its inception in 2011, the Managed Service Network for Children and Young People with cancer has made enormous progress, creating and fostering partnerships. The first Plan enabled these partnerships to flourish and gave a shared understanding of the work needed to mould a single service. The time is now right to build on this early work and set out a new phase of activity for the Managed Service Network for the next 3 years.

I am therefore pleased to introduce the second Cancer Plan specifically for children and young people, which puts them at the centre of a pan-Scotland service.

Although the number of children and young people who are diagnosed with cancer every year is small compared to adults, the care and treatment they need is every bit as complex and the life time consequences of the disease and its therapy carry a significant health legacy which needs active management. This Plan provides a clear description of how the best outcomes will be delivered to children and young people: ”right diagnosis, right treatment, right team, right place”.

I am sure that all involved in providing this service will find the second national cancer plan for children and young people both stimulating and informative. I am confident that the spirit of working together which the Plan articulates, can only grow in strength as we work to improve the lives of Scotland’s children and young people who face a diagnosis of cancer.

Shona Robison

Shona Robison, MSP
Cabinet Secretary for Health, Wellbeing and Sport

"Right diagnosis, right treatment, right team, right place"

The Managed Service Network for Children and Young People with Cancer in Scotland (MSN) has a vision to deliver a safe, sustainable world class national service for children and young people with cancer.

The objective is for all young patients with cancer to receive the right diagnosis and be treated with the right treatment, by the right team in the right place on their cancer journey. They will always have the opportunity to participate in any national or international cancer clinical trial for which they are eligible.

To provide 21st century cancer care for our young people in Scotland, patients may have different elements of their care journey from diagnosis to survivorship carried out in different places; but with the confidence and reassurance of a national team approach to this care.

The most important driver for *right diagnosis, right treatment, right team, right place* is setting standards of care to achieve the very best clinical outcomes, whilst putting the needs of the patient and their loved ones at the centre.

The MSN is committed to developing and implementing world class standards of care throughout Scotland so that our young patients will have the best chances of long-term survival with the lowest likelihood of long-term effects arising from their treatment.

Professor Hamish Wallace
National Clinical Director, MSN

Introduction

The first cancer plan for children and young people with cancer[1] (2012- 2015) was published as the Managed Service Network for Children and Young People with Cancer in Scotland (MSN) was launched. It set out the proposals for structures and functions of the network, as well as the vision of how to create a single service for all children, teenagers and young people in Scotland who receive a diagnosis of cancer. This was set against a historical backdrop of the different regions and hospitals in Scotland treating their own patients in their own way.

As new structures were put in place, they were tried and tested to ensure that they delivered on the MSN's objectives and that they contributed to the management of every aspect of care for children and young people who have a diagnosis of cancer.

Many aspects of the network have delivered beyond expectation with some areas having found abundant support with improvement happening easily.

Other areas have been more challenging, with the MSN encountering obstacles that have prevented some of our early plans converting into meaningful actions. As the network moves into the next phase, it is hoped that any remaining organisational, professional and cultural barriers can be overcome.

The benefits and virtues of a collaborative and unified service model - based on the concept of a single service for all Scotland's children and young people with cancer is challenged by the practical reality of patients being dispersed across 14 territorial Health boards. As such, the legal responsibility and duties of governance reside with the territorial health boards which may have different priorities from those being progressed by the MSN.

An example of this disparity is the delay in the design and implementation of a single system for electronic prescribing and delivery of chemotherapy across Scotland. This issue relies on one health board assuming a lead role on behalf of all other Scottish boards which has been challenging despite central funding being available for this important project.

Another example exists in the administrative, legal and bureaucratic barriers in place which prevent the network acting as a single centre for inclusion of patients into existing clinical trials. While Scotland is leading the nations of the UK with regard to the rate of cancer trial recruitment in teenagers and young adults, the actual rate in this age group is substantially lower than that of the paediatric population. The direct relationship between the rate of trial entry and patient outcome suggest that we need to do better.

Looking forward

Exciting and substantial developments are in train at this time, which will translate into significant change in clinical practice: a new hospital complex for children and adults recently opened in Glasgow and a new children's hospital will open in Edinburgh within the timescale of this plan, co-located with adult services. Proton radiotherapy will shortly be available in the UK.

This is an era of earlier and better detection of cancer and enhanced optimisation of care with fewer of the side-effects that often accompany the intensive treatment required to treat cancers of childhood and young adulthood successfully. An era where genomic typing and analysis may be able to identify those most likely to benefit from certain treatments; and those whose disease will be more resistant. That form of precision or personalised medicine constitutes a paradigm shift from the current protocol based ‘one approach for all’ provision of care.

The increasing complexity of cancer therapy highlights the advantages of clinicians working together in a collaborative way across Scotland and with our partner agencies in the UK and is an endorsement of the national model represented by the MSN. This model maximises the impact of expertise, be that already available or future emerging, thereby ensuring the highest quality of care is delivered to all patients.

The MSN will therefore make contact with all agencies that sustain and promote well-being in the young.

Consequently, the MSN will be championing the importance of early detection of cancer linked to equitable access to specialist services across Scotland. It will vigorously pursue the ideal of all patients being involved in clinical trials knowing that this optimises care and outcome. It will strive to preserve the wellbeing of all family members and retain as best, the quality of life through treatment regimens as can be obtained. It will provide the survivors of cancer treatment with the details of their care so that their risk of late complications and late morbidity posed by cancer treatment can be both assessed and managed.

It is vital that the MSN is in full possession of the facts and the necessary data measure performance against the standards set out in the first cancer plan and those which have continued to be refined thereafter. An evaluation of the efficiency and effectiveness in producing end of treatment summaries and risk-stratified follow-up arrangements are now in place. A much-needed comprehensive enhanced cancer registry for children and young people with cancer is now ready to launch.

This second cancer plan rightly and properly continues working on actions contained within first edition but it also opens up the way for new possibilities in therapy, diagnoses and in treating children and young people with cancer by the right team in the right place.

The plan emphasises the things that matter in continuity of care and after-care, and in maintaining wellbeing throughout the patient's journey. Care, where cure is not possible, is as important as every other aspect of treatment. All of this raises the bar for the challenges that everyone in cancer care faces.

It recognises that the network needs to remain agile and reactive; not just to respond in an efficient way to staff, hospitals, patients and parents but also to look forward and prepare for the hugely exciting changes that are going to affect cancer care for all in Scotland and for the young in particular.

As an MSN we are enormously grateful to the clinical leadership shown by Professor Brenda Gibson, previous National Clinical Director, and by Dr Derek King, previous Lead in Governance and Quality Assurance. Both of these individuals have played a large part in setting the foundation for this plan.

We also would like to thank those who contributed to the production of this plan and their continued commitment and support to realise the vision of *right diagnosis, right treatment, right team, right place* for all children and young people with cancer in Scotland.

We welcome Professor Hamish Wallace as our new National Clinical Director as we enter this exciting and challenging next stage of the MSN.

Geo A Youngson

Professor George Youngson **Dr Iain Wallace**

Co-chairs, MSN

"Right diagnosis, right treatment, right team, right place" - How will this be achieved in Scotland?

- By robust data collection; all patients between 0-24 years of age will be registered on the Scottish enhanced cancer registry, thereby forming the basis of comparison with other countries in the UK and beyond
- By investing in infrastructure; to enable national access to services and information for treatment and beyond
- By working nationally; to enable a sustainable, seamless service across Scotland, recognising their treatment and aftercare may be delivered in different places, and a new model of care for teenagers and young adults (TYAs) with cancer will be required
- By working as a national multidisciplinary team; the holistic needs of patients will be measured and will inform treatment planning
- By working safely; with clinical collaboration across paediatric and adult services, and the implementation of national protocols
- By creating an environment to improve research opportunities; to ensure that all children and young people have an opportunity to participate in appropriate cancer clinical trials
- By proactively managing care after treatment; working with others, and harnessing technology to support young patients after active treatment
- By developing the workforce; all staff will have access to education, support and training
- By patient involvement and feedback; we will work with children, young people and their families in the design of services
- By strengthening collaborations and partnerships with others in Scotland and beyond; to ensure the needs of children and young people with cancer are sufficiently recognised

How we will we measure success?

- Measuring service performance against agreed five Quality Performance Indicators (QPIs) :
    - Time between referral and diagnosis
    - Time between diagnosis and start of treatment
    - Proportion of patients with cancer who are offered a Clinical Trial
    - Patients' management discussed by a national multi-disciplinary team
    - End of treatment summary completed
- By measuring patient outcomes – survival rates at 1, 5 and 10 year intervals
- Harnessing feedback from patients and their carers
- Comparing performance with other healthcare systems

How will this look for the patient?

Cancer is relatively rare in children, accounting for less than 1% of all cancers. In 2009-2011, there was an average of 1,574 new cases of childhood cancer per year in the UK: 862 (55%) in boys and 713 (45%) in girls, giving a male:female ratio of around 12:10.[2]

The crude incidence rate shows that there are 152 new cancer cases for every million boys aged 0-14 in the UK and 132 for every million girls aged 0-14.[3]

In Scotland there are approximately 150 new cases every year.

In Great Britain, children's cancer incidence has increased by more than 40% since the late 1960s[4]. The reasons for this are poorly understood, though improvements in diagnosis and registration are likely to have played a part.

Leukaemia is the most commonly diagnosed cancer in children with brain tumours and lymphomas accounting for more than two-thirds of all cancers diagnosed in children. The highest incidence rates for all childhood cancers combined are in the under-five age group for both sexes, with almost half (47%) of all childhood cases being diagnosed in this age group.[5]

Cancer presenting during early adult life between 16 – 24 years is still rare and yet malignancy at this age is more frequent than in children.[6] [7] There is an average of 2,200 new cases of teenage and young adult cancer per year in the UK, with approximately 180 of these cases occurring in young people in Scotland. It accounts for less than 1% of cancers at all ages, yet the incidence of all TYA cancers in the UK has increased by approximately a fifth since the mid 1990's. Cancer prevails as the lead cause of death after non accidental death in this age group; accounting for 9% of all deaths in males and 15% of all deaths in females.[8]

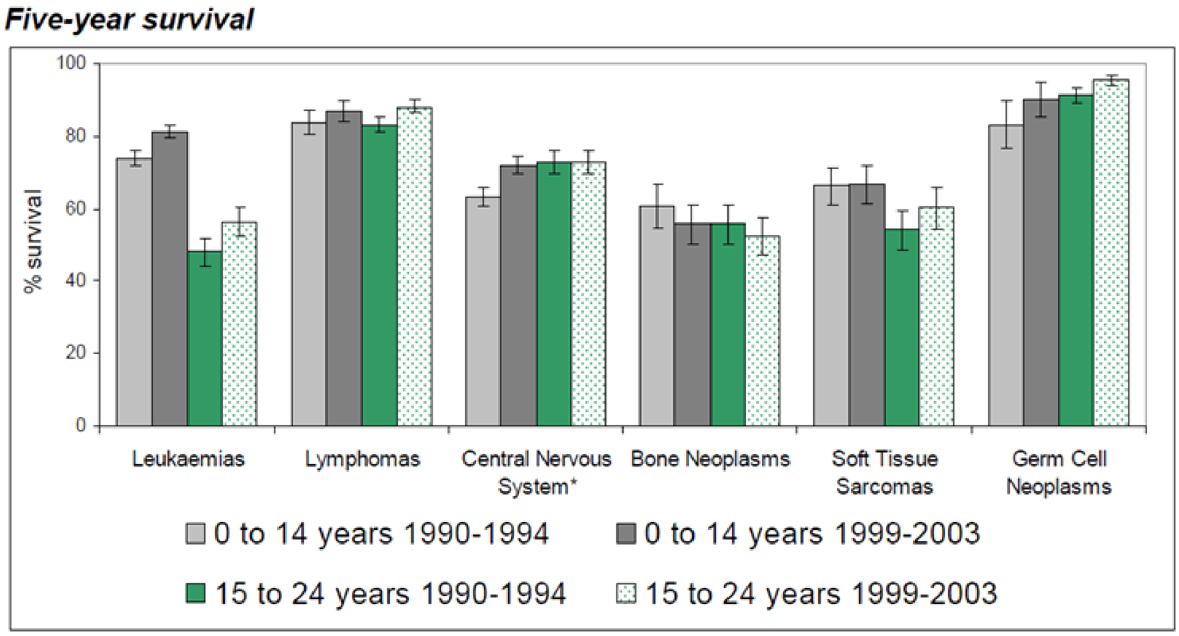
Cancer in the TYA age group incorporates the late onset of paediatric tumours and early onset of adult tumours; including lymphomas, germ cell tumours, brain tumours, leukaemias, melanoma, bone tumour, soft tissue sarcoma, carcinomas and other rarer tumours.[9] Some tumours are adult diseases presenting at an early age, especially some carcinomas; others for example Hodgkin's disease and bone tumours have an incidence peak in young adults.

Notably, the spectrum of cancers diagnosed in this age range is unique; there is no other age group that has a similar pattern and evidence suggests that types of cancers occurring are biologically different and thereby have different aetiologies.[10]

Improvements in survival rates have been seen with more than 80% of young people diagnosed with cancer in the UK now surviving for at least 5 years.[11]

However, survival is significantly lower in the TYA age range than in children for several cancer types (Figure 1), with factors relating to diagnosis, different treatment protocols and low levels of participation in clinical trials linked to some of the differences.

Figure 1: Trends in five-year survival rates (%) since 1990 for 0-14 and 15-24 age groups for the main cancer diagnostic categories applicable to 0-24 age group in England[12]



*includes borderline and benign tumours. Error bars represent 95% Confidence Intervals

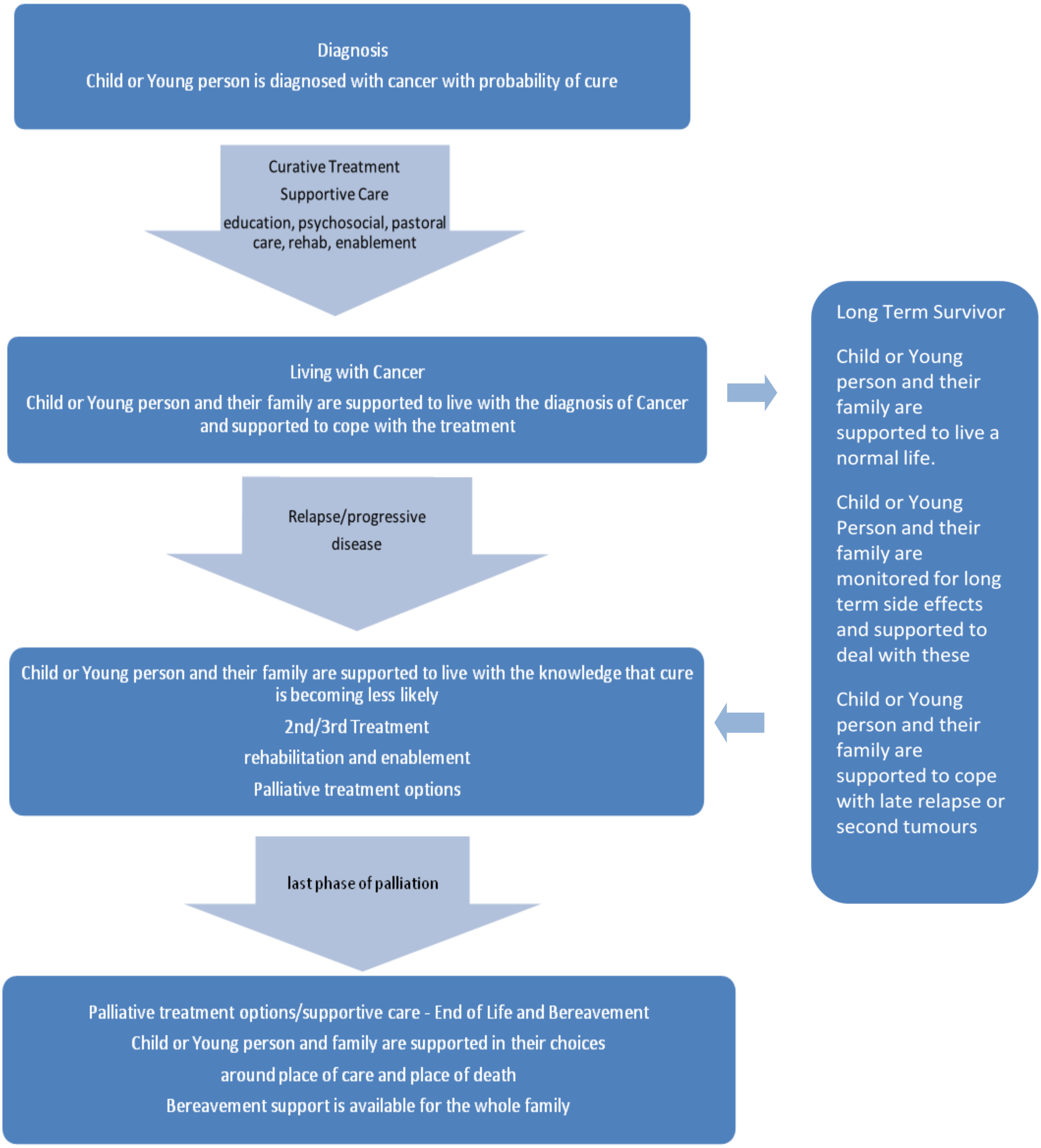
At the end of 2005, it was estimated that approximately 26,000 people in Great Britain were long-term childhood cancer survivors - those who had survived five years or longer after being diagnosed with childhood cancer.[13] It is estimated that by the end of 2012 there will be at least 33,000 people in the UK who are alive having previously been diagnosed with a childhood cancer and who survived their cancer for at least five years.[14]

There is no doubt that a diagnosis of cancer is life changing for all involved.

The focus of this plan is to offer information, support and care based on the individualised needs of the patient and those who care for them from diagnosis, treatment and beyond.

Research carried out by third sector organisations[15] [16] [17] [18] will continue to shape care in Scotland. Working with the Patient and Parent Network, and the newly formed Youth Advisory Forum will enable the MSN to progress services that are cognisant of the needs of children and young people with cancer going forward at all stages of the cancer journey (Figure 2).

Figure 2: Stages of the journey for children and young people with cancer



Diagnosis

Child or Young person is diagnosed with cancer with probability of cure

Curative Treatment

Supportive Care

education, psychosocial, pastoral care, rehab, enablement

Living with Cancer

Child or Young person and their family are supported to live with the diagnosis of Cancer and supported to cope with the treatment

Relapse/progressive disease

Child or Young person and their family are supported to live with the knowledge that cure is becoming less likely

2nd/3rd Treatment

rehabilitation and enablement

Palliative treatment options

last phase of palliation

Palliative treatment options/supportive care - End of Life and Bereavement

Child or Young person and family are supported in their choices around place of care and place of death

Bereavement support is available for the whole family

Long Term Survivor

Child or Young person and their family are supported to live a normal life.

Child or Young Person and their family are monitored for long term side effects and supported to deal with these

Child or Young person and their family are supported to cope with late relapse or second tumours

Priorities outlined in this cancer plan should begin to address these needs, such as ensuring all patients:

- Are diagnosed early and treatment is started without delay
- Have equitable access to the appropriate care and support at time of first/initial diagnosis
- Have an identified key worker at every stage of the care pathway/ journey
- Are provided with education and information; and also making this available to families and carers
- Are given the best care - knowing that their treatment has been discussed nationally to ensure care is given safely in the most appropriate place
- Have access to appropriate clinical trials and are recruited to them
- Receive age appropriate care
- Are given equitable access to holistic care
- Receive ongoing assessment of needs during and after treatment
- Have the best quality of life after treatment – with ongoing support after cancer care

With Scotland representing one third of the UK land mass and less than ten percent of the UK population, equitable access to the pathway of care for young people with cancer is an MSN priority.

These pathways recognise that for some treatments and procedures, patients will need to travel within and out with Scotland. Currently around 20-30% of young patients requiring radiotherapy are travelling to the USA for Proton radiotherapy supported by the National Services Division (NSD).[19]

How will this look for the multidisciplinary team?

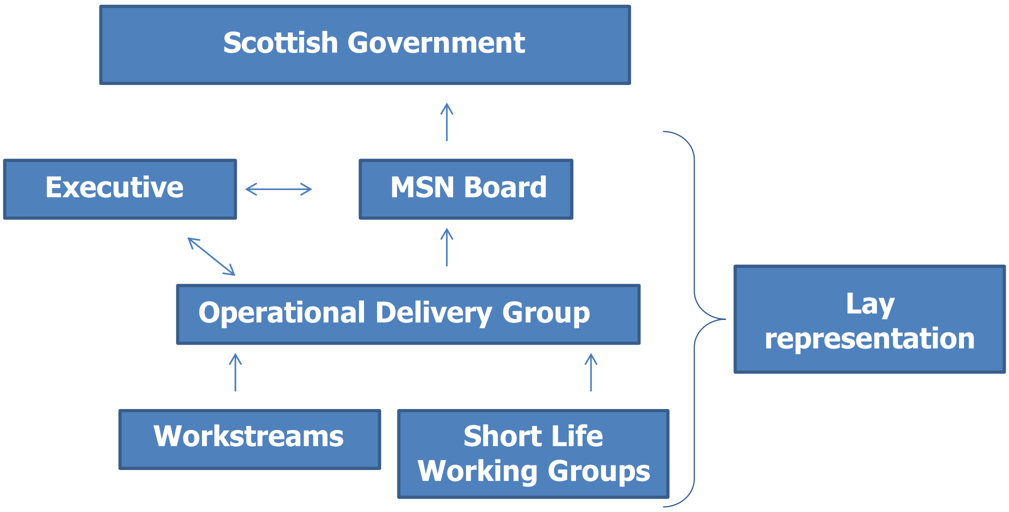
Leadership

Leadership is key to the success of this cancer plan. The MSN will work closely with the relevant NHS Boards to practically address some of the challenges around job planning and resource that challenges progress of this plan. The MSN National Clinical Director will have overall responsibility for the progress and success of the cancer plan, with support from Clinical Leads and Chairs in the following workstream areas:

- Aftercare
- Allied Health Professionals
- Neuro-oncology
- Nurses
- Palliative Care
- Pharmacy
- Psychological Health
- Teenagers and Young Adults

The input to and output from the workstreams will be agreed through the Operational Delivery Group (ODG) to ensure that progress is supported by NHS Boards through to implementation. The ODG, now encompassing Governance and Quality Assurance, will have oversight of the progress of the MSN workplan and will be responsible for implementing a single, sustainable, cohesive service for children and young people with cancer in Scotland. The ODG will be responsible to the MSN Board, the MSN Executive Group, and ultimately the Scottish Government (Figure 3).

Figure 3: Structure of the MSN



Priority areas

Data

All patients aged 0-24 years (inclusive) will be registered on the new Scottish Enhanced Cancer Registry. Enhanced diagnostic, staging, treatment and prognostic dataset data will be collected and inform outcomes research on patients recruited to clinical trial and non-clinical trial patients.

This will provide high quality cancer data and intelligence and ensure data analyses within Scotland, across the UK and other European countries. This improved data collection system will bring about benefits for the entire cancer journey. The ability to have regular standard reports on incidence of cases, where patients are treated and on their survival, will now underpin future Morbidity & Mortality meetings. There also will be regular reporting of the QPIs for monitoring.

The MSN has developed five Quality Performance Indicators (QPIs) to measure performance:

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. Patient's management discussed by a National multi-disciplinary team (MDM)
5. End of treatment summary completed

Within the life of this cancer plan, we will build on these QPIs, and link in with existing QPIs being measured, relevant to this cohort of patients.

The development and implementation of a set of standards for TYA cancer will ensure high quality cancer services for teenagers and young adults in Scotland: the standards will form the basis of benchmarking of services and will inform the development of future services to meet the specialised health needs of young people with cancer.

Infrastructure

The focus of the cancer plan for the next 3 years in terms of infrastructure will be to deliver a national governance framework for the delivery of systemic anti-cancer therapy (SACT) protocols across children's cancer services and continue to progress with a national chemotherapy prescribing system.

This will support the infrastructure for the national multidisciplinary teams, ensure equitable and safe delivery of SACT to children and young people managed from children's cancer services and form the basis for implementation and development of a single national paediatric chemotherapy electronic prescribing and administration system (CEPAS) utilising ChemoCare©.

An option appraisal undertaken in 2011 agreed that a national system linking both principal treatment centres and shared care centres was the preferred option as this would improve continuity of care and address issues on the safe administration of chemotherapy, in compliance with CEL 30(2012): Guidance for the safe delivery of Systemic Anti-Cancer Therapy (SACT).

It was also agreed that audits undertaken in each of the centres in relation to CEL 30 were important in terms of the overall governance of the MSN CYPC - these being a necessary part of ensuring the delivery of a safe service. The implementation of CEL 21(2009): Safe administration of intrathecal cytotoxic chemotherapy was also discussed and the MSN has representation within a working group which is looking to make improvements in non-Luer lock devices for administration of intrathecal drugs.

Working nationally

Cancers in children, teenagers and young adults are rare diseases which require national collaboration to share expertise and to ensure equity of high quality cancer care. This cancer plan covers 0-24 years of age and one of the greatest challenges in achieving national collaboration is forging a TYA specialist model of care across paediatric and adult cancer settings.

We are currently engaged, under the chairmanship of Professor Brenda Gibson, in a project to map the activity and co-dependencies of all specialities involved in the delivery of children’s cancer services throughout Scotland. Improved pathways of care are central to our commitment to deliver high quality service and excellent clinical outcomes. The aim is not to reconfigure services but to ensure that we fulfil our vision of *right diagnosis, right treatment, right team, right place*, while focusing on the needs of the patient. Phase 2 will map TYA cancer services.

The MSN recommends that all patients are discussed at national multi-disciplinary team meetings (MDMs). The challenge of achieving this is not to be under-estimated and will require development of a new infrastructure to support real-time clinical decision making processes. Existing MDMs in haematology, solid tumours and palliative care will be audited and evaluated, ensuring that they are, and continue to be, fit for purpose.

We have recently launched a national MDM for teenagers and young adults with the intention that all patients aged 16-24 years inclusive will be discussed at a cancer site-specific MDM and a national TYA cancer multi-disciplinary meeting.

The added value of a TYA cancer multi-disciplinary meeting is to ensure that young people benefit from a holistic method of care including rehabilitation, enablement and psychosocial support which is coordinated throughout their cancer journey.

The MSN has appointed a clinical lead for neuro-oncology who will develop this new workstream and will lead to greater collaboration with the Managed Service Network for Neurosurgery. The workstream will provide advice on how best to enhance multi-disciplinary team working and will develop standards for patients with Central Nervous System (CNS) tumours.

The specific psychosocial and physical needs that teenagers and young adults with cancer have as they transition from childhood to adulthood require a different model of care to that of younger children and older adults.

The MSN is committed to providing patients aged 16-24 years with the advantages of an age appropriate environment and support network, where young people benefit from the expertise of both cancer-site specific and TYA teams.

This approach will require the MSN to foster new clinical collaborations that link across adult and paediatric cancer services. Achieving successful partnerships between these different, yet complementary groups has potential to provide a fruitful area for research collaboration and clinical service development.

Scoping of current services and pathways of care for teenagers and young adults throughout Scotland has highlighted gaps in service provision. Addressing these issues will lead to better services incorporating greater support for young people and their families, hopefully leading to improvements in survival and quality of life.

The national model will identify those key elements which need to be met across the country to ensure equity of care. To support this goal, the TYA workstream will develop standards of care for TYA services.

Working as a multidisciplinary team

There is widespread recognition of the need for expert psychosocial care for children, young people and their families during their cancer journey.

The long-term strategic goal of the MSN is to maximise emotional and psychological wellbeing in young cancer patients, enabling and empowering them to grow into strong, independent adults.

Over the last decade there has been an increased investment in psychosocial support for young cancer patients and their families; this is largely through the services and support provided by CLIC Sargent social workers, nurse specialists, play specialists, play therapists, clinical psychologists, Teenage Cancer Trust youth support coordinators, spiritual care services and allied health professionals.

Work is ongoing to identify families that require psychological support or advice on other relevant services available.

From initial work carried out within the psychological health workstream there is recognition that many of the previous disciplines offer emotional support but this is variable across age and geographical boundaries.

Clinical psychologists and neuropsychologists can provide evidence based targeted psychological interventions for the children, young people and families who need them.

The MSN will work with all disciplines to integrate psychological and emotional support services, in line with clearly defined pathways that incorporate minimum screening standards, at intervals along the patient's journey.

Following the successful piloting of the Paediatric Care Measure as a tool for obtaining patient and parents' feedback on their experience of the Allied Health Professionals Healthcare Service, the Allied Health Professionals (AHP) workstream will be looking at the inclusion of the Care Measure and its longer term use to improve outcomes in relation to rehabilitation and patient centeredness.

The Paediatric Care Measure is now a recognised standard of care for AHPs working with children and young people in Scotland and many services have continued to use it as their departmental quality assurance or patient reported outcome measure (PROM) tool. Similarly, patient and parental feedback has been useful in facilitating communication between patient, parent and AHP staff. This feedback will be used to measure, plan and improve the service.

An example of recent work carried out by the AHP workstream is the circulation of a national leaflet explaining their role. Future work will incorporate TYA age appropriate care. The aim of the leaflet is to inform patients and families of services available and to provide contact details for the local AHP team.

There is now a focus on collaborating with colleagues who treat the adult cancer population, for the benefit of TYA patients and families. There are profession specific networks that meet regularly for peer review, joint service development and enhancing patient care. Such networks include adult colleagues with the aim of developing collaborative partnerships and improving AHP services for young people. This has been welcomed and has involved local training and updating of clinical information as well as guidance on the clinical and educational work of the MSN.

The physiotherapy group have been working with third sector agencies and local community services to design physical activity programmes tailored for young people across Scotland.

Working safely

Child health is one of the constituent streams within the Maternity/Neonatal and Children's Quality Improvement Collaborative (MCQIC).[20] The subject matter and clinical issues contained within the collaborative are all highly relevant to cancer services for young people in Scotland, particularly given the potential for harm in immunocompromised patients undergoing major ablative/resectional surgery, radiotherapy and intense chemotherapy regimens.

Early diagnosis and management of sepsis is one area where the drivers behind the "sepsis six" model are important, recognising that the default clinical approach provided by the model may need modification to accommodate coexisting morbidity and drug specific factors associated with the chemotherapy agents used. As such, consistent management of febrile neutropenia is an example where speciality specific considerations need to be added to the management promoted by the safety programme.

Following on from the implementation of the febrile neutropenia guideline across Scotland, the MSN intends to audit its implementation. Anti-emetic therapy, management of tumour lysis and assessment and management of hyperglycaemia related to steroid therapy protocols will now follow. The development and implementation of such protocols also need to be extended into adult services that treat teenagers and young adults.

Medicines reconciliation is another extremely important element of oncological practice where the potential for harm in drug interaction, omission or maladministration (given the potential toxicity of the agents in use) has high consequences. Complex calculations of potent drugs are the order of the day in this specialty. The historic and well-publicised case histories of errors leading to death in routes of administration is another exemplar of the low incidence/high consequence sequelae of drug error in this specialty area, hence the emphasis given by the MSN to the development of a single electronic system of chemotherapy prescribing and administration across Scotland as a way of promoting safe practice and improving communication.

Most, if not all, hospital acquired infection is avoidable. Furthermore, the clinical consequences of blood stream infection associated with line sepsis in cancer patients (and almost all patients have some form of central venous access, at some point in time) makes insertion and management policies all the more important and the strict adherence to hand washing policies and other measures of sterility during line usage, absolutely essential.

These aspects of safety practice are recognised by all clinicians but monitoring and scrutiny of implementation needs rigorous adherence to policy as is the need for consistency in practice in the individual centres involved.

The safety measures around perioperative care drivers are as pertinent to oncological surgery as they are to any other form of paediatric surgery and strict compliance with WHO surgical safety checklist [21] and other aspects of safer surgery remain extant.

The journeys that patients with tumours, cancer or leukaemia go on for diagnostic procedures, scans, line insertion, chemotherapy administration and many others, are complex and are carried out by many different members of staff. They require multiple arrangements, consents and tests to be completed and complied with before it is safe for the procedure to be carried out.

Clinicians in NHS Lothian are creating electronic procedural check lists with the help of the University of St Andrews; these will be held on electronic devices by key members of staff to ensure that patient journeys are safe, arrangements are in place and necessary checks and tests are carried out to facilitate safe and coordinated care within the hospital.

More generic points of patient safety include early detection of the deteriorating patient, the watchers scheme, the use of team huddles and briefings. All practices that are utilised across the children's hospitals in Scotland are areas that might be considered for expansion within oncological practice. Paediatric Early Warning Signs (PEWS) is used in all wards where paediatric cancer patients are cared for, with the National Early Warning System (NEWS) used for the TYA age range.

The above constitutes areas of safety in practice - serious safety events and serious medication events - that are universally accepted within the MSN. There is scope for a more consistent approach to recording adverse events beyond the current Datix risk management system and that is an area for future development.

Improving research opportunities

Best practice[22] [23] recommends that all children (aged 0-15 years), teenagers and young adults (aged 16-24 years) with cancer should be able to participate in cancer clinical trials (from time of diagnosis) due to reported benefits in survival and patient experience[24] [25] [26].

While 60-80% of children enter clinical trials, teenagers and young adults with cancer are significantly under-represented in clinical trial recruitment and this may contribute to the lower reduction in cancer mortality rates compared with children or older adults (Figures 4, 5).

Understanding the reasons for this is complex and a strategic model to improve clinical trial recruitment has been developed[27] focusing on addressing five key areas: clinician awareness, trial availability, access to trials, age-appropriateness and acceptability.

Figure 4: Proportion of children, teenagers and young adults, and older adults entered into selected cancer trials[28]

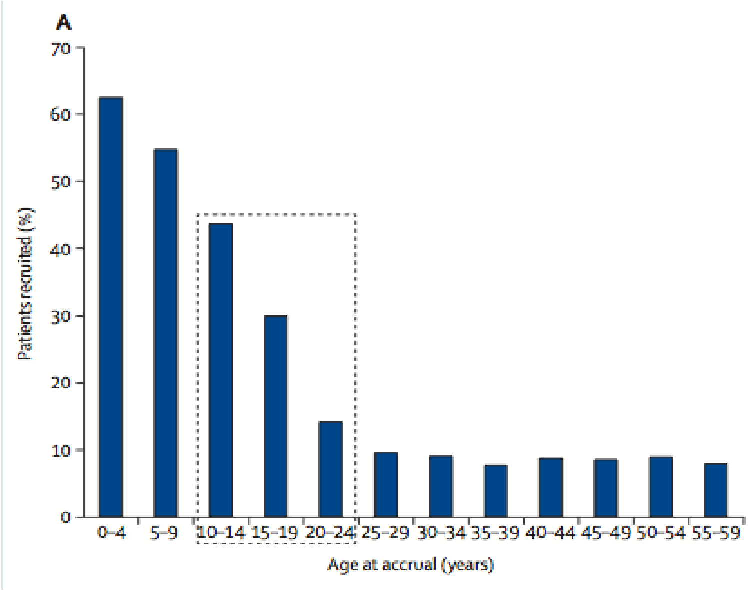
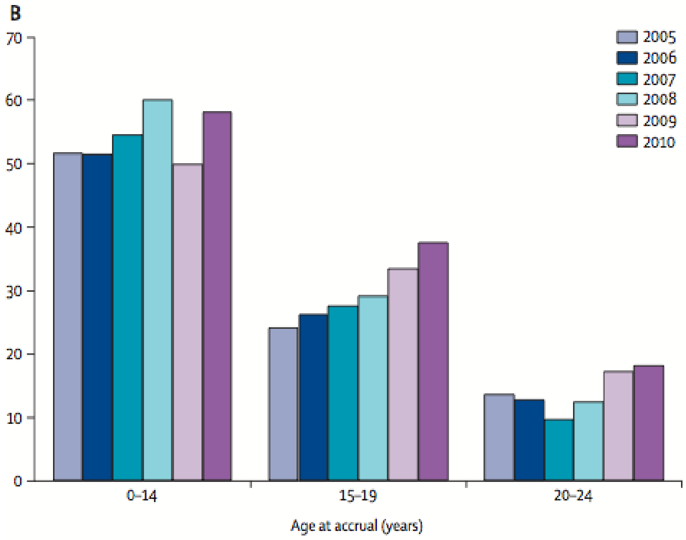


Figure 5: Changes in proportion of patients entered in selected cancer trials per year[29]



A recent scoping exercise of clinical trial availability was carried out in Scotland.[30] Children, teenagers and young adults in Scotland have reduced access to trials of cancer therapy compared to the UK as a whole.

This ‘trial gap’ is exacerbated by incomplete listing of available trials, and for TYA, by their dispersion amongst numerous treatment centres. Treatment of children with cancer (aged 0-15 years) is concentrated in 3 centres while TYA may be treated in one of 23 centres (4 TYA units, 19 adult hospitals).

Introduction of enhanced cancer registration will provide high quality cancer data and intelligence. Data collection on clinical trials, particularly relating to availability, eligibility and recruitment, will be a key objective of both the paediatric and TYA multi-disciplinary team meetings.

The MSN is committed to exploring the barriers to opening more clinical trials for young people with cancer and by working with others[31], improving the recruitment of more young people to clinical trials that are available to them.

Understanding why clinical trial recruitment is successful in paediatrics may lead to improved accrual rates for teenagers and young people with cancer.

Managing care after treatment

Many, but not all survivors of cancer in childhood and adolescence are at risk of developing late complications following cancer treatment. One of the aims of the MSN is to develop a robust and integrated national system of follow-up to meet the needs of a growing community of children, teenagers and young adults who have survived cancer.

Greater awareness of these problems dictates the need for vigilant long-term follow-up (LTFU) of survivors, with early intervention, treatment, and appropriate counselling.

The objective of cancer aftercare is to provide health surveillance, together with psychosocial support and education of survivors to encourage them to develop into independent adults.

Focus groups have provided insight into the many and diverse needs of these survivors. They informed us that there was:

- a lack of education and awareness of the risks of late effects, particularly fertility issues
- a lack of understanding of the need and benefits for LTFU
- a lack of peer support and access to psychosocial support

Concerns have also been raised in relation to readjustment into society, school, university, the workplace and concerns regarding physical ability and nutrition. Once treatment is finished the lack of signposting to support groups and resources available has been highlighted; one young survivor said she felt unsupported by the education system and had to just slot back into school once she finished treatment and subsequently struggled for years thereafter.

As part of this plan, the MSN will begin to tackle this through the recently appointed aftercare nurses who will build up relationships with others in the third sector and community, including social care and education in an advocacy role to begin to raise awareness and improve support for those wishing to re-enter education and/or employment.

Development of a service that can deliver personalised comprehensive, therapy-based care is essential. The MSN will develop an integrated, national system of nurse-led follow-up, with protocol driven health surveillance for survivors at low/moderate risk of treatment related late effects.

This risk stratified approach to follow up[32] [33] [34] [35] with end of treatment summaries and care plans for all patients who complete treatment, will be shared with all health professionals involved and with the patient and their family.

The MSN recognises the importance of efficient transition from the paediatric cancer services into an appropriate adult service for certain selected patients with significant on-going medical needs and will support existing clinics and identify and support future needs in this area.

This pan-Scotland approach aims to provide an equitable service for all survivors. The cancer aftercare nurses funded by the MSN will also facilitate education sessions for patients and staff and signpost survivors to local resources.

They will build links with Primary Care and develop pathways for greater involvement of Primary Care with Level 1 and level 2 survivors, (see Figure 6).

Figure 6: Therapy-based recommended levels of follow-up[36]

Level	Treatment	Follow up	Frequency	Examples
1	**Surgery alone Low risk chemotherapy**	**Postal or telephone**	**1-2 years**	**Low risk Wilms' LCH (single system) GCT (surgery only)**
2	**Chemotherapy Low dose cranial irradiation (<24 Gy)**	**Nurse-led or Primary Care**	**1-2 years**	**Majority of patients (eg ALL)**
3	**Radiotherapy (>24Gy) Megatherapy**	**Medically supervised LTFU clinic**	**Annually**	**Brain tumours Post BMT Any stage 4 patients**

Alongside this, it is believed that an electronic person held record will contribute to greater engagement in follow-up programmes and improve medical and psychosocial care for young people with cancer.

The MSN will develop an e-Passport for young patients with cancer. This will be made available to them on their smartphone or tablet and will link to selected parts of their own medical records, incorporate their treatment summary, be interactive and personalised.

It should provide an opportunity to engage with their experiences and hold details and the effects of treatment that will facilitate care as they move on from treatment and begin to redevelop their independence.

The focus of work within palliative care for children and young people with cancer will be to begin collecting data for agreed audit points, enabling the development and setting of standards across Scotland for palliative care.

The MSN has been working with the Scottish Children and Young People Palliative Executive (SCYPPEx) and Children's Hospice Association Scotland (CHAS) to ensure our work aligns with the Framework for the Delivery of Palliative Care for Children and Young People in Scotland. The MSN, in partnership with CHAS, has funded a project looking at the palliative care needs for children and young people in Scotland, and the outcomes of this work will influence the priorities for action in this area over the next 3 years.

End of Life Care Planning using the Lothian model is being adopted across Scotland. This will incorporate the use of Children/young people acute deterioration management plans (CYPADM) into every day practice. This will involve liaising with primary care colleagues to improve communication, access to health care records and involvement at the end of life. From the patient's and carer's perspective, with support and understanding, care at the end of life can be positive, with opportunities to set goals and achieve aspirations that improve quality of life.

The MSN will examine how primary, secondary and tertiary care sectors, alongside the voluntary sector, can improve information sharing and the recording of symptom burden with the use of information technology.

Following a scoping exercise which explored bereavement services, the gaps identified in the provision of bereavement services across all sectors in Scotland has been highlighted by the palliative care workstream and is an area for MSN focus.

The palliative care MDM has highlighted areas of good local practice and has facilitated the integration of palliative care for children across all health sectors. Provision for young adults remains poor, in common with the rest of the UK, therefore this will be an area of focus for the MSN going forward.

Developing the workforce

Patients deserve the best possible clinical outcomes and this is best achieved in a quality integrated service where all parts of the service have the opportunity to network, share best practice ideas and acknowledge the philosophical debates that surround the advances in this complex and rapidly changing specialty.

Education and development are key areas for the MSN. Annual meetings such as the Education Day and the Morbidity and Mortality days have added to the sense of a single community of healthcare workers committed to cancer care in the young. The MSN intends to continue with such national meetings and to develop and support tailored education packages for staff at all levels working with children and young people with cancer. A scoping exercise for this area is currently underway.

National scoping of TYA cancer services by the Lead Nurse for teenagers and young adults in Scotland has identified gaps in nursing education in TYA cancer care; a gap also identified by the Royal College of Nursing (RCN) and Teenage Cancer Trust. This is a priority which needs to be addressed. It is recommended that healthcare professionals working in this field should have at least a basic level training in TYA cancer care.

Basic level training will include attendance at TYA cancer specific education days and participation in educational opportunities provided by the TYA cancer multi-disciplinary team meetings. Staff whose main responsibility is to work with young people with cancer should be encouraged to complete specialist accredited education.

To progress nurse education in TYA cancer care, the MSN TYA Clinical Advisory Group will work in collaboration with Cancer Networks, Health Boards and Educational establishments to implement the competency framework into nursing practice.

Funding routed through NHS Greater Glasgow and Clyde from NHS Education Scotland looking into developing best practice standards and identifying self-perceived training needs in the wider staff group, has also highlighted that multi-disciplinary team staff feel they require more training in psychological aspects of oncology.

The psychological health workstream is also planning how they will meet the needs identified above and how to devise training that is flexible and accessible for all staff, particularly those who are ward based and often find it harder to access training.

The allied health professionals (AHP) workstream group have been proactive in identifying the learning needs across the AHP population and have started to address this issue. A Learning Needs Analysis (LNA) was completed to establish the learning needs of Scottish AHPs and the development of online resources hosted on the Managed Knowledge Network website. The group are planning to undertake another LNA, to reflect changing learning needs especially in light of TYA care.

A centralised education and information resource for services supporting children in the community and in hospitals will continue to be developed by the workstream.

Through the nursing workstream of the MSN, Scottish Paediatric Haematology/Oncology nurses will be a better informed and connected workforce that can identify it's training requirement. The workstream will review national clinical practice and documentation to standardise care across Scotland. An educational pathway for nurses' professional development will be developed to introduce a consistent approach to learning. The MSN will provide Scotland-wide opportunities for staff to visit and work with colleagues from other centres, to promote better integration of services across the country.

In addition, the CLIC Sargent Key Worker Education Package is now hosted on the MSN website; available to all healthcare professionals.

The MSN, through its links with other organisations such as NHS Education for Scotland (NES), National Cancer Research Institute (NCRI), Children's Cancer and Leukaemia Group (CCLG) and Teenage and Young Adult Cancer (TYAC), will ensure that the opportunities for education and training are shared and supported.

Involving patients

The MSN has been extremely fortunate to benefit from the insight and experience of the Patient and Parent Advisory Forum, which has proven a valuable sounding board for our direction and progress. The network plans to build on this and extend engagement to the TYA age group through the development of a Youth Advisory Forum.

Contributions from young people on healthcare decisions that affect them are valued by the MSN and the network is committed to engaging with them to promote the development of TYA cancer services in Scotland. The MSN TYA Clinical Advisory Group will work with young people to develop a forum which will facilitate their involvement in developing services to meet their needs. The young person's advisory forum will deliver benefits to young people, health professionals and health services and will also meet national and international good practice standards.[37] [38] [39]

The MSN will invest in training and support of its patient representatives and commits to ensuring that their involvement influences the activities of the network. The MSN will work with others to develop patient reported outcome measures for children and young people with cancer; the findings from this engagement will feed directly into the MSN workplan, to improve outcomes and experiences.

Strengthening collaborations and partnerships

The plan outlines the MSN's intentions around care for those diagnosed with cancer aged between 0-24 years. The MSN’s responsibility for this cohort overlaps with other plans and priorities generated outwith the MSN, so the MSN will ensure that the needs of this cohort are represented wherever this is appropriate for the benefit of children and young people with cancer. The MSN will proactively engage with our adult oncology colleagues to manage the needs of young people with cancer. The MSN will also feed into the UK and global scene of children and young people with cancer to drive up standards and outcomes.

Ambitions around holistic care during and after treatment will drive activity and promote relationships with external agencies such as Education, Health and Social Care partnerships and the third sector. Enormous commitment and goodwill has come from a great many staff across Scotland in order to make the MSN a vehicle for successful care. That commitment has been mirrored in the third sector by the likes of Teenage Cancer Trust and CLIC Sargent and by CHAS in respect of the close working between NHS Scotland and agencies responsible for palliative care. The MSN will continue to work closely with and support such partners to realise the ambitions of this plan.

The visibility of the MSN in the rest of NHS Scotland is ready to rise and the new website (www.youngcancer.scot.nhs.uk) will help achieve that. The website will be the MSN's 'shop window' - a hub of information and expertise on children and young people with cancer. Visitors and users of the website will be able to monitor the progress of this cancer plan, associated workplans and annual reports.

How this cancer plan works in the Scottish context

This plan sets out Scotland's vision for Cancer Services for children and young people up to their 25th birthday. The Cancer Plan for Children and Young People with cancer cannot exist in isolation; it will influence and be influenced by the other contextual factors pertaining to patient care in Scotland.

The NHS Scotland *Healthcare Quality Strategy*[40] aims to deliver the highest quality of healthcare to the people of Scotland. The cancer QPIs developed as a result and the subsequent data resource should be used as part of the outcome measurements relevant to this plan, i.e. TYA cancers. These principles resonate with this Cancer Plan; delivery of care which is safe, patient-centred and effective. The MSN will look at how its activity can support and take account of the wider cancer care improvement strategy across Scotland.

A key piece of legislation is the Children and Young People (Scotland) Act 2014. All aspects of the Act are relevant to children and young people with cancer; however of particular note are Parts 4, 5 and 18 which address aspects of *Getting It Right for Every Child* (GIRFEC).

Getting It Right for Every Child (Appendix 1) is founded on 10 core components which can be applied in any setting and in any circumstance. The GIRFEC approach ensures that services are brought together more effectively to provide help and support for children; this approach is reflected in this cancer plan. GIRFEC recognises that services must be responsive to the needs of children and how their needs change as they get older - the MSN and specialist services will fully embrace the principles of GIRFEC.

Recent consultative proposals make the identity and role of the ‘named person’ quite clear. It seems probable that the lead professional role could be effectively fulfilled by paediatric oncology outreach nurses (POONs) so these aspects of GIRFEC legislation appear feasible.

The eight indicators of wellbeing (Appendix 2) will influence how the MSN works with other agencies to ensure the indicators are met in all situations, during and after cancer care. Strong links require to be developed with local authorities to ensure that end of treatment summaries for children and young people, feed into the proposed Child’s Plan[41] to support the single planning process, and their re-integration into mainstream activities. For young people, the work of the MSN and the *Transforming Care After Treatment* programme (TCAT) will no doubt offer opportunities for learning on both sides for the benefit of children and young people with cancer. TCAT’s investment to facilitate development and implementation of models of aftercare aligns with the MSN's ambitions in this area.

The small numbers of children and young people diagnosed with cancer across Scotland and the associated challenges are not unlike dealing with a rare disease. The Implementation Plan for Rare Diseases in Scotland[42] supports the drive to deliver the Scottish Government’s 2020 Vision[43] that *by 2020 everyone is able to live longer healthier lives at home, or in a homely setting*. By 2020 Scotland will have *a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported self-management.* The Implementation Plan was prepared in discussion with specialists, NHS Boards, the third sector and patients. The parallels are obvious and will no doubt offer learning opportunities on both sides in how we can deliver services for these challenging patient groups.

The MSN will also keep abreast of the opportunities which *The Public Bodies (Joint Working) (Scotland Act) 2014 (Health and Social Care Integration)* will offer in terms of integrated working and improved transitions for young people. It is acknowledged that this landscape is complex, all the more so since some Integrated Joint Boards do not currently have a remit over Children's Services. Nonetheless, the creation of Joint Children's Services Plans as described in the *Children and Young People (Scotland) Act 2014*, will further support this area of work.

Our workforce is key to the successful delivery of quality services. The *Everyone Matters: 2020 Workforce Vision Implementation Framework*[44] sets out 5 priorities for action by NHS Boards which also underpins the MSN’s approach: healthy organisational culture; sustainable workforce; capable workforce; integrated workforce; effective leadership and management.

APPENDICES

APPENDIX 1

Getting it right for every child is founded on 10 core components which can be applied in any setting and in any circumstance:

1. A focus on improving outcomes for children, young people and their families based on a shared understanding of well-being
2. A common approach to gaining consent and to sharing information where appropriate
3. An integral role for children, young people and families in assessment, planning and intervention
4. A co-ordinated and unified approach to identifying concerns, assessing needs, agreeing actions and outcomes, based on the *Well-being Indicators*
5. Streamlined planning, assessment and decision-making processes that lead to the right help at the right time
6. Consistent high standards of co-operation, joint working and communication where more than one agency needs to be involved, locally and across Scotland
7. A *Lead Professional* to co-ordinate and monitor multi-agency activity where necessary
8. Maximising the skilled workforce within universal services to address needs and risks at the earliest possible time
9. A confident and competent workforce across all services for children, young people and their families
10. The capacity to share demographic, assessment, and planning information electronically within and across agency boundaries

APPENDIX 2

The four capacities aim to enable every child and young person to be a **successful learner**, a **confident individual**, a **responsible citizen** and an **effective contributor**.

The eight indicators of wellbeing

Safe ***Healthy*** ***Achieving*** ***Nurtured***

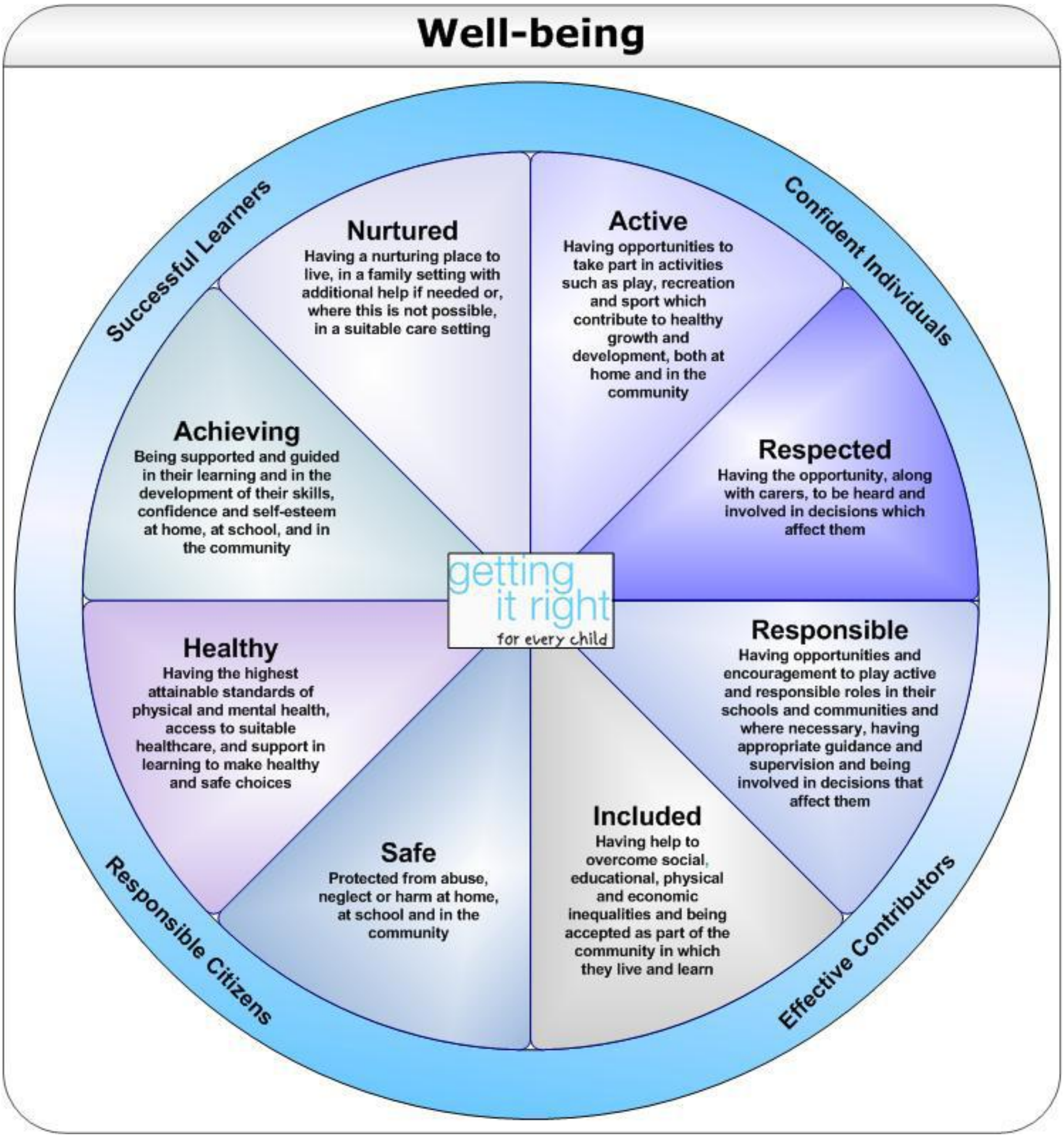
Active ***Respected*** ***Responsible*** ***Included***

These are the basic requirements for all children and young people to grow and develop and reach their full potential. They are shown in the following diagram which we call the Wellbeing Wheel.

The wellbeing Indicators are used to record observations, events and concerns and as an aid in putting together a child's plan - if one is needed. The My World Triangle and the Resilience Matrix are used to gather, structure and help with assessing and analysing information.

Children and young people will progress differently, depending on their circumstances but every child and young person has the right to expect appropriate support from adults to allow them to develop as fully as possible across each of the wellbeing indicators.

All agencies working with or for children and young people must play their part in making sure that young people are healthy, achieving, nurtured, active, respected, responsible, included and above all, safe.



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