MSN
For Children & Young People with Cancer

NHS
SCOTLAND

Cancer Plan for Children and Young People in Scotland 2012-15

Managed Service Network for Children and Young People with Cancer in Scotland

The Scottish Government

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The Scottish Government, Edinburgh 2012

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Foreword

I am pleased to introduce the first ever Cancer Plan aimed specifically at children and young people in Scotland. Investing in the future of Scotland's children and ensuring they have the best start in life and are able to fulfil their potential is cornerstone of our policy.

Every year a small number of children and young people are diagnosed with cancer. Our services must ensure these children and young people attain the best possible outcomes and have access to appropriate specialist services, as locally as possible, that are both safe and sustainable, supported by consistent pathways of care, regardless of where they live.

It has long been accepted that there should be a single service for children and young people with a diagnosis of cancer in Scotland. In April 2011, I established the Managed Service Network (MSN) for Children and Young People with Cancer for Scotland and charged that Network with delivering our vision for cancer services. This Cancer Plan for Children and Young People in Scotland is the first important stage in delivering that vision and sets the priorities for the next three years. I will expect NHS Boards and individual clinicians to work with the MSN to deliver the best possible patient care and establish a service in Scotland that is the best in Europe.

Nicola Sturgeon, MSP

Nicola Sturgeon

Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy

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"All changed, changed utterly" [1]

The implications of a diagnosis of cancer in a child or young person are enormous. Life for that child or young person and their family will never be quite the same again. For the child or young person, the immediate future is occupied with months and years of tests and treatment, in a hospital environment initially strange, but one that will almost become a second home. Parents and young people want to know, what will happen, when it will happen, who will do it, where will it be done, will it be the best that is available them, and of course, the initially unspoken, what are the chances of survival? Families and friends all want to support to ensure that the best happens.

For the clinical carers, the many different clinicians, including surgeons, oncologists, haematologists, radiologists, pathologists, nurses, therapists, pharmacists, psychologists and physiotherapists; all want to deliver for each child and young person and provide the best available care that our system allows.

The MSN for Children and Young People with Cancer has a single purpose, to ensure delivery of the “best available” for each child and young person with cancer through structures and processes that enable the best possible outcomes; and to do that by fostering a patient centred culture of integration, collaboration and support, as well as developing the abilities of the workforce. It will draw on the unfinished business of the last 10 years of planning and investment in specialist services for children and young people through the National Delivery Plan[2]. It aspires to go beyond the substantial developments made by the managed clinical network, CATSCAN, and build on the recurring investment of an additional £3.2 million in cancer services for children and young people in Scotland.

This plan intends to foster easier and earlier access to services, ensuring that every child or young person is diagnosed promptly, that experts formulate the right care plan, at the right time and it is easier for everyone in the system to communicate and collaborate, making sure that the care is as safe as can be expected from drugs that are powerful and surgery that is major and radical.

This plan is not about the specific treatment regimens that will be applied to each disease within the spectrum of paediatric cancer, although that will be absorbed within it, but it is about production of a system that delivers and builds on an organisational culture which utilises the most expert opinion and skill base, the most timely investigation protocol, the best informed treatment policy and the family support for every child and young person with cancer in Scotland. It is a plan for a system that spans across Scotland, and ensures equity of care irrespective of residence, that plans care for those who need to travel beyond our national boundaries for rare cancers and very specific treatments; that plans to care for those where the nature of the illness dominates over the ability of the treatment and where supportive palliative care is needed.

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[1] Smith R, All changed, changed utterly, BMJ 1998; 316:1917-8.

[2] (2009) “Better Health, Better Care: National Delivery Plan for Children and Young People’s Specialist Services in Scotland” January 2009, Scottish Government. www.scotland.gov.uk. RR Donnelley B57674 01/09

The MSN will make that happen and importantly will ensure that it realises how it can happen. The plan will make certain that each child and young person newly diagnosed with cancer in Scotland gets individualised care guided by the most recent knowledge of research and clinical trials and will achieve that by investing in its workforce and enhancing research and development, educational opportunities for staff, and ensuring that communication across Scotland happens easily. We need to build a system that is intelligent and informed, a workforce that is resilient and sustainable, and care pathways from start to finish that are vigilant and allow the earliest diagnoses, detection of problems as soon as they appear and find a resolution. We intend to invest in academic and research profiles that will bring Scotland to the leading-edge of cancer care for children and young people by developing standards of care informed by international models that have something to offer Scotland. The network will plan for each case, learn from all new experiences, invest in its workforce and aspire to deliver excellence in clinical care in a consistent fashion for all Scottish children and young people with cancer.

When we were appointed as the co-Chairs for the MSN in April 2011, we identified, through a series of visits to centres and discussions with stakeholders, how the MSN could achieve these objectives to establish a single service for Scotland, which transcends NHS Board boundaries but still ensures local ownership and we identified a number of key themes to be addressed. These include Leadership, Service Delivery, Health Outcomes and Measurement, Interfacing, Transitions and Resources. Our Cancer Plan for Children and Young People identifies what we need to do to make this happen.

The Cancer plan therefore is about constructing a system that enables the best people to provide the best care for the best outcomes.

We commend our plan to you.

Geo A Youngson

Prof George Youngson CBE, **MSN Co-Chair**	**Dr Iain Wallace,** **MSN Co-Chair**

Executive Summary

Cancer services for Children and Young people will be delivered as a single and sustainable service across Scotland.

National multi-disciplinary team working is pivotal to delivering a single and sustainable service for Scotland.

Every child and young adult with cancer in Scotland will be enrolled into and treated on a clinical trial where one is available.

The MSN will review Care pathways to ensure that these deliver consistent, safe and effective care for all patients.

The MSN will develop outcome measures against which services can be evaluated.

The MSN will introduce an integrated and systematic approach to long term follow-up based on risk.

The MSN will develop services appropriate to the needs of teenagers and young adults up to age 25.

The MSN will introduce and support the development of the Framework for Palliative Care for Children and Young People.

The MSN will harness the experience of patients, and their parents or carers, to inform the shape of services for children and young people with cancer.

The MSN will ensure involvement of third sector partners in key decisions about services for children and young people with cancer.

The MSN will ensure equity of access to the best possible care and will strive to improve outcomes for children and young people with cancer in Scotland.

What does success look like?

We aim to have a model of care in Scotland that is the best in the world. There will be a whole systems approach with strong leadership working across NHS Board boundaries. Service delivery will be consistent across Scotland, and the focus will be on delivering safe services as locally as possible. Pathways of care must be clear and consistent, and all children and young people with a diagnosis of cancer should have access to appropriate clinical trials, which will be organised and governed through a national facility.

Patient care is at the heart of the service model with patients and their families being involved in their care decisions. We will minimise delays in diagnosis, and aim to meet patient expectations by providing access to the best possible care underpinned by strong academia and research. Age appropriate care should be available to all patients along with appropriate transition arrangements.

To achieve such success NHS Scotland has identified a number of Critical Success Factors for the MSN and these are summarised below.

The MSN will

- Develop a single, cohesive, and sustainable service for Scotland, including a children and young people’s cancer plan, and guidance on service development, supported by robust shared care arrangements and an MDT way of working.
- Develop a governance framework that supports the work of the MSN, and ensures the safety of children and young people with cancer.
- Ensure that all children in Scotland with a diagnosis of cancer have the opportunity to be included in an appropriate clinical trial.
- Develop and monitor standards, protocols and guidance including patient pathways and transition arrangements.
- Develop data standards and supporting systems to ensure consistent data collection.
- Build on the work of CATSCAN while supporting its transition into the clinical governance and quality arm of the MSN.
- Ensure patient involvement at all levels, including Network activities and monitor patient satisfaction.
- Develop sub-specialisation including 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 MDTs and delivery of services.
- Arrange mutual support between units to be implemented when required.
- Lead on national education and training issues, research, and establishment of a national academic resource.
- Promote the early detection of cancer in children and young people.
- Ensure that the work of the MSN is widely communicated to all stakeholders.

How will we achieve success?

Capabilities and Culture

We need to develop a single, virtual service for children and young people with cancer in Scotland. The model outlined in Figure 1 illustrates the MSN structures and functions focused around the patient. The MSN Board will be supported by the Multi-Disciplinary Team (MDT) Group, in coordinating the delivery of treatment and care, the Operational Delivery Group, in ensuring the operational delivery of the work of the MSN, along with and the Governance and Quality Assurance Group, which will evaluate the service and ensure the delivery of high quality care.

One of the first priorities is the development of Multi-Disciplinary Teams (MDTs) for delivering care.

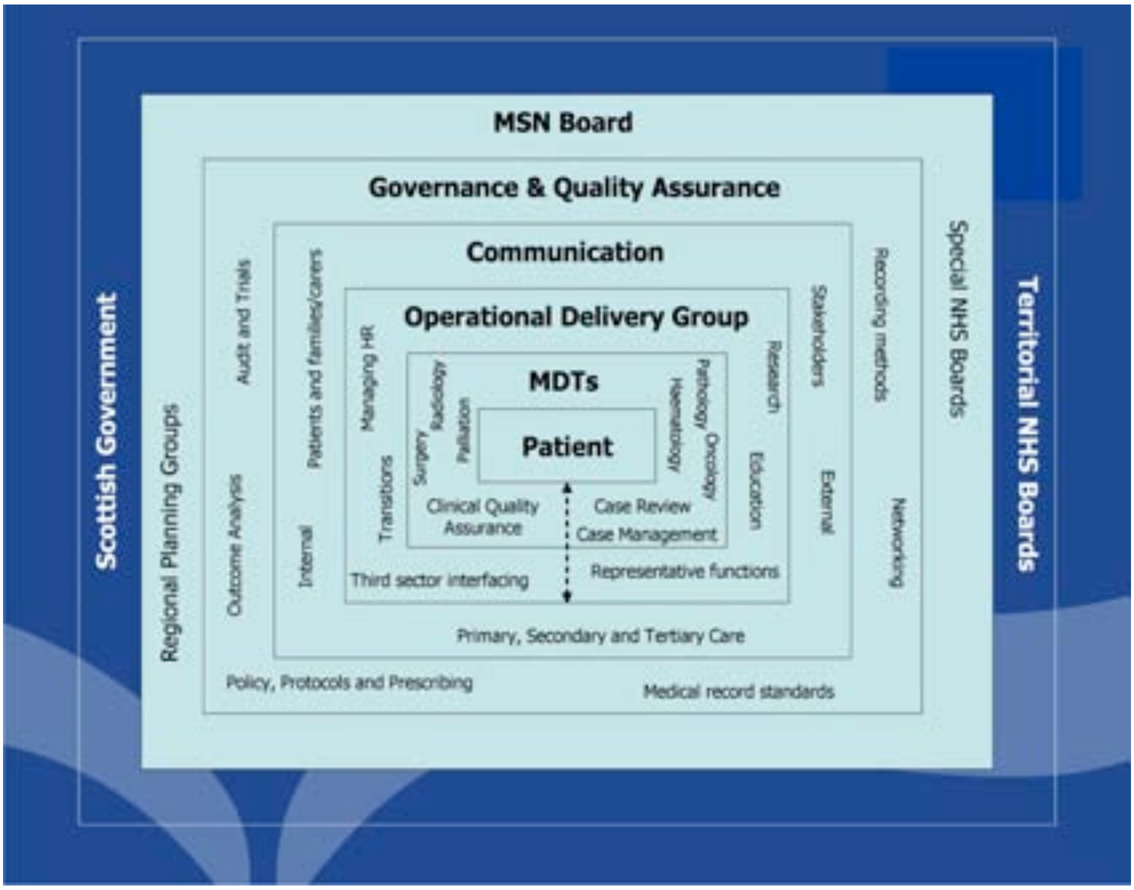

Figure 1: MSN structures and functions.

Leadership

The role of the MSN is to provide a focus for services and ensure that the plan is coherent across Scotland, delivering patient centred, safe and effective services. Services for children and young people with cancer will be delivered as a single service for Scotland but access to services will continue to be through local NHS Boards. The aims of the MSN will be delivered through a partnership between the MSN Board, NHS Boards and front line clinical staff.

The development of strong clinical leadership within the MSN will be key to its success. In addition to the appointment of a National Clinical Director, with overall responsibility for delivery of a pan-Scotland approach, the MSN has already appointed a Clinical Leader for Governance and Quality Assurance, and will strengthen arrangements to ensure a particular focus on the needs of teenagers and young adults, survivors and those who need palliative care. The Governance and Quality Assurance Group will ensure that the approach across Scotland is driven by evidence and best practice and that service delivery is based on standards and protocols. This group will ensure that all children and young people have the opportunity to be entered into an appropriate clinical trial. A National Network Manager has been appointed to ensure delivery of the aims of the MSN.

The MSN Board will set the overall direction for services reporting to The Scottish Government and the territorial NHS Boards. Operational delivery of MSN plans will be achieved through the Operational Delivery Group, which will have clinical and managerial representation from the cancer centres and shared care services.

Delivering a Single Service for Scotland

The role of the MSN is to facilitate an approach for Scotland that allows access for all children and young people with a diagnosis of cancer to the best possible care that Scotland can provide. Services will operate as a single, cohesive and sustainable service for Scotland with care provided in a variety of settings but led by the decisions made by the Multi-Disciplinary Team (MDT) to promote consistency and equity of care.

Hospital care is mainly provided by the four children’s hospitals in Scotland, although the range of services provided in each centre is different and any individual patient’s care may be shared between centres. Both Edinburgh and Glasgow are defined as Principal Treatment Centres (PTCs), and Glasgow hosts the National Bone Marrow Transplant Service. Aberdeen Children’s Hospital does not provide as extensive a range of services as Glasgow and Edinburgh, but does manage many children locally for much of their pathway of care and shares care with other centres. Dundee operates in a shared care arrangement with Edinburgh, Inverness with Aberdeen, Edinburgh and Glasgow, and Dumfries with Edinburgh and Glasgow.

A diagnosis of cancer devastates any family and treatment can be intense and prolonged. Minimising disruption to normal family life and limiting time away from home, from other children, from family support and from work is important in helping families cope. Despite the intensity and complexity of current cancer treatment, elements of treatment can, and will, be delivered as locally as possible. District General Hospitals will vary in the level of care they provide, but all must be able to make a diagnosis of suspected cancer, refer timeously to a treatment centre and provide emergency care for any child or young person who becomes acutely unwell whilst at home in their locality.

Cancer services for Children and Young people will be delivered as a single and sustainable service across Scotland.

Multi-Disciplinary Team Working

Good practice and evidence from across the world highlights the importance of the role of the MDT in improving outcomes in the care of cancer patients. One of the first priorities of the MSN is the development of Scotland-wide MDT meetings with responsibility for confirming diagnosis and agreeing the key treatment decisions throughout the pathway of care for every patient.

National MDTs are the structure through which care will be delivered as locally as possible, whilst prioritising safety. They will have a registration role, will facilitate data collection and audit and will be of strong educational benefit.

MDT working brings together the wide range of healthcare professionals involved in the care of a child or young person with cancer and galvanises their different expertise to ensure that a holistic decision is made about the pathway of care for each individual. Such MDTs can have a variety of purposes, including confirming diagnosis, making treatment decisions and considering the psychosocial needs of the patient.

All children and young people with cancer will have their diagnosis confirmed and their treatment agreed at a series of regular national MDT meetings facilitated by video-conferencing or web-based systems. Clinicians, nurses and allied health professionals from all hospitals involved with the care of children and young people with cancer will contribute to these meetings, although the clinical responsibility for the patient will continue to reside with the responsible consultant. All patients will be discussed at diagnosis, at agreed stages of treatment, at the occurrence of significant toxicities and, if necessary, at relapse. This will mean that every child and young person will have the benefit of the best medical expertise and opinion at each stage of their treatment. Patients and families find reassurance in knowing that their children’s treatment has been discussed by a number of experts. Referral pathways and place of treatment, including which elements of treatment should be delivered centrally and which can safely be delivered locally, will be agreed by the MDT. MDTs will facilitate successful networking across Scotland.

National multi-disciplinary team working is pivotal to delivering a single and sustainable service for Scotland.

eHealth

Delivery of a single service for Scotland with local access will be built on an eHealth platform. The use of modern technology and common systems to help deliver care, including telehealth, and supported common or interfacing systems.

The MSN is working on a number of eHealth projects including the development of mechanisms to support a national MDT way of working, exploring common systems for chemotherapy prescribing, and the development of electronic individualised care plans to facilitate the long-term follow-up of survivors of cancer in children and young people.

Clinical Trials

Treatment on a clinical trial is regarded as the gold standard of care and paediatric trial recruitment has led all other cancers in this area. One of the main aims of the MSN is that every child and young adult with cancer in Scotland is enrolled into and treated on a clinical trial, where a clinical trial for their particular cancer is available.

The current excellent survival rates for many paediatric cancers are due to serial improvements over time, which have been achieved through comparing different treatment strategies within large national and international trials which recruit sufficient numbers of patients to power the randomised questions. The 150 new cases of cancer in the 0-15 year age group and 150 new cases in the 15-24 year age group, presenting each year in Scotland, represent a spectrum of cancers with insufficient patients with any specific cancer to run independent trials. Children and young people treated within Scotland will therefore be entered into trials which may be exclusively United Kingdom based, but are more likely to be European or international trials. Whatever the recruitment population, it is likely that these trials will be part of the National Cancer Research Institute (NCRI) portfolio and be approved and overseen by the NCRI Children’s Cancer and Leukaemia Study Group. Whilst membership of this group is by appointment, the MSN currently has representation on this group through its current Clinical Director.

The regulatory requirements of the European Directive on Clinical Trials has made the opening and running of clinical trials extremely onerous and as a result the number of open clinical trials available to children has fallen. The MSN will ensure equity of access to open clinical trials to children with cancer across Scotland irrespective of place of residency. Accrual to trials across the age range will be monitored and audited for comparison with UK wide data.

The Cancer Research UK (CRUK) Clinical Trials Unit based at the University of Birmingham is the main, but not exclusive, sponsor and clinical trials unit for paediatric cancer trials in the UK. Sponsors have regulatory responsibilities which can be particularly challenging for shared care centres. The MSN will work with the network of shared care centres in Scotland to facilitate the delivery of treatment within clinical trials as locally as possible, whilst meeting the sponsor’s regulatory requirements.

Whilst the majority of children and young people with cancer are cured, a minority relapse and require novel therapies. Phase I and II trials, involving new therapeutic agents, are organised under the auspices of the Innovative Therapies in Children with Cancer (ITCC) Europe. There are nine ITCC accredited centres in the United Kingdom, one of which is Glasgow. All children and young people in Scotland will have access to new agents available within phase I and II trials, although not all of these trials will be open in Scotland. The MSN will ensure regular communication across the network to all centres, including research nurses, with details of phase I and II trials open to recruitment.

Every child and young adult with cancer in Scotland will be enrolled into and treated on a clinical trial where one is available.

Research and Development

All clinical trials must comply with the European Directive on Clinical Trials. In the UK, it is the responsibility of the sponsor to apply for Medicines and Healthcare products Regulatory Authority (MHRA) and Research Ethics Committee (REC) approval. Each clinical centre must then apply for and obtain ethical approval from its local Research and Development (R&D) department.

At present in Scotland, this involves three R&D offices in Aberdeen, Edinburgh and Glasgow. This is a cumbersome process with considerable variation in the length of time taken by centres to open a clinical trial. The MSN aims to streamline this process by working with an identified Regulatory Administrator and Clinical Trial Coordinator, at one of the R&D offices, to facilitate a pan-Scotland approach that will smooth and speed up the process.

Increasingly trials are extending their upper age limit to recruit young adults into combined trials for children and young adults, particularly where outcomes are superior for patients treated on paediatric protocols. Traditionally, teenagers and young adults are less likely to be treated on a clinical trial than children. The MSN will work with the R&D offices to open trials across the age range at all appropriate sites in a timely manner.

The MSN aims to facilitate the R&D approval for clinical trials for children and young people with cancer in Scotland such that centres open in unison and that all children and young people have access to clinical trials at the same time. The time from notification that central approval has been granted to the trial opening will be monitored and audited.

Education and Training

The first aim of the MSN is to guarantee sustainability of services for children and young people with cancer and this will only be achievable through a well educated and trained workforce. This is a priority for the Scottish Government in all areas of the NHS and across the whole workforce. The MSN will map the training requirement of the workforce discipline by discipline while being mindful of predicted changes in the workforce and pattern of treatment delivery.

Paediatric haematology and oncology is a fast moving field with continuing developments in diagnostic and prognostic indicators and in treatment. Scottish clinicians are at the forefront of some of these developments. Education across the range of disciplines will be delivered through attendance at MDTs, national Mortality and Morbidity meetings and specialist national and international meetings. Discipline specific meetings will identify additional national training and educational needs.

The role of nurses continues to develop as nursing staff assume many roles previously the domain of medical staff. The MSN will promote the continuing extension of the traditional nursing role and the progression to Clinical Nurse Specialist and Advanced Nurse Practitioner level.

Each of the Scottish centres has specific strengths. Doctors training in the specialties of paediatric oncology and haematology will benefit from experience in sub specialist training available at each of the centres. Both nursing and medical staff from shared care centres may spend time at treatment centres for additional experience or training in specialist areas.

Generic training in child protection and paediatric life support remain mandatory for all clinical staff. Training in Good Clinical Practice (GCP), a regulatory requirement for clinical trial participation, will be extended to shared care centres to facilitate local involvement in clinical trials.

The development of e-health as an educational tool will help provide a web based learning facility eliminating the need for travel. E-health will host educational material appropriate to all disciplines. MDT meetings are currently held by video-conference to minimise travel and all educational meetings will have a video-conferencing facility, wherever appropriate, to allow access to all.

Clinical Attitudes

Change always presents challenge and the MSN recognises that achievement of the stated ambitions will be challenging for many clinical colleagues and may require a change in the way that some clinicians have traditionally worked. The MSN is committed to open dialogue, productive challenge and collegiate decision-making. Centres will be expected to support each other, provide clinical advice and training opportunities as necessary. Once pathways of care are agreed, all clinicians will be expected to adhere to them.   Similarly with individual treatment plans or protocols. Through this approach, consistency of patient management will be achieved.

The MSN will also need to be alert to issues of concern arising from this new way of working and will help to broker solutions where this is required, but things will only work if clinicians believe in the benefits of working together. There are some hurdles that will need to be overcome. As mentioned above the MSN will harness technology to support the provision of clinical care and decision making at a distance. It will also provide opportunities for clinicians to meet and train with colleagues from other centres so that any barriers that may exist are broken down.

Communication

The quality of communication that underpins clinical interactions is critical to providing a safe, effective and person-centred environment for patients, parents and carers. The MSN will work with all stakeholders to develop and embed better ways of communicating that ensures the right information is available at the right time to inform clinical decision making. The MSN will support the widespread adoption of the SBAR method of communicating critical information that is being rolled out as part of the Scottish Patient Safety Paediatric Programme and will harness telemedicine to support the work of MDTs.

The MSN will develop easily accessible information for patients and their families using both print and web-based media. To this end, the MSN intends to construct and maintain a children and young people with cancer website to act as a central resource for communicating reliable, targeted information for children and young people with cancer and their families.

The MSN Board will regularly engage with staff, families and partner agencies through a variety of means including site visits, a newsletter and, where appropriate, social media.

The MSN will arrange Scotland-wide educational meetings and will provide opportunities for staff to visit and work in other centres to promote better integration of services across the country. Through all of the above the MSN will deliver a better informed and better connected workforce. This in turn will make care safer and more consistent for patients and their families.

Processes and Structures

Operational Delivery

The MSN will work closely with NHS Boards to ensure the delivery of a single cohesive service for children and young people with cancer in Scotland. At times the service specific priorities of the MSN may conflict with existing priorities for NHS Boards, in relation to workforce requirements or utilisation of supporting systems for example. The MSN Operational Delivery Group, which has clinical and managerial representation from the children's cancer centres, is already in place to anticipate issues and to seek to resolve them in a collaborative way.

Governance and Quality Assurance

To ensure the provision of a quality service on an equitable basis throughout Scotland the MSN will develop standards against which the service can be measured. We will ensure that these relate to comparable international standards for care (see Appendix 1), including those developed for the other UK countries[3] [4].

Outcomes will reflect the Healthcare Quality Strategy[5] in that they will ensure care is patient centred, effective, efficient, timely, and provided in the right place by staff who have the appropriate training and expertise. Through dialogue with clinical and managerial staff across Scotland, the MSN has developed a range of outcome measures which are detailed in Appendix 2.

Assessment of outcomes requires that there is good data recorded for Scotland's patients. One of the priorities of the MSN will be to establish a national database, to allow local entry of data for national analysis. The previous work to agree a minimum dataset will be further developed and refined to answer appropriate questions related to outcomes. This will also allow for international comparison.

The MSN will develop Quality Performance Indicators (QPIs) so that compliance with expected outcomes can be measured. In doing so it will learn from the work undertaken by the National Cancer Quality Steering Group which has developed QPIs for adult cancers and will also seek the support of Health Improvement Scotland in taking forward this work.

The Governance and Quality Assurance Group will coordinate an annual morbidity and mortality review of all patient deaths and clinically significant complications to reduce early toxicity and morbidity and improve outcomes in the longer term. There will also be an annual review of expected deaths to assess palliative care provision.

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[3] (2005) "Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer: the manual" August 2005, National Institute for Health and Clinical Excellence. London. ISBN:1-84629-067-8

[4] (2011) "National Standards for Children with Cancer aged 0 to 15 years", Welsh Government, Cardiff. ISBN: 978-0-7504-6267-9

[5] (2010) "The Healthcare Quality Strategy for NHSScotland" May 2010, The Scottish Government, Edinburgh. www.scotland.gov.uk ISBN: 978-0-7559-9323-9

With the aim of the MSN to provide a nationally delivered service it is important to have consistency of care across all the units. CATSCAN previously developed supportive care guidelines, one for blood transfusion and one for management of febrile neutropenia. These guidelines will be reviewed, their implementation audited and where appropriate, other guidelines will be developed.

The MSN will develop outcome measures against which services can be evaluated.

Survivorship

Today, over 7,000 children and young adults under 24 years old, living in Scotland, have had a diagnosis of cancer and, of those, about 6,000 were diagnosed more than five years ago. With cancer survival rates approaching 80%, the number of cancer survivors is likely to grow by 4% per year[6]. By 2030, it is projected that the population of young cancer survivors will be in the region of 11,000, constituting 1 in 100 of the young adult population[7].

Completion of treatment for primary cancer does not signify the end of the journey for these young people, many of whom are at increased risk of morbidity and mortality[8]. Following cancer treatment, it is reported that about two thirds of survivors of cancer in childhood and adolescence, have at least one physical or psychological problem affecting their health and well-being and around one quarter have had a severe or life threatening late complications of therapy. Greater awareness of these problems dictates the need for vigilant long-term follow-up of survivors, with early intervention, treatment, and appropriate counselling. There is no available evidence to define an optimum model of follow-up for long-term survivors, and there is currently wide variation in the time that survivors are discharged from follow-up clinics. Indeed many survivors are followed up in paediatric oncology clinics long into adulthood. In addition, there is increasing recognition that current practice, in many cases, does not meet the psychological or social needs of survivors.

The MSN intends 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. The Survivorship Initiative, led by the Clinical Lead for Late Effects, aims to improve services for survivors by developing a risk-based approach[9] [10] [11] to follow-up, in an age-appropriate environment, with the introduction of key workers and nurse-led services, supported by a web-based electronic system. This service will provide health surveillance, together with psychosocial support and education of survivors to encourage them to develop into independent adults.

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[6] Cancer Research UK. Childhood Cancer - UK Statistics. Cancer Research UK; 2004. http://info.cancerresearchuk.org/cancerstats/childhoodcancer/

[7] Campbell J, Wallace WH, Bhatti LA et al: Cancer in Scotland: trends in incidence, mortality and survival 1975-1999. Edinburgh. Information & Statistics Division; 2004. www.isdscotland.org/cancer_information

[8] Oeffinger KC, Eshelman DA, Tomlinson GE et al: Grading of late effects in young adult survivors of childhood cancer followed in an ambulatory adult setting. Cancer 88:1687-1695, 2000.

[9] SIGN Guideline 76 on Long Term Follow-up of Survivors of Childhood Cancer, Scottish Intercollegiate Guidance Network 2005.

[10] Wallace et al, Developing Strategies for Long Term Follow Up of Survivors of Childhood Cancer. BMJ 2001;323;271-274.

[11] Therapy based Long-term follow-up. Practice Statement. UK Children's Cancer Study Group, Late Effects Group. Editors Skinner R, Wallace WHB, Levitt GA. 2nd Edition, 2005.

A recent Scottish study has shown that therapy-based, risk-stratification of long-term survivors of childhood and teenage cancer can safely predict which patients are at significant risk of developing moderate to severe side effects and require high intensity long-term follow-up[12]. Furthermore, it has been identified that the development of a nurse-led service, supported by the Late Effects MDT, with protocol driven health surveillance, would be appropriate for more than half of survivors. The MSN has recently appointed a National Late Effects Clinical Nurse Specialist to scope the requirements for the development of a nurse-led service.

The MSN is committed to the introduction of an integrated and systematic approach across Scotland, developing models of care to ensure that those living with and beyond cancer have access to safe and effective care and receive the support they need to lead as healthy and active a life as possible[13]. Improved awareness of cancer survivorship as a chronic health problem will facilitate the development of care pathways that will meet the needs of every patient throughout their lifetime.

Long term follow up services must be flexible enough to accommodate the needs of young survivors as they grow older and their differences, reflecting the wide range of treatment exposure and adverse long-term sequelae. Development of a service that can deliver individualised, comprehensive, therapy-based care is essential. The Late Effects Clinical Nurse Specialist will play an integral role in this service.

Improved communication of cancer information to patients and their families and between health care providers may contribute to greater engagement in follow-up programmes. It also raises awareness of potential late effects amongst survivors and enables clinicians to diagnose and, where possible, treat late effects earlier. Based on national guidelines, we have developed a template for the End of Treatment Summary and Individualised Care Plan, or ‘Health Passport’, which was introduced nationally in January 2012, and welcomed by health professionals and survivors.

Stratification of patients according to risk of late morbidity will make best use of NHS resources and provide age appropriate care as locally as possible. With increasing time from completion of treatment, it is hoped that the majority of adult survivors will be independent and take responsibility for their own health, with health care support provided by their primary care physician and with a readily identifiable pathway back in to the hospital system when indicated. As a result, the primary care team is likely to play an increasing role in the long-term follow-up of survivors of childhood cancer. Good communication between the hospital services and primary care will be essential. The introduction of the web-based personalised care plans will facilitate the long-term care of survivors by family doctors[14].

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[12] Edgar AB, Duffin K, Borthwick S, Marciniak-Stepak P, Harrison S, Haywood M, Wallace AH. Intensity of long term follow up for survivors of childhood or teenage cancer can safely be determined by therapy-based risk-stratification. (Submitted January 2012)

[13] Models of care to achieve better outcomes for children and young people living with and beyond cancer. National Cancer Survivorship Initiative. Children and Young People Workstream. http://www.ncsi.org.uk/what-we-are-doing/children-young-people/

[14] Blaauwbroek R, Barf HA, Groenier KH et al: Family doctor-driven follow-up for adult childhood cancer survivors supported by a web-based survivor care plan. J Cancer Surviv. 2011 [Epub ahead of print].

Structured, risk-adapted follow-up of childhood cancer survivors, following evidence-based guidelines would reduce unnecessary evaluations and focus individual health care delivery. Education of survivors and health care providers will reduce the burden of chronic health problems and improve quality of life for the growing population of children and young people who have been treated for cancer.

The MSN will introduce an integrated and systematic approach to long term follow-up based on risk.

Teenagers and Young Adults

The MSN is committed to ensuring that a strategy is developed for teenagers and young adults with cancer in Scotland which is consistent with approaches adopted in other UK countries. A pan-Scotland teenagers and young adults' service will ensure that all young people will have access to age appropriate care.

Standards of care will be developed as will the development of a national Multi-Disciplinary Team (MDT) for the discussion of all teenage and young adult (TYA) cancer cases. The TYA MDT will ensure a holistic approach to care, which is sensitive to the needs of this age group.

The MSN will work with key third sector partners, including the Teenage Cancer Trust and CLIC Sargent, in the development of age-appropriate services for young adults, including making recommendations on age.

The MSN will develop services appropriate to the needs of teenagers and young adults up to age 25.

Palliative Care

Any diagnosis of cancer in a child or young person is a Life Threatening Illness (LTI). Fortunately medical advances over the last 50 years now mean that 70% of children and young people are cured. However, this still means that 30% of children and young people in Scotland who are diagnosed with cancer will die of this disease or a second cancer. The requirement for palliative care may therefore be identified at the point of diagnosis or may become apparent as the health of an individual patient deteriorates, or the care requirements and need for symptom control increase.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both the child or young person and their families/carers at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage.

Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of the child or young person and their parent or carers facing progressive illness and bereavement.

Furthermore, the child or young person can move in and out of palliative care because of successful medical interventions. This clearly applies to the child or young person with cancer where the main intent of treatment is cure but where we have to ensure in every case that treatment of distressing symptoms caused by the cancer or the treatment are managed appropriately.

Children and Young people with cancer will be diagnosed within appropriate secondary, tertiary and quaternary children's services in Scotland and they will receive much of their ongoing care within these services. The stages of the treatment journey each child and family travels is outlined in Figure 2.

The MSN will ensure that palliative care is embedded in all stages of the child or young person's illness and care. The Scottish Children and Young People's Palliative Care Executive (SCYPPEx) group has recently developed a framework for palliative care services for children and young people[15] which includes a self check assessment. The recommendations outlined within the Framework should apply equally to primary, secondary and tertiary care. The MSN supports the use of the Framework for those children and young people with a diagnosis of cancer.

Although treatment for Cancer in children and young people is ever more successful approximately 30% of children and young people will die of their cancer or as a result of a complication of their treatment. There is accumulating evidence that children young people and their families express a preference for death at home or at least close to home. This is different from where they wish to receive curative treatment which is at tertiary facilities which offer the best chance of cure[16].

Statistics for Scotland demonstrate that, overall, the majority of children die in hospital. This is despite the preference for home death in patient and parent surveys. There are many explanations for this which require to be explored to ensure that lack of local facilities and services is not the main cause.

Providing end of life care to children or young people who have been cared for in a very intervention oriented hospital environment is a challenge but by following the principles and guidance in the Framework document this challenge can be addressed.

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[15] Framework for Palliative Care Services for Children & Young People – Final Draft (to be published)

[16] Progressive Cancer:A Study by Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. J Vickers Et Al *J Clin Oncol 25:4472-4476. © 2007 by American Society of Clinical Oncology*

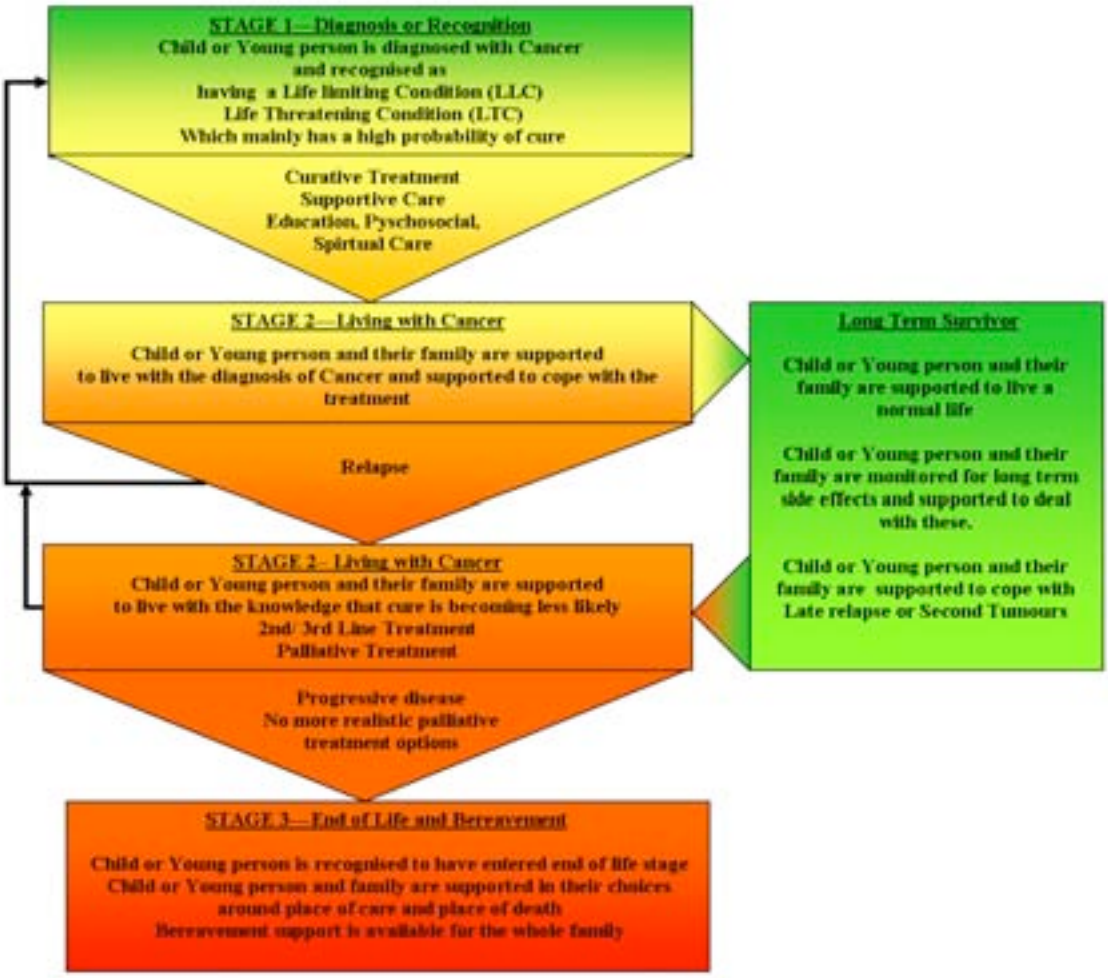

Figure 2: Stages of Journey for Children and Young People with Cancer

Good palliative care is a vital part of oncology care, and as such, the MSN recognises and supports the continuing requirement for a Clinical Lead for Palliative Care. It is important that palliative care for children and young people with cancer is seen as part of an overall cancer treatment. By joining forces with other subspecialties common needs will be more likely to be met. It is essential that there is a good network developed between primary, secondary, and tertiary care, to ensure that children, young people and their families have access to the right care in the right place at the right time.

The MSN will introduce and support the development of the Framework for Palliative Care for Children and Young People.

Care Pathways and Disease-Specific Considerations

Developing a blueprint for care of individuals and, at the same time, generating a plan for overall care pathways, is one of the major tasks the MSN faces. The plan will require effective use of finite resources, clarity of organisational structure and coordination of, and collaboration by, all those involved. It will also require an assurance process with a continuous feedback loop to maintain quality. Responsibilities, expectation and leadership need to be explicit from the outset. Pathways must provide consistency, context and reference but not be so inflexible as to create barriers.

Existing Care Pathways

Provision of care must be founded on a number of principles, including:

- Consistency in access irrespective of social, economic and cultural background or location.
- Local care, when possible and if preferable, but access to specialist care when required.
- Clinical, social, and psychological support at every stage, in every place.
- Timely access to specialist assessment, diagnostic investigation and interdisciplinary team management.
- Every opportunity for involvement in clinical trials.
- Continued surveillance post-treatment, as required.
- Continuum in quality from primary to tertiary care.

Care Pathways also have to accommodate a number of additional factors, including: Condition specific considerations; the need for family and social support; choice – of patients and their parents; centre capacity and availability and the requirement to access clinical support services.

Pathways within Scotland

Pathways are already developed and, if functional and satisfactory at present, should be evaluated for their sustainability, but no assumption will be made about retention of existing facilities and workforce. The MSN needs to be vigilant and sensitive to the numerous pressures, drivers and changes which affect the availability and style of the existing service. Additionally, the MSN should determine future care pathways based on feasibility and practicality of their ability to deliver according to need.

At present, these pressures include:

- Increasing and proper emphasis on a consultant delivered service;
- reducing numbers of specialist registrars in paediatric specialties;
- regulation of working hours for both trainees and consultants;
- increasing regulation of entry conditions into clinical trials;
- continuity of service 24 hours each day and 365 days a year; and
- sustainability of the consultant workforce.

Criticisms of existing care pathways surround their evolution which has less to do with health care strategy or premeditated clinical consensus but more, that they have been opportunistic and often forged through the informal contact of the clinicians involved. If effective, then that model may be acceptable. Equally it may reflect a lack of consistency, cohesion and congruence and be potentially at odds with the delivery of other pathways and responsibilities within the same health care systems.

Some children and young people currently receive different elements of care in different Health Board areas, for example, the same child in Dumfries may access endocrinology in Edinburgh, chemotherapy in the Royal Hospital for Sick Children, in Glasgow and have neurosurgery in the Southern General Hospital, in Glasgow. This example, might suggest inconsistency and lack of continuity unless very carefully managed. Similarly, one child/young person from Highlands can have surgery and chemotherapy for a solid organ malignancy in Aberdeen and the next child/young person having leukaemic care will be managed in conjunction with Glasgow. These arrangements subject referring clinical staff, particularly nursing staff, to a range a different policies and practices, for example, in central line care, adding unnecessary complexity to their duties.

Care Pathways are therefore less about where care is delivered than they are about the need for consistency in standards and policies and crucially, real-time decision-making, implementation and recording.

The MSN through its governance and quality assurance work stream will maintain scrutiny and change as required on grounds of quality or as directed by evidence-based information.

Pathways out of Scotland

Referral outside Scotland is condition specific and is usually provided within a national contract agreed by National Services Division (NSD) with UK and other specialist commissioning and provider units. These conditions and treatments are highly specialised and access to such is tightly controlled through NSD. These pathways include referral to Birmingham Children's Hospital for Retinoblastoma; referral to Kings College, London for Liver Tumours and referral to University of Florida in the USA as part of a UK agreement for Proton therapy.

The MSN will ensure that the care integrates with care plans available within Scotland and receives congruent and collaborative management.

The impact on children, young people and their families of a referral to a hospital remote from home – either in England or abroad – is enormous. As a result it is important that the clinical benefits to the child or young person of such a referral outweigh the disruption to the child and family. The MSN will work with NSD to ensure clear, consistent, care pathways for such referrals, which are integrated with services close to the patient’s home, and which ensure the involvement of further expert clinical opinion to supplement and confirm the initial assessment. The MSN will support this process through the governance and quality assurance committee.

Pathways – future developments

Future developments of care pathways will seek to ensure both accurate and rapid diagnoses, reduce the burden of treatment and produce outcomes from care that are equal to the best available.

Preparatory work, instigated by the MSN through a review of existing sites and services, suggests little redundancy either in terms of workforce or indeed of the existing facilities. The MSN is also mindful of the plans for new builds of RHSC Edinburgh and Glasgow. Those plans, now well underway, need to assure the existing capacity as a minimum for cancer services, to avoid any unintended consequences to care plans and unintended changes to referral practices over the short to mid-term.

Mitigation against disruption of the service will be best achieved by clarity around expected and accepted pathways.

The MSN is also mindful of the parallel work being done by the MSN for Neurosurgery and close cooperation between that MSN and the MSN for Children and Young People with Cancer to design and assure appropriate pathways for neuro-oncology will be essential.

Clinical leadership and coordination are key to the success of any care pathway, the more complex, the greater the need. A good support system requires flexibility and consistency in equal measure. These apparent contradictions exemplify the complexity that cancer care involves, but it is crucial that the MSN does not recreate a “paternalism" that has little place in clinical behaviours. A facility to customise and individualise care, provide for the exceptional yet produce consistency, is a challenge.

The following will be essential ingredients of the care plan that each child and young person receives:

- A key worker;
- Consistent care from primary through shared care to the primary treatment centre
- support for family;
- Recognition and appreciation of the role of charities and voluntary sector;
- Coordinated and careful follow-up;
- Care informed by international research and treatment options;
- Ongoing planning informed by outcome analysis;
- Predefined journey for each child and young person from presentation and referral through diagnoses, treatment, supportive care, rehabilitation and palliation, when required.

The MSN will impose no boundaries or limits in the pursuit of a cure, but when palliation is required, every avenue will be explored to ensure care at home, where that is what is needed.

The MSN will review existing Care pathways to ensure that these deliver consistent, safe and effective care for all patients.

Interfaces and Interdependencies

The third sector plays an important and increasing role in the support of children and young people with cancer and their families. There are, however, a wide range of nationally and locally based organisations and the MSN is committed to engaging at different levels, as appropriate. Some third sector partners, particularly CLIC Sargent and the Teenage Cancer Trust also provide funding for specific posts and services, which is extremely important in the delivery of holistic care to children and young adults.

The MSN is keen to engage with all relevant organisations and will explore how this can best be achieved to ensure involvement across the scope of the MSN.

The MSN will ensure involvement of third sector partners in key decisions about services for children and young people with cancer.

Patient and Parent Involvement

The MSN needs to gain insight into the service across Scotland through the experiences of patients and their parents or carers which reflect current services. Representation of patients and their families will be important throughout the MSN framework.

CATSCAN had particular success, through the work of parent representatives in the development of accessible and appropriate pre-treatment DVDs aimed at children. The MSN will build on this success and will seek to engage across Scotland, and provide support for those who seek to represent the views of service users.

The MSN will harness the experience of patients, and their parents or carers, to inform the shape of services for children and young people with cancer.

Workforce

Key to sustainability will be an appropriately skilled and available workforce, trained to deliver the best treatments. Care will be delivered by teams, within and between different centres in Scotland. The MSN will need to ensure that there are sustainable skills and competencies within individual centres and that the overall aim of the MSN can continue to be delivered. This will include providing oversight of all medical appointments and ensuring that services for children and young people with cancer are supported by appropriate workforce plans.

Funding

Through the National Delivery Plan for Specialist Services[17] £3.2m of additional investment has been made in cancer services for children and young people, with the majority, (£2.4m) going into supporting front line services. There has also been further investment in the National Bone Marrow Transplant Service in Glasgow and in the Edinburgh service to ensure that it can provide the level of service expected of a Principal Treatment Centre.

A small amount of funding was allocated to Scotland-wide initiatives identified elsewhere in this plan, including funding of key clinical leadership posts and the Late Effects, Palliative Care and Teenagers and Young Adults projects.

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[17] (2009) “Better Health, Better Care: National Delivery Plan for Specialist Services for Children and Young People” January 2009, Scottish Government, Edinburgh. RR Donnelly B57674 01/09. Referred to hereinafter as ‘The NDP’.

How will we demonstrate success?

Improved Outcomes

The ultimate outcome for the treatment of a patient with cancer is survival. However, the relatively small number of new patients diagnosed each year in Scotland and the diverse nature of the cancers make changes in survival difficult to measure, as the effect of any change in treatment may take a number of years to become apparent. It is therefore important to have other measures to assess quality of care and these may ultimately lead to improvement in overall survival and the quality of that survival.

The MSN has already developed a small number of outcome measures, which will be used to evaluate the service and demonstrate improvement (Appendix 2). The measures will review the organisation of care, referral to treatment, patient centeredness, MDT working, stages of the disease process, rehabilitation, survivorship and palliative care.

Earliest diagnosis

Any delay in diagnosis may potentially allow spread of the cancer. The MSN will link with colleagues in primary care and secondary care to explore times when there may be delay in referral or diagnosis and if there are interventions which may improve this.

Access to the right care at the right time

The MSN will develop pathways of care so that every patient will have access to the appropriate specialised care at both diagnosis and later in their management.

Consistency

By delivering the service on a national basis and having supportive care guidelines, the quality of care for an individual patient will be the same, irrespective of where they are treated. Emphasis will be placed on improved communication between the various units treating the patients. This will include the use of shared information on an electronic basis.

Sub-specialisation

It is recognised that certain patients will have to be referred out with Scotland for optimal care. There are nationally agreed referral arrangements for patients with retinoblastoma and with liver tumours requiring surgery, and more recently international referral for proton therapy.

Access to trials

The MSN will deliver equity of access to clinical trials irrespective of geography and age. Recruitment by trial availability across the age range will be monitored and audited.

Appropriate transitions

The majority of children and young people with cancer will become long-term survivors. It is important that both the treatment and follow-up is in a setting appropriate to their age group. The survivorship program will be integral to ensuring appropriate transition for all patients.

Academic and research profile

NHS Scotland has a long tradition of research and academia and a strong teaching ethos. Edinburgh has a Chair of Paediatric Oncology and Glasgow the only full time academic paediatric haematologist in the United Kingdom.

Scottish paediatric cancer centres have been, and will continue to be, strong supporters of clinical trials and of translational and basic research. The MSN acting as a single service for children and young people with cancer in Scotland will encourage and facilitate national research from a wider population base than previously available to any individual centre. A national paediatric cancer research forum will be established with membership encouraged not just from paediatric haematology and oncology, but from the paediatric subspecialties with which cancer interfaces and from adult leukaemia and cancer researchers. It is expected that the Chief Scientist Office will be supportive. The non–clinical trial research portfolio should include basic, translational and clinical research and reflect the interests of a multidisciplinary specialty and the entire age range.

Quality of life issues and late effects are assuming increasing importance as outcomes improve. Scotland has an international reputation in the management of the late effects of chemotherapy, particularly in the area of fertility preservation lead by Professor Hamish Wallace. The SIGN Guideline on the Long term Follow-Up of Survivors of Childhood Cancer (2004) is currently being updated. The haematology molecular laboratory at RHSC, Glasgow has been and remains one of a small number of paediatric laboratories active in translational research, mainly in the field of minimal residual disease, which is now used to risk stratify childhood leukaemia, allowing the tailoring of treatment and the limiting of side effects.

The MSN recognises the importance of a strong research ethos to medical trainees and for retaining and attracting a high calibre workforce to Scotland.

Links to the UK and EU

The prime aim of the MSN is to achieve the best possible outcomes for children and young people with cancer throughout the patient pathway and comparisons require the collection of robust data. Data collection is important both for comparison of outcomes and incidence analysis. The MSN will strengthen links with the Information Services Division (ISD), NHS National Services Scotland to ensure data collection continues to be of the highest possible standard and that the data collected allows meaningful comparisons. ISD exchanges information with UK wide organisations, such as the National Cancer Research Network (NCRN), National Cancer Intelligence Network (NCIN), National Cancer Research Institute (NCRI) and historically, has done so with their predecessors. This is a valuable relationship which allows comparisons of Scottish outcomes by cancer type with those of the rest of the UK. UK organisations in turn link with the European Network of Cancer Registries, which provides wider comparisons. All cancers in children and young people are rare compared to adult cancers and the MSN recognises that interpretation of comparisons may be limited by small numbers.

The MSN will ensure equity of access to the best possible care and will strive to improve outcomes for children and young people with cancer in Scotland.

What this means for NHS Boards

Access to patient centred, safe and effective care is a priority for all territorial Boards. The National Delivery Plan, which provided front line funding for many specialist children's services across Scotland recognised that:

> "the need for children to be able to access specialist care is self evident. The challenges faced in providing such care are very real, not least because the number of children requiring highly specialist care within any given specialty is often small…[18]
>
> "…this…is not just about hospital provision, it is about improving the care of children and young people through a network of services working together."[19]

Through establishment of the single service for Scotland, which the Managed Service Network for Children and Young People with Cancer has been set up to deliver, NHS Boards can be assured that services will be safe, effective and most of all patient centred.

The MSN does not exist as an independent entity but is a vehicle of the NHS Boards, Scottish Government and a variety of interest groups to ensure that the care for children and young people across Scotland with a diagnosis of cancer is optimal. To deliver care as a single service the MSN will be the vehicle through which these interfaces and interdependencies will be identified and addressed.

Where necessary, the MSN will facilitate Service Level Agreements (SLAs) between service providers, such as the SLA agreed between NHS Greater Glasgow and Clyde and NHS Grampian to provide support in times of exceptional need. The MSN will broker such arrangements as are necessary to ensure one virtual service across Scotland.

There are a number of specific actions for NHS Boards to ensure that the ambitions of this plan will be delivered.

- The MSN for Children and Young People with Cancer is jointly accountable to Scottish Government and territorial NHS Boards. NHS Boards must commit to the MSN and work with it to achieve the service improvements required.

- NHS Board representation at the MSN Board and on the Operational Delivery Group, will ensure that NHS Boards can shape the service development within the MSN and that those decisions can be given operational effect within NHS Board services.

- Clinicians within NHS Boards are key to the success of a single service for Scotland. Recognising that any change in the way services are planned and delivered will impact on the daily working lives of clinical

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[18] (2009) "Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland" p 2, January 2009, Scottish Government. www.scotland.gov.uk. RR Donnelley B57674 01/09

[19] Ibid, piii

staff, within Boards. NHS Boards will be expected to work with the MSN, through the Board and the various sub-groups to influence these changes and to ensure that, when agreed, these are given operational effect within Boards.

- In establishing the MSN, Scottish Government and NHS Scotland agreed that the MSN Board should have oversight of key appointments, particularly in relation to senior clinical staff. NHS Boards must ensure that the MSN Board is involved in decisions in relation to the recruitment and replacement of senior medical staff involved in delivering cancer care to children and young people.

- NHS Boards must ensure that their data collection systems are robust and can provide the data required to monitor care of children and young people with cancer.

Appendix 1

International Comparators

The MSN board has made contact with a number of clinicians in other countries. International literature has also been reviewed. Responses and particularly helpful comments have been obtained from New Zealand and Scandinavia and we would wish to acknowledge the contributions made by other countries to our proposed design for our MSN.

Whilst the experience of paediatric oncology services in other countries is an important influence on how the Scottish service should operate, there are necessarily limitations on this influence. The differences between Scotland and many other countries are easier to identify and articulate than are the similarities.

The main differences which distinguish Scotland from other international models surround:

- The low volume of cases per year.
- The distribution of the Scottish population in relation to the landmass (>50% of the population is contained within 3 health board areas).
- The uneven distribution of resources (2 large University children's hospitals 50 miles apart).
- Challenges of climate and geography and hence, travel.
- Quality of national clinical databases.
- The link between general practice and paediatric specialties.

Based on these elements, several countries stand out as important exemplars and sources of experience.

Norway

With a population of 4.7 million people containing 975,000 children under the age of 16, Norway is divided into 4 geographical and administrative health regions (Southeast, West, Middle, and North) with one serving University Hospital in each region. 55% of the population live in the south-eastern health region but all 4 regions treat their own children with little in the way of cross regional flow (with the exception of the densely populated Stavanger region (Rogaland) which is traditionally referred patients to the National Hospital in Oslo instead of Bergen to which the patients geographically belong. This has historic, logistical as well as political reasons).

Reports to the Norwegian Cancer Registry are compulsory and there are regular national meetings between paediatric oncologists and other clinicians to exchange experience and ensure common practice. Divergence in treatment strategies between the regions are infrequent and although adherence to protocol may theoretically vary there is an extensive collaboration between centres and frequent use of second opinion reviews by pathologists.

Sweden

Sweden has consolidated paediatric care in recent years by merging smaller hospitals and devising "chains of care" to ensure integration across community, primary and specialist care. First access is provided by general practitioners trained in paediatrics working closely with paediatricians and children's nurses in local health centres. The model of co-locating general practice and paediatrics in health centres could potentially make an impact upon the early diagnosis of childhood cancer in Scotland and has implications for multidisciplinary education including primary care.

The Netherlands

Holland has a general practice system similar to the UK but it operates within a "transmural" system designed to bridge the gap between primary and secondary care. A near universal youth service provides a range of services to children from birth to 19 years including health promotion and disease screening. The service supports education and exchange of shared guidelines and the jointly managed service between primary care and paediatricians has direct incentives to cooperate.

Canada

With scale and a widely distributed population being a major challenge, children's Cancer services in Canada are delivered from 17 different centres to accommodate their 1300 new cases of cancer per year in children under age 18. The directors of these 17 treatment centres constitute "C 17" the Council of Directors and it is this body that ensures that research, education, communication and engagement is consistent across Canada. Whilst each clinical unit functions in an individual fashion, policies and programs are consistent as is commitment to trial entry, (C 17 has 185 clinical trials open as members of COG (Children's Oncology Group). Trials are approved by Health Canada and C 17 enjoys strong educational grant support with regular substantial charitable donations to the C 17 council which is able to effect a pan-Canada oncology service in spite of the geographic challenges posed by its landscape and climate. A frequently unrecognised feature of the Canadian population is its ethnic mix with 19.8% of the Canadian population being immigrant adding the additional feature of diversity into the challenges posed to the clinical service.

New Zealand

The National Health Board and Ministry of Health has produced a National plan for children's cancer services in New Zealand which is the first national service plan to be developed. This plan has responded to increasing subspecialisation, quality and safety concerns and has resulted in consolidation of specialist oncology centres from 5 throughout the country in 1995 to 2 by 2011: one in North Island (Auckland-100 cases per year) and one in South Island (Christchurch, with shared care with Wellington-50 cases per year). Like Scotland, the service has approximately 150 new cases of cancer diagnosed per year with just over 300 children receiving active therapy at any point in time. The service was considered vulnerable because of the small paediatric oncology workforce available and the need for service reconfiguration was highlighted with the un-planned closure of a regional service destabilising services in South Island.

The New Zealand model formalises shared care arrangements and plans to develop a national clinical network built on the foundation of the existing paediatric oncology steering group. The balance between minimum numbers for a viable unit, maximizing clinical outcomes, minimizing disruption to family, and ensuring access of all patients to a consistent and high level of care are all key considerations and objectives of their network.

Several messages emerge from these countries which are relevant if not important items for our service. Pointers can be taken from each as follows:

- Provider volume is not itself the sole proxy of quality of care in paediatric oncology.
- The link between primary and secondary care is key to early referral and collaborative working.
- GP training in paediatrics and making the” first point of contact” as expert as possible is a key educational objective.
- Achieving consistent policy and practice in the face of differing geographies problems and experiences requires collaboration best served by integration into a single service network.
- Investment in today's trials produces tomorrow's optimal outcome treatments.
- Most centres in the world have too few patients to conduct large studies; international collaboration between sites is a prerequisite.
- Commitment to a national database is essential in order to facilitate outcome analysis on the mid to long term and provide the requisite assurance of quality of care.

Just as the MSN aspires to represent the component parts of the service within Scotland, so is it important that its horizons are sufficiently wide to encourage collaboration with not only our immediate neighbours in the United Kingdom but also with international collaborators. There is relatively little collaboration between North America and Europe and the MSN should seek collaboration in clinical provision and trial and research enterprises on an equitable basis with all willing partners.

Outcome Measures for Children and Young People with Cancer in Scotland

The Outcome Measures for children and young peoples' cancer care in Scotland have been developed through dialogue with clinical and managerial staff across Scotland. They relate to comparable international standards for care, including those developed for the other UK countries, and they reflect the NHS Scotland Healthcare Quality Strategy ambitions to deliver patient centred, safe and effective care, provided in the right place by staff who have the appropriate training and expertise.

Performance Indicators will be developed in order to measure compliance with the Outcome Measures.

1. OUTCOME: Organisation

The Managed Service Network (MSN) for Children and Young People with Cancer will bring together key stakeholders involved in the planning and provision of cancer care, in an open and transparent management structure.

Key Objective
1.1. The MSN will define care pathways for the management of all children and young people in Scotland with cancer.
1.2. The MSN will be constituted to ensure representation across Scotland and across the various disciplines involved.
1.3. The MSN will appoint a National Clinical Director supported by clinical leads for: 1.3.1. Governance and Quality Assurance 1.3.2. Palliative Care 1.3.3. Survivorship 1.3.4. Teenagers and Young Adults
1.4. Governance and Quality Assurance: 1.4.1. Organisational Governance 1.4.2. Clinical Governance which will include: • Setting standards and measuring compliance • A quality assurance process
1.5. The MSN will produce a Cancer Plan periodically and an annual report.

2. OUTCOME: Initial Referral to treatment

All Children and Young People diagnosed with Cancer must be referred, diagnosed and treated in a timely and appropriate fashion. The majority of children and young people with cancer have acute or rapidly progressing disease which requires prompt diagnosis and treatment. For certain types of cancer the definitive treatment policy is initial surveillance with specific anticancer therapy deferred until such time as it is clinically indicated.

Key Objective
2.1. The MSN will agree referral guidelines for use by the national MDTs and treatment centres that are in accordance with best practice guidelines.
2.2. The MSN will determine and monitor the referral pathways for children and young people with suspected cancer from whichever point they access the system.

3. OUTCOME: Patient Centred Care

All Children and Young People diagnosed with Cancer, and their parents or carers will have support and all the information they require regarding the diagnosis, treatment options and treatment care plan. Patient, and parent or carer, choice should be delivered wherever possible. Appropriate support will be available to ensure children, young people and families can carry on with as normal a life as possible whilst having treatment for cancer.

Key Objective
3.1. The MSN will ensure that the referring clinician informs the child/young person (where appropriate) and their parents or carers of the possibility of a diagnosis of cancer prior to transfer to a treatment centre.
3.2. The MDT advising on diagnosis and management, through the Responsible Consultant must ensure that all decisions about diagnosis and management are fully communicated to the child/young person (where appropriate) and their parents or carers in an appropriate way.
3.3. Treatment centres and shared care units must communicate about diagnosis and management decisions in real time between themselves and primary care. The direction of flow of information will be determined by the consultant making the decision.
3.4. Children and young people will have access to age appropriate facilities and age appropriate multimedia information.
3.5. Parents and carers will have access to appropriate facilities to stay with their child and will have access to appropriate multimedia information.

4. OUTCOME: Multidisciplinary Teams

All Children and Young People diagnosed with Cancer will be discussed within a National MDT setting which will ensure that all cancer care for children and young people is provided by specialist multidisciplinary teams locally. Care provided by teams should be well co-ordinated to provide an efficient, effective and safe service to all patients, which is age appropriate.

Key Objective
4.1. There will be National MDTs for: 4.1.1. Leukaemia 4.1.2. Solid Tumours including Lymphoma 4.1.3. CNS tumours These will convene and operate as agreed by the MDT Project Board.
4.2. There will be appropriate national arrangements, including national MDTs if necessary, for: 4.2.1. Palliative Care 4.2.2. Survivorship 4.2.3. Teenagers and Young Adults These will convene at an appropriate frequency to deliver care effectively, and will vary.
4.3. The National MDTs' decisions will be communicated to the Treatment Centres and Shared Care units who will then deliver care locally via local MDTs which will include management and supportive care.
4.4. The Lead Consultant for each patient will have the overall clinical responsibility for delivering care for that patient.

5. OUTCOME: Diagnosis, Staging and Treatment

Children and young people with cancer should be diagnosed, staged and treated promptly and in line with nationally agreed best practice guidelines and/or appropriate national/international clinical trials.

Location of treatment should ensure that the best treatment is delivered at all times but taking into account that some treatments and supportive care may be possible at shared care units. This should be delivered by appropriately trained staff who have the required expertise (for some highly technical or novel treatment this may mean treatment outside Scotland).

Key Objective
5.1. **Diagnostics** All Children and Young People with Cancer will have access to high quality diagnostic services e.g. pathology, genetics, radiology, haematology, biochemistry etc where and when they need them.
5.2. **Surgery** All Children and Young People with Cancer will have access to high

quality surgical services whatever the subspecialty required.
5.3. **Radiation Oncology** All Children and Young People with Cancer will have access to high quality radiation services.
5.4. **Paediatric and Clinical Oncology** All Children and Young People with Cancer will have access to high quality Chemotherapy and Pharmacy services.
5.5. **Support Services** All Children and Young People with Cancer will have access to high quality support services including PICU, HDU, Psychological services, Pain management etc.

6. OUTCOME: Rehabilitation

All Children and Young People with Cancer will have access to high quality rehabilitation services which will maximise their capabilities.

Key Objective
6.1. All Children and Young People with Cancer will have access to high quality rehabilitation services which will maximise their capabilities.

7. OUTCOME: Survivorship

All Children and Young People with Cancer will have access to high quality long term follow up care.

Key Objective
7.1. All Children and Young People with Cancer will have access to an integrated and systematic approach to long term follow-up.

8. OUTCOME: Palliative Care

All Children and Young People with Cancer will have access to high quality palliative care needs at all times and in every setting. This will include care of dying patients, their families and carers.

Key Objective
8.1. The framework for Palliative Care for Children and Young People in Scotland will be used to provide Palliative Care for children and young people with cancer in Scotland to ensure equitable, safe, effective palliative care for patients and families where and when they require it.

The Scottish
Government

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