

An update from the Co-Chairs

The last few weeks has seen activity on several fronts in the MSN executive, but most importantly amongst these has been preparation for our next Cancer Plan which will cover the time period 2016 through to 2018. The Plan will highlight some of the lessons learned in the first three years of the MSN and, in particular, the challenges of executing a model of care that is designed and implemented at a national level.

The next few years offers promise through the provision of precision or personalised medicine. **Proton beam therapy** will also become available within the United Kingdom from 2018 saving families having to travel to the USA (France, Switzerland, Germany or Czech Republic). Our registration database goes live this year and the work being led by Professor Hamish Wallace on survivorship is making significant progress in improving the management and support for those children, teenagers and young adults who develop after effects of their treatment. In addition, the appointment of clinical nurse specialists and an MDT co-ordinator for the TYA group will help implement advances in care for this age range.

At the same time as our cancer specific work is being undertaken, the MSN is also mindful of ensuring that we integrate other national initiatives such as the patient safety programme as part of the **Maternity and Children Quality Improvement Collaborative (MCQIC)** and the continuing legislative progress of **Getting it Right for Every Child (GIRFEC)** into our work programme. We are also keen to minimise variation in care delivery across Scotland by emphasising the need for consistency in policy and practice. There is nowhere where this is more important than in the prescribing and delivery of chemotherapy. The MSN is currently working with eHealth colleagues and the National Services Division (NSD) to explore the potential for a national electronic chemotherapy prescribing and administration system to support this aspect of care.

The **MSN website** has now been launched and is being used by a wide range of individuals. Perhaps the heaviest use has been in those areas associated with social media, whereas our blog pages, designed to help patients and parents share experiences, have yet to achieve their full potential. Any 'handy tips' for patient and/or their families should be placed **on this part of our website**.

Scottish government is involved in an engagement exercise in palliative care as the next phase following on from the **"Living and Dying Well" initiative**. The paediatric aspects of palliative care are featuring prominently in that consultation process. Our close association with third sector partners such as **CHAS** strengthens the advice and recommendations which will be used to shape the future configuration of palliative care services for children, teenagers and young people.

There is a significant amount of work outstanding on our ambition to have a single centre approach to clinical trial entry. This would simplify matters for our researchers and would facilitate entry into trials for all age groups and would address the current situation where many of our teenage group do not have the benefit of participation.

So, the MSN has its work cut out but we continue to focus on our aim of creating a sustainable and effective service for children, teenagers and young people with cancer in Scotland. Your support and the support of all concerned in making this ambition a realistic goal is really appreciated.

George Youngson Iain Wallace

New Appointments The MSN Team welcome new members Dawn Crosby, National Network Manager; Jane Belmore and Bernadine Wilkie, National Clinical Nurse Specialists for Long Term Follow-up of Survivors of Childhood and TYA Cancers, and Marnie Goldsmith, Teenager & Young Adult MDT Co-ordinator. **List of Managed Service Network members**.



Update from the Clinical Director of the MSN for Children & Young People with Cancer

Many changes have taken place this year with new members joining the network; the creation of a cancer registry/database and the mapping of cancer services for the teenager and young adult population.

My recent visits to Tayside Childrens Hospital in Dundee and the Royal Hospital for Sick Children in Aberdeen were opportunities to meet clinical and non-clinical staff, introduce myself as the MSN's new clinical director and to gain some insight to the other children's centres in the east of Scotland. Both hospitals provide comprehensive medical services for children from prenatal to adolescence, including specialist services such as cancer care. The Vision for our network is to provide a safe and sustainable national service for young people with cancer so that all patients are treated for the **Right Diagnosis** by the **Right Teams** in the **Right Place** at the **Right Time**.

A new project is underway to develop an electronic health record called an '[ePassport](#)' for children, teenagers and young adults. The ePassport is being developed to guide patients through their journey, enabling them to take ownership of parts of their personalised health record. The electronic health record will be accessible to them on any device and can be shared with family and friends. The ePassport includes details about the patient's illness and treatment - this information could be helpful as a diary for appointments, scans and treatments. The ePassport could also contain contact details for the hospital and also store photographs taken by the patient. It is loosely based on the e redbook (<http://www.eredbook.org.uk/>), which is a baby's digital health record held by their parents.

If development of the ePassport goes well, it may allow patients to access parts of their own hospital case record, including letters written to their GP and recommendations made by the treatment centre. The development of the ePassport is progressing and I am very interested to hear your thoughts on this project – if you have any questions or comments please use the [MSN's Community Forum](#).

Final testing is underway on the new **Cancer Registry** and the database should go live shortly. The collection of information will not only fulfil the need for Scotland to have a national database for children and young people with cancer but enable measurement of the progress of the service. Measurement of the quality of service and care provided, will be readily available to report on when patient data has been loaded into the live system; previously the service uploaded their data to the UK National Register of Childhood Tumours (Oxford) and the UK National Register of Teenagers and Young Adults with Cancer (Manchester).

Dr. Angela Edgar, Liz Watt and Marnie Goldsmith are working to develop a **governance framework for the teenage and young adult (TYA) population** which will set out the standards of care and service to be provided by the health service. The governance framework will also contain newly developed national TYA Multi-disciplinary Team (MDT) standards for management, with the aim of improving recruitment of TYA patients into clinical trials and the holistic quality of their care in general.

The network are currently working on the **new Cancer Plan for 2016-18**, this should be published before the end of this year. I look forward to hearing any thoughts you may have on the electronic passport project or any other areas you are interested in.

Professor Hamish Wallace, Clinical Director of the MSN for Children & Young People with cancer.

Cancer Registration Database The new enhanced registry is in the final stages of testing and it is expected that the system go live before the end of 2015. Thanks for all of the input and feedback. The collection of information, comparable with England will not only fulfil the need for Scotland to have a national database for children and young people with cancer but enable national reporting against the network's 5 QPI's.



New Network Manager Dawn Crosby has recently taken up post as Interim National Network Manager for the Managed Service Network, covering Wendy Croll for a period of 12 months. Dawn has been seconded from Teenage Cancer Trust, where she was Regional Service Manager for Scotland and Northern Ireland.

Dawn says "I'm delighted to be covering this role at a key stage in the network's development. The upcoming Cancer Plan for 2016-18, imminent launch of the enhanced cancer registry, new national posts in TYA and Aftercare, coupled with other national collaborative projects will undoubtedly enhance and support

Scotland's children and young people with cancer, ensuring that their journey is safe, sustainable and supported. I will be getting in touch with many of you over the coming weeks by way of introduction and look forward to supporting you for the next 12 months". Dawn can be contacted on dawncrosby@nhs.net

Dates for your diary

SEPTEMBER IS CHILDHOOD CANCER AWARENESS MONTH



Conferences

Scottish Cancer Conference 2015 The Scottish Cancer Conference taking place on 16 November 2015, unites patients, clinicians, academics, officials and industry over one day to discuss the big issues from prevention through to patient care. [Register for the event.](#)

Education & Training Events

Paediatric Oncology Solid Tumours Study Day 14 September 2015 at The Marsden Education Conference Centre, London. There are other events coming up in the coming months including Foundation Oncology Skills for Nurses Working in Paediatric and Adolescent Cancer Care (30 Sept 2015) and Targeted Treatments for Paediatric Cancers (15 Sept 2016). [Find more courses/study days.](#)

National Workshop for Cancer Trackers 10 September 2015 - This is a one day National event aimed at NHS Cancer Trackers/ Patient Pathway co-ordinators and any other staff who are involved with Cancer Waiting Times. The aim is to provide a forum for the Cancer Tracking staff in all the Scottish Health Boards to interact with each other through scenario base.

Head & Neck National Education Meeting, Glasgow. 4 December 2015. [Information to follow.](#)

MSN Education Day - 5th February 2016, Royal College of Surgeons, Edinburgh. Information to follow.

Rediscovering Holism: the future for Palliative Care. The 11th Palliative Care Congress, 9 - 11 March 2016, Glasgow.

Courses offered by **St Margaret of Scotland Hospice**, More information about the courses below is available from [Margaret Donnelly](#) 0141 435 7017

Other Events

British Sarcoma Group meeting, Manchester Town Hall from Wednesday 3 February to Friday 5 February 2016. [Abstract submission BSG 2016 now open, closes 20 November 2015.](#)

For information

New Royal Hospital for Children in Glasgow The Royal Hospital for Sick Children in Glasgow has now moved from Yorkhill to the new Queen Elizabeth University Hospital Campus (1345 Govan Road, Govan, G51 4TF) and has been named as the Royal Hospital for Children.

Across the workstreams... an update from Joanne Thomas, Senior Occupational Therapist and Lead for the Allied Health Professionals (AHP) Group

The AHP group meet approximately 3 times per year in addition to any Study Days. We are currently working collaboratively within the MSN to develop web pages to share good practice and online information for patient use.

In addition we are in the process of evaluating the paediatric Care Measure (PROM), currently being implemented successfully across many Scottish paediatric healthcare sites. We are also continuing to find new ways to support the wider rehabilitation community through the use of online resources on the MKN e.g. community paediatric and adult colleagues and participation in AHP study events.

Communications update

The MSN [Website](#) requires a small amount of work within the [Healthcare Professionals](#) section with regards to Research, Guidance and Education - this should be completed in the coming months.

Our [Facebook](#) and [Twitter](#) pages are getting more popular each month—please follow us and share with colleagues—tell us what you are doing and we will share with the wider community. We hope to gain further awareness of the network by means of promotional items—we would appreciate your views on what would be useful. The [Community Forum](#) on the website is available for patients, parents, carers and staff to use - share your experiences with others—read Professor Wallace's recent post on the benefits of the [ePassport](#).

Detect Cancer Early

[The Scottish Referral Guidelines for Suspected Cancer \(August 2014 PDF\)](#) have been updated to take account of new research evidence and the findings of audits undertaken since the last revision.

The aim of these guidelines is to facilitate referral between primary and secondary care for patients whom a GP suspects may have cancer. The guidelines should help GPs, the wider primary care team, other clinicians and patients and carers to identify those patients who are most likely to have cancer and who therefore require urgent assessment by a specialist. Equally it is hoped that the guidelines will help GPs to identify patients who are unlikely to have cancer and who may appropriately be observed in a primary care setting or who may require non-urgent referral to a hospital. [A Quick Reference Guide](#) has been produced by the Scottish Primary Care Cancer Group with support from The Scottish Cancer Group and the Scottish Government.

CONTACT US

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If you would like to contribute to the next newsletter please contact Sarah Ritchie, details above.