

Volume 1 Issue 2 – August 2021

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Headline

Welcome to the second issue of our newsletter.

The newsletter will be published biannually and if you have any news that you feel would be of interest to the network members please let Dr loanna Nixon know and it will be included it in subsequent editions.



I take the opportunity to thank all the members of the Scottish Sarcoma Network (SSN) for the continuous support you provide to the network and for your evident passion to improve care for sarcoma patients.

I was privileged to be the Clinical Lead for the SSN since 2015 and looking back, we have come a long way together! My tenure is coming to an end in October 2021 and I look forward to welcoming and offering my support to my successor.

I have **three** messages for you today.

- ✓ Reflect we have come far! We should reflect on what we have achieved, on the challenges and take time to affirm.
- ✓ Plan we need to plan the next steps in supporting our patients the most.
- ✓ Act take action!

Look after yourselves and look out for each other!

Dr Ioanna Nixon, PhD, MPH, FFMLM, FRCR Consultant Clinical Oncologist and Scottish Sarcoma Network's Clinical Lead

Quality Improvement (QI): Sarcoma Team at the Beatson finalists at the HSJ Awards 2021



This quality improvement project aimed to improve the chemotherapy pathway and patient experience for patients with soft tissue sarcomas. The project was led by Dr Jeff White with the support of Miriam Brady, sarcoma Clinical Nurse Specialist (CNS), Dr Ioanna Nixon and in collaboration with Eli Lilly. The project led to significant improvements in the chemotherapy pathway and also patient experience. The <u>team's</u> presentation is on the SSN website.

QI: Telemedicine project on sarcoma patients - What Matters to Us: impact of telemedicine during the pandemic in the care of patients with sarcoma across Scotland.

The SSN in collaboration with the University of Strathclyde and the Royal Marsden Hospital looked at patient and professional experience on telemedicine for sarcomas in Scotland. The project was led by Dr Ioanna Nixon, supported by Holly McCabe, PhD Student in Management Science at Strathclyde University and SSN colleagues. A similar study was performed by Prof Robin Jones and team at the Royal Marsden Hospitals and the same questionnaires were used to allow for comparison. Next step is qualitative research to allow more in depth understanding of patients' needs and inform service re-shaping tailored to their needs. The project has been published in the ASCO JCO Journal.

QI: Professional Experience of Virtual Sarcoma MDTs: a UK Survey of all sarcoma MDTs

The SSN in collaboration with other networks in the UK are leading on a survey to assess professional views and experience of virtual sarcoma MDTs. The project is led by Dr Ioanna Nixon, supported by Holly McCabe and SSN colleagues, and is at the analysis stage.

Special thanks to Lorraine Stirling for her support on both projects.

Working with Patients and Carers

Our second RISE (*Resilience, Inform, Support, Empower*) event for patients and carers is planned for Friday 27th August 2021, 1:00-2:30 pm, via Zoom.

The event aims at providing supportive information to patients and carers, discuss challenges and create avenues for peer to peer support for both patients and carers. The first RISE event was hosted in October 2018 in Forth Valley and was the first patient and carer event hosted by the Network and the first event focusing on carer's needs too. The event was facilitated by Sandra Campbell, Lead Cancer Nurse and Dr Ioanna Nixon, with the support of Catriona Graham, sarcoma CNS and clinical psychologists Dr Clare McGowan and Dr Chris Hewitt. The event was hugely welcomed by patients and families, hence being organised again this year tailored to previous feedback. This year we will invite patients to share stories to empower others and also we are delighted to have Maggie's Glasgow explain financial support available for people with cancer.

Spread the word!

To register for this event please click here



Research

New studies available:

STRASS II Study opening at the Beatson West of Scotland Cancer Centre:

The EORTC 1809 STRASS II study is the first official trial looking into potential benefits of chemotherapy before surgery to improve disease control and survival in patients with retroperitoneal sarcoma, a rare and aggressive cancer with a low survival rate. STRASS II is a pan-European (13 countries) study with a transatlantic collaboration with multiple specialized sarcoma centres in Australia, Canada and North America. This collaboration recently completed inclusion of the first randomized controlled trial in retroperitoneal sarcoma ever, the STRASS trial examining the role of pre-operative radiotherapy in these tumours. In contrast to many other cancer types, an official trial looking into potential benefits of chemotherapy before surgery in these tumours has never been performed. 250 patients will be recruited over a period of 5.5 years. Additional follow-up of 1.5 years is expected to provide the targeted number of events for analysis. The study is coordinated by Dr.Alessandro Gronchi (Milan) and Dr. Winan van Houdt (Amsterdam).

Standard arm:

Large en-bloc curative-intent surgery within 4 weeks following randomization- Experimental arm.

Experimental arm:

- 3 cycles of neoadjuvant chemotherapy starting within 2 weeks following randomization:
 - High grade Liposarcoma(LPS): ADM (doxorubicin) 75 mg/m2 (or the equivalent EpiADM 120 mg/m2) + ifosfamide 9 g/m3 Q3 weeks.
 - Leiomyosarcomas(LMS): ADM 75 mg/m2 + DTIC (dacarbazine) 1 g/m2 Q3 weeks
- re-assessment of operability
- curative-intent surgery within 3-6 weeks of last cycle of chemotherapy

For more information on STRASS II Study contact Principal Investigator, Dr Ioanna Nixon

PANTHR Study opening at the Beatson West of Scotland Cancer Centre

ICR and Royal Marsden researchers have been awarded a 2.5m grant to set up the world's largest digital hub of sarcoma research data. This 5 year project is led by Prof Robin Jones, at The Royal Marsden NHS Foundation Trust.

The SSN is having one of the leading roles in the Consortium. Dr Ioanna Nixon, Dr Jeff White and the Clinical Trials Unit in Glasgow are leading on one of the study work streams on behalf of the consortium, and Dr Larry Hayward in Edinburgh is also part of the collaborative. Co-Investigators on the project include teams based at University of Birmingham, Instituto Nationale dei Tumoti-Milano, and Instituto de Biomedicina de Sevilla.

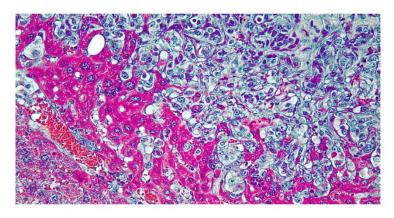


Image: Metastasis in a Kaposi sarcoma mouse model. Credit: <u>Anthony B. Eason</u> via NIH Image Gallery or flickr, CC BY-NC 2.0

The Cancer Research UK announcement is: https://www.icr.ac.uk/news-archive/world-s-largest-sarcoma-research-database-aims-to-revolutionise-sarcoma-treatment-after-multi-million-pound-investment

This collaboration is in line with the Scottish Sarcoma Research Strategy.

For more information on PANTHR Study contact Principal Investigator, Dr Ioanna Nixon

SSN Collaboratives

Breast Cancer collaborative, led by Mr Steven Lo: Collaboration with the West of Scotland Breast Cancer Managed Clinical Network (MCN) to produce consensus guidelines for the management of breast sarcomas with Dr Janet Litherland, Dr Mark McCleery, Dr Elaine MacDuff, Mr James Mansell, Dr Sophie Barrett, Dr Fiona Cowie, Dr Jeff White and Dr Ioanna Nixon. A paper led by Mr Lo was <u>published in the Journal of Plastic</u>, Reconstructive and Aesthetic Surgery.

Head and Neck (H&N) Sarcoma collaborative, led by Dr Ioanna Nixon: UK wide collaborative to produce consensus guidelines for the management of head and neck sarcomas. A UK wide survey was led by Dr Ioanna Nixon to understand current pathways in the management of head and neck sarcomas in the UK.

The survey was developed with the support of Prof Jim McCaul (WoS Head and Neck Cancer MCN Lead), Dr Fiona Cowie, Mr Jeremy McMahon, Mr Steven Lo, Dr Aisha Miah, Mr Nicholas Kalavrezos (The London Sarcoma Network), Professor Vin Paleri (The Royal Marsden, BAHNO), Dr David Thomson (Christie), Mr Stuart Winter (Oxford), Dr Bernie Foran (Sheffield), Professor Peter Brennan (Portsmouth). The survey was endorsed by the British Sarcoma Group (BSG) and British Association of Head & Neck Oncologists (BAHNO). Through the survey it was evident there is need to develop UK consensus guidelines. Dr Ioanna Nixon in collaboration with the BSG is taking this forward.

In addition, there is commitment by H&N surgeons to provide input to the sarcoma MDT for H&N sarcoma cases. A meeting was held with the West of Scotland H&N MCN representatives and Dr Ioanna Nixon, where it was agreed all H&N sarcoma cases should be referred to the Scotlish Sarcoma MDT and surgeons will provide input for these cases.

Skin Cancer collaborative, led by Mr Steven Lo: Collaboration with the West of Scotland Skin Cancer Managed Clinical Network to review consensus guidelines for the management of skin sarcomas with Dr Ruth Blair re-auditing practice for 2015-2019.

Follow-up collaborative, led by Dr Ioanna Nixon: Survey of patients/carers and Clinicians across Scotland on the use of telemedicine is being utilised for reviewing the follow-up guidelines for sarcoma.

SSN COVID-19 rapid response group, led by Dr Ioanna Nixon: The group aims to ensure fluid communication, support and prompt action between all 5 sarcoma centres and has representation from all specialties; Mr David Boddie, Dr Trevor McGoldrick, Dr Annie Kennedy, Dr Michelle Fergusson, Dr Aisling Hennessey, Mr Sam Patton, Dr Mark McCleery, Dr Elaine MacDuff, Mr Ashish Mahendra, Mr Sanjay Gupta, Mr Pete Chong, Ms Martha Quinn, Mr Steven Lo, Dr Walter Mmeka, Marnie Black and Lindsay Campbell. The pandemic has generated joint guidelines from the British Sarcoma Group, British Orthopaedic Oncology Society and the UK sarcoma specialist centres.

Education

The COVID-19 pandemic means our quarterly education days cannot go ahead in person and we are preparing for our first virtual education day after the RISE event.

Website

The <u>SSN website</u> is now updated and thanks to Dr Jeff White and Alan Abraham for leading the review. The SSN members were surveyed to identify improvements, including selecting the new logo. The website is being developed and maintained according to our new standard operating procedure that will be published shortly.

Audit

The Scottish Sarcoma Network has published year six (2019/20) of the sarcoma quality performance indicators and the report is available on the website at:

https://www.ssn.scot.nhs.uk/audit

The indicators will now be reviewed, beginning in December 2021, with publication planned for June 2022.

Thank you and for all your support

Scottish Sarcoma Network Virtual Steering Group

Name	Specialty	Unit	Region
Ioanna Nixon	Consultant Clinical Oncologist and Scottish Sarcoma Network Lead	Glasgow	WoSCAN
Aisling Hennessy	Consultant Medical Oncologist and Edinburgh Centre Lead	Edinburgh	SCAN
Alison Mitchell	Consultant in Palliative Medicine	Glasgow	WoSCAN
Ashish Mahendra	Consultant Surgeon and Surgical Lead	Glasgow	WoSCAN
Chris Nicholas	Consultant Radiologist and Joint Radiology Lead	Glasgow	WoSCAN
Debi Kirk	Lay Representative and Website Designer		
David Boddie	Consultant Surgeon and Aberdeen Centre Lead	Aberdeen	NCA
Elaine MacDuff	Consultant Pathologist and Pathology Lead	Glasgow	WoSCAN
Fiona Cowie	Consultant Clinical Oncologist and Oncology Lead	Beatson West of Scotland Cancer Centre	WSCAN
Jane Law	Clinical Nurse Specialist and Nurse/AHP Lead	Glasgow	WoSCAN
Jeff White	Consultant Medical Oncologist	Beatson West of Scotland Cancer Centre	WoSCAN
Larry Hayward	Consultant Medical Oncologist	Edinburgh	SCAN
Lindsay Campbell	National Managed Clinical Network and Improvement Manager	Glasgow	National
Lorraine Cowie	Regional Manager (Cancer)	NHS Grampian	NCA
Lorraine Stirling	Network Administrator and Webmaster	Glasgow	National
Mark McCleery	Consultant Radiologist and Joint Radiology Lead	Glasgow	WoSCAN
Michelle Ferguson	Consultant Clinical Oncologist and Dundee Centre Lead	Dundee	NCA
Milind Ronghe	Consultant Paediatric Oncologist	Glasgow	WoSCAN
Peter Chong	Consultant Surgeon and Joint Glasgow Centre Lead	Glasgow	WoSCAN
Sam Patton	Consultant Surgeon	Edinburgh	SCAN
Steven Lo	Consultant Surgeon and Joint Glasgow Centre Lead	Glasgow	WoSCAN
Sinclair Dundas	Consultant Pathologist and Research Lead	Aberdeen	NCA
Stuart Hamilton	Consultant Surgeon	Edinburgh	SCAN
Ute MacGregor	Consultant Clinical Oncologist and Inverness Centre Lead	Inverness	NCA

Updated August 2021