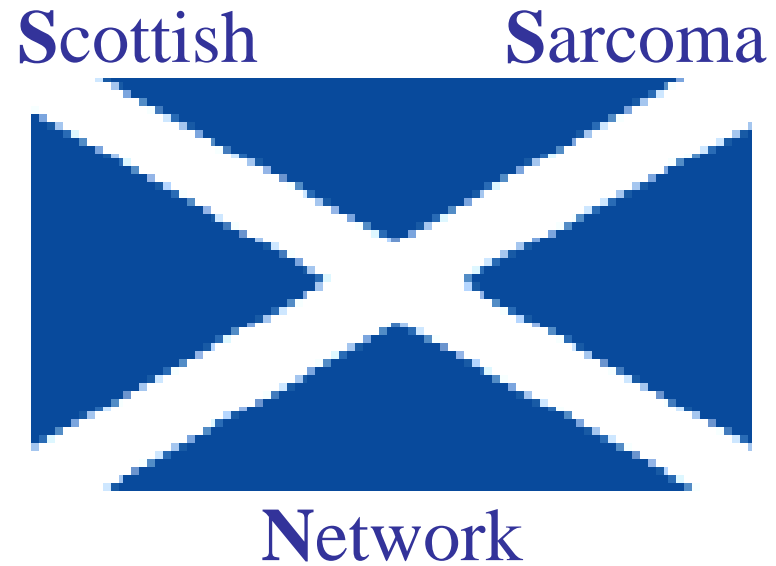


National Managed Clinical Networks

Annual Report for 2008-2009



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Lead Clinician's Report

I have now completed my first full year as Lead Clinician. During this time there has been considerable consolidation within the Network. Lindsay Campbell, our manager, has clearly established himself in his role, and has demonstrated the tenacity and drive to press on with our vision for better communication, better use of information technology, and better data. We have at last recently been able to appoint a National Coordinator (Chris Burns) who is currently introducing himself throughout the Network. His arrival will complete a vital missing link in our structure and serve to streamline our meetings and ensure data capture thereby enabling us to ensure quality of service for sarcoma patients in Scotland.

On a clinical front, I continue to be impressed with the cooperation between the various centres with groups working within each centre better than they have perhaps since the Network was created. Indeed we have clinical evidence from the Aberdeen group that this is indeed the case. On the surgical side, we continue to see close cooperation across the Network, with both advice and clinical skills being sought. Pathology maintains a very high quality service with double or even triple reporting of specimens. All sarcomas within the Network are being discussed at the two MDT's with recorded minutes and action plans. We continue to have a strong education and research program, with regular meetings both in specialty groups and multidisciplinary events.

On the nursing side, Dawn Currie has now formalised a Sarcoma module at the University of the West of Scotland (UWS) for paramedical staff wishing to improve their knowledge in the care of sarcoma patients.

The Network hosted the Sarcoma UK meeting in Glasgow in March 2009. This conference was expertly organised by Jeff White and the team at the Beatson, achieving the highest attendance figures ever at this event since its inception. This conference was

attended by all those involved in Sarcoma care from clinicians to patients to carers and to charities. A great success – well done Jeff!

With regard to the future, the National Musculoskeletal Sarcoma Service (as reported last year) is now coming to the conclusion of an option appraisal exercise chaired by Dr R Masterton, Executive Medical Director of NHS Ayrshire and Arran. Many of us in the Network have contributed to this exercise, and I appreciate the efforts made by both team members and those at NSD. We await the results of this exercise.

Two issues deserve continued attention. We know sarcoma continues to present late through a combination of factors relating to the patient, the primary care service and the secondary care setting. There is no question that massive improvements have been achieved in referral pathways ensuring that patients get to see the right team quickly. This however needs to be audited and further improved. Whilst much of the improvement has been achieved by a greater awareness of the Network by other secondary care teams, I believe that using electronic referral pathways by primary care physicians we can speed and better target referral destinations.

And finally, as again I reported on last year, data, data, and more data. We now have (at last) a coordinator, a mechanism of capturing cases, agreement across the Network, a way of tracking outcomes (ISD), so that next years report will include a crystal clear picture of the actual work of the Network, and, after that, a tight audit trail to show patients are being treated appropriately, swiftly and well.

References

Delays in referral of soft tissue sarcomas. Johnson GD, Smith G, Dramis A, Grimer RJ. Sarcoma, 2008:378574

Surgical margins, local recurrence and metastasis in soft tissue sarcomas: 559 surgically-treated patients from the Scandinavian Sarcoma Group Register. Trovik CS, Bauer HC et al. Eur J Cancer 2000 Apr;36(6):710-6.

Sam Patton, National Lead Clinician

31st May 2009

Introduction

The Scottish Sarcoma Network (SSN) is now in its fifth year. The inaugural meeting was held in November 2004.

Description of the Network

The Scottish Sarcoma Network is a National Managed Clinical Network as defined by the NHS MEL (1999) 10 and NHS HDL (2007) 21.

The Network links groups of health professionals and organisations from primary, secondary and tertiary care, and promotes working in a coordinated manner with the aim of delivering high quality, clinically effective and equitable care to patients irrespective of their geographical location.

Mr Sam Patton (Edinburgh) is the National Clinical Lead.

Paul Welford until 31/8/2008 and Lindsay Campbell from 1/9/2008 is the Network Manager.

Lynsey Connor provides administrative support and Keith Bryce provides web site support from the West of Scotland Cancer Network (WoSCAN).

Katie Hannah is our Patient Representative

Our web site is www.ssn.scot.nhs.uk.

The Network is hosted by the West of Scotland Cancer Network (WoSCAN) which in turn is hosted by NHS Greater Glasgow and Clyde. Funding for the National Clinical Lead, Network Manager and WoSCAN support is provided by National Services Division (NSD).

The Network comprises of persons with an interest in the management and support of patients with sarcoma across Scotland and a desire to work together to improve existing services. The Network also includes links and support from patients, carers, charities and pharmaceutical companies.

The Network is integrated with the North of Scotland Cancer Network (NoSCAN) and the South East Scotland Cancer Network (SCAN).

Surgery for adult sarcomas takes place in 3 sites; Aberdeen, Edinburgh and Glasgow.

Surgery for paediatric and adolescent sarcomas takes place in 2 sites; Edinburgh and Glasgow

Oncological treatment is provided in 5 sites; Aberdeen, Dundee, Edinburgh, Glasgow and Inverness.

There are currently two multi-disciplinary team (MDT) meetings. A weekly Monday afternoon video conference meeting links Aberdeen, Dundee, Glasgow and Inverness. Edinburgh holds its own weekly meeting on a Wednesday afternoon.

A single, weekly, national MDT is planned but is contingent on the hiring of a National Coordinator. This has been achieved and the National Coordinator starts on 18th May 2009. This will allow all new sarcoma cases to be registered and discussed locally, regionally and nationally, as required.

A steering group meets quarterly and reports back to the Annual General Meeting, which is held in November.

Purpose of the Network

The purpose of the network is to;

1. register referral, radiological, pathological, surgical, oncological and ongoing treatment details of patients with bone or soft tissue sarcomas throughout Scotland
2. provide a Scotland wide forum for service improvement and education
3. provide data for audit and research purposes
4. optimise the treatment of patients with sarcoma in Scotland

Working groups address key priorities;

1. Database and audit
2. Referral guidelines
3. Nursing and allied health professional group
4. Imaging guidelines
5. Pathology guidelines
6. Surgery guidelines
7. Oncology and radiotherapy guidelines
8. Research and education
9. Patient information and involvement

The strong links with the British and Scandinavian Sarcoma Groups have been maintained.

Objectives of the Network

The objectives of the Network have been agreed with NHS Quality Improvement Scotland (QIS) and are detailed in the Quality Assurance Framework that was finalised in October 2007. The Network Manager can provide this agreement.

Organisation of the Network

The network is led by a Steering Group who meet quarterly.

Sub-specialty groups report to the Steering Group along with any short working life groups tasked with specific work.

The Steering Group has the following members:

Mr Sam Patton	Lead Clinician/Orthopaedic Surgeon, Edinburgh
Dr Fiona Cowie	WoSCAN Lead /Oncologist, Glasgow
Dr Michelle Ferguson	NoSCAN Lead/Oncologist, Dundee
Dr Larry Hayward	SCAN Lead/Oncologist, Edinburgh
Dr Milind Ronghe	Paediatric Oncologist, Glasgow
Mr Daniel Porter	Orthopaedic Surgeon, Edinburgh
Dr David Ritchie	Radiologist, Glasgow
Dawn Currie	Sarcoma Nurse Specialist, Glasgow
Gill Harley (retired and replacement being identified)	Teenagers and Young Adults Nurse Specialist, Edinburgh
Katie Hannah	Sarcoma Patient Representative, Dundee
Dr David Linden (stepped down and replacement being identified)	General Practitioner, Ayrshire and Arran
Professor Paddy O'Dwyer	General Surgeon, Glasgow
Mr Stuart Hamilton	Plastic Surgeon, Edinburgh
Dr Alison Mitchell	Palliative Care Specialist, Glasgow
Professor Donald Salter	Osteoarticular Pathology, Edinburgh
Mr David Boddie	Orthopaedic Surgeon, Aberdeen
Mr Mike Jane	Orthopaedic Oncologist, Glasgow
Susan Groom	General Manager, Glasgow
Dr Jeff White	Oncologist, Glasgow
Cameron Raynor	Prosthetist, Aberdeen
Peter Gent	NoSCAN Coordinator, Aberdeen
Lindsay Campbell	MCN National Manager, Glasgow

Services covered

A wide range of clinical services are involved and locally funded, apart from the nationally funded Musculoskeletal Sarcoma Surgery Service. NSD are currently conducting an Options Appraisal on this nationally funded service.

The medical staff who provide services to patients with sarcomas do not only provide this subspecialty service, but are involved with management of patients with other diseases within their specialty (e.g. other medical or surgical conditions or other cancer types). There is currently one Sarcoma Clinical Nurse Specialist, based in Glasgow.

The services covered include the following:

Radiology

Pathology

Surgery (Orthopaedic, General, Cardiothoracic, Plastic, Vascular)

Oncology

Palliative Care

Clinical Psychology

Sarcoma Specialist Nurse

Nursing and Allied Health Professionals

Please note the Children and Teenagers Scottish Cancer Network (CATSCAN) started in November 2007 and children and teenage sarcoma patients are managed through the CATSCAN MDT with specialist support from the SSN MDT.

Membership

All health professionals, patients, carers, charities and pharmaceutical companies with an interest in sarcomas are cordially invited to join and participate in the Network.

Currently SSN has 132 members.

Resources

National Clinical Lead (1 session per week).

National MCN Manager (0.33 WTE).

WoSCAN Administrative support (as required).

WoSCAN website support (as required).

Clinical Facilities

There are full facilities for Radiology at all five centres.

There are full facilities for Pathology at three centres; Aberdeen, Edinburgh and Glasgow.

There are full facilities for Surgery in adults at three centres; Aberdeen, Edinburgh and Glasgow.

There are full facilities for Surgery in children at two centres; Edinburgh and Glasgow.

There are full facilities for Oncology at all five centres.

Palliative care provision throughout Scotland is available at all five centres.

Prosthetic and orthotic support is available to basic NHS standards. There are areas of unmet need, eg provision of high quality and sports prosthetics.

Routine PET provision is available on request for sarcoma patients when necessary.

There are sarcoma Specialist Nursing facilities in Glasgow only, so far.

Clinical Quality Indicators

1. GP's refer suspected sarcoma to a sarcoma centre as early as possible

2. All patients with a suspected sarcoma are seen at a Specialist Clinic
3. Imaging is undertaken by a Radiologist specialising in sarcoma work
4. Biopsy is taken either by a Surgeon or Radiologist with specialist interest in a sarcoma centre
5. All imaging and biopsy findings are discussed at the MDT to establish an accurate diagnosis
6. A definitive plan of clinical management is agreed by the MDT with patients entered into appropriate trials
7. There is multi disciplinary surgical input (e.g. orthopaedics, vascular, plastics, general, thoracic) to allow an appropriate surgical treatment plan to be developed
8. Resection specimen, pathology is fully and dually reported to the MDT to allow the MDT to determine response of bone tumours to chemotherapy and adequacy of margins, and to establish whether radiotherapy may be required post-operatively
9. Specialist nursing advice is provided by the sarcoma Nurse Specialist or Link Nurse with an interest in sarcoma
10. Each patient has a coordinated support package that includes;
 - a. Follow-up imaging
 - b. Follow-up oncology
 - c. Follow-up surgery
 - d. Palliative medicine
 - e. Access to prosthetics
 - f. Physiotherapy
 - g. Occupational therapy
 - h. Nutrition/dietary advice
 - i. Self help group
 - j. Psychological support

Activity Report

2008-2009 Work Plan

Issue	Key Milestones and Specific Actions	Responsible Lead	Due date	Progress or Completion Date
MAKING IT HAPPEN				
NHS Quality Improvement Scotland (QIS) Quality Assurance Framework (QAF)	Reviewed at year end for conformance, with quarterly Steering Group meetings, quarterly education meetings and annual general meeting	Sam Patton and Lindsay Campbell	1/4/2009	2007/8 Annual Report accepted by NHS QIS as compliance with our QAF
PREVENTION & EARLY DETECTION				
Promoting referral guidelines for suspected sarcoma	<ol style="list-style-type: none"> 1. SCI team to implement electronic referral for GP's to Network 2. Radiology, Chemotherapy, Radiotherapy, Surgery and Palliative Care guidelines created and implemented. 	<ol style="list-style-type: none"> 1. Lindsay Campbell 2. Sam Patton 	<ol style="list-style-type: none"> 1. 31/3/2009 2. 31/3/2009 	<ol style="list-style-type: none"> 1. Demo to Network by SCI on 20/3/2009 for approval to proceed 2. Treatment Algorithms and Radiotherapy Guidelines have been implemented
IMPROVING QUALITY OF SERVICE DELIVERY				
Prospective auditing	Audit data entered into ECASE and analysed once a year at least	Lindsay Campbell	31/3/2009	ECASE ready but Boards do not have Auditors to collect and input the data yet
IMPROVING CANCER TREATMENT AND CARE / ENSURING EQUITY				
National MDT and public access protocols	<ol style="list-style-type: none"> 1. 2 regional MDT's to be combined into 1 national MDT 2. Protocols to be made available to the public through the website 	<ol style="list-style-type: none"> 1. Sam Patton and Lindsay 	<ol style="list-style-type: none"> 1. 31/3/2009 2. 31/3/2009 	<ol style="list-style-type: none"> 1. MDT Coordinator not in post yet so cannot be achieved 2. Protocols added to the

		Campbell 2. Lindsay Campbell		website and website is accessible by the public
INVESTING IN STAFF AND TECHNOLOGY				
National Coordinator recruited and Cancer Nurse Specialists available nationwide	<ol style="list-style-type: none"> 1. National Coordinator to coordinate patients from referral (GP or Consultant) to discharge (back to GP or Consultant), enter specialist centre audit data into ECASE (Boards do the rest) and coordinate patients with their host Boards 2. Expand the network of Nurses with a specialism in Sarcoma nationwide 	<ol style="list-style-type: none"> 1. Lindsay Campbell 2. Dawn Currie and Lindsay Campbell 	<ol style="list-style-type: none"> 1. 31/12/2008 2. 31/3/2009 	<ol style="list-style-type: none"> 1. Interviews planned for 26/3/2009 (20 applications received) 2. Expansion of CNS's being coordinated with Chief Nursing Office, Boards and RCAG's. UWS Sarcoma Nursing module available from summer 2009.
SUPPORTING RESEARCH AND DEVELOPMENT				
Educating Primary Care	GP education in Soft Tissue Sarcoma through training module	Sam Patton	31/3/2009	Difficult to achieve given rarity (GP will care for 1 patient during their working life) and looking at other options

Accomplished service improvements

Robert Young of the SCI team has demonstrated SCI GATEWAY, SCI OUTPATIENTS and SCI DISCHARGE to the Steering Group and demonstrations will now be arranged for the 5 Centres.

Guidelines have continued to be created and published on the website.

ECASE is ready to receive audit data but Auditors need to be assigned by the Boards to enter patient audit data.

The 2 MDT's are awaiting the start of the National Coordinator (18th May 2009) before combining into 1 MDT.

Sarcoma Nurse Specialists for the Aberdeen, Dundee, Edinburgh and Inverness Centres have been highlighted as a priority and possible solutions are being explored. A Sarcoma Nursing Module has been developed with the University of the West of Scotland (UWS) and is due to take its first cohort in February 2010.

Number of Meetings held and brief summary of meetings

The Steering Group met five times; 8th April 2008, 6th June 2008, 12th September 2008, 28th November 2008 and 20th March 2009.

8th April 2008 Steering Group Meeting

Prof. Donald Salter took over as Pathology lead. Options appraisal of the Musculoskeletal Sarcoma Surgery Service and Scottish Sarcoma Network agreed with National Services Division (NSD). Mr Mike Jane and Susan Groom to join the Steering Group, representing the Musculoskeletal Sarcoma Surgery Service. Guidelines were progressed. Creation of a national MDT was agreed. Young adults with cancer would be managed by CATSCAN with specialist sarcoma support from SSN. Updates from the working groups. 2008-2009 work plan was reviewed. Paul Welford is being replaced by Peter Gent as NoSCAN Coordinator, and Network Manager is being recruited by WoSCAN.

6th June 2008 Steering Group Meeting

Mr Ashish Mahendra's job plan had been updated as recommended. National MDT was dependent on National Coordinator, who was still to be recruited.

12th September 2008 Steering Group Meeting

Lindsay Campbell participated for the first time. National Coordinator recruitment is a priority. Gillian Harley is retiring. Retrospective and Prospective audit is a priority. Quarterly education meeting and 2008 AGM confirmed. The web site needs to be updated with the latest guidelines. Patient involvement is being confirmed. 2008-2009 work plan was reviewed. CATSCAN and SSN joint working reconfirmed.

28th November 2008 Steering Group Meeting

2007-2008 annual report was approved for submission to NSD. 2008-2009 work plan was reviewed and Radiology capacity was to be worked in parallel with 18 weeks RTT programme. National MDT is planned for Mondays. Options appraisal is progressing. National Coordinator recruitment progressing.

20th March 2009 Steering Group Meeting

EORTC participation prioritised. Guidelines creation progressing and request for secure web site for detailed guidelines for staff to use. Auditors had not been assigned yet by each Board but using Scottish HepatoPancreatoBiliary Network to aid this. National Coordinator interviews arranged. Sarcoma CNS's for Aberdeen, Dundee, Edinburgh and Inverness being explored with each Board. Sarcoma Nursing Module from University of the West of Scotland (UWS) is planned to start February 2010. Options appraisal requires more information from the Service and the Network. Patient information strategy proposed and being reviewed. Demonstration of SCI GATEWAY, SCI OUTPATIENT and SCI DISCHARGE approved for demonstration to each Centre.

Public and Patient Involvement

The British Sarcoma Group Conference 2009 took place in Glasgow on 18th to 20th March 2009. Details are available from;
<http://www.bsgconference.org.uk/abs2009.html>

Audit Activity

Bone sarcomas are registered by the Scottish Bone Tumour Registry, managed by Jean Campbell (jean.campbell3@nhs.net).

Bone and Soft Tissue sarcomas are currently not prospectively audited as the Boards have not assigned Auditors. This is a high priority for the Network and the Network Manager is resolving this with the Boards. In the meantime the Network is attempting to retrospectively audit, with Aberdeen able to demonstrate how patient care has improved since the Network started, Mr David Boddie (david.boddie@nhs.net) can provide more detail.

Quality Assurance Framework (QAF)

The network has maintained its accreditation with NHS Quality Improvement Scotland (QIS) and it is due for renewal in October 2010. The renewal will include the mapping from the Quality Assurance Framework (old) to the Quality Assurance Programme (new).

Research and Teaching Activity

Full details are available from Mr Daniel Porter (Daniel.Porter@ed.ac.uk).

Scottish Bone Tumour Registry and education meetings are alternating quarterly between Edinburgh and Glasgow.

The Annual General Meeting (AGM) was held on the 28th November 2008 in Perth Royal Infirmary. There were 33 attendees and the agenda was;

0945-1015	Registration & Coffee	
1015-1045	Introduction and Lead Clinician Report	Mr Sam Patton
1045-1115	Patient's perspective	Prof Aubrey Manning
1115-1130	Coffee Break	
1130-1200	Invited Lecture - Imaging in Soft Tissue Sarcomas	Dr Simon Ostlere, Nuffield Orthopaedic Centre, Oxford
1200-	Palliative Care in Sarcoma Patients –	Dr Alison Mitchell, Glasgow

1230		
1230-1245	Outcome data prior to the network – improved outcome in paediatric osteosarcoma 1937- 2005	Mr Daniel Porter
1245-1300	Outcome data subsequent to the network – NOSCAN changes in practice	Dr Sinclair Dundas
1300-1400	<i>Lunch</i>	
1400-1415	Oncology Trial Updates	Dr Fiona Cowie
1415-1430	Research in the Network 2006-7	Mr Daniel Porter
1430-1445	British Sarcoma Group, Glasgow 2009	Dr Jeff White
1445-1515	Interesting Cases	
1515-1530	<i>Tea Break</i>	
1530-1600	Interesting Cases	
1600	Close	Mr Sam Patton

Work Plan for 2009-2010

Objective	Please include reference to specific actions within National Policies e.g. Better Cancer Care (BCC); Living & Dying Well (L&DW)	Key Milestones & Specific Actions	Named Lead	Due date	Progress/Outcome
Prevention					
No Sarcoma specific work planned					
Early Detection					
No Sarcoma screening programme planned					
Referral					
Referral guidelines already in place so aiming for 100% electronic referral and vetting	Efficiency Target of 90% by 12/2010	SCI GATEWAY configured, trialled and implemented for SSN	Lindsay Campbell	30/6/2009, 30/9/2009 and 31/12/2009	SCI GATEWAY team reviewing SSN requirements and creating demonstrations for Q1, CY2009
Diagnostics					
Radiology guidelines updated	“good inter-professional communication” P47	Update, finalise and implement	Dr David Ritchie	31/3/2010	Updating existing guidelines
Treatment					
Surgery and Chemotherapy guidelines updated and created	“good inter-professional communication” P47	Update and create, finalise, implement	Mr Mike Jane/Mr Ashish Mahendra/Mr Paddy O’Dwyer and Dr Fiona	31/3/2010	Updating existing Surgery guidelines

			Cowie		
Service Provision & Access					
MDT and Patient Pathway coordination implemented	Efficiency Target of 62 days maximum wait from referral to treatment or 31 days from decision to treat to treatment by 12/2011	Recruit Glasgow-based person, develop national MDT, coordinate with Boards	Lindsay Campbell	1/4/2009, 30/9/2009 and 31/3/2010	Closing date for applications 27/2/2009
Living with Cancer					
Improving Quality of Cancer Care for Patients					
National audit via ECASE operational	“Ensure by 2010, all tumour networks take part in national audit” P90	In collaboration with Boards start collecting audit data via ECASE	Lindsay Campbell	31/3/2010	ECASE defined and tested and Boards already engaged with first Scottish HPB Network national audit
Delivery					
Workforce CNS capacity matches demand	“effective workforce planning is required in order to quantify numbers” P95	Demand and capacity analysis by Board and Region in collaboration with Sandra White and Gillian Knowles	Lindsay Campbell	31/3/2010	Scottish Sarcoma Network has only 1 CNS based at WoSCC and Dawn Currie has Nursing Module available through UWS
eHealth					

<i>Network Development</i>					
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Finance

The network is operating within budget.