



## **Annual Report for 2005 - 2006**

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## 1. Lead clinician's report

Following the inaugural meeting of the Scottish Sarcoma Managed Clinical Network in November 2004, a multi disciplinary project team was established including a patient representative who has played a very active role in the management of the network.

The prime aim of the network is to promote the provision of a comprehensive high quality service for patients in Scotland with a bone or soft tissue sarcoma. The network will strive to promote early diagnosis and referral of sarcoma patients, and has established a research and educational network.

An important aspect of the project team's work was to establish working groups looking at various aspects of sarcoma care in Scotland. Thus far, significant progress has been made. A General Surgeons Working Group (Chair - Professor Paddy O'Dwyer in Glasgow) has produced guidelines for retro-peritoneal sarcomas. The Orthopaedic Referral Guideline Group (Chair – Mr Mike Jane, Orthopaedic Surgeon, Glasgow) has revised guidelines for bone and soft tissue sarcomas to be published in Scottish Cancer Guidelines as part of cancer strategies for the Scottish Executive. Strong nursing links have been established throughout the country by Dawn Currie in Glasgow and Jill Harley in Edinburgh. Nurses throughout Scotland are networking extremely well and nursing sarcoma study days have been planned for the future. The Pathology Working Group (Chair – Professor Donald Salter) has established a standard format for reporting sarcomas and is promoting molecular diagnosis for certain soft tissue sarcomas. It has also made a significant contribution to promoting referral of patients to the Multi Disciplinary Sarcoma Group. The Education and Research Group (Chair – Daniel Porter, Edinburgh) has promoted attendance at National and International Scientific Meetings, has developed a register of various ongoing research projects, and will encourage a national co-ordinated involvement in certain projects.

A very successful Annual General Meeting was held on the 23<sup>rd</sup> November 2005 with a strong educational component including a keynote lecture by

Professor Henrik Bauer, Stockholm, on the work of the Scandinavian Sarcoma Group. A very effective and stimulating talk was presented by the patient representative. Dawn Currie is currently working with our patient representative to develop an effective policy for dissemination of information to patients by means of nationally available patient information leaflets.

A weekly teleconferencing link between Glasgow, Aberdeen, Dundee and Inverness has been established. At these meetings patients from all four centres are formally presented with assessment of both radiology and pathology. Treatment is discussed and an agreed treatment plan is formed and minuted. A more comprehensive document is currently being developed which will be filled out at the end of the Multi Disciplinary Team Meeting and put in the patient's records.

For logistical reasons Edinburgh has its own Multi Disciplinary Team Meeting every second Wednesday. Audit of diagnosis between the two teams has been established with double reporting of bone and soft tissue tumours. Both teams meet on a quarterly basis under the auspices of the Scottish Bone Tumour Registry, and ways to modify the format and content of these meetings to make them more relevant to the National Managed Clinical Network are currently being explored.

While much has already been achieved, a major challenge due to financial restriction is data collection. The Data Audit Group is chaired by Mr Paul Cool, Orthopaedic Surgeon, Oswestry, with a particular interest in data collection. This group has established that the database devised by Mr Cool, and currently used in the Bone Tumour Registry, will form the basis for data collection and audit. Unfortunately, due to financial restriction, the network has no single designated data collector. Patients from the teleconferenced Multi Disciplinary Team Meeting are added to the database by the already overburdened Scottish Bone Tumour Registry Data Manager. However, resources do not allow central collection of all data from Edinburgh. Bone tumours from Edinburgh are registered with the Bone Tumour Registry and therefore are in the same data system. Soft tissue sarcomas, however, are not added to the national database but are being collected prospectively in Edinburgh. We are in urgent need of funding to allow all Edinburgh data to be collected; otherwise, national audit and our performance against the various indicators for quality improvement

Scotland will be difficult to measure. To date our attempts to find funding have fallen on stony ground, and the issue of data collection needs to be resolved before the data group can make any further significant progress.

Tom Scotland

Lead Clinician

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May 2006

## 2. Introduction

### *Background & Description of the network*

Scotland has had experience in the management of patients with sarcoma for many years. The Scottish Bone Tumour Registry has been in existence since 1961 and contains details of all cases of bone sarcomas and most benign bone tumours in Scotland over that period. Its remit is to register clinical, radiological, oncological and pathological details of patients with bone tumour and tumour-like conditions throughout Scotland, to provide a Scotland-wide forum for education and service improvement, and to provide data for audit and research purposes.

Following a Ministerial announcement, a centrally-funded national Scottish Endoprosthetic Bone Tumour Service was established in Glasgow in April 2001, and it was agreed that patient management could take place in Aberdeen, Edinburgh and Glasgow.

Recognition of the necessity for a coordinated approach to the management of soft tissue tumours as well as those of bone led to the creation of the Scottish Managed Clinical Network for Patients in Scotland with Sarcoma in 2004. Like the Endoprosthetic Bone Tumour Service, this initiative was funded by National Services Division. Following the appointment of a network manager in August 2004, the inaugural meeting of the network was held in Perth in November 2004. Mr Tom Scotland was elected lead clinician. A project team (advisory board) was established and several working groups. These reported to the second network annual general meeting in November 2005.

### *The Scottish Sarcoma Network as Scotland's first national cancer network*

National networks had already been established in Scotland for cleft palate (CLEFTSIS) and phototherapy (PHOTONET); but this was the first national cancer network in Scotland. Despite the relatively low incidence of sarcoma (1-2% of all cancers), geographic factors have justified the concentration of surgery in three centres and full treatment in five centres (Aberdeen, Dundee, Edinburgh, Glasgow and Inverness). The network evolved organically from already established national resources such as the Scottish Bone Tumour Registry and the Scottish National Endoprosthetic Service. Because the network, along with the more recently established Scottish Hepatobiliary & Pancreatic Cancer Network, is hosted by NHS Greater Glasgow and the West of Scotland Cancer Network, its organisational position reflects this. The network is of course additionally accountable to the SCAN RCAG and the NOSCAN RCAG, as well as National Services Division.

### *Purpose of the network*

To optimise the treatment of patients with sarcoma in Scotland. Working groups have been set up to address key priorities:-

Database & audit.  
Referral guidelines.

Imaging protocols.  
Treatment protocols.  
Patient information & involvement.  
Nursing & AHP interventions.  
Pathology protocols.  
Surgical protocols.  
Research & education.

A close link has been established through Professor Henrik Bauer with the Scandinavian Sarcoma Group, whose model, thought to be more appropriate to the geography of Scotland than models of care in England & Wales, has been adopted by the network.

### *Services covered*

A large number of clinical services are included, most of which are locally funded. These include but are not limited to:-

Orthopaedic surgery & oncology  
Medical & clinical oncology  
Paediatric oncology  
Paediatric surgery  
General surgery  
Thoracic surgery  
Vascular surgery  
Plastic surgery  
Radiology  
Pathology  
Palliative Care  
Nursing  
Interventions by allied health professionals

The endoprosthetic service is funded nationally. Non-clinical services such as audit, education, and patient information are supported by a mix of local and national funding. Network management is funded nationally.

### *Membership*

The network currently has one hundred and sixteen members; ranging from orthopaedic surgeons to clinical psychologists, and from sarcoma patients to general practitioners.

The network elected a lead clinician in November 2004 to serve for three years. Each of the regions has elected a regional lead; and the lead clinician has nominated one of them as his depute. This core group has co-opted further network members to achieve geographical and practitioner balance. The current membership is:-

Mr Tom Scotland – Lead Clinician – Orthopaedic Surgeon – Aberdeen  
Dr David Cameron – SCAN Lead – Oncologist – Edinburgh

Prof Elaine Rankin – NoSCAN Lead – Oncologist – Dundee  
Dr Robin Reid – WoSCAN Lead – Pathologist – Glasgow  
Dr Fiona Cowie – Medical Oncologist - Glasgow  
Dr Milind Ronghe – Paediatric Oncologist – Glasgow  
Dr Daniel Porter - Orthopaedic Surgeon – Edinburgh  
Dr Christine Walker – Radiologist – Dundee  
Ms Dawn Currie – Sarcoma Nurse Specialist – Glasgow  
Ms Gill Harley – Teenagers and Young Adults Nurse Specialist – Edinburgh  
Sarcoma Patient – Aberdeen  
Dr David Linden - General Practitioner – Ayrshire & Arran  
Prof Paddy O’Dwyer - Abdominal Surgeon - Glasgow  
Dr Stuart Hamilton - Plastic Surgeon – Edinburgh  
Dr Alison Mitchell – Palliative Care Specialist - Glasgow  
Dr John Mooney – Network Manager

The project team has appointed nine working groups to undertake tasks to improve patient management:-

1. Data and Audit Collection

A database group is established at the Western Infirmary Glasgow to improve the collection and collation of patient data.

2. Referral Guidelines and Treatment Protocols

A key objective of this group is to improve the diagnosis of soft tissue sarcomas.

3. Radiology

Protocols for bone and soft tissue sarcomas to provide consistency of radiological imaging.

4. Pathology

Double reporting is now routinely performed on all sarcomas, and the pathology working group are striving to achieve general availability of molecular diagnosis for certain soft tissue sarcoma types.

5. Research and Education

The key objective of this group is to identify named individuals to represent the network at scientific meetings, both national and international. Another aim is to create a register of projects and ideas for ongoing research.

6. General Surgical

This group works on protocols for abdominal and retroperitoneal sarcomas.

7. Oncological Protocols

This group aims to produce national protocols for oncology.

8. Nursing & AHP Interventions

Interventions by nurses and allied health professionals (AHPs) will be identified and assessed by this group. These will include physiotherapy, prosthetics, orthotics, palliative care and psychological support.

## 9. Patient Information & Involvement

This group will assess the information currently available, further information needs and how meaningful patient involvement can be achieved.

It is anticipated that working groups 8 & 9 will work closely in areas such as prosthetics to identify unmet needs and work creatively with outside agencies, e.g. the charitable sector, to help meet these needs.

The working groups report to the project team, which in turn reports to the network AGM. The network reports annually to the three Regional Cancer Advisory Groups (RCAGs) and National Services Division (NSD). This is in accordance with the accountabilities agreed by the network in its constitution:-

1. The network shall be known as the Scottish Sarcoma Network.
2. The aim of the network is to optimise the management of patients with sarcoma in Scotland. This shall be achieved through development of a national database, development of standardised treatment protocols, and whatever other means the network shall deem appropriate.
3. All individuals interested in sarcoma in Scotland shall be eligible to join the MCN. These include, but are not limited to; physicians, surgeons, pathologists, nurses, allied health professionals, patients and their families, research workers, etc. These individuals need not be based in Scotland.
4. The MCN shall meet annually.
5. At the first meeting, the MCN shall elect a lead clinician to serve for three years.
6. Each region shall elect a representative to the project team (advisory board).
7. The project team may co-opt further members during the course of a year.
8. The lead clinician shall nominate a depute.
9. Should the lead clinician resign during the course of a year, the depute will take over until the next annual meeting.
10. The project team shall, so far as possible, be made up of a balance of clinicians and other professions, and shall also include sarcoma patients. There should also be a geographical balance, so far as possible.
11. The project team shall reflect the various specialists involved in treating sarcoma patients, so far as possible, e.g. oncologists, surgeons, paediatricians.
12. The project team shall meet quarterly to discuss progress and shall appoint working groups on various issues, e.g. treatment protocols, patient involvement. The working groups shall be drawn from interested members of the MCN.
13. The working groups shall meet periodically to discuss their topics and report back to the project team.
14. The project team shall report back to the MCN.
15. The workings of the MCN shall be co-ordinated by the network manager, who shall serve as a point of contact for the membership.

### *Resources/facilities*

Network resources



National network manager (0.5 FTE).  
Some support for audit from SBTR and WoSCAN  
Some support for administration from WoSCAN and NoSCAN

#### Clinical facilities

There are full facilities for primary oncological care at five sites.  
There are full facilities for primary surgical care at three sites.  
There are full facilities for sarcoma surgical care at three sites.  
There are full facilities for conventional diagnostic imaging at all sites. Routine PET provision is not yet available.  
Prosthetic and orthotic care is available to basic NHS standards. There are areas of unmet need, e.g. provision of high-quality and sports prosthetics.  
Palliative care provision throughout Scotland requires to be mapped. Services may be patchy.

### 3. Activity Report

- Specific service improvements  
→ accomplished

a) Weekly teleconferenced MDT meeting between Glasgow, Aberdeen, Dundee and Inverness. For logistical reasons, the Edinburgh MDT meeting is held separately once a fortnight. The teleconferenced link allows patients to be presented along with their diagnostic imaging and pathology, and an action plan agreed on and documented. This link has greatly facilitated the management of patients.

b) Strong nursing links have been established throughout the country. A national sarcoma study day has been proposed. Ward manager of the orthopaedic unit in Aberdeen has contacted the Beatson Oncology Centre in Glasgow to encourage exchange of ideas. The nursing network is working on a managed knowledge network in collaboration with the eLibrary.

c) Pathologists doubly report all material, and molecular diagnosis for certain soft tissue sarcomas has been made available through the pathology working group. Pathologists now word their reports to encourage referral of patients from outwith the network to the MCN.

d) General surgeons under the leadership of project team member, Professor Paddy O'Dwyer, have now completed a national protocol for retroperitoneal sarcomas.

e) Orthopaedic surgeons under the leadership of Mr Mike Jane have produced referral guidelines.

→ in progress

- a) There is ongoing work on a poster targeted at GPs to highlight the frequent delay in referral and encourage earlier referrals.
- b) Dawn Currie, specialist sarcoma nurse at the Beatson, is working with our patient representative to provide patient information leaflets on bone and soft tissue tumours. The aim is to standardise patient information throughout Scotland.
- c) A database & audit working group is agreeing a minimum dataset with ISD. The group will assess the quality indicators for the network QAF; and will decide which fields are necessary for patient management and audit.

→ planned

- a) Sarcoma database to move from stand-alone to web-based system.
- b) Assessment of quality indicators for the QAF.
- c) The minimum dataset will be incorporated into the MDT minutes form as part of patient management package. It is proposed to create a document to put in the patient's notes.

- d) Imaging working group will prepare national diagnostic imaging protocols, including PET scanning and treatment follow-up protocols.
- e) Expansion of research & education remit of the network; e.g. quarterly educational meetings on bone and soft tissue sarcomas and GISTs; a network presence at sarcoma conferences.

- Network Meetings

The network has held two AGMs in November 2004 and November 2005. At the first meeting a lead clinician was elected for three years, the lead clinician appointed a depute, the three regions elected representatives, and a constitution incorporating the aims, structure and accountabilities of the network was adopted. The lead clinician and regional leads formed the core project team, which was expanded by co-opting further members to maintain geographical and practitioner balance. At the second meeting progress in the first year was reported by the lead clinician, and plans for the following year were discussed. There was also a full educational programme including a keynote lecture by Professor Henrik Bauer of the Scandinavian Sarcoma Group.

The project team has met five times – in February, May, August and December 2005, and March 2006. The first meeting set up the working groups. The second meeting took reports from the working groups, and looked at the requirements for further working groups. The success of the national teleconferenced MDT was discussed, as was our guideline submission to SIGN and our participation as a stakeholder in the NICE guidelines. The third meeting received further reports from the working groups, including the development of the soft tissue sarcoma poster for GPs. Links were being established between nurses throughout Scotland, and work was beginning on national patient leaflets for bone and soft tissue sarcoma. Annette Thain from the eLibrary gave a presentation on MKNs, and the options for a network MKN were discussed. At the fourth meeting several issues were discussed regarding improving dissemination of information in the network. These included structured reporting at the MDT and a patient leaflet on endoprosthetic replacement. At the fifth meeting several funding issues regarding national initiatives were discussed. These included funding for nursing and AHP courses, national patient information leaflets, and network educational meetings. It was reported that the QAF had been submitted to NHSQIS; but that our SIGN guideline proposal had been unsuccessful. Elaine Rankin was confirmed as the new NoSCAN representative, Fiona Cowie was co-opted to represent oncology, and suggestions for a new primary care representative were given. The latter was subsequently confirmed as David Linden of Ayrshire & Arran and the WoSCAN primary care group. It was reported that Mike Jane has been co-opted to the Scottish Referral Guidelines Group, and that the referral poster was now ready for distribution to GPs. It was reported that national agreement had been reached on the management of retroperitoneal sarcomas. The subject of charitable donations was discussed. It was agreed that this required liaison between the nursing and AHP group and the patient representative, and possible links with appropriate charities. The format for the third AGM was discussed.

There have been several meetings of the various working groups. Action points arising:-

1. Soft tissue sarcoma poster to be published in the context of the Scottish Referral Guidelines.
2. Database to move to a web-based system using minimum dataset for audit and patient management.
3. Protocol for management of retroperitoneal sarcomas to be submitted to Scottish Referral Guidelines Group.
4. Pathologists doubly report all material, and molecular diagnosis for certain soft tissue sarcomas has been made available through the pathology working group. Pathologists now word their reports to encourage referral of patients from outwith the network to the MCN.
5. Strong nursing links have been established throughout Scotland.

- Audit Activity

Audit currently takes place by discussion at quarterly SBTR meetings, input of MDT patients into the database, and direct reporting to the database by the current data input form being sent to Glasgow. As previously reported, there is a problem with Edinburgh soft tissue sarcoma and GIST patients not being reported to the database because of lack of capacity. In addition, there is reason to believe from retrospective audit that a significant percentage of “lumps and bumps” removed at plastics clinics are sarcomas. Audit of treatment is incomplete. For example, the present database cannot track a patient over multiple chemotherapy cycles.

The network proposes that the current database should move to a web-based system based on the minimum dataset for patient management and audit with the capacity to enter multiple treatment cycles. This may involve further audit resource requirements outwith Glasgow. It is proposed to audit the effects of the operation of the network.

- Research/Teaching Activity

The network AGM currently serves as a vehicle for an annual education meeting. It is proposed that the remit of the quarterly SBTR meetings should be expanded to include soft tissue sarcomas and GISTs.

A sarcoma study day for nurses has been proposed.

A number of research projects have been proposed. These include a pilot project on the effect of improved referral guidelines for GPs in conjunction with a centralised referral process.

- Achievements

August 2004: Network manager appointed.

November 2004: First AGM. Constitution agreed. Lead clinician elected. Core project team established.

December 2004: First report to RCAGs.

February 2005: First meeting of project team. Working groups appointed. First educational meeting held.

July 2005: Guideline application submitted to Scottish Intercollegiate Guidelines Network (SIGN).

November 2005: Second AGM, including second educational meeting.

February 2006: Network invited to join Scottish Referral Guidelines Group.

March 2006: Quality Assurance Framework submitted to NHS Quality Improvement Scotland (NHSQIS) after consultation with stakeholders.

May 2006: Sarcoma referral guideline ready for publication. First annual report ready for submission to NSD and presentation to RCAGs.

#### 4. Plans for the year ahead

1. It has been decided to establish a web-based sarcoma database encompassing bone and soft-tissue sarcoma from the whole of Scotland. It is anticipated that this will allow robust audit of sarcoma data as well as optimising the use of audit resource. The database may also have utility as a patient management tool.
2. Funding is now available for an update of the Scottish GIST guidelines. Unfortunately, the first edition lacked a section on imaging; and it is hoped to redress this with the update. Moreover, other developments, such as the proposed changes in PET provision, will be dealt with by the Imaging Working Group.
3. Further guideline development is required. The options are a further submission to SIGN or a critical review of the NICE guidelines.
4. Research & Education. Present educational provision is good for bone tumours and GISTs. However, more provision is required for soft-tissue sarcomas. The need for more research on adult sarcomas has been highlighted by the working group as has the need for a network profile at scientific conferences and a network register of research projects.
5. Interventions by nurses and allied health professionals (AHPs) in sarcoma are a relatively neglected area. These will include physiotherapy, prosthetics, orthotics, palliative care and psychological support. A similar situation prevails for patient information & involvement. It is anticipated that these working groups will work closely together in areas such as prosthetics to identify unmet needs and work creatively with outside agencies, e.g. the charitable sector, to help meet these needs.