

National Managed Clinical Networks

Annual Report for 2009-2010



Lead Clinician's Report	3
Introduction	6
Purpose of the Network	7
Objectives of the Network	7
Organisation of the Network	8
Services Covered	9
Membership	11
Resources	11
Clinical Facilities	11
Clinical Quality Indicators	12
Activity Report.....	13
2009-2010 Work Plan	13
Accomplished Service Improvements	15
Number of Meetings held and brief summary of meetings	17
28 th July 2009 Executive Group Meeting	17
27 th November 2009 Executive Group Meeting	18
25 th March 2010 Executive Group Meeting.....	18
Research.....	19
Public and Patient Involvement	19
Audit Activity	20
Work Plan for 2010-2011	21
Finance	22
Appendix 1	23
Appendix 2.....	24
Appendix 3.....	26

Lead Clinician's Report

The Scottish Adult Neuro-Oncology Network has now been working together for three years and the initial hard work to establish the Neuro-Oncology National Minimum Dataset, via the ECASE system, has been fruitful and is now actively being used to gather some data on new brain tumour patients in Edinburgh. A coalition with the Scottish Neurosurgical Managed Service Network (SNMSN) Audit Group saw brain tumours as being the lead condition chosen for early neurosurgical audit. As ISD had already approved the SANON dataset, we were thus ahead of the game. Part-time neurosurgical audit funding from SNMSN was married with local funding from the Neurosciences and Oncology in Edinburgh to provide a full time MDT coordinator/auditor post. As the other neurosurgical audits (e.g. pituitary and cervical spine) develop their dataset the time allocated to Neuro-Oncology may reduce, but it is good to welcome Ms Anne Addison into this post in Edinburgh and also Ms Susan Chivers as MDT coordinator in Glasgow. A full-time audit assistant post is due to be readvertised by the SNMSN in Glasgow and hopefully further posts will be rolled out to Aberdeen and Dundee in 2010/11, where brain tumours will again be one of the first areas audited. Sadly, Aberdeen and Dundee have no formal MDT coordinator support and no formal audit assistance at present. The requirement for audit and MDT support has been brought to the attention of the Regional Networks and Scottish Cancer Taskforce.

The lack of MDT and audit support means that waiting times information and data on which to gauge clinical improvement are not available, however, with the assistance of medical students in Edinburgh and Glasgow, we will gather crucial audit information on neurosurgical brain tumour work and SANON neuropathology guidelines, based on incident cases from 2009.

SANON guidelines continue to be discussed, debated and revised. I have been on the NICE Guidelines Group for Rare Brain Tumours (pineal region tumours, primitive neuro-ectodermal tumours (PNET), primary CNS lymphoma (PCNSL) and optic nerve glioma) and the views of the SANON Board will be requested before final publication later this year.

The Annual SANON Meeting for Brain Tumour Awareness Week was held in Dundee in November 2009 and was organised by Prof Sam Eljamel (Consultant Neurosurgeon) and focused on brain tumour research in Scotland. It is good to see that all regions have some involvement in neuro-oncology research and trials and there is a commitment to increase trial involvement. We are very pleased with the amount of educational activity in neuro-oncology, at all levels, over the last year in Scotland ranging from a Patient Information/Awareness Day supported by Samantha Dickson Brain Tumour Trust; Nurses Educational Day supported by Brain Tumour Action; the Neuro-Oncology National Training Day for neurology trainees and the teaching afternoon at the Scottish Association of Neurological Sciences Meeting. Ms Joannie McCutcheon, our patient involvement advocate and IT support has ensured that SANON has a more visible face through the SANON website www.neurooncology.scot.nhs.uk

There have been a number of changes in personnel, within SANON. Our first Supportive and Psychological Care Group Lead, Dr Shirley Anderson died last year. Shirley started some excellent preliminary work setting the future objectives of the group and reviewing the UK literature on supportive care in cancer. Mr Laurence Dunn, stepped down from the neuro-oncology MDT Lead and Lead for SANON audit, for family reasons, and I would like to thank him for his invaluable help in developing the nationally agreed minimum dataset. We welcome Mr Jerome St George and Dr Allan James as joint leads of the neuro-oncology MDT in Glasgow. We also welcome Dr Hannah Lord, a Clinical Oncologist with an interest in brain tumours, as the neuro-oncology MDT lead and SANON lead in Dundee. She will also take over from Mr Eric Ballantyne as SANON Education lead as Eric has become the Lead Clinician with the SNMSN. Mr Pragnesh Bhatt, will replace Mr David Currie as the Neurosurgery Neuro-Oncology Lead in Aberdeen. Pragnesh will be arranging the SANON Annual Meeting in Aberdeen in November 2010. Lastly, but not least, we see a change in Clinical Oncology Lead in Glasgow, with the retirement of Prof Roy Rampling. Roy has been a major international and national advocate for neuro-oncology, through his work in trials, standards, guidelines and teaching. He was on the NICE Committee for Improving Outcomes Guidance for Brain & CNS Tumours that resulted in the impetus for establishing a Scottish

Adult Neuro-Oncology Network. Roy's guidance will be missed on the SANON Committee, but Dr Allan James has already been influential in producing pathways in neuro-oncology, guidelines and the first SANON patient information booklet which has primarily been developed by the Neuro-Oncology Clinical nurse specialists (Mary Fraser -Glasgow, Shanne McNamara-Edinburgh and Margaret Ritchie-Aberdeen) with advice from the SANON Group and Brain Tumour Charities. Dr Willie Stewart, Lead Neuro-pathologist, Glasgow and Lindsay Campbell our National Network Manager have driven the development of this with an aim to hopefully have it available for the British Neuro-Oncology Society Meeting in June 2010.

A challenging SANON Work Plan has been produced for 2010, at a time when funding may become even more restricted, however, by working closely within the SANON Network and with other associated groups e.g. NMCN and SINAPSE, we hope SANON will continue to develop.

Robin Grant, National Lead Clinician

31st May 2010

Introduction

Brain and Central Nervous System (CNS) tumours have an incidence of approximately 7.1/100,000 and account for less than 2% of all tumours. Most recent *Cancer in Scotland* statistics published in April 2009 report that the lifetime risk of developing brain tumour is 1 in 147 males and 1 in 216 females and that tumours of brain, meninges and CNS are projected to increase from 1,791 between 2001-2005 up to 2,298 between 2016-20. The 1 year survival for all primary brain and CNS tumours (benign and malignant) is between 31-35% and the 5 year survival is between 12-13%.

The Scottish Adult Neuro-Oncology Network (SANON) 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. Dr Robin Grant (Edinburgh) is the National Clinical Lead with Professor Roy Rampling (Glasgow) as Deputy Lead. Lindsay Campbell is the SANON National Managed Clinical Network Manager. Lynsey Connor provides administrative support and Keith Bryce provides web site support from the West of Scotland Cancer Network (WoSCAN). Joannie McCutcheon is our Patient Participant and also manages our web site (www.neurooncology.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. The Network comprises of persons with an interest in the management and support of patients with brain tumours 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).

Purpose of the Network

The purpose of the SANON Managed Clinical Network is to optimise the management of people with primary brain tumours in Scotland to produce a single Scottish service with accessible regional teams in the network bringing together the existing Clinical Neuro-Oncology services in Scotland in a planned, co-ordinated single system for delivery of quality patient care through common protocols. This is in accordance with the summary conclusions from the Scottish Audit of the Royal College of Physicians Clinical Guidelines for Good Practice in the Management of Malignant Glioma (Scottish Office CRAG Report (2000) and the Royal College of Physicians (London) Guidelines (1997)). The Scottish Adult Neuro Oncology Network is a prime mechanism for maintaining the collaboration and progressing improvements in service. It also fosters the development of and access to clinical research.

Objectives of the Network

- Improve patient care and access to the best treatment.
- Ensure equity of access
- Establish and agree pathways of care for patients across Scotland, so they are seen in a timely manner and by the correct clinical teams.
- Identify gaps in the evidence base to inform clinical trials portfolio.
- Produce nationally comparative data on agreed clinical outcomes to identify variations, and where appropriate put in place plans to manage these variances.
- Increase the number of patients in research studies irrespective of geography.
- Improve teaching of neuro-oncology on a Scottish wide basis, improve training in neuro-oncology at all levels, undergraduate and post graduate in all areas pertinent to neuro-oncology.
- Generate better value for money.

- Improve communication for patients on a Scotland wide basis.
- Provide a group expertise on which stakeholders groups can draw advice from.

Organisation of the Network

The network is led by an Executive Board which meets quarterly.

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

The Executive Board members were/are;

SANON Lead Clinician	Dr Robin Grant (Neurologist, Edinburgh)
Deputy Lead Clinician	Prof Roy Rampling (Oncologist, Glasgow)
NoSCAN Lead Clinicians Aberdeen Dundee Inverness	Dr David Hurman (Oncologist, Aberdeen) Dr Hannah Lord (Oncologist, Dundee) Dr Kay Kelly (Oncologist, Inverness)
SCAN Lead Clinician	Dr Sara Erridge (Oncologist, Edinburgh)
WoSCAN Lead Clinician	Mr Laurence Dunn (Neurosurgeon, Glasgow)/Mr Jerome St George (Neurosurgeon, Glasgow) and Dr Allan James (Oncologist, Glasgow)
Lead Clinician Audit Group	Mr Laurence Dunn (Neurosurgeon, Glasgow)/Dr Robin Grant (Neurologist, Edinburgh)
Supportive & Psychological Care Group	Dr Ally Rooney (Psychiatrist, Edinburgh)
Pathology Group Lead	Dr Willie Stewart (Neuropathologist, Glasgow)
Primary Care Group Lead	Dr Julie Read (GP, Edinburgh)
Research Group Lead	Prof Ian Whittle (Neurosurgeon, Edinburgh)/Dr Robin Grant (Neurologist, Edinburgh)
Training and Education Group Lead	Mr Eric Ballantyne (Neurosurgeon, Dundee)/Dr Hannah Lord (Oncologist, Dundee)
Pathways Lead	Shanne McNamara (Nurse Specialist, Edinburgh)
Radiology Group Lead	Dr Rod Gibson (Radiologist, Edinburgh)
Palliative Care Lead	Dr Pamela Levack (Consultant, Dundee) - Advisory
Patient Participant & Web	Joannie McCutcheon

Master	
SCAN Lead Clinician	Dr John Davies (Haematologist, Edinburgh)
SCAN Manager	Kate MacDonald
SANON Network Manager	Lindsay Campbell

The Executive Board are leads of sub-specialty groups, have a geographical spread and spread of services and include charity and patient involvement. The role of the Executive Board is to agree and monitor the implementation of the work plan and inform strategy for SANON. The Executive Board hear reports from the Section Leads every three months and accept suitable proposals as SANON recommendations. Each Section lead will contribute to the Annual Report, which will be drawn together by the Lead Clinician and the Network Manager.

Services Covered

The clinical services involved are funded through their local Health Boards and where supra-regional services are provided in Neurosciences and Oncology, financial arrangements have been made with the providing Health Boards for these. There is no nationally funded service in Adult Neuro-Oncology in Scotland, as yet. Medical staff who provide services to patients with brain tumours, 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 neurological conditions or other cancer types). Some of the clinical nurse specialists are fully employed in management of neuro-oncology.

The services covered include the following:

Neuro-radiology

Neuro-Oncology Specialist Nurses

Neurology

Neurosurgery
Neuro-pathology
Clinical Oncology
Palliative Care
Clinical Psychology
Nursing and Allied Health Professionals

The NICE guidelines (England & Wales) requires that a neuro-oncology neurosurgeon should spend more than 50% of their programmed activity involved in neuro-oncology and be regularly involved in a dedicated specialty clinic. (www.nice.org.uk/nicemedia/pdf/CSG_brain_manual.pdf). These requirements have been supported by neurosurgical professional bodies (SBNS - Society of British Neurosurgeons) and oncological societies. Neurosurgical services in Scotland are provided in four regional centres with no foreseeable prospect of centralisation, and “*Better Care*” supports this model of service, with the proviso that some more specialised techniques and procedures will require tertiary referral. There should be a move to sub-specialise within centres, where the case can be made, for this being a safer neurosurgery, e.g. awake craniotomy and tumour directed epilepsy surgery.

NICE guidelines for Rare CNS tumours (e.g. pineal region tumours, Primary CNS Lymphoma, Optic Nerve Glioma and Adult PNET), suggest only a few centres in England and Wales coordinate care, protocols for investigation, management, and clinical research in these rare tumours. Dr Grant is a member of the Rare CNS Group and represents the opinions of many SANON members re: management of these rare tumours. Some surgical and oncological highly specialised procedures are available only in some Neuroscience or Oncology centres in Scotland e.g. awake craniotomy, neuro-endoscopy, and stereotactic radiotherapy. Where these techniques are considered highly desirable, because of improved safety or effectiveness, a simple mechanism to

allow transfer of patients/ specimens between Scottish centres is required. This could be along the same lines as the intracranial aneurysm coiling agreement for subarachnoid haemorrhage.

Membership

All health professionals with an interest in primary brain tumours were invited to be part of one or more sections. Each section lead is responsible for holding section meetings to progress their group. All were invited to attend the second national meeting of SANON on 27th November 2009 in Ninewells, Dundee. Patient participants from each of the four centres with Neuroscience Centres, Support Group Meetings and charities (Brain Tumour Action, Brain Tumour UK, Samantha Dickson Brain Tumour Trust and the International Brain Tumour Alliance) were approached. Currently SANON has a database of 110 persons, who wish to be directly or indirectly involved.

Resources

National Clinical Lead (1.5 sessions per week)

National Network Manager (0.33 WTE)

Administration support (as required)

Web site support (as required)

Clinical Facilities

Full facilities for Radiology (e.g. CT and MRI) in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness Centres

Full facilities for Pathology in Aberdeen, Edinburgh and Glasgow Centres; with Dundee supported by Edinburgh

Full facilities for Neurosurgery in Aberdeen, Dundee, Edinburgh and Glasgow

Full facilities for Neuro-Oncological care in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness Centres

Full facilities for Palliative Care in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness Centres

Clinical Quality Indicators

All patients are to be treated within 62 days of urgent referral.

Patient care should be prospectively audited

All patients should be discussed at a regional or multi-regional MDT meeting

All patients should have access to other disciplines as required (e.g. Dietetics, Palliative Care, etc.)

All patients should have access to approved clinical trials

The Network to be accredited by NHS Quality Improvement Scotland (NHS QIS)

The Network to complete an Equality Impact Assessment (EQIA)

Activity Report

2009-2010 Work Plan

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	Status at 1 st April 2009
Early Detection					
TS and NF suitable for genetic testing?	"A small proportion of cancers is caused by inherited genes that predispose individuals...to the development of malignant changes" P41	In collaboration with Scottish Cancer Genetic Service and charities, identify their recommendation for screening families for CNS tumours	Dr Robin Grant	31/3/2010	
Referral					
Referral guidelines in place but need to be improved	"GPs will see many patients with signs and symptoms which ...turn out to be...benign ailments" P48	Improve referral guidelines and test out in NHS Lothian	Dr Robin Grant	30/6/2009 and 31/12/2009	
Diagnostics					
TelePathology from Dundee to Edinburgh	"specialised investigations...offered in a timely way" P49	In collaboration with the Scottish Pathology Network (SPAN) trial and implement TelePathology	Dr Colin Smith	30/9/2009 and 31/3/2010	SPAN investigating Dundee and Edinburgh facilities during Q1, CY2009
Molecular Diagnostics	SANON	1p19q testing available for all	Dr Colin	30/9/2009	

available to all patients across Scotland to the same high quality	Neuropathology Guideline	patients and audit of appropriate patients treated in 2009	Smith and Dr Willie Stewart	and 31/3/2010	
Implement Radiology guidelines	"good inter-professional communication" P47	Finalise draft and implement with targets for reporting time, discussion with Neurosurgeon and referral to MDT	Dr Rod Gibson	31/3/2010	First draft circulated 12/2008.
Treatment					
More guidelines created	"good inter-professional communication" P47	Draft and finalise surgical guidelines, oncology guidelines for malignant gliomas and guidelines for Primary CNS Lymphoma in conjunction with NICE/BNOS	Mr Laurence Dunn, Prof Roy Rampling and Dr Robin Grant	31/3/2010	
Ensure access to clinical trials for patients	"ensure recruitment continues to exceed 13.9%" P67	Ensure SANON patients can participate in available trials	Dr Robin Grant	31/3/2010	
Service Provision & Access					
MDT and Patient Pathway coordination fully implemented in all 5 centres	Efficiency Target of 62 days maximum wait from referral to treatment or 31 days from decision to treat to treatment by 12/2011	Edinburgh Coordinator moved from non-recurring to recurring funding Coordinators justified and implemented for Aberdeen, Dundee and Inverness	Lindsay Campbell	31/3/2010	Glasgow Coordinator recurrently funded and being used as role model for other 4 centres
Living with Cancer					
SANON patient information booklet	"improving quality and access to information" P72	In collaboration with patients, carers and charities create and implement this booklet via the CNS's	Shanne McNamara	31/3/2010	Using WoSCAN prostate cancer patient information booklet and existing information with review planned for 12/3/2009

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	31/12/2009	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	Lindsay Campbell	31/3/2010	Started this for Scottish Sarcoma Network as they have only 1 CNS

Accomplished Service Improvements

After discussion with Regional Cancer Genetic Leads, there is now a SANON guideline that all patients with a new diagnosis of brain tumour associated with Tuberous Sclerosis, Neurofibromatosis or von Hippel Lindau disease should be referred to the appropriate Scottish Cancer Genetic Service for counselling, family screening and regular monitoring according to agreed Clinical Genetic Protocols.

Referrals to Department of Clinical Neurosciences from NHS Lothian GP’s through the computerised GP referral service with an alert “Suspicion of Cancer” were seen in an urgent Neurology Clinic within 2 weeks, by a Neuro-Oncology Training Fellow. Fewer than 5% of cases were found to have a brain tumour after assessment. The frequency of referral did not merit a special new brain tumour clinic, therefore the new patient clinic kept only two 30 min appointment slots for “Suspicion of Cancer cases”.

The Edinburgh group applied to NES and were granted funding, on behalf of SANON, to produce an educational video for GPs and Optometrists on “Headache and Papilloedema”, in conjunction with University of Edinburgh Video Unit. The individual sections of

the video were completed by April and are being edited. Video sections were completed by: Dr Julie Read (GP); Dr Robin Grant (Neurologist); Dr Simon Kerrigan (SDBTT Neurology Neuro-Oncology Training Fellow); Dr S Madill (Neuro-ophthalmologist); Dr J Polley (Lead Optometrist, NES).

There is no neuro-pathologist in Dundee. The tele-pathology trial was successful and Dundee patients can now be diagnosed by the neuro-pathologists in Edinburgh via this system. The SANON Standard is that all patients with a possible oligodendroglial component in their tumour should have Ch1p19q molecular diagnostic testing. This is available for all Scottish patients, although different techniques are currently used. Compliance with this standard is being audited for all incident cases in 2009, through a medical student audit.

Radiology, Surgery and Oncology guidelines are in progress. Surgery guidelines are being developed in collaboration with the Scottish Neurosurgery Managed Service Network (SNMSN).

Patients are participating in existing multi-centre clinical treatment trials and several new trials are in development. Scottish Cancer Research Network will be managing and reporting trial entry. A prospective two centre (Edinburgh & Glasgow), trial assessing frequency and time course of DSM IV clinical depression in glioma has been completed in April 2010, lead by Dr Rooney, Supportive and Psychological Care Group Lead. Results will be presented at the British Neuro-Oncology Society Meeting (June 2010 and European Association of Neuro-Oncology (Sept 2010).

The Aberdeen and Inverness MDT is still informal, as it needs a Coordinator and an Auditor. The Dundee MDT started on 1st July 2009 and is informal, as it needs a Coordinator and an Auditor. The Edinburgh MDT is formal and audit data has been collected since appointment of a combined Coordinator/Audit post in December 2009. The Glasgow MDT is formal with a Coordinator but

needs an Auditor. The generic timed pathway for the first 62 days of care is agreed for high grade glioma and is attached as Appendix 1.

The patient information booklet is in progress and is planned to be launched at the British Neuro Oncology Society (BNOS) 2010 conference in Glasgow (23rd – 25th June 2010). A Patient Information Day in Edinburgh with the Samantha Dickson Brain Tumour Trust (SDBTT) was held on 19th March 2010. There have been several other educational meetings over the year.

Audit and entry of data on the ECASE database started in Edinburgh on 1st January 2010. There are plans for SNMSN to be temporarily supporting Glasgow, Aberdeen and Dundee with Neurosurgical auditors.

Inverness is determining how to provide clinical nurse specialist (CNS) care. Aberdeen has one CNS, Dundee has one CNS, Edinburgh has one CNS and Glasgow has two CNS's.

The annual meeting was on 27th November 2009 in Dundee and next meeting will be in Aberdeen on 5th November 2010. Joannie McCutcheon, patient participant, upgraded the SANON website to newer technology and it went live in February 2010.

Number of Meetings held and brief summary of meetings

Three Executive Group meetings were held; 28th July 2009, 27th November 2009 and 25th March 2010.

28th July 2009 Executive Group Meeting

Genetic testing progressed. Referral guidelines reviewed for trial in NHS Lothian. TelePathology trial between Dundee and Edinburgh arranged. 1p19q molecular diagnostic test is standard for all suitable patients in Scotland. Radiology guidelines in progress. Mr Laurence Dunn stepped down as WoSCAN and Audit Lead. Clinical trials were discussed. Supportive and

Psychological Care sub-group update provided. Patient information booklet in progress. Permanent funding for Edinburgh Coordinator secured and recruitment started. Auditor post for Edinburgh temporarily funded by SNMSN and recruitment started. Auditor posts for Glasgow, Aberdeen and Dundee being temporarily funded by SNMSN. Website upgrade in progress. First 62 days of care timed pathway in progress. Education events discussed. Photo Dynamic Therapy proposal for pathway being circulated. Dr Robin Grant invited applicants for National Clinical Lead.

27th November 2009 Executive Group Meeting

Dr Allan James participated for the first time. First 62 days of care timed pathway accepted for GBM's. Dr Robin Grant will lead the development of standards and the first three were agreed. Neuropathology update provided. Radiology guidelines are in progress and will be shared with SNMSN.

25th March 2010 Executive Group Meeting

Sheena MacKenzie participated for the first time. The new website is working well with over 4,000 hits in the first 5 weeks from around the world. Regional Genetics Leads agree with SANON guideline to refer all new patients with Tuberous Sclerosis, Neurofibromatosis and von Hippel Lindau disease to clinical genetics services for screening and monitoring. Edinburgh pathology team have a vacancy. Radiology guidelines will wait for international guidelines. Oncology guidelines are out for approval. Supportive and Psychological Care Group progressing and have new members. Palliative Care Group need a new lead. Nursing group are meeting at BNOS. Coordinator/auditor started in Edinburgh 14th December 2009. QPI are being drafted. CACTUS considering Edinburgh research proposal. Dr Hannah Lord is taking over from Mr Eric Ballantyne as Training and Education Lead. Patient Information Booklet is in review and is planned to be launched at BNOS 2010. 2010-11 work plan was agreed. Update on audit of neuropathology guidelines Ch1p19q. Plans for e-learning video discussed. Proposed links with SINAPSE (Scottish Imaging Network – A Platform for Scientific Excellence) about Neuro-Oncology imaging research and standardisation of sequences. Next Meeting will be at BNOS June 2010.

The annual meeting was on 27th November 2009 in Dundee and the programme is attached as Appendix 2. There were 27 attendees and 42.7% responded to the survey, saying they would attend the 2010 annual meeting.

Research

Clinical trials are coordinated by the Scottish Cancer Research Network.

A 2008-9 collaborative study between Edinburgh and Glasgow was performed, using the NCCN tool at the start, 3 months and 6 months after starting radiotherapy. This revealed significant distress was present in between 34-36% of people at each of the three time-points. Younger age, functional impairment and major depression were independently associated with high distress (logistic regression χ^2 for model=39.882, $p<0.001$, R Square=0.312). At each time-point, 84.3%-87.7% of patients reported at least one cause of distress. The most frequently reported problems were worry, fatigue, sleep difficulties and sadness. There was also some evidence that patients with epilepsy reported more distress and distressing problems.

Public and Patient Involvement

International Brain Tumour Awareness week was celebrated by each Centre during 1st – 7th November 2009 and was announced in the Scottish Parliament by Dr Richard Simpson MSP.

The major Charities are involved in the creation of the Patient Information Booklet.

Audit Activity

Edinburgh started prospectively auditing on 1st January 2010 and the SNMSN are currently working with Glasgow, Aberdeen and Dundee to enable prospective audit to be started in these Centres. Neurosurgical deaths and morbidity are discussed within neurosurgical units (M&M meetings) as well as being part of Scottish Audit of Surgical Mortality (SASM).

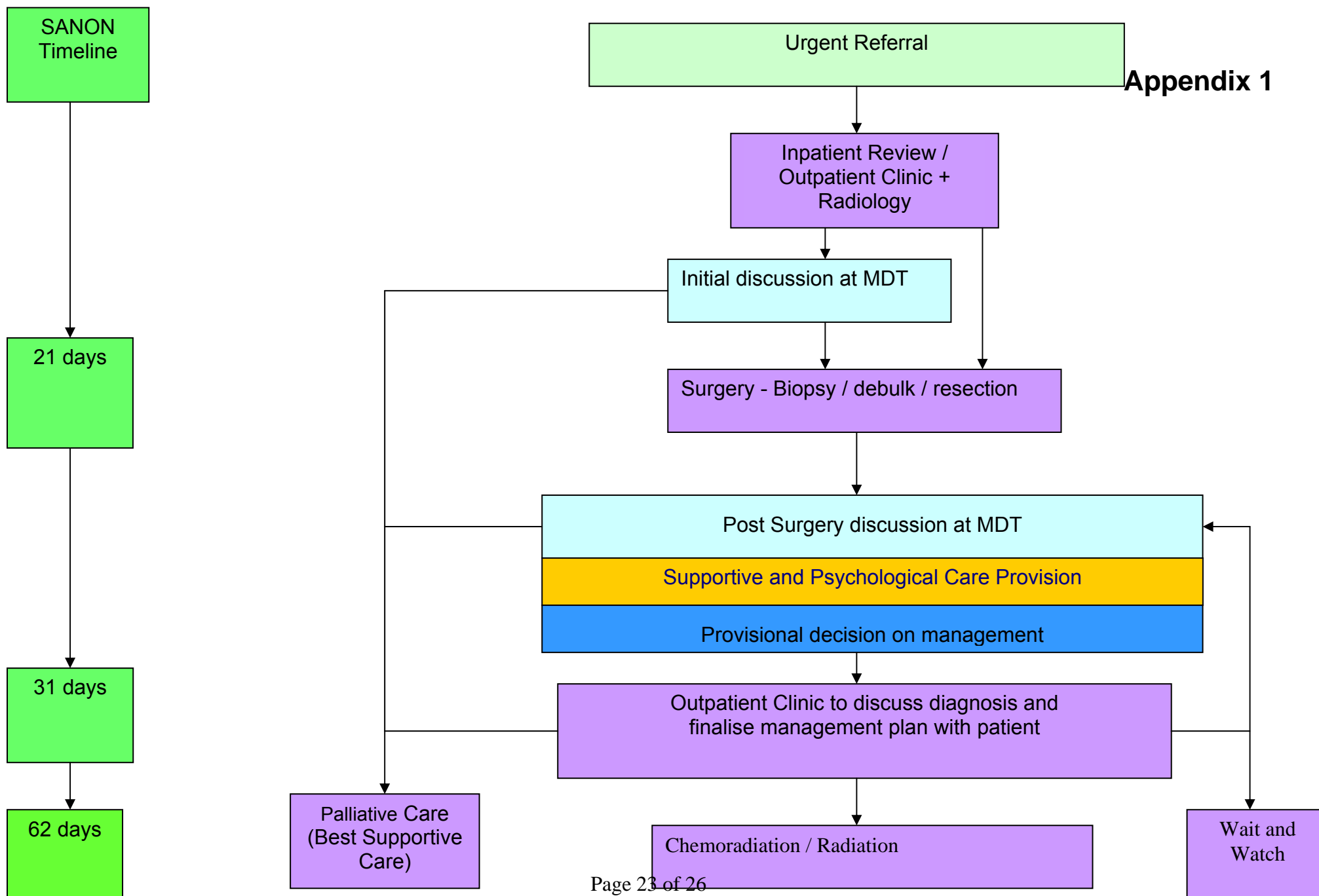
ISD data on deaths, registrations and trends are shown in Appendix 3. Registration of primary brain tumours are increasing towards 460 new cases each year in Scotland. The increase in registration may reflect better identification of cases or changing demographics with increasing numbers of elderly people where the incidence of glioma is higher.

Work Plan for 2010-2011

Ref.	Objective (What is the Goal?)	Priority Ranking High (H) Medium (M) Low (L)	Deliverables / Outcomes (Tangible / Measurable benefits)	Planned Timescales		Alignment with National/ Regional Strategies (Reference to Cancer Strategies /LDW etc)
				Start Date	End Date	
1	Radiology, Surgery and Oncology guidelines finalised and implemented	H	Draft guidelines finalised and then implemented	1/4/2010	31/3/2011	"good inter-professional communication" P47
2	In collaboration with the Health Boards and Scottish Cancer Taskforce establish Auditors to enable prospective audit	H	Auditors assigned to brain/central nervous system and clinical data added to ECASE	1/4/2010	31/3/2011	"Ensure by 2010, all tumour networks take part in national audit" P90
3	Undertake preparatory work to identify top 10 QPI's and develop initial list of QPI's to report against <i>(adopt methodology currently being developed by National Cancer Quality Steering group)</i>	H	Top 10 brain/central nervous system QPI's defined and able to be measured	1/4/2010	31/3/2011	As required by NCQSG
4	In collaboration with the Health Boards expand Coordinators to Aberdeen and Dundee Centres	H	Coordinators assigned to brain/central nervous system to coordinate MDT and patient pathway	1/4/2010	31/3/2011	"Equitable Care" P87
5	In collaboration with the Health Boards and Scottish Cancer Taskforce expand Clinical Nurse Specialists to Inverness Centre	H	Clinical Nurse Specialist in each Centre or plans in place for their establishment	1/4/2010	31/3/2011	"Equitable Care" P87
6	In collaboration with the Scottish Cancer Research Network ensure access to trials	H	"to ensure recruitment continues to exceed 13.9%" P67	1/4/2010	31/3/2011	Support SCRNs as required
7	Undertake an in-depth critical review of MDT practices across the region to optimise efficiency and effectiveness.	H	Clear action plans developed to address issues raised within the specified timescale	1/4/2010	31/3/2011	"Seek ways to improve and speed up communication to patients and between professional disciplines and service" P79

Finance

The Network operated within budget.



Appendix 2

Time	Topic	Speaker
9.00-9.30	<i>Registration, refreshments and networking</i>	
	Brain Tumours – A Scottish Dimension Chair: Dr Robin Grant (Edinburgh)	SANON Network Manager
9.30-9.50	Scottish Adult Neuro-Oncology Network 2008/9 review	Dr Robin Grant Lead - SANON
9.50 – 10.00	Scottish Neurosurgical Managed Service Network	Mr Eric Ballantyne – Clinical Lead MSN
10.00-10.30	Guest lecture: Surgical advances	Prof Walter Stummer Dusseldorf
10.30-10.45	<i>Refreshments and networking</i>	
	Current and Potential New Treatments Chair: Dr Robin Grant (Edinburgh)	
10.45-12.30 Clinical Trials Research in Scotland: (30min + 5 min discussion)	Scottish Clinical Oncology Trials – the way forward	Prof Roy Rampling (Glasgow)
	Scottish Neurosurgical Trials – the way forward	Prof Ian Whittle (Edinburgh)
	Photo-Dynamic Therapy (PDT) in Dundee	Prof Sam Eljamel (Dundee)
12.30-1.30	<i>Lunch, networking & SANON Executive Board meeting</i>	
	Improving Patient Care Chair : Dr David Hurman (Aberdeen)	
1.30 – 2.00	SANON Supportive and Psychological Care staff survey and analysis	Dr Ally Rooney SPC Lead
2.00-2.15	Understanding the Supportive care needs of Glioma patients and their relatives: a qualitative longitudinal study	Ms Debbie Cavers
2.15-2.30	Towards speeding up diagnosis of brain tumour – proposed studies	Dr Simon Kerrigan
2.30-2.45	Consenting patients for Glioma surgery: what should be offered?	Ms S Eljamel

2.45-3.00	Listening to patients –evaluation of a patient concerns inventory	Dr Ally Rooney
3.00 -3.15	Using the NCCN Thermometer	Ms Margaret Ritchie
3.15-3.30	Fatigue and anti-epileptic drug use in Glioma patients	Ms Lesley Jackson
3.30-3.45	Development of a Referral Pathway for Malignant Spinal Cord Compression	Ms Jackie Whigham
3.45-4.00	Summary Linking Research in Scotland	Dr Robin Grant
4.00-5.00	<i>Refreshments and networking</i>	

Sponsored with educational grants from Schering-Plough and Archimedes

Appendix 3

