SCAN is a multidisciplinary NHS network which was established to improve cancer care in the South East of Scotland by facilitating communication and partnership working across the four South East Scotland health boards.
Introduction

SCAN’s role as a cancer network is all about fostering collaborations which improve services for cancer patients. Our experience shows that we achieve more if we pool expertise and resources across the region.

Productive collaboration happens at all levels. At a regional level we have:

- facilitated support from Edinburgh Radiologists for breast cancer imaging in Borders
- established an acute oncology short-life working group to agree standards and priorities, share good practice and provide peer support
- brought nursing, medical, pharmacy and IT colleagues together to implement an electronic chemotherapy prescribing system
- worked with members of the SCAN tumour-specific groups to refresh and relaunch the SCAN website.

We also have fruitful connections with the other cancer networks, third sector organisations and national government groups:

- the SCAN Urology Group joined forces with the Maggie’s Cancer Caring Centre in Edinburgh to establish a support group for patients with bladder cancer, which we think is the first of its kind in the UK.
- clinicians, patients and managers have contributed to the development of national quality standards – Quality Performance Indicators (QPIs) – and the processes for reporting and monitoring progress in achieving them.
- we are organising more national events. This year these included a meeting on management of the sentinel node positive patient with breast cancer, a rectal cancer study day and a national ovarian cancer networks meeting.
- we have worked with the Scottish Government and Macmillan Cancer Support in planning the Transforming Care After Treatment Initiative and we are looking forward to building on existing good practice in the region and supporting development projects which will improve the support available to people after they have completed their initial treatment for cancer.

SCAN’s role as a cancer network is all about fostering collaborations which improve services for cancer patients.
In spite of the difficult financial climate, we have continued to explore new ways of working which offer the potential to improve patient experiences. NHS Borders and NHS Fife have been testing new models for managing acute oncology which aim to ensure that patients who present with complications arising from their treatment, disease progression or previously undiagnosed cancers have improved access to oncology support, earlier assessment and appropriate onward referrals and reduced lengths of stay in hospital. NHS Dumfries & Galloway piloted the use of videoconferencing in oncology clinics for breast cancer patients and, going forward, we will consider the lessons from this project to determine how telehealth technology might be used to support the ongoing delivery of high-quality health services in the face of increasing demand. With support from the Teenage Cancer Trust a dedicated facility for older teenagers and young adults with cancer is being developed in NHS Lothian and the Edinburgh Cancer Centre now offers a number of day case systemic anti-cancer treatments on Saturdays.

SCAN has always been justifiably proud of its high-quality audit reporting and acknowledges the excellent work done by its audit staff. For many years the audit team was led by Alison Allen and her enthusiasm and attention to detail were well recognised and admired. Alison retired in Spring 2013 and will be greatly missed on both a personal and professional level.

I would like to thank all network members for their hard work and enthusiasm during the past year. Within our region progress and improvements are only possible as a consequence of the contributions of high calibre individuals. Can I take this opportunity to request your continued support in ‘working regionally to improve cancer services’ in the year ahead?

Dr Val Doherty
SCAN Clinical Director
National and Regional Initiatives

Chemotherapy

**Safe administration of cytotoxic chemotherapy**

In July 2012 the Scottish Government published revised guidance for the safe administration of cytotoxic chemotherapy. CEL (2012) 30 provides NHS boards with a framework for safe practice in the prescribing, preparation, administration and disposal of systemic anti-cancer therapy which will minimise the risks to patients and protect staff from occupational exposure to these hazardous medicines. In accordance with the governance framework and audit tool approved by the Scottish Cancer Taskforce in March 2013, SCAN boards need to complete an audit against CEL (2012) 30 and report back to the Scottish Government by September 2013. This work will be taken forward through the SCAN Chemotherapy Group and boards have already undertaken preliminary audits to identify key areas of risk.

CEL (2012) 30 offers an opportunity to identify chemotherapy leads in each of the SCAN boards who will have the main responsibility for safe delivery of chemotherapy within their board. Discussions are ongoing to agree the most appropriate individuals to undertake this role.

**Chemotherapy electronic prescribing**

Electronic chemotherapy prescribing offers significant advantages over paper-based systems in terms of patient safety and the efficient and effective use of resources. It also offers a potential solution to the challenges of the increasing demands which will be made of chemotherapy services as a result of increases in cancer incidence (due to the ageing population) and the introduction of new, more complex chemotherapy treatments.

As a result of collaboration between nursing, medical, pharmacy and IT colleagues from across the region, implementation in SCAN of ChemoCare, the nationally approved chemotherapy electronic prescribing and administration system, is nearing completion. The roll-out has been more complex and has generated more work for the nurses, doctors and pharmacy staff involved than was originally anticipated. The process has required thorough review and updating of the clinical protocols for patient management.
(haematology, for example, has 140 protocols, including clinical trials). Unlike in the North and West of Scotland Cancer Networks, which were already using older versions of ChemoCare, SCAN was moving from a paper-based system and this added to the challenges of the project, as greater changes in business processes and behaviours were required. We are very grateful to staff for all their hard work and for the way in which they have embraced new ways of working and taken on the challenge of electronic prescribing of chemotherapy, working collaboratively regionally to identify solutions to issues as they have arisen and keeping patients at the centre of service delivery. Implementation of ChemoCare is due to complete by the end of 2013.

A short-life working group met on 11th March 2013 to consider the regional requirements for reporting on ChemoCare and the specifications have been submitted to NHS Lothian’s eHealth Department. Reporting requirements will be developed to align with the requirements stated within CEL (2012) 30, including the national data set for chemotherapy 30-day mortality, and will give a far clearer indication of patient outcome data in one central report. Reports will also meet local and regional requirements agreed by regional partners through the ChemoCare Management Group.

Radiotherapy

Capacity planning

Discussions between SCAN and the West of Scotland Cancer Network (WOSCAN) about radiotherapy capacity in central Scotland have concluded and an options appraisal exercise resulted in Monklands Hospital being identified as the preferred site for a satellite radiotherapy facility in the West. This decision and the funding required will now need to be addressed with Scottish Government. In addition, it was recommended that the newly-formed national Radiotherapy Programme Board should support work by SCAN to consider additional capacity solutions for the East of Scotland.

In January 2013 SCAN established a short-life radiotherapy capacity working group to consider the medium to long-term capacity planning issues for the region.
representatives from NHS Forth Valley and NHS Tayside, to ensure links into the WOSCAN work programme and consider cross regional boundaries and working. The working group will look at the impact of forecast population changes and cancer incidence on demand, capacity and service response options in the central belt and will be supported by ISD (Information Services Division) and NHS Lothian’s Analytical Services Team. Progress was reported to the Regional Cancer Advisory Group (RCAG) on the 12th April 2013 and it was agreed that a fuller paper should be brought to the September RCAG meeting.

**Modernising equipment**
The national ‘Better Cancer Care’ strategy included a commitment to making modern radiotherapy treatments available to Scottish cancer patients. The Edinburgh Cancer Centre has been upgrading its equipment as part of a rolling programme and the South East and Tayside Regional Planning Group (SEAT) has approved proposals to replace a further two linear accelerators in 2014/15. This will result in the region having six modern machines with the capability to deliver Intensity Modulated Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT).

**Detect Cancer Early**
The national Detect Cancer Early programme was launched in February 2012 and commenced with a general social marketing campaign to highlight the importance of seeking medical advice for key cancer symptoms. A specific breast cancer media campaign ran from September to December 2012 and the bowel cancer campaign, which focused on increasing screening uptake, started in February 2013. The lung cancer campaign is expected to be launched later in 2013. The Scottish Government provided national investment in the programme to support an increase in screening and diagnostic capacity.

Responsibility for meeting the government’s HEAT target – ‘a 25% increase over the baseline proportion of those diagnosed and treated in the first stage of cancer (for breast, colorectal and lung cancer) by the end of December 2015’ lies with NHS boards – and progress reports are included in the health board sections of this report (see pages 44–60).
Cancer Modernisation

The Scottish Government continued its programme of cancer modernisation funding in 2012/13 and SCAN boards were allocated a total of £667,215 to support projects related to surgical oncology, radiotherapy capacity and acute oncology. As a result, work has been undertaken to:

- review cancer patient emergency admissions and test new models of care which aim to provide more accessible oncology support, improve communications, provide earlier assessment and onward referral and reduce length of stay
- facilitate earlier palliative care interventions
- develop a one-stop breast service at St John’s Hospital in Livingston
- build on recent service development in the early management of cancer of unknown primary by rolling out the service across NHS Lothian
- purchase equipment to maximise quality and efficiency in surgical oncology
- develop and expand enhanced recovery after surgery
- redesign cancer pathways.

A further £671,401 has been awarded to the network and SCAN boards for the financial year 2013/14.

Pilot of Using Videoconferencing to Support Breast Cancer Clinics

One of the recommendations from the regional review of non-surgical oncology services undertaken by SCAN between 2010-12 was to explore the use of videoconferencing to support clinical consultations in remote and rural locations in the region. In the spring/summer of 2012 a small-scale pilot was undertaken to explore the feasibility and acceptability of using videoconferencing to link an Oncologist at the Edinburgh Cancer Centre and the breast oncology clinic at Dumfries & Galloway Royal Infirmary. The pilot aimed to explore whether this approach was feasible and satisfactory for both patients and the oncology clinical service. A Telehealth Short-Life Working Group, with clinical and managerial representation from NHS Dumfries & Galloway and NHS Lothian, was established to oversee the pilot. Two video-linked oncology clinics were held during the pilot period and patient and staff experiences were evaluated using qualitative and quantitative
questionnaires and semi-structured telephone interviews with patients and carers.

Patients and carers were generally positive about the experience of using videoconferencing technology for clinic appointments. Staff felt that the technology and environment were appropriate for selected patients but identified issues in relation to delays in care provision, waiting times, impact on other clinics, staff resources and cost effectiveness. This small-scale study indicated that videoconferencing could be used to provide limited support to the breast oncology clinical practice but not in the current service configuration, as used for the pilot. Full implementation of videoconferencing in oncology would require significant change in service delivery and major redesign of oncology clinics across the region. It was not clear whether it would provide any advantages in terms of cost effectiveness. The findings of the pilot will be used as the basis for discussion with clinicians, e-health colleagues and the RCAG about future developments in telehealth. (See also page 20 and page 47.)

Navigation Study
In a collaboration between Macmillan, Coventry University and the Edinburgh Cancer Centre, Navigation has now been trialled within four different tumour groups; prostate cancer (2008-10), breast cancer (2008-10), colorectal cancer (2011-13) and high grade glioma patients (2011-13).

The ‘Navigation’ intervention facilitates patient preparation for, and involvement in, treatment decisions. Navigation involves supporting patients to structure a list of questions for an oncology appointment. Patients are then provided with an audio recording of their oncology consultation and a written record of the key points discussed. This written summary is also sent to the patient’s GP.

Trials of Navigation for breast and prostate cancer patients in SCAN, undertaken between 2008-10, demonstrated that Navigation increased patients’ confidence and reduced their uncertainty and regret about treatment choices. This report provides an update on subsequent trials in colorectal cancer and high-grade glioma, which commenced in 2011.

SCAN piloted the use of videoconferencing to link an Oncologist at the Cancer Centre with the breast oncology clinic in Dumfries.
**Colorectal cancer study**

This randomised control trial aims to evaluate ‘decision quality’, i.e., how confident and certain patients feel with the treatment decisions they have made.

137 (67 intervention, 70 control) patients were recruited from an eligible 404, a recruitment rate of 33.92%. Patients in the intervention group were Navigated for three clinic appointments over six months. Data has been collected from patients in both the intervention and control groups via questionnaires and interviews. The study is now in the follow-up phase and collection of data from the participants still active in the study will be complete by December 2013. Results will be available in 2014.

**Navigation with high-grade glioma patients**

Twenty patients (11 female, 9 male, age range 24-78 years) attending the Edinburgh Neuro-oncology Centre and diagnosed with a high-grade glioma were invited to participate in Navigation and serial evaluation interviews. Patients were Navigated for three clinic appointments over six months. Interviews were undertaken at baseline and then post-Navigated clinic appointments.

Preliminary results include:

- **Lack of information before diagnosis**: Knowledge about diagnosis and further treatment was lacking before patients met their oncologist. This meant the diagnosis came as a shock following surgery.

- **The importance of preparation**: Preparing a question list encouraged patients to address their needs and facilitated them to ask about more than results.

- **A personalised tailored consultation**: Preparing questions and using them with the consultant ensured a personalised experience with less possibility of information gaps.

- **Facilitating understanding and memory**: Summaries and recordings were used as memory aids, as most patients remembered little.

- **Difficult to listen again**: Some patients did not listen to their CD: listening to phrases such as ‘incurable’ was too difficult.
This study has now completed recruitment and full analysis will be undertaken this year (2013). The results will form part of a doctoral thesis and will be published in peer reviewed journals.

**Impact of Navigation on primary care**
As part of the Navigation process GPs are provided with their patient’s consultation summary, a document that details what was spoken about within the clinic. Edinburgh University first year medical students undertook an evaluation of Navigation in primary care. They found that the consultation summaries provided GPs with more patient-focused information from oncology than the usual clinic letter; specifically knowing ‘what the patient had been told’ was reported as a great advantage. This extra information equipped GPs to have clearer discussions with patients about their oncology treatments, without concerns about contradicting specialists, and supported them in providing further care for patients.

**Next steps**
Results of the current studies will be analysed and published. Further funding is being sought to undertake development work to enable appropriately supported volunteers from third sector partners to deliver Navigation services. The SCAN Regional Cancer Planning Group (RCPG) will consider the outcomes of both studies in 2013/14 and how this research might inform the development of cancer services.

**Transforming Care After Treatment**
The impact of cancer does not stop when treatment is over – people have to deal with the effects on their physical condition, finances and emotional wellbeing. The Scottish Government and Macmillan Cancer Support have announced that they will be working in partnership with the NHS, local authorities and the voluntary sector to drive forward improvements in the care and support for cancer patients at the end of their treatment. The Transforming Care After Treatment (TCAT) initiative is a major component of the Scottish Cancer Taskforce workplan and Macmillan will be investing £5 million over the next 5 years to support clinical teams and other partners to ‘review, redesign and test new approaches to post treatment care and support within an agreed programme framework’.
The aim of the TCAT programme is to ensure that all people in Scotland living with and beyond cancer have the care and support they need, based on the premise that care after treatment could be improved by developing new approaches to care after treatment that:

- have a greater emphasis on recovery, health and wellbeing
- enable patients to play a more active role in managing their care through personalised care planning and tailored support
- better integrate the services provided by the NHS, local authorities and the voluntary sector.

SCAN’s Network Manager and Clinical Director sit on the TCAT Programme Board, which has been making plans for implementing the initiative. Work has also been undertaken on a regional basis to gather existing examples of good practice and proposals for pilot projects.
Clinical Quality Monitoring and Improvement

The SCAN network has built up a strong body of good quality cancer audit data over the years. Data collection systems necessarily have to keep pace with changing requirements at national level, yet maintain essential integrity of the data and confidence in its validity. There has been an increasing recognition by the Scottish Government of the value of this important resource and a resulting determination to utilise the cancer audit data to further improve patient care. The maturing of the use of audit data for improvement has been supported by an interweaving of national, regional and local developments in which clinicians and audit staff in the three cancer networks and their health boards, as well as the Scottish Cancer Taskforce, Healthcare Improvement Scotland (HIS) and the Information Services Division (ISD) have been involved.

Quality Performance Indicators

The National Cancer Quality Steering Group (NCQSG), a sub-group of the Scottish Cancer Taskforce, has led the project to develop nationally-agreed Quality Performance Indicators (QPIs). As at April 2013 QPIs have been published for breast, renal, prostate, hepatobiliary (HPB), oesophagogastric, lung and colorectal cancers. Development is in process for the other main adult cancer sites, to be completed by the first half of 2014.

QPIs come as a ‘package’ including an agreed dataset and definitions and, very importantly, a measurability document to promote comparability of results across Scotland.

A very positive aspect of QPI development is that there has been widespread involvement of patients, clinicians and audit staff from the three Scottish cancer networks, including SCAN, as well as from ISD, in the development of QPIs.

Reporting of QPIs has been mandated through the Scottish Government letter CEL (2012) 06, and health boards and regional networks will have the responsibility for ensuring annual
comparative reporting, review of results and development of action plans, as well as contributing to a three-yearly process of national review of results.

In 2012 the NCQSG and HIS took initial steps towards developing the reporting process, involving expert review of results and identification of who should take action where improvement is required. The process was piloted using lung cancer results from national networks’ reporting 2009-2011. Breast and renal cancers were the first QPIs to be implemented, for the 2012 patient cohorts, and will be the first to report, later in 2013.

Regional Comparative Audit Reporting
SCAN has a well-established programme of regional comparative audit reporting, and will adapt to reporting against QPIs as these are implemented for specific cancer sites. For the 2011 cohort of 6,201 newly-diagnosed patients recorded in audit, comparative reports for eight cancer sites have been clinically reviewed and signed off and will be available on the SCAN website (www.scan.scot.nhs.uk) by the end of June 2013. The report for HPB cancers, including data collected in SCAN, can be found on the national HPB MCN website (www.shpbn.scot.nhs.uk).

Continuous Quality Improvement – Development of Action Plans
In recent years SCAN Groups have taken a lead in looking more closely at the results of audit to identify where improvements are required and to propose actions. Action points are reported within SCAN annual comparative audit reports, available on the SCAN website. The issues are reported to the Regional Cancer Planning Group (RCPG) which follows progress with changes. The introduction of Quality Performance Indicators (QPIs) will strengthen governance processes within the network and health boards, ensuring that there is appropriate accountability for implementing improvements.

Reporting at UK and International Level
SCAN has continued to contribute to reporting at UK level, with submissions of audit data to the UK bowel cancer audit (for Lothian, Fife, and Borders), the UK lung cancer audit (NLCA), the British Association of
Urological Surgeons (BAUS) and the BASO (breast surgery data) audits. This provides additional information with which to compare the standard of care in South East Scotland. Reports from the lung and bowel audits are available on the NHS Information Centre website (www.ic.nhs.uk). In 2012, for the first time, all three Scottish lung cancer networks, including SCAN, contributed to the pilot of the European Lung Cancer project (EuLaCa) which is looking at the feasibility of ongoing European-level audit.

**National Networks’ Meetings**

SCAN Audit played a full part in ensuring that comparative audit data from the network could be presented at three nationally-supported networks’ meetings in 2012, for head & neck, lung and breast cancers. Although, over a number of years, lung and breast cancer clinicians had become accustomed to and confident in the value of such meetings, this was the first opportunity for the head & neck clinicians to view national comparative audit data. Clarity about the data arrangements for meetings of this type has been improved over the year through the National Cancer Quality Operational Issues Group (a sub-group of the National Cancer Quality Steering Group), on which cancer audit networks are represented.

**Reporting on Survival**

For patients and clinicians the analysis of survival and outcomes of treatment may be the most important results to derive from audit of their cancers. With the availability of several years’ high-quality data there has, in 2012, been improved availability of these results. At the head & neck cancers networks’ meeting in October 2012, for example, Dr Elizabeth Junor, Consultant Oncologist, presented results on survival using data obtained from the Edinburgh Cancer Centre database and from SCAN Audit.

There is more work to be done, however, to ensure that survival analysis is routinely reported, through finding the most efficient ways of collecting follow-up data and in providing resource in statistical expertise to carry out the analysis. It is to be welcomed that ISD now provides survival analysis as a standard feature of nationally-supported networks’ meetings at which comparative audit data is shared. This arrangement has scope for development to ensure that there is
good communication between ISD, key clinicians and local audit to ensure that the analysis is well-targeted and makes best use of networks’ audit data as well as Scottish Cancer Registry data.

Audit Resource and Confidence in Quality of Data, Data Analysis and Reporting

Since the inception of SCAN Audit there has been a huge development in confidence amongst clinical and other staff in the quality of the audit data collected and in the consequent analysis and reporting.

This is, in part, based on a more structured approach to obtaining clinical sign-off for data and results. SCAN comparative audit reports and all other outputs would not be possible without the essential and greatly valued input of interested clinicians who are willing to spend time on reviewing data and providing advice and guidance.

Reliability of data and resulting analysis is of critical importance, as has been demonstrated in recent UK-wide healthcare issues at Stafford and elsewhere. A very positive feature of the QPI development is the re-introduction in 2013 of external data quality assurance (QA) by ISD, checking data against the national datasets, and in SCAN we are confident this will demonstrate continuing high quality of data capture.

The quality of the data collection and the output from it depends critically on the quality of the audit staff on whom the process relies for implementation. All of us working in audit are aware that confidence in data takes a long time to develop and can be undermined very quickly.

SCAN has continued to be very fortunate during 2012 in the hard work and commitment of the staff across the network despite many pressures, including the development of the workload arising from the Detect Cancer Early project, and from other duties placed upon them. It will be important in the future to support staff and ensure adequate resource to enable this area of key importance in ensuring quality of patient care is used to best effect.

Alison Allen
SCAN Audit Manager

ISD now provides survival analysis as a standard feature of nationally-supported networks’ meetings at which comparative audit data is shared.
Patient Involvement and Information

As we look back over the last year, the focus has been on strengthening existing work, such as the SCAN website and supporting our tumour-specific groups. We have also been looking at how to encourage new people to join us, which we could not have done without the help of clinical colleagues from across the NHS and voluntary sector partners, so our thanks to them.

In addition, there have been new initiatives, such as helping to set up a support group for people with bladder cancer and working in partnership with other parts of the NHS, eg NHS 24’s TIPS project (Tailored Information for the People of Scotland).

The nature of the work means that people can very much dip in and out of SCAN, joining us when something interests them and taking a back seat on things that don’t feel so relevant. Our virtual forum helps a great deal with this and I hope people feel connected to what we do on the terms that suit them.

SCAN Website

The website (www.scan.scot.nhs.uk) was relaunched in May 2012 and patients and carers were very much involved in thinking about the design and ease of use of the website, as well as content. What we learned via their feedback was that people value a single resource where they can find specific information relevant to their situation, eg tests and treatment options, as well as practical help about travelling to the hospital, where to get financial advice and other forms of support. While there are many cancer websites available, it is the more local, practical help that can be difficult to find in one place and the SCAN website aims to meet this gap in patient information needs. As well as seeking patient feedback throughout the development process, the website is promoted by local patient groups, which illustrates the strong and ongoing co-operation we have.

Comparisons of website usage statistics (Google Analytics) before and after the relaunch of the site in May 2012 show that visitors are now staying longer and viewing more pages. In the six months from July – December 2012 we had 7,473 visitors to the site who viewed 49,490 pages. Compared with 2011, visitors

“Since becoming involved with SCAN as a member using the virtual forum, I feel I have helped and it is nice to be included and feel involved when you are unable to travel to meetings, seminars etc. Great work by all involved and a hugely important group.”

Roberta, patient from NHS Borders
spent more than double the time on the site, the number of pages viewed per visit rose by 85% and visitors moving straight away without viewing any pages fell by a third.

Supporting SCAN’s Tumour-Specific Groups
Several of the tumour-specific groups have patient representatives who attend meetings and make an important contribution to the work, making sure that the lay perspective is a key part of our discussions, debates and decision making. We have welcomed new people to these roles this year, which has helped to ensure that we benefit from a wide range of people’s experiences.

On the SCAN website
“I like the new website; easy to use and very clear. Good work.”

“This is so much better. It looks good and navigates well.”

“What a great job you have done.”

“It has been very fulfilling and enjoyable being a patient rep for SCAN. It has enabled me to feel that relating my experiences and effects of my journey – through diagnosis, treatment and after care – are of some value in assisting others. The meeting topics are varied and everyone is very friendly, incredibly dedicated and immensely knowledgeable in their own field – and as eager to improve the lives and treatment of cancer patients as I am. It is a rewarding role and I enjoy being of any assistance that I can.”

Lesley, SCAN Head & Neck Group patient representative and patient representative for the national Head & Neck Quality Performance Indicator Group

As well as recruiting new patient representatives and the work to update the website, which is ongoing, we have a role in supporting patient involvement activities for SCAN’s tumour-specific groups. This year we have worked closely with the Urology and Haematology Groups.

SCAN Urology Patient and Carer Reference Group
The Urology Patient and Carer Reference Group has broad representation from across the SCAN network in terms of patients and carers, NHS colleagues and the voluntary sector. We have focused on information, communication and support and there is a direct link to SCAN’s Urology Group via the patient representatives. Key issues have included looking at how to work towards consistency in terms of patient access to services and links with primary care.
**Bladder Cancer Support Group**

A gap in support was identified and SCAN, in partnership with NHS staff and the Maggie’s Centre in Edinburgh, helped facilitate this group getting off the ground. Although it is in its early stages, we have now met three times and all meetings have been lively, positive and well attended. Several people have expressed an interest in being a ‘buddy’, i.e. a ‘listening ear’ for another patient who is at an earlier stage in his or her treatment and would like to talk to someone who has been in a similar situation. In response to this, Maggie’s have kindly offered to support this by providing people with training. We aim to meet quarterly at Maggie’s in Edinburgh.

**Haematology patient experience work**

Feedback from patient experience surveys in 2012 with people who had undergone high-dose treatments confirmed that the provision of meals needed to be more flexible. These treatments can affect taste and appetite, as well as making people feel nauseous and tired, and so we wanted to look at what would help during their time in hospital. It was clear that a more responsive and flexible approach was required, so that rather than offer food at three set meal times, snacks and lighter meals would be available throughout the day. Clinical staff have worked with the Western General Hospital’s catering department to make this happen and the service was introduced in April 2013. This has made a real difference to the patients in the inpatient unit and the feedback has been very positive. This clearly demonstrates how patient involvement has improved the wider patient experience.

Following on from the work undertaken at the outpatients clinic at the Western General Hospital in Edinburgh, we have been using questionnaires and one-to-one patient interviews to collect the experiences of haematology patients treated at the two hospitals in Fife, in Kirkcaldy and Dunfermline.

Initial results have been very positive, with patients telling us how highly they valued clinical staff and the care and treatment they received. Typical statements included ‘everything went well’, ‘first class’, ‘supportive and friendly staff’, ‘caring and positive attitude’ and ‘the unit is nice and calm’. The survey has also highlighted areas we need to look at, such as patient information and appointment waiting times.

“This is a very welcome initiative. The Bladder Cancer Support Group’s meetings so far have been well attended, informative and helpful. I am sure they will continue to be so, especially as members get to know each other better and the existence of the group gets better known.”

Alan, Edinburgh
results will be shared with NHS Fife staff and SCAN’s Haematology Group.

Supporting SCAN Projects
Patient involvement formed an important part of the pilot of using videoconferencing to support breast cancer clinics in Dumfries and Galloway (see also page 8 and page 47). Patient feedback was gathered via questionnaires before and after patients had seen their Consultant via videolink, and via follow-up phone interviews with patients and carers.

Patients and carers generally felt that videolinked consultations were acceptable, provided:

- the consultation was not being used to deliver bad news
- the patient had already met the doctor and formed a relationship
- the service remained mindful that this form of consultation might not suit those unfamiliar with technology.

Working in Partnership
SCAN aims to be an outward-looking organisation and, in terms of patient and carer involvement, we contribute where we can to areas of work led by others, whether they are part of the NHS or the voluntary sector.

NHS 24’s Tailored Information for the People of Scotland (TIPS) and the Quality Performance Indicators (QPIs) are two examples where SCAN has supported people to be part of and contribute towards regional and national work. In addition to the tumour specific QPIs, we are also working on a set of patient experience QPIs. Three themes have been identified – information, communication and shared decision making. In addition to having patients working directly as part of the strategic group, focus groups have taken place across Scotland to inform and develop the work.

TIPS (www.nhsinform.co.uk/cancer/tips) aims to support NHS staff and Macmillan volunteers to guide patients towards identifying the information that is useful to them at specific points in time and avoid ‘information overload’.

“The videolink was good, no connection loss or anything, so no great difference from face to face. Just that the doctor wasn’t physically present. Having the nurse there helped and provided reassurance.”
The design and development of TIPS has involved patients and carers from the start, via membership of planning groups, taking part in discussions and focus groups. The feedback and input from the planning groups has contributed to the development of the project and we are very happy to support the initiative and will continue the relationship as TIPS moves into its delivery phase.

The Future

Looking forward, there are regional and national programmes that must have direct input from patients and carers, such as Acute Oncology and Transforming Care After Treatment (TCAT). TCAT is a five-year programme which will look at what is needed to support people, keep them well and help them manage their own care once they have left active treatment.

It is part of my job to think about how we work creatively and meaningfully with patients and carers and how we can be as inclusive as possible. We hope the different projects and pieces of work contribute to the huge agenda of improving cancer services. The involvement of those who have direct experience of services makes the work richer and more relevant. We are grateful to patients and carers, past and present, support groups, user groups, our NHS colleagues and voluntary sector partners who all help to keep patient involvement on the agenda.

Sandra Bagnall
SCAN Patient Involvement Manager

The involvement of those who have direct experience of services makes the work richer and more relevant.
Reports from SCAN Groups

Breast Group

At the San Antonio Breast Cancer Symposium in 2011 reports of studies around the management of the axilla in patients with a positive sentinel node biopsy caused great debate within the breast cancer community. In May 2012 the SCAN Breast Group hosted a conference, on behalf of all Scottish breast cancer networks, in Edinburgh which was videoconferenced throughout Scotland. This stimulated debate and a national consensus on changed practice was reached which was ratified at a second conference in October 2012. It is hoped that this type of co-operation can be continued in the future in an effort to ensure equity of care throughout the country.

The Mammography Department at the Edinburgh Breast Unit has undergone refurbishment with the help of Walk the Walk, the Breast Cancer Institute and NHS Lothian. This now enables us to offer a complete breast service in a single, state-of-the-art unit comprising clinics, theatres, ward and radiology service, all completed in the last five years. No time to rest though as a further upgrade of the clinic waiting facilities is taking shape on the drawing board!

In Fife the breast service at Queen Margaret Hospital has been overhauled following the removal of acute services to Victoria Hospital, Kirkcaldy. One of the major changes has been the introduction of 23-hour stay. This has been very successful and has received positive patient feedback.

The Edinburgh multidisciplinary meeting (MDM) changes introduced last year have now bedded in and are working well. Feedback to date from patients and staff has been very positive but we will continue to review the service and address any issues that arise.

The Detect Cancer Early (DCE) campaign started in September 2012. Initially there was little impact but the number of referrals did increase quite dramatically after 6-8 weeks of the programme and this lasted for several months. Within the SCAN group we had to deal with this increased number of referrals and maintain waiting times, and so a series of extra clinics were performed throughout the region. Referrals have now returned to their pre-campaign level and I am
pleased to say that waiting times have largely been maintained across SCAN. Full data regarding the extra diagnosis of cancer in this time is not yet available but does appear to have been relatively small.

**Priorities for 2013**

Sentinel node biopsy is now the standard of care for women with breast cancer who have clinically and radiologically negative axillae. The technique involves the use of radiolabelled isotope and is not available throughout the SCAN network. Work is already underway to ensure that this facility is available at Queen Margaret Hospital and Dumfries and Galloway Royal Infirmary. We will monitor the situation to ensure that this takes place within the year.

With regard to radiology, ultrasound equipment has been installed at St John’s Hospital and it is envisaged that a one-stop clinic will be available there within the year. Regional collaboration is supporting imaging services in Borders General Hospital and we will continue to work to ensure that adequate staffing levels are maintained to ensure equity of delivery of service across the SCAN region.

Quality performance indicators (QPIs) are now in place and there are plans to review these within the SCAN region in September 2013. This is an important time as we move away from Quality Improvement Scotland (QIS) standards. The situation will require to be monitored to ensure that we are collecting data relevant to the clinical workforce.

There have been a few changes proposed to the use of endocrine agents in the extended adjuvant setting. Work is underway within the SCAN region to review current policy with a view to sharing it with other breast cancer networks in Scotland in a manner analogous to the agreement in the management of sentinel node positive axillae.

*Mr Glyn Neades*

*Chair, SCAN Breast Group*

**Colorectal Group**

During the last year the Colorectal Group has been busy with many different activities. The absolute
number of colorectal cancers rose for the fifth consecutive year and we are now treating 25% more colorectal tumours in SCAN than we were in 2008. The outcome results remain extremely good in comparison to other UK regions.

This year has seen the introduction of the Detect Cancer Early programme for colorectal cancer and the SCAN team, along with the other managed clinical networks, has played an important role in ensuring that this focuses on increasing uptake of bowel cancer screening rather than symptomatic disease. This approach should maximise the chances of picking up patients with early, potentially curative disease. SCAN Colorectal Group members have also been involved, over the last year, in the development of new referral guidelines for colorectal cancer and have continued to influence national policy on the use of colonoscopy and colonic imaging.

Members of the SCAN Colorectal Group played a central role in developing the Quality Performance Indicators (QPIs) for colorectal cancer which came into effect from April 2013. The QPIs focus on clinical measures of quality and should ensure that important markers of the quality of care are achieved nationwide to an acceptable standard.

Mr Hugh Paterson, Senior Lecturer in Coloproctology, has undertaken a research study on social deprivation and equity of access to care in South East Scotland. His findings suggest that, in the main, patients receive equitable care and further studies are ongoing. As part of an international project, an in-depth assessment of colorectal cancer care in Lothian is in progress. The results are expected to be available in late 2013.

New developments continue to occur within the region. Laparoscopic colorectal surgery is now routinely available for suitable cases in all of the region’s hospitals. A regional TEMS (Transanal Endoscopic Microsurgery) service has also been established which will allow patients with premalignant lesions or early cancers to undergo minimally-invasive surgery transanally that previously would have required a major operation.

The SCAN Colorectal Group organised a multidisciplinary rectal cancer study afternoon in April.
2013. There was a large turnout of delegates from around Scotland and this was a valuable educational event.

Mr James Mander  
Chair, SCAN Colorectal Group

Gynae Group

The SCAN Gynae Group is about to see the publication of the national Quality Performance Indicators (QPIs) for ovary cancer, to which many of the group contributed in 2012/13. The Group organised a well-received regional education day on rare gynaecological cancers in November 2012 with CPD accreditation. 2012 also saw progress on electronic chemotherapy prescribing for all gynaecological cancers; this has been implemented for all Lothian, Fife and Borders patients, with plans for Dumfries to follow soon. It is hoped this development will facilitate the repatriation of chemotherapy to Fife over the coming year.

Members of the group collaborated with the menopause clinic in Lothian in developing guidelines for the use of hormone replacement therapy after gynaecological cancer and this consensus document has now been published on the SCAN website. The Group also completed the updating of the SCAN endometrial cancer management protocol and agreed a new regional protocol to streamline the multidisciplinary meeting (MDM) process. Work is ongoing, with the support of the psychology department, to develop a CA125 blood test decision aid tool for patients with ovary cancer.

The SCAN Gynae Group continues to be a high recruiter to many research trials at local, national and international level. In particular, 2012/13 saw the SCAN region being the lead recruiter in the UK for an intraperitoneal chemotherapy trial called PETROC. On a more local level, a trial is about to commence looking at the impact of steroids during chemotherapy on glucose levels in gynaecological cancer patients.

The Group has published the 2011 comparative audit of ovary cancers treated in the region with implementation of actions from the 2010 audit. We intend to produce our first audit report on ‘other’ gynaec cancers in the region in the coming year.

SCAN’s Gynae Group continues to be a high recruiter to many research trials at local, national and international level.
Clinical Nurse Specialists (CNSs) perform an essential role in supporting cancer patients and we are delighted that an additional gynae CNS is to be appointed to provide a service for surgical patients treated at the Royal Infirmary of Edinburgh. Ensuring adequate CNS cover for all gynae patients across the region remains a priority for the Gynae Group, as does implementing joint pelvic surgery in Lothian.

_Dr Melanie Mackean  
Chair, SCAN Gynae Group_

**Haematology Group**

During 2012 the SCAN Haematology group saw the successful implementation of electronic prescribing of chemotherapy within Lothian, with plans for this to be extended to Fife in the near future.

The patient survey was extended to the rest of the network following the success of the pilot survey within the Western General Hospital last year. The majority of the feedback was extremely positive but the survey did help identify some areas where improvements could be made. This has resulted in modification of current practice to allow greater ease of access to departmental and disease information. *(See also page 19.)*

Work on the new regional unit for the management of haematological malignancies in adolescents and young adults is due to be completed by summer 2013 and considerable work has gone into developing protocols to support this. Work is ongoing with respect to transitional care.

Management of the elderly patient is one of the most pressing issues in cancer services. The current model of care is not ideal and there is a recognised need for improved support of older people with a cancer diagnosis. We have been successful in obtaining funding to support a project which, over the next 24 months, will assess individual patient needs as well as service needs to try and identify an alternative model of care. The overall aim is to provide a proactive and collaborative service for older, frailer patients with haematological malignancies.

Audit continues to be a strength of the group. The audit team continue to develop outcome data for
patients with lymphoma and leukaemia treated with curative intent. They have also helped collate data for the planned national haematology cancer network meeting in September 2013.

Key priorities for 2013 include:

- Implementation of lymphoma Quality Performance Indicators (QPIs)
- Development and implementation of QPIs for acute leukaemia
- Audit: continue to improve content and format of annual report
- Review management pathway for older, frailer patients with haematological malignancies
- Development of follow-up guidelines for lymphomas treated with curative intent.

*Dr Fiona Scott*
Chair, SCAN Haematology Group

**Head & Neck Group**

One of the recommendations from the service improvement programme undertaken in NHS Lothian as part of the Scottish Government’s ‘Better Together’ patient experience programme was that a one-stop head and neck clinic should be established to improve the efficiency of the service and quality of care for patients with neck lumps. With support from NHS Lothian’s Modernisation Team, a neck lump clinic was established in East Lothian in March 2012 and this has been running successfully under the guidance of Richard Adamson, Andy Evans and Jim Morrison. However additional capacity is required and consideration is being given to expanding the head and neck clinic held at the Lauriston Buildings in Edinburgh or establishing a neck lump clinic at St John’s Hospital in Livingston, where ENT services are based.

The National Cancer Quality Steering Group (NCQSG) has opted to progress the development of Head and Neck Cancer Quality Performance Indicators (QPIs) as part of the ongoing national cancer quality work programme. This work commenced in September 2012 and three sub-groups were established to discuss QPIs for diagnosis and staging, surgical management and non-surgical management. Members of the SCAN Head & Neck Group are
contributing to these sub-groups and to the overarching steering group.

National tumour-specific network meetings, at which audit data is discussed, are another element of the national cancer quality programme. A successful national head and neck cancer networks meeting was held in Glasgow in October 2012 at which the SCAN Head & Neck Group was well represented both as presenters and in the wider meeting. The SCAN Head & Neck Group will work with the other two head and neck cancer networks in Scotland to facilitate further national meetings in future.

During the year we welcomed two new faces; a dedicated Multidisciplinary Meeting (MDM) Coordinator was appointed in March 2013 to provide enhanced administrative support for the weekly meetings where patient treatment options are discussed and the new patient representative on the Head & Neck Group is already making a valuable contribution.

We are looking at alternative accommodation for the Combined Head & Neck / Oncology Clinic to ensure that we are able to maintain high standards and equity of service. Two possibilities have been identified – redesigning provision at the Western General Hospital in Edinburgh or moving the clinic to St John’s Hospital in Livingston. A patient questionnaire survey has been undertaken to establish patient opinion and a short-life working group will be set up to consider some of the practical issues in more detail.

We expect the steady increase in the workload for the head & neck service, mainly due to rising incidence of HPV (human papillomavirus)-related oropharyngeal carcinoma and increased requirements for intensity modulated radiotherapy (IMRT), to continue in the year ahead and cancer waiting times targets are therefore likely to remain a challenge.

Another priority for the Head & Neck Group in 2013 will be reviewing the information for head and neck cancer patients on the SCAN website and a short-life working group has been established to take this forward.

Mr Guy Vernham
Chair, SCAN Head & Neck Group
Lung Group

I am pleased to report on a range of activities to further enhance the quality and uniformity of the care of patients with lung cancer across the South East Scotland network and on contributions nationally.

A number of protocols have been reviewed. New protocols have been developed for massive life-threatening haemoptysis and for the radiological follow up of incidentally-discovered small pulmonary nodules. Systems for the capture and clinical supervision of such individuals will differ in board regions and are under final development.

A patient information leaflet for patients undergoing the endobronchial ultrasound (EBUS) procedure in the Lothian hospitals has been developed. Other information on the SCAN website is undergoing review for current appropriateness.

Several members of the group have been heavily involved in the initial development of lung cancer Quality Performance Indicators (QPIs) and all members were involved in the subsequent critique of a final draft prior to the national launch. Such involvement, though requiring time commitments, ensures clinical buy-in and relevance to the end product. Individuals have also been involved in exploration of clinical governance mechanisms for Health Improvement Scotland (HIS) and in reviewing the Scottish Lung Cancer Primary Care Referral Guidelines.

Educational and development opportunities continue. A very successful lung cancer study day was held in Lothian. We hosted the national tri-network clinical and audit meeting in November 2012. All the data from all three networks was presented and critiqued. An educational update on the Detect Cancer Early programme, blood screening for lung cancer and aspects of the English lung cancer audit programme were shared.

New radiotherapy techniques for treating early stage lung cancer are being developed in the Edinburgh Cancer Centre which will enable treatment to be given in fewer visits with less damage to adjacent healthy lung tissue.
up of lung cancer patients are under development and we will contribute to a planned national debate that will develop guidance on the best practice in following up such individuals.

I must record thanks to Dr Ron Fergusson, past Chair of the SCAN Lung Group, who has now retired from the NHS; Alison Allen, Audit Manager since SCAN's conception, who will also have retired by the time you read this and Ailsa Patrizio, Lung Cancer Audit Co-ordinator, who has taken her skills to pastures new with the Scottish Government Cancer Workforce. It gives me great pleasure to work with such a dynamic and driven group of individuals and I remain grateful for their support.

Dr Colin Selby
Chair, SCAN Lung Group

Skin Group

Having taken over from Dr Danny Kemmett as Chair of the SCAN Skin Group in January 2013, I am pleased to be able to report on a number of positive developments in relation to skin cancer in South East Scotland. These include the modernisation of facilities in Edinburgh and Fife, a comprehensive review of protocols and the development of patient information resources.

Cancer modernisation funding from the Scottish Government has been used to create a high-quality skin cancer and Mohs micrographic surgery suite in Edinburgh and to enhance facilities at the Victoria Hospital in Kirkcaldy.

Cancer modernisation funding from the Scottish Government has been used to create a high-quality skin cancer and Mohs micrographic surgery suite in the Dermatology Department in Edinburgh, increasing surgical capacity and providing a more equitable and streamlined service for skin cancer patients. We hope that this environment will make it possible, in future, to offer a joint East of Scotland cutaneous and Mohs' micrographic surgery training fellowship. In Fife, cancer modernisation funding has been used to enhance the accommodation and equipment available at Victoria Hospital, Kirkcaldy to match what was already in place at Queen Margaret Hospital. The new accommodation comprises two new clinic rooms, a surgical suite and a breaking bad news room.

We have continued our efforts to improve the information available for people with skin cancer. Our Skin Cancer Clinical Nurse Specialist, with support from our new patient representative and relevant
clinicians, has updated our existing patient information leaflets (on melanoma skin examination, melanoma, sentinel lymph node biopsy, basal cell carcinoma, squamous cell carcinoma, having a skin biopsy, after having a skin biopsy and in situ melanoma) and has been developing new leaflets on melanoma recurrence, lymphoedema management and Mohs surgery.

We have also reviewed and updated the skin cancer section on the SCAN website. In response to patient feedback we plan for the coming year to include information about health professionals on the SCAN website.

Ensuring equitable access to treatment, regardless of where a patient lives, is one of the key objectives for cancer networks and clinical protocols play an important part in achieving this. During the past year, members of the SCAN Skin Group have reviewed and agreed revised regional protocols for melanoma, squamous cell carcinoma and basal cell carcinoma.

Regional cancer network audit data is presented at an annual Scottish Melanoma Group / Scottish Dermatology Skin Cancer Group meeting. 2011 audit data revealed that a higher proportion of melanomas were excised in primary care in SCAN than in other regions and that GP excisions in Fife were particularly high. We will write to all GPs in SCAN to remind them of the existing guidance which recommends referral to secondary care of suspicious pigmented lesions. GPs in Fife will be offered specific tumour clinic teaching and the opportunity to join a 'minor surgery' special interest group.

SCAN is well represented on the Melanoma Quality Performance Indicator (QPI) Development Group, which held its first meeting on 26th March 2013, and one of the priorities for the coming year will be to put arrangements in place to collect and report on the new national standards for melanoma cancer when they have been finalised. This will involve recruiting a replacement for our very experienced Audit Facilitator, Gillian Smith, who has done so much over the years to ensure that high-quality clinical audit data on skin cancer is available for our network.

Data collected for the annual SCAN melanoma comparative report is essential in ensuring we deliver
an efficient, equitable service that meets the needs of patients and physicians. This data is invaluable when assessing demand, capacity and service provision. We will work with the SCAN audit team to ensure that collection of high-quality data continues in conjunction with the advent of QPI data collection.

Dr Megan Mowbray  
Chair, SCAN Skin Group

Upper GI Group

The data collection required for reporting on Quality Performance Indicators (QPIs) for both the hepatobiliary (HPB) and oesophagogastric (OG) groups began on 1\textsuperscript{st} January 2013. QPI reporting will allow accurate comparison of results between units and between regions against accepted targets and standards of care for patients. A regional audit meeting has been arranged for September 2013 to report on the QPIs for Jan-March 2013 to ensure the correct processes are in place to allow accurate reporting for 2013.

The new electronic multidisciplinary team (eMDT) system has been operational since September 2011 for OG patients. This allows real-time entry of results and discussions at the multidisciplinary meeting (MDM). All patients from Borders, Fife and Lothian are entered on to the system. MDM outcomes are sent electronically to both the GP and the referring consultant on the day of discussion.

The HPB team, in conjunction with the TRAK team, has started to modify a system suitable for their needs. It is intended that all tumour groups within Lothian will use TRAK for the running of MDMs and for reporting on MDM outcomes in the future.

The TRAK electronic audit system in Lothian is working well. Analysis for 2012 has been achieved using Business Objects. It has been agreed that the national OG meeting on 15\textsuperscript{th} November 2013 in Perth will be a trial attempt at reporting the QPIs for 2012 in preparation for the compulsory reporting for 2013.

The Upper GI unit in Lothian has obtained funding for a two-year post for an audit facilitator and Joanne Douglas started in post in March 2013.

A study on PET/CT in the staging process for oesophageal cancer patients demonstrated that metastatic disease was identified in 20\% of patients with operable disease on CT imaging. This has had a major impact on treatments offered and staging investigations required.
A study on the impact of the introduction of PET/CT in the staging process for oesophageal cancer patients demonstrated that metastatic disease was identified in 20% of patients with operable disease on CT imaging. This has had a major impact on treatments offered and staging investigations required.

Key objectives for 2013 will again be the presentation of SCAN data at national meetings but also ensuring that all regions are able to report on the QPIs. Clinically there is an increasing demand on the endoscopic ultrasound (EUS) service for more complex interventions and this is currently being assessed.

Mr Graeme Couper  
Chair, SCAN Upper GI Group

Urology Group
The SCAN Urology Group serves a large group of men and women (over 1,200 new cancer patients in 2012) and manages a diverse group of malignancies (prostate, bladder, kidney, testis and penile cancers). During the past year the Urology Group developed a Quality Performance Indicator (QPI) implementation programme, consolidated its patient reference group and established a bladder cancer support group.

Quality Performance Indicators for renal and prostate cancers were the first to be agreed under the national programme and data collection started for renal cancer in January 2012 and for prostate cancer in July 2012. We particularly welcome the inclusion of outcome measures such as treatment toxicity and PSA relapse in these national standards.

The SCAN Urology Group worked with the Maggie’s Centre in Edinburgh to establish a bladder cancer support group. We believe this is the only support group in Scotland for men and women with bladder cancer.

The SCAN Urology Group worked with the Maggie’s Centre in Edinburgh to establish a bladder cancer support group. This group met for the first time in September 2012 and we believe it is the only support group in Scotland for men and women with bladder cancer.

The SCAN Urology Patient and Carer Reference Group has now become an established part of the SCAN Urology Group, having had regular meetings for just over a year, with commitment from relevant patient representatives and enthusiastic support from SCAN’s Patient Involvement Manager. With
representation from patients, the four health boards, a carer and the main Scottish urological cancer charities, this initiative has given a voice to the patient group and strengthened lay involvement. A key to its success is the fact that the SCAN Urology Group patient representatives also sit on this patient and carer reference group, providing a robust feedback and reporting link, thereby ensuring a healthy relationship between the two groups. (See also page 18.)

The weekly urology multidisciplinary team (MDM) meetings in Edinburgh and Fife are extremely complex as they deal with a large volume of varied cancers. They have now become the central venues for assessment and management planning for the vast majority of patients, in keeping with the true spirit of multidisciplinary team involvement.

Looking to the future, the SCAN Urology Group will need to develop strategies to deliver increasingly complex state-of-the-art treatments, not only to improve cancer survival but importantly to deliver better quality outcomes for an ageing population with complex medical backgrounds. It will also need to develop strategies to support the large number of men and women living with urological cancers by delivering a robust, patient-centred follow-up programme. As the first step towards this, the Urology Group is currently developing a dedicated prostate cancer follow-up service, supported by IT systems, which will deliver high-quality, streamlined and efficient after care that will benefit all patients as well as enable optimal and efficient use of staff resources. This innovative model envisages that patient follow up will continue to be overseen by secondary care staff but will be delivered in partnership with staff in primary care and laboratory medicine.

Mr Prasad Bollina
Chair, SCAN Urology Group
**SE Scotland Cancer Research Network**

The Scottish Cancer Research Network (SCRN) was established to provide the NHS with an infrastructure to support prospective trials of cancer treatments and other well-designed studies, and to integrate and support research undertaken by cancer charities. Its aim is to improve the speed, quality and integration of research, ultimately resulting in improved patient care. The South East Scotland Cancer Research Network (SESCRN) is one of four regional divisions of SCRN.

In 2012/13 SESCRRN maintained high levels of recruitment and continued to increase opportunities for patients to participate in studies in their local hospitals, expand the research portfolio beyond the most common cancers and develop new types of research.

Recruitment to studies in South East Scotland has remained consistently high and levels increased further in 2011/12 in comparison to 2010/11. However the figures for 2011/12 highlight a backdrop of studies now targeting smaller but more specific groups. This reflects a move towards targeting specific patient genetic profiles rather than targeting the type of cancer the patient has been diagnosed with. This trend is expected to continue, resulting in lower recruitment levels in future. On the other hand, there are also areas where patients have an increased choice of study. These include melanoma, palliative care and ovarian cancer.

Figure 1 (overleaf) demonstrates the overall recruitment year on year from 2007/08 until 2011/12 and captures all patients who consented to individual research projects across South-East Scotland.

The workload involved in delivering research studies has also increased. The preparatory complexities of the regulatory process and the increased screening requirements for targeted studies present significant challenges for SESCRRN and it is tribute to the many multidisciplinary areas such as pathology, radiology, laboratory, pharmacy and research and development that all work together that these studies are being brought to patients within a very short time frame.

Many of the Principal Investigators for the studies are oncologists working within our hospitals who are now taking on their own portfolio of studies. This increase

The research portfolio has been expanded to include melanoma and palliative research studies.
Research in the number of researchers across SESCRN gives patients greater choice with regard to research studies and access nearer their own homes.

Translational Research

The Edinburgh Cancer Research UK Centre (CRUK) and the Experimental Cancer Medicine Centre (ECMC) take a comprehensive approach to cancer research, transcending laboratory-based and clinical disciplines. They study the genetic and biological basis of cancer and disease pathology and shape these results into new forms of therapy which are then used as part of our studies within SESCRN. Our collaborative work with the Edinburgh Cancer Research Centre (CRUK), Experimental Cancer Medicine Centre (ECMC) and the Institute of Genetic and Molecular Medicine (IGMM), which all support this form of research, has grown year on year and these collaborations are now expanding to including cross-network research with Dundee and Glasgow. This means that patients may be able to be treated as part of a study in another region if no similar study is available nearer home. This in turn helps build the tissue bank which the ECMC is generating to support future research. This year we appointed a research nurse with the specific remit of working across any tumour site running a study with a translational

More randomised control studies are now available covering a wider range of cancers.

**Figure 1: Total recruitment to trials in South East Scotland**

![Bar chart showing total recruitment to trials in South East Scotland from 2007/08 to 2011/12.](chart.png)
element as part of it. This role has been very successful and highlights the need for expansion in this area.

Throughout the South East of Scotland a varied selection of studies is now being offered to patients in Fife, Borders, West Lothian and Dumfries & Galloway. The success of this service is largely due to our Lead Nurse for the outlying teams, Vivienne Wilson, who has supported the staff in the four hospitals and has, with the help of all the research staff, produced a good portfolio of studies at every hospital.

*Table 1: Recruitment to trial types in SE Scotland (from 2007/08 to 2011/12)*

<table>
<thead>
<tr>
<th>Tumour Area</th>
<th>Total Patients Recruited</th>
</tr>
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<tbody>
<tr>
<td>Bladder</td>
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</tr>
<tr>
<td>Brain</td>
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<tr>
<td>Breast</td>
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<tr>
<td>Colorectal</td>
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<td>Gynaecology</td>
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<td>Haematology</td>
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<td>Head &amp; Neck</td>
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<tr>
<td>Lung</td>
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</tr>
<tr>
<td>Lymphoma</td>
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</tr>
<tr>
<td>Melanoma</td>
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</tr>
<tr>
<td>Palliative Care</td>
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<td>Primary Care</td>
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</tr>
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<td>748</td>
</tr>
</tbody>
</table>

Note: The reporting period used is 1st April of each year until 31st March the following year.
A record number of studies are now being offered in all the region's hospitals.

At the **Borders General Hospital** recruitment continues to be steady and patients with haematological, breast, colorectal and now lung cancer all have opportunities to take part in a clinical study. This work is supported by the part-time research nurse funded by NHS Borders.

The S ESCRN continues to provide funding for the research nurse in **Fife** and this has allowed Fife to expand the post and provide some data manager support as well. We hope that this extra input will result in increased recruitment numbers and an increase in studies available both locally and regionally.

**NHS Dumfries & Galloway** remains fully committed to offering their patients the opportunity to participate in a variety of clinical studies including studies on palliative care and breast, colorectal and lung cancer.

Fife, Borders and Dumfries & Galloway are all examples of smaller general hospitals working well above expectation with limited resources to allow patients greater opportunities and choices.

**St. John's Hospital in West Lothian** has several breast cancer studies in their portfolio and patients are followed up by a research nurse who has an expanded role and runs her own clinic. The target this year will be to expand the portfolio and offer haematology studies to West Lothian patients.

**Western General Hospital**
In the past year the S ESCRN once again found itself going through further management change. Professor Charlie Gourley, the clinical lead, continues to provide strong leadership for the network whilst working on innovative new laboratory work and overseeing a large portfolio of ovarian trials. The clinical team leads have rotated and this has brought renewed vigour and enthusiasm to each of the teams within the network. Rotating the clinical team leads underlines our commitment to supporting and encouraging all consultants to participate in clinical research and help grow our international reputation. We have been fortunate in that three of our young research active consultants have received NRS (NHS Research Scotland) fellowships, freeing up protected time for research. This will facilitate research in sarcoma, colorectal cancer, melanoma and early phase clinical trials and is extremely welcome.
It is with sadness that we have to report on the untimely death earlier this year of Karen Klein-Woolthuis, the SESCRN Network Manager. Karen had only been in the post for a short time but her vision and contribution gave the network many benefits and the work she started will be carried on. She is greatly missed by all her colleagues throughout the network and the Western General Hospital, where she was based.

SESCRN continues to be the top recruiter for many studies across the whole of Scotland and is at the forefront of much collaboration with other institutes and hospitals. As we enter our tenth year, changes to how the network is funded and how it functions are inevitable. However everyone associated with SESCRN is committed to ensuring that these changes ensure we are fit for purpose to enable us to meet the challenge of improving cancer patients’ outcomes year on year.

*Dorothy Boyle*
*Acting Network Manager, SESCRN*

For more information on the South East Scotland Cancer Research Network, see [www.sescrn.org.uk/](http://www.sescrn.org.uk/)
Pharmacy Network

The Pharmacy Network constitutes a geographically dispersed group of staff which includes specialist oncology pharmacists and technicians. The services provided range from dispensing and aseptic preparation of cancer treatments (including treatments delivered in the context of clinical trials) to full clinical pharmacy support for the multidisciplinary teams and patients within the cancer centre. For cancer patients this ensures continued and consistent quality of cancer care, especially in maintaining and improving patient safety with respect to the prescribing, verification and administration of cancer medicines.

The main focus of the Pharmacy Network has been the continued roll-out of the chemotherapy electronic prescribing and administration system (ChemoCare). This is being implemented board by board across SCAN, with full implementation predicted to be complete by the end of 2013. This is a positive step in the modernisation of services with clear benefits to patient safety. Sheena to add x-reference to main ChemoCare section.

Edinburgh Cancer Centre

At the Edinburgh Cancer Centre the major focus for the pharmacy team continues to be ChemoCare implementation:

- Clinical pharmacists have worked with the cancer tumour site leads to revise master chemotherapy prescription charts for entry on to the electronic system.
- The ChemoCare Pharmacist has continued to educate, train and support all staff groups and has ensured entry of all protocols on to the system as part of a safe and appropriately validated process.

The pharmacy team have taken lead roles in the update of:

- NHS Lothian safe use of systemic anti-cancer therapy governance guidelines – which will continue through 2013. The audit tool for the associated Scottish Government Chief Executive Letter (CEL (2012) 30) has been trialled and developed in conjunction with Health Improvement Scotland and the audit will be undertaken by September 2013.
- Supportive medicines protocols updated through local Medicines Governance Committees – including antiemetics, supportive medicines and, in particular, renal function guidelines.

The Lead Pharmacist has worked closely with the Regional Cancer Advisory Group (RCAG) to develop and agree a Non-formulary and Individual Patient Treatment Request process across SCAN to improve communication and transparency of decision-making processes.

**Dumfries & Galloway**

In the Dumfries & Galloway pharmacy department one of the main areas of work for 2012 was the support and implementation of ChemoCare, with the Lead Clinical Pharmacist acting as the main contact between the Cancer Centre and the Unit. Scheduling for all tumour groups and prescribing in colorectal and upper gastrointestinal cancers was implemented during 2012 and the remaining solid-tumour specialities and haematology will be implemented during 2013.

Following the submission of a joint nursing and pharmacy business case, highlighting the increasing demand for services, NHS Dumfries & Galloway approved the appointment of two additional staff – an oncology pharmacist and a technician. This will ensure that there is pharmacy capacity to continue to allow patients to be treated locally and adequate back up for the single-handed pharmacy service.

**NHS Fife**

The pharmacy service in NHS Fife has continued to develop their pharmacy technician resource by providing a clinical pharmacy technician role. This role has responsibilities for patient counselling on oral chemotherapy and supportive care medicines and provides a link for patients to discuss any issues they may have with their medicines. The implementation of ChemoCare continues across the two cancer hospital sites in NHS Fife and this will support the ongoing ‘repatriation’, from Lothian to Fife, of patients requiring chemotherapy.

Recruitment for a replacement Pharmacist at the Victoria Hospital, Kirkcaldy has been completed and the new postholder will start during July 2013.

The appointment of additional pharmacy staff will help to ensure that many patients in Dumfries & Galloway will continue to receive their chemotherapy treatment locally.
NHS Borders
The last year has seen a 5% increase in workload which is a reflection of treatment being repatriated from Lothian to the Borders to ensure patients are treated nearer their home. However some of these treatment regimes are more labour intensive and require increased capacity within the cancer unit. NHS Borders has also opened a dedicated palliative care facility – The Margaret Kerr Unit – made possible by local fundraising and input from Macmillan Cancer Support. This new unit will be a great asset for Borders patients and their families. However, both of these developments highlight the need for additional specialist pharmacy support in cancer and palliative care and work on the supporting business case for this continues.

The introduction of ChemoCare has provided its own challenges and adjustment to working practices. However all members of the team are committed to making this work for the benefit of the service.

Excellent working relationships between the pharmacy service and the broader multi-disciplinary team in the cancer unit and the palliative care facility ensure that a high-standard and timely service is provided. Working practice development has also meant that any wastage of dispensed medication continues to be kept to a minimum.

Paediatrics
Cancer services for paediatrics are managed regionally from the Royal Hospital for Sick Children in Edinburgh as part of the national Managed Service Network for Children and Young People with Cancer. The children’s cancer pharmacy team appointed a senior pharmacist in 2012/13. This is the first time since 2010 that this has been a permanent post and the appointment has allowed stabilisation within the team and the ability to develop policies and guidelines within the children’s cancer service to support safe delivery of systemic anti-cancer therapy in accordance with government guidance.

Furthermore, it is hoped to re-establish a rotational training pharmacist post within the children’s cancer pharmacy team, for the first time since 2010, to enable contingency planning and career progression. Key work for 2013/14 will be competency-based pharmacist
education and training within children’s cancer, and contribution to planning the relocation of the children’s hospital to the Royal Infirmary site at Little France in Edinburgh during 2017.

Ewan Morrison
SCAN Lead Pharmacist

The responsibilities of the clinical pharmacy technician role developed by NHS Fife include patient counselling on oral chemotherapy and supportive care medicines and discussing any issues patients may have with their medicines.
NHS Borders

The past year continued to challenge us all in terms of resources and workload, yet despite this NHS Borders continued to perform well in relation to cancer waiting times targets, with no breaches of the 95% target for 31-day or 62-day pathways reported in the year April 2012 to March 2013.

The year saw further progress with some of the projects and pieces of work commenced in 2011/12, namely:

Chemotherapy electronic prescribing
NHS Borders went live with electronic prescribing for oncology patients treated locally during 2012/13 and plans to be fully live with haematology in 2013/14.

Work is ongoing on chemotherapy capacity planning using the C-PORT tool.

Palliative care
Borders was the only mainland health board in Scotland without a dedicated palliative care facility but, following the emergence of a significant legacy in 2010 to be utilised in the area of palliative care, work was undertaken throughout 2011/12 with NHS Borders and many partnership organisations and local charities to create a dedicated palliative care facility. A public fundraising appeal engaging the Borders community raised the final £1 million required for this.

We are delighted to report that, after an eight-month construction phase, patients moved into the Margaret Kerr Unit on 7th January 2013. The Unit has already started to transform the way inpatient specialist palliative care is delivered at the Borders General Hospital. Patients and their families have been hugely impressed by the spacious, comfortable and well-equipped rooms and the picturesque surroundings.

Cancer modernisation

Acute oncology
Regionally NHS Borders has been involved in the short-life working group to share ideas and practice around the subject of acute oncology.

The opening of the Margaret Kerr Unit has transformed the delivery of inpatient specialist palliative care at Borders General Hospital.
Locally a review of acute oncology was undertaken which involved a three-month benchmark period followed by a six-month pilot of a nurse-led acute oncology service. Preliminary data from the pilot project suggests that the nurse-led acute oncology service improved patient safety, patient experience and patient flow within the organisation. Further detailed data analysis of the pilot project will be undertaken in 2013/14 with a view to developing a business case for a funded nurse-led acute oncology service. Other outcomes of the project to be implemented this year will be an education programme for non-specialist staff, development of an acute oncology microsite and consideration of electronic alert systems for specialist teams.

**Surgical oncology**
The Colorectal Enhanced Recovery After Surgery (ERAS) Programme was introduced to NHS Borders in January 2013. There had been a great deal of interest shown in ERAS prior to the appointment of the Programme Lead and this continued enthusiasm has enabled changes to be introduced in the care of colorectal patients. A number of ‘tests of change’, in line with the Scottish Patient Safety Programme (SPSP), have been undertaken and a full Value Stream Mapping day in May 2013 will allow all disciplines involved in patient care to come together and discuss how the programme can be fully implemented in NHS Borders.

The Consultant Surgeons have been steadily increasing the number of laparoscopic colorectal procedures carried out in NHS Borders over the past three years and this, in conjunction with the engagement of a Consultant Anaesthetist, has ensured that the roll-out of the full Colorectal ERAS programme should be achieved by the end of June 2013. The 23-hour Breast ERAS Programme will be introduced as soon as the colorectal programme has been established.

**Breast cancer**
Following the purchase a specialist probe to detect radioactivity in axillary sentinel nodes in the treatment of breast cancer, radioactive isotope can now be used to carry out full sentinel node biopsy. This approach, recognised as being the gold standard for sentinel node biopsy, has been up and running successfully for six months now.
The Detect Cancer Early (DCE) breast cancer awareness campaign was launched in September 2012, followed by the colorectal cancer awareness campaign in February 2013. Locally we have been monitoring the impact of these campaigns on our referral patterns and screening uptake figures. Additional breast clinics were held in March 2013 to deal with an initial surge in referrals following the awareness campaign. For colorectal, an additional colonoscopy list was set up to deal with the anticipated increase in referrals from the bowel screening service. Funding has also been allocated to increase the hours for the Clinical Nurse Specialist (CNS) post for lung cancer, in advance of the lung campaign.

Working closely with Health Improvement, a local communication plan was put in place to support the national awareness campaign. The plan maximises opportunities to use existing networks such as Lifestyle Advice and Support Services (LAS), Keep Well (community and workplace) and Healthy Living Networks (HLNs). A brief local resource has been developed to support the distribution of national materials. Plans are also underway to undertake an online survey of our staff to evaluate the effectiveness of the recent colorectal screening campaign.

A programme structure is now in place, with a Programme Manager, steering group, project team and sub-groups on communications and data & definitions.

A Clinical Nurse Specialist has been appointed to provide a point of contact and assist in co-ordinating pathways for patients with hepatobiliary (HPB) cancer.

In conjunction with our SCAN colleagues and the Edinburgh Cancer Centre, and building on the work that has been completed over previous years, we have continued to work to deliver care as close to home as possible for the inhabitants of Dumfries & Galloway.
Perhaps because of the challenges of our rurality and geography we have developed a keen interest in using technology to reduce travel time for staff and patients whilst maintaining high-quality and responsive services that respect and accommodate patient choice.

Working with our local primary care partners we have continued to use IT to expedite referrals into the system and monitor them effectively so that individual feedback can be given to the referrer and the patient can be effectively tracked through their treatment episodes.

As part of the regional service redesign we hosted a pilot study involving remote patient consultations (using a videoconferencing link) with consultants based in Edinburgh for a select patient group in Dumfries who were supported by local specialist staff. This was the first such study held in our region for cancer patients, although the methodology has been used in other disciplines. The patients involved evaluated the experience well and gave some valuable insights into when the method might be used to best effect. Using a telehealth framework to determine the outcomes showed that we have already successfully moved patient care to a multi-professional team base spanning treatment and monitoring of patients over the longer term. (See also page 8 and page 20.)

We continue to use telehealth in a broader sense to link locally-based staff with regional colleagues for multidisciplinary team meetings (MDMs), planning and implementation meetings which significantly reduces the amount of staff time spent in travel and the cost.

The use of IT to underpin clinical systems has also progressed with the adoption of the electronic chemotherapy prescribing system. All staff who use the system have now been trained in its use and the programme is being rolled out to all cancer specialities and to the Galloway Community Hospital, where the outreach chemotherapy unit is still based. This national system is a secure method of prescribing and recording the administration of chemotherapy treatments for all patients. It will replace the paper systems that have been used for some years and negate the need for dual sets of medication notes to be held.

As part of the regional service redesign NHS Dumfries & Galloway hosted a pilot study involving remote patient consultations (via videoconference) with consultants based in Edinburgh.
The Detect Cancer Early (DCE) programme is being taken forward under the aegis of the DCE Strategy Group which includes representatives from acute and community care and the third sector. Oversight of the programme is by the Lead Cancer Team and the board has recently approved the use of DCE funding to appoint to key posts in audit, communications and project management in order to support the work going forward. Local social marketing campaigns have been undertaken and the focus is on increasing the uptake of national screening programmes, particularly in hard to reach groups, and building capacity within diagnostics.

The Cancer Information and Support Centre is adopting the latest methods of delivering information from the Macmillan TIPS (Tailored Information for the People of Scotland) project. Whilst it had been envisaged that it might start in one speciality, learning taken from the project’s evaluation has shown that all specialities have something to gain by offering this system of pulling together information from different sources for patients and carers. Volunteers within the centre are being trained as guides to help people through the plethora of information sources to find the one that is most appropriate for them.

Building on the work of the Breast Cancer Care Pledge that the breast team made with Breakthrough Breast Cancer, post-treatment exercise classes continue to be held across the region. The service has been so well received and has made such a difference to people’s lives and physical activity that we are currently planning to extend the service to other patients. It is this type of support and encouragement that people value as a way to return to a more normal way of life after their initial treatments are completed.

In conjunction with Marie Curie Cancer Care, we have successfully continued to provide a responsive out-of-hours nursing service for palliative patients 365 days per year. The service has successfully married acute and primary care input to this patient group in order to support them to be cared for at home and complements the overnight service. It has now extended its remit to include nursing homes so that patients can be seen wherever they are. In the near future it is hoped that the service can be delivered across the whole of the region.
NHS Fife

Detect Cancer Early

In response to the launch of the Government’s Detect Cancer Early (DCE) programme in late 2011, NHS Fife completed its implementation plan in May 2012. Implementation of the programme became a workstream of the Elective Flow Improvement Group and was prioritised within the health board’s activities. Outcome measures were agreed and reported to this group. A DCE Programme Board met for the first time in June 2012 and managerial and clinical leads were appointed, together with a project manager. An operational Project Group met for the first time in July 2012. Membership of the Programme Board was drawn from NHS Fife (Lead Cancer Team, primary and secondary care, public health and health promotion), lay representation and the third sector. A Public Awareness and Screening Sub Group was set up specifically to address issues relating to earlier presentation/detection of the three main cancer groups and to liaise with the national awareness-raising projects.

Funding provided for the implementation of the programme was allocated during 2012/13. Given the delay due to advertising and recruitment, more than £345,000 in 2012/13 was approved with the expectation of additional funding in 2013/2014. The Senior Management Team approved the allocation of recurring funding of £564,000 for a Consultant Radiologist, Gastroenterologist, Respiratory Physician, Pathologist and nurse endoscopists to address the potential increase in demand generated by the programme. In addition £124,000 of non-recurring funding was allocated to support local screening procedures, information platforms for the public, a website for GPs and other health promotion activities. In the past NHS Fife attempted unsuccessfully to recruit a Lead Cancer GP. DCE funding was allocated to provide sessions for such a post with an emphasis on the DCE Programme. A local GP has now been appointed and will take up post in July 2013.

Capital funding was also provided by the Scottish Government and two projects (for a breast vacuum biopsy unit and thoracoscopy equipment) have been approved. So far good progress has been made against the local implementation plan.

In response to the launch of the national Detect Cancer Early programme, NHS Fife invested in additional staffing, providing support for local screening procedures, information platforms for the public, a website for GPs and other health promotion activities.
**Cancer modernisation**

During 2012/2013 projects funded by the Cancer Modernisation Programme in 2011/2012 continued to be developed. An Acute Oncology Nurse Practitioner took up post in July 2012 and evaluation of the fully-developed 23-hour breast care pathway at Queen Margaret Hospital and a nurse-led one-stop colorectal assessment have been undertaken.

In addition NHS Fife was successful in obtaining funding from the Cancer Modernisation Programme for:

- Continuation of the project to test a new model of care for managing acute oncology. Pathways for patients who present acutely have been made available on the NHS Fife Intranet.
- Enhanced recovery for colorectal patients. LiDCO monitoring equipment has been purchased and used in the enhanced recovery pathway for colorectal cancer surgery which commenced in December 2012.
- Development of dermatology accommodation and equipment which will allow organisational developments of the cutaneous oncology and surgical service at Victoria Hospital (building works almost complete).

**Implementation of regional non-surgical oncology review**

NHS Fife identified as its top five priorities:

- To develop a model for the delivery of acute oncology.
- Local and regional patient pathways, clinical management guidelines and protocols across SCAN to be developed, audited and monitored by members of the wider multidisciplinary team.
- Each tumour site to review their existing follow-up practice and consider if current pathways could be redesigned.
- Oncology services to utilise service improvement methodology to test and redesign service delivery through use of e-health and telehealth tools and technology.
- Outreach services provided by clinicians based at the Edinburgh Cancer Centre should be redesigned to ensure maximum resilience and efficiency.
Discussion of these five priorities continued throughout the year, with particular focus on the transfer from the Edinburgh Cancer Centre to Fife of chemotherapy related to gynaecological cancers. The assessment of roles of existing staff and the potential requirement for further staffing to ensure the safe delivery of oncology services within Fife continue to be considered.

**Electronic chemotherapy prescribing**

NHS Fife is in the process of implementing ChemoCare, which is an electronic prescribing system for chemotherapy. To date ChemoCare is being used in prescribing for breast, upper GI and colorectal cancers. It is anticipated day-case chemotherapy for lung cancer will be transferred to electronic prescribing in April 2013, with day-case haematology and inpatient lung cancer following in May 2013.

**Chemotherapy CEL 30 (2012)**

The [Revised] Guidance for the Safe Delivery of Systemic Anti-Cancer Therapy (SACT), published by the Scottish Government in July 2012, provided updated guidance on the safe delivery of SACT and was endorsed by the Scottish Cancer Taskforce (SCT). NHS Fife is currently undertaking the self assessment of SACT services, using the audit tool which must be completed for all SACT services within six months of publication (ie by September 2013).

**Waiting times**

Waiting times continue to be a challenge, particularly for certain types of cancer. Fife’s achievement of the targets was good during 2012, however work continues to review and improve pathways when the wait is not what we would hope for individual patients.

**Move of acute services**

The move of acute services to the Victoria Hospital, Kirkcaldy site in January 2012 has led to the improved management of cancer, particularly in the areas where collaboration between specialities has been required, eg surgery for gynaecological cancers requiring gynaecology and general surgery input.
Throughout 2012/13 NHS Lothian continued to develop and implement its cancer programme plan ‘Better Cancer Outcomes in Lothian – A Strategy for Cancer 2011–2015’. This provides a focus on the board’s major cancer workstreams and highlights strategic priorities, such as:

- prevention and earlier detection
- improving quality, outcomes and experience
- pathway improvement and service modernisation
- increasing our focus on living with cancer and care after treatment
- improving palliative and end-of-life care
- maintaining cancer access standards.

Increasingly, over the year, the cancer strategy helped to develop thinking and planning work on the future model of care and estates requirements for future cancer care in Lothian and this work will be explored further in 2013/14.

This brief report, which incorporates a highlight report of the work of the Edinburgh Cancer Centre, provides a summary overview of key work and achievements over the year.

Detect Cancer Early programme

In 2012 NHS Lothian established a Detect Cancer Early (DCE) programme, under the executive leadership of Dr Alison McCallum, Director of Public Health and Health Policy. A high-level plan was developed and a Programme Board was formed to develop and steer the programme over a three year period (2012/13 – 2014/15). The approach has been based on a review of the cancer inequalities evidence base and the national DCE programme framework. It focuses on tackling inequalities and identified complex issues in cancer care, building up diagnostic and treatment capacity, integrating early detection into our existing service redesign work across Lothian and, increasingly, on targeted action to identify opportunities and service approaches to detect more cancers at stage 1 of disease. In year one of the programme investment went into the diagnostic and treatment services providing care for patients with lung, breast and colorectal cancer, as well as primary care, audit, e-health and cancer informatics.
Cancer modernisation
The Lothian Cancer Modernisation Programme was developed in 2012 with the Lothian Cancer Planning and Implementation Group (LCPIG) and the SCAN Regional Cancer Planning Group (RCPG). Strategically, investment was prioritised against realising efficiencies and effectiveness in the service, strategic fit with the Lothian cancer plan and the Detect Cancer Early programme, patient benefit, improvements to treatment and impact on health inequalities. A programme of work is now funded over two years, across 2012–2014, which focuses on improving acute oncology (including the management of emergency and unscheduled presentations, pathway improvement and earlier identification of palliative and end-of-life care needs), further developing surgical oncology services in dermatology, gynaecology and breast cancer services and developing and delivering new technologies in radiotherapy.

Maintaining cancer access standards
The 62-day and 31-day cancer access standards continue to be monitored closely across the service via cancer tracking and weekly reporting, with the production of additional monthly management information and quarterly public reporting against standards by ISD (Information Services Division). Throughout 2012/13 NHS Lothian invested in additional staff and equipment and delivered additional service capacity to maintain 62-day performance, particularly in the tumour group areas of colorectal, urology and head and neck. Performance in the latest published period (Quarter 4, 2012) was 97% for the 62-day target. The 31-day decision-to-treat-to-treatment standard was consistently delivered throughout the year, with performance in Quarter 4, 2012 being 98.6%.

McKinsey colorectal cancer improvement network
In 2012 NHS Lothian was one of five health systems which signed up to be part of an international, in-depth focus on the management of colorectal cancer (from screening to end-of-life care) run by McKinsey & Company. As well as NHS Lothian, the other systems participating in the network are the Queensland Department of Health (Australia), Victoria Department of Health (Australia), Singapore Ministry of Health and NHS Central South Coast Cancer Network. Throughout 2012/13 an intensive period of diagnostic
work was undertaken, followed by analysis, review and identification of improvement objectives.

NHS Lothian hopes to achieve the following important objectives from this process:

2. Ensure value in every component of the colorectal cancer pathway.
3. Highlight any areas of current practice that expose a lack of equity of access, uptake or survival amongst different socio-economic groups.
4. Minimise morbidity and mortality from colorectal cancer in Lothian.

Improvement priorities which have been identified are:

- increasing the proportion of screen-detected cancers
- reducing the emergency presentation rate
- finding more cancers with fewer colonoscopies.

For a further year, 2013/14, the improvement work will continue to be led locally, with ongoing support from McKinsey.

**Cancer QPI programme and e-health / audit**

The National Cancer Quality Programme is an important part of developing the arrangements that underpin continuous quality improvement in cancer care. The National Cancer Quality Programme is an important part of developing the arrangements that underpin continuous quality improvement in cancer care in NHS Lothian. Following the publication of *CEL 06 (2012) – National Cancer Quality Programme*, NHS Lothian has progressed a number of key actions to implement the programme locally. These include actions to ensure:

- collection and submission of validated data for regional comparative analysis and reporting
- that the national cancer quality work is embedded within established NHS Lothian governance arrangements
- that work to address variance is taken forward with the regional cancer network.

In addition, a number of key enabling actions have been progressed, including:

- TRAK system development, which includes the development of TRAK cancer audit modules and development and roll-out of the TRAK multidisciplinary meeting (MDM) module
an ambition to achieve stronger integration of real-time pathway data as much as possible, thereby maximising its value and use
improving data capture to support reporting against the Detect Cancer Early programme and associated HEAT targets.

**Teenage Cancer Unit development**
In 2012 NHS Lothian approved proposals to create a dedicated inpatient and day-case facility for older teenagers and young adults (aged 16 to 24 years) with cancer at the Western General Hospital. A formal development agreement between NHS Lothian and the Teenage Cancer Trust (TCT) was signed to initiate the development and ward refurbishment commenced at the end of 2012, with an expected completion date of July 2013. This initiative will create an environment which provides positive benefits to young people with cancer and cater for the needs of patients, family and friends of those with cancer. The development is supported through a charitable capital fund donation of up to £1.35 million from the Teenage Cancer Trust.

**Palliative care**
The NHS Lothian Acute Hospital Palliative Care Service has continued to see a rise in referrals for specialist assessment and support from hospital teams caring for patients with cancer and other advanced, progressive conditions. A number of service developments and quality improvements have continued throughout the year.

The Liverpool Care Pathway (LCP) team has continued an effective programme of implementation, audit and staff training. The Edinburgh Cancer Centre and all target areas in Lothian’s acute hospitals are now using the LCP to support best practice in end-of-life care, however recent press coverage in relation to the LCP has meant further training and support has been required to support its ongoing use within certain areas in the acute service.

Service users’ views about the quality of end-of-life care in Lothian hospitals have been evaluated using a survey, brief interviews and focus groups. The Supportive and Palliative Care Indicators Tool (SPICT) has been recommended for use throughout NHS Scotland and a paper on its development has been accepted for publication in *BMJ Supportive & Palliative Care*. A growing number of teams and services in the
UK and internationally are interested in using SPICT and the latest version (June 2013) is available via the website (www.spict.org.uk).

The palliative care teams are contributing to the Acute Oncology Programme Board and the Lothian and NHS Scotland Deteriorating Patient Programmes. Work in this area has included a hospital staff survey about oncology and palliative care services, a quality improvement project on care planning for patients who are deteriorating with advanced conditions and a new supportive care intervention project (SCIP) designed to address local and national targets for improving hospital palliative care.

**Palliative care service redesign**

In 2012 NHS Lothian and Marie Curie UK jointly sponsored and initiated the Lothian Palliative Care Redesign Programme. The programme utilises the Marie Curie ‘Delivering Choice’ programme methodology. A Lothian Palliative Care Redesign Programme Board has been established and representation is in place from NHS Lothian services, City of Edinburgh Council, Midlothian Council, independent care home providers, Edinburgh University and St Columba’s Hospice. Through Marie Curie UK, a Service Redesign Consultant has been appointed to support the Lothian work programme.

The overall aim of the redesign programme is to assist in taking further the community-based model of palliative care in place across Lothian – maximising the time spent in people’s preferred place of care, minimising emergency admissions where these can be avoided and supporting choice of place of death where this can be realistically achieved.

**Highlight report from the Edinburgh Cancer Centre**

**Radiotherapy**

The radiotherapy department has continued to develop the spectrum of radiotherapy techniques in order that patients can benefit from the latest advances. These improvements have been resourced, in part, by cancer modernisation funding from central government. Key developments have included:

- Installation, acceptance testing, commissioning and clinical implementation (January 2013) of a replacement iX Silhouette Linear Accelerator and a
replacement TrueBeam Linear Accelerator as part of the national procurement programme.

- Expansion of the availability of RapidArc (which maximises the radiation dose the tumour receives and minimises exposure of the surrounding healthy tissue) for patients with head & neck cancer and prostate cancer. Implementation of RapidArc for some brain sites based on clinical need.

- Introduction of field-in-field breast radiotherapy planning, which allows a more uniform radiotherapy dose to be delivered throughout the breast while shielding more sensitive areas, such as the heart. There are plans to expand capability with recruitment to the FAST FORWARD trial, expected to start in summer 2013. This study will compare a very short 5-fraction regime with a conventional 15-fraction one and has the potential to improve patient experience, as the number of visits to the department will be reduced, and free up linear accelerator capacity.

- Implementation of the Dosimetry Check system. This system, which measures the actual radiotherapy dose delivered to patients, is currently implemented on three of the Cancer Centre’s six linear accelerators and is being used to verify all RapidArc treatments (the most complex treatments and hence those with greatest potential risk). This approach will be rolled out to all the other linear accelerators as they are replaced. The Edinburgh Cancer Centre is recognised to be the world leader in clinical use of Dosimetry Check.

- Work up for 4D planning of lung cancer (which takes tumour movement into account) for stereotactic ablative radiotherapy (SABR) is nearing completion. Training for planning staff is underway and the first patient is expected to be treated in the summer of 2013. SABR delivers 3-5 fractions of radiotherapy for patients with small stage 1 tumours who currently receive 20 fractions of treatment.

- Installation of the Radiotherapy Planning Online Resource Tool (R-PORT) – the system is currently undergoing testing.

- QABeamChecker+ has been tested clinically and roll-out into routine use for linear accelerator quality assurance is expected by summer 2013. The system will streamline linear accelerator quality assurance checks.
**Systemic anti-cancer treatment (SACT)**

The two main issues within SACT services in the last year continued to be treatment capacity management, in light of steadily rising demand, and implementation of the ChemoCare electronic prescribing and administration system. The service has successfully expanded its day-case systemic anti-cancer treatment service delivery to Saturdays, for predominantly maintenance regimens (Rituximab and Trastuzumab) as well as supportive therapy. Investment in nursing staff recruitment and training and education of new staff within the facility have been priorities.

A successful bid to develop two additional part-time advanced nurse practitioner roles for oncology and a full-time post for haematology within day-care services has been funded by Macmillan Cancer Support for three years and the postholders are having a positive impact on meeting service needs whilst working towards building additional capacity within the team. As a result of this investment and support, a nurse-led oral chemotherapy clinic has recently been established within the day-care treatment area, offering a more efficient and responsive service for patients with colorectal cancer and central nervous system cancer.

The publication of CEL 30 (*Guidance for the Safe Delivery of Systemic Anti Cancer Therapy*) and the development of the Chemotherapy Toxicity Helpline (CTH) have resulted in the redesign of triage processes, including expansion of the oncology assessment facility to deliver a service between 8am and 9pm, 7 days a week, with the support of UKONS (UK Oncology Nursing Society) trained hospital at night (HAN) nurses overnight 7 nights per week. The clinical team from NHS Lothian has been instrumental in developing the national telephone helpline service due to be launched in June 2013.

Within Lothian, ChemoCare has been rolled out to the majority of oncology tumour groups, with central nervous system tumours and sarcoma outstanding and due to go live by the end of summer 2013. Haematology day-case regimes are fully implemented and outpatient oral therapy is due to go live by July 2013.

Ward 1 has had some further refurbishment which has expanded the reception area and created a cohort bay.
to manage respiratory infections in the haematology patient group.

**Acute oncology**
An Acute Oncology Programme Board has been established to oversee service development within six work streams:

- malignant spinal cord compression
- cancer of unknown primary
- early intervention palliative care
- chemotherapy toxicity helpline
- oncology assessment expansion
- patient/stakeholder feedback.

The metastatic cancer of unknown primary (mCUP) service has been established and the first phase successfully evaluated as part of the acute oncology project, demonstrating improved patient pathways and efficiencies within healthcare through streamlined care, reduced investigations and reduced length of stay. This service is due to expand, with one-year funding secured, to support the Royal Infirmary of Edinburgh site. A robust evaluation to identify patient and service benefit will be an integral part of this development project.

**Oncology**
With the expanding volume of patients with cancer and a necessary focus on supporting and managing people in the outpatient and day-care setting, pressures with clinical nurse specialist resource have been identified in some teams due to their expanding and increasingly complex services. Additional funding for clinical nurse specialists has been secured to expand existing resource in the gynae-oncology and colorectal services. Part funding has been identified for the neuro-oncology nursing service, but further resource will be required and will remain a priority for 2013/14, along with hepatobiliary cancer.

The local management of oncology and haematology patients has been enhanced by five advanced nurse practitioners (funded by Macmillan Cancer Support) who are undergoing a three-year training programme and are now key to the delivery of inpatient and day-care pathways within the subspecialty teams in the service.
Haematology
Whilst Haematology is now fully staffed from a medical perspective, it remains under considerable pressure given improving survival rates and an ageing population. Work started in 2013 on an Older People’s Project which will see closer working with Medicine of the Elderly teams to ensure appropriate delivery of care for this patient group and facilitate earlier discharge, where possible, through targeted interventions.

In response to recognised need for a large, and often complex, patient group, a new post of Clinical Nurse Specialist in Lymphoma has been prioritised and funded within the department through redesign of existing resource.

Breast services
NHS Lothian adopted and implemented the Breakthrough Breast Cancer Service Pledge at the Western General and St John’s Hospital and the breast service is now contributing to the development of a similar pledge for secondary breast cancer services.

Further to the launch of the Detect Cancer Early (DCE) national campaign, the service has been able to expand its delivery of multidisciplinary new patient clinics and provide additional theatre sessions.

Service redesign has enabled 23-hour discharge for selected patients post mastectomy to be realised which has improved the experience for patients.
# Network Staff and Group Chairs

## SCAN Core Team

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Dr Val Doherty</td>
<td>Clinical Director</td>
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<tr>
<td>Mrs Kate Macdonald</td>
<td>Network Manager</td>
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<tr>
<td>Mrs Rachel Russell</td>
<td>Executive Assistant/PA to Clinical Director</td>
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<tr>
<td>Ms Sheena Mackenzie</td>
<td>Communications &amp; Groups Co-ordinator</td>
</tr>
<tr>
<td>Mrs Sandra Bagnall</td>
<td>Patient Involvement &amp; Information Manager</td>
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<tr>
<td>Mr Ewan Morrison</td>
<td>Lead Pharmacist</td>
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<tr>
<td>Mrs Carole Ritchie</td>
<td>Patient Involvement Administrator (P/T)</td>
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<tr>
<td>Mrs Amanda Garden</td>
<td>Information Systems Developer (P/T)</td>
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<tr>
<td>Mrs Alison Allen</td>
<td>Audit Manager</td>
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## SCAN Group Chairs

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<th>Name</th>
<th>Group</th>
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<tr>
<td>Mr Calum Campbell</td>
<td>Regional Cancer Advisory Group</td>
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<tr>
<td>Dr Angus Cameron</td>
<td>Regional Cancer Planning Group</td>
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<tr>
<td>Dr Jeremy Thomas</td>
<td>Breast Group (<em>until Sept 2012</em>)</td>
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<tr>
<td>Mr Glyn Neades</td>
<td>Breast Group (<em>from Sept 2012</em>)</td>
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<tr>
<td>Mr James Mander</td>
<td>Colorectal Group</td>
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<tr>
<td>Dr Melanie Mackean</td>
<td>Gynae Group</td>
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<tr>
<td>Dr Fiona Scott</td>
<td>Haematology Group</td>
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<tr>
<td>Mr Guy Vernham</td>
<td>Head &amp; Neck Group</td>
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<td>Dr Colin Selby</td>
<td>Lung Group</td>
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<tr>
<td>Dr Daniel Kemmett</td>
<td>Skin Group (<em>until Dec 2012</em>)</td>
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<tr>
<td>Dr Megan Mowbray</td>
<td>Skin Group (<em>from Jan 2013</em>)</td>
</tr>
<tr>
<td>Mr Graeme Couper</td>
<td>Upper GI Group</td>
</tr>
<tr>
<td>Mr Prasad Bollina</td>
<td>Urology Group</td>
</tr>
<tr>
<td>Dr Peter Hutchison</td>
<td>Primary Care Group</td>
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</tbody>
</table>
### List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>CPD</td>
<td>Continuing professional development</td>
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<tr>
<td>CRUK</td>
<td>Cancer Research UK</td>
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<tr>
<td>CT</td>
<td>Computerised Tomography (A CT scanner uses X-rays and a computer to create detailed images of the inside of the body.)</td>
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<tr>
<td>DCE</td>
<td>Detect Cancer Early (<em>National programme to promote earlier detection of cancer.</em>)</td>
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<tr>
<td>ECMC</td>
<td>Edinburgh Cancer Research Centre</td>
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<tr>
<td>ENT</td>
<td>Ear, nose and throat</td>
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<tr>
<td>HEAT</td>
<td>Health Improvement, Efficiency, Access to Services and Treatment (<em>The Scottish Government sets HEAT targets for health boards as part of the performance management system for the NHS.</em>)</td>
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<tr>
<td>HIS</td>
<td>Health Improvement Scotland</td>
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<tr>
<td>ISD</td>
<td>Information Services Division (<em>ISD is part of the NHS in Scotland and provides health information, health intelligence, statistical services and advice to support quality improvement, planning and decision making.</em>)</td>
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<tr>
<td>LCP</td>
<td>Liverpool Care Pathway (<em>The Liverpool Care Pathway for the Dying Patient covers palliative care options for patients in the final days or hours of life and was been developed to help doctors and nurses provide quality end-of-life care.</em>)</td>
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<tr>
<td>MDM</td>
<td>Multidisciplinary meeting (<em>Regular, usually weekly, meeting where health professionals from different disciplines review the results of diagnostic tests and discuss treatment options for patients.</em>)</td>
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<tr>
<td>NCQSG</td>
<td>National Cancer Quality Steering Group</td>
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<tr>
<td>QPI</td>
<td>Quality Performance Indicator (<em>QPIs are nationally-agreed standards for cancer services.</em>)</td>
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<tr>
<td>PET</td>
<td>Positron Emission Tomography (<em>A PET scanner uses a very small dose of a radioactive chemical to produce 3-dimensional images of functional processes within the human body.</em>)</td>
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<tr>
<td>RCAG</td>
<td>Regional Cancer Advisory Group</td>
</tr>
<tr>
<td>RCPG</td>
<td>Regional Cancer Planning Group</td>
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</tbody>
</table>
SACT  Systemic Anti-Cancer Therapy (*cancer drug treatments*)
SESCRN  South East Scotland Cancer Research Network
SCRN  Scottish Cancer Research Network
TCAT  Transforming Care After Treatment (*National programme which aims to improve the quality of support available to patients who have completed their initial treatment for cancer.*)
TIPS  Tailored Information for the People of Scotland (*National project to provide health information tailored to the needs of individual patients - www.nhsinform.co.uk/Cancer/TIPS.*)
TRAK  TRAK (or TrakCare) is the nationally approved patient management system for NHS Scotland.