BETTER CANCER OUTCOMES IN LOTHIAN – A STRATEGY FOR CANCER 2014/15 - 2020
CONTENTS

INTRODUCTION ................................................................................................................................. 4
Overview .................................................................................................................................................. 4
What does the Cancer Strategy cover? ................................................................................................. 4
Planning and partnership working at local, regional and national levels ........................................ 5
Challenges, changing experience, and service responses ................................................................. 5
1. THE CHALLENGE OF CANCER IN LOTHIAN ............................................................................. 6
2. PRIORITISE PREVENTION, REDUCE INEQUALITIES AND PROMOTE LONGER HEALTHIER LIVES FOR ALL ......................................................................................................................... 8
Preventing Cancer in Lothian ............................................................................................................. 8
Public Health, Primary Care, and Health Improvement ..................................................................... 8
Reducing the damage caused by the use of tobacco ........................................................................... 8
Tackling obesity, improving diets, and increasing physical activity .................................................. 9
Tackling alcohol misuse ..................................................................................................................... 10
Human Papillomavirus (HPV) and Hepatitis C ................................................................................... 10
Tackling Cancer Inequalities .............................................................................................................. 10
Managing the late effects of cancer .................................................................................................... 11
3. PUT IN PLACE ROBUST SYSTEMS TO DELIVER THE BEST MODEL OF INTEGRATED CARE FOR OUR POPULATION – ACROSS PRIMARY, SECONDARY AND SOCIAL CARE ................................................................................................................................. 11
Earlier detection of Cancer ............................................................................................................... 11
Providing population Screening Programmes: .................................................................................... 12
Bowel Screening Programme ............................................................................................................ 12
Breast Screening Programme ........................................................................................................... 13
Cervical Screening ............................................................................................................................. 14
Primary Care, and the Primary Care cancer workplan ....................................................................... 15
Lymphoedema ..................................................................................................................................... 16
4. ENSURE THAT CARE IS EVIDENCE-BASED, INCORPORATES BEST PRACTICE, FOSTERS INNOVATION AND ACHIEVES SEAMLESS AND SUSTAINABLE CARE PATHWAYS FOR PATIENTS ................................................................................................................................. 17
Better Treatment: ............................................................................................................................. 17
Radiotherapy ........................................................................................................................................ 17
Chemotherapy ...................................................................................................................................... 17
Cancer surgery ..................................................................................................................................... 18
Clinical Radiology and Oncology Imaging ......................................................................................... 18
PET scanning provision in the South East of Scotland ..................................................................... 18
Oncology Emergency Care – Effective Acute Cancer Services ....................................................... 18
Cancer Modernisation and Innovation: ............................................................................................. 19
South East of Scotland Non-Surgical Oncology Review .................................................................. 19
Colorectal Cancer Services Improvement ....................................................................................... 19
Cancer Multi-Disciplinary Meetings (MDM’s) .................................................................................. 20
Access to Cancer Medicines ............................................................................................................. 20
Cancer Informatics ............................................................................................................................ 21
Robot-assisted surgery for urological cancers ................................................................................... 22
5. DESIGN OUR HEALTHCARE SYSTEMS TO RELIABLY AND EFFICIENTLY DELIVER THE RIGHT CARE AT THE RIGHT TIME IN THE MOST APPROPRIATE SETTING ................................................................................................................................. 23
Teenage Cancer .................................................................................................................................. 23
Children and Young Adults – Managing Transitions in Care Provision ........................................24
Transforming Care After Treatment..........................................................................................24
Breast Service Redesign .........................................................................................................26
Palliative and End of Life Care .................................................................................................27
Bereavement Care in NHS Lothian ..........................................................................................28
Tumour specific Group issues: .................................................................................................29
6. INVOLVE PATIENTS AND CARERS AS EQUAL PARTNERS, ENABLING
INDIVIDUALS TO MANAGE THEIR OWN HEALTH AND WELLBEING AND THAT
OF THEIR FAMILIES ........................................................................................................30
   Cancer patients input to service programmes and the Better Together Patient
   Experience Programme .........................................................................................................30
   NHS-24 Cancer Treatment Helpline ..................................................................................30
   Transforming Care After Treatment (TCAT) ......................................................................30
   Patient Experience Cancer Quality Performance Indicators (QPI’s) ................................30
   Tailored Information for People of Scotland (TIPS) ..........................................................30
   Better Together Patient Experience Programme ..................................................................30
   SCAN Patient Forum ............................................................................................................31
7. USE THE RESOURCES WE HAVE – SKILLED PEOPLE, TECHNOLOGY,
BUILDINGS AND EQUIPMENT – EFFICIENTLY AND EFFECTIVELY ................32
   Our Vision for Cancer Care Delivery: Cancer Centre Reprovisioning and the
   Western General Hospital .....................................................................................................32
   eHealth and Cancer in Lothian ............................................................................................33
   Access to Cancer Care in Lothian .......................................................................................34
   Cancer Research ..................................................................................................................34
8. STRATEGY MEASUREMENT .........................................................................................35
   Routine measures ...............................................................................................................35
9. STRATEGIC RESOURCING .........................................................................................38
APPENDIX 1 - GOVERNANCE – CANCER PLANNING AND MANAGEMENT
   PROCESSES .....................................................................................................................39
APPENDIX 2 – TRENDS IN CANCER SURVIVAL 1983-2007 .........................................41
INTRODUCTION

Overview
This document outlines NHS Lothian’s Cancer Strategy for 2014/15 – 2020. Its direction is in line with our public health and major health service plans in Lothian, the South East of Scotland Regional Cancer Plan, and the national Better Cancer Care plan workstreams.

The document is structured around the six aims previously developed in our Strategic Clinical Framework and now included in our Strategic Plan 2014-2024 - “Our Health, Our Care, Our Future”. The six aims are:

1. Prioritise prevention, reduce inequalities and promote longer healthier lives for all.
2. Put in place robust systems to deliver the best model of integrated care for our population – across primary, secondary and social care.
3. Ensure that care is evidence-based, incorporates best practice, fosters innovation and achieves seamless and sustainable care pathways for patients.
4. Design our healthcare systems to reliably and efficiently deliver the right care at the right time in the most appropriate setting.
5. Involve patients and carers as equal partners, enabling individuals to manage their own health and wellbeing and that of their families.
6. Use the resources we have – skilled people, technology, buildings and equipment - efficiently and effectively.

These six aims seek to ensure we can deliver safe, effective and person-centred health and social care. And in turn, these aims are aligned with the triple aim objectives of the 20-20 Vision around improving quality of care; improving population health and securing value and financial sustainability. Sections 2 to 7 of this document use one of the six aims as the section heading, to support linking the domains of the cancer strategy clearly to the wider strategic aim.

This document should also be read in conjunction with ‘Living and Dying Well in Lothian – Lothian’s Palliative and End of Life Care Strategy 2010 – 2015’. This strategy, and supporting materials, is available on NHS Lothian’s website at:

http://www.nhslothian.scot.nhs.uk/OurOrganisation/Strategies/ladwinlothian/Pages/default.aspx

A summary of the aims of the Palliative Care strategy, and our strategic redesign programme, is given in section 5 of this document also.

What does the Cancer Strategy cover?
‘Better Cancer Outcomes in Lothian – A Strategy for Cancer 2014/15 – 2020’ provides an overview of:

- The changing demand and challenge of cancer in Lothian and South East Scotland
• Our required focus on prevention and tackling cancer inequalities
• Our need for integrated care, to be delivered across primary, secondary and social care and regionally across the South East of Scotland
• The rapid pace of technological change and our need to modernise cancer care based on evidence, best practice and innovation
• Our work to deliver care in the right place and in a way that is appropriate to particular needs
• Our mechanisms for patient involvement in cancer planning
• Our vision for cancer care delivery and in particular our need to redevelop the Edinburgh Cancer Centre
• How the Lothian cancer programme is measured
• Some key strategic resource considerations associated with pursuing the cancer strategy

Planning and partnership working at local, regional and national levels
NHS Lothian, in partnership with other statutory and voluntary sector agencies provides a wide range of services and support related to cancer in Lothian. These include prevention, screening, genetics, and primary, secondary and tertiary healthcare services. Specialist assessment, diagnostic and treatment services are provided across Lothian. In partnership with other agencies, support services such as welfare rights, disability assessment, information and advice, and counselling and support services are provided.

NHS Lothian is also engaged in the registration, collection and reporting of cancer statistics vital to national, regional and local planning. An extensive programme of cancer research is also undertaken, some in partnership with the University of Edinburgh, in Lothian and across the South East of Scotland, including laboratory research, clinical trials, service research, evaluations, and work to assess patient experience.

In addition to territorial NHS Board level planning and delivery, NHS Lothian is part of the SCAN regional cancer network. Through participation in this network NHS Lothian works collaboratively with NHS Borders, NHS Fife, and NHS Dumfries & Galloway to plan and deliver cancer services across the South East of Scotland.

NHS Lothian, and SCAN clinical and management leads, participate in national level policy and planning through for example groups such as the Scottish Cancer Taskforce, the Detect Cancer Early Programme Board, the Radiotherapy Programme Board, the Chemotherapy Advisory Group, and the Living & Dying Well National Advisory Group for Palliative and End of Life Care. Additionally, service redesign and our population health screening programmes such as breast, bowel and cervical screening are co-ordinated with the national planning agencies (such as National Services Division) via the public health screening co-ordinator and strategic planning.

Challenges, changing experience, and service responses
In common with most of the world, the incidence of cancer is rising in Lothian and in all areas of the South East of Scotland region, and the rate of increase is higher than in previous years due to population change. Many more people however are living with and beyond cancer. Focussing on prevention and early detection, improving
treatment, and tackling known cancer inequalities will help to meet the challenge of cancer, and improve cancer care and survival further.

1. THE CHALLENGE OF CANCER IN LOTHIAN

Age-standardised cancer incidence in Lothian, South East Scotland, and in Scotland overall is significantly higher than the UK average. The incidence of cancer is increasing, and the rate of increase is faster than experienced in the last few decades. Over the current decade in Lothian (2010 – 2020) it is estimated that there will be a 20.5% increase in the incidence of cancer. The most common cancers in South East Scotland region are prostate, lung, colorectal, and breast cancers. The projected change in the South East of Scotland, by tumour type, is shown in chart 1 below.

Most of these cancers, for Lothian residents or residents of other South East Scotland NHS Boards, will be referred to NHS Lothian (either for assessment, diagnosis, staging, treatment, or all of these elements of the cancer pathway).

The prevalence of many cancers is also increasing (due for example to increasing incidence, better treatment and survival). As cancer is often a disease of old age, and more people are surviving cancer, increasingly multi-morbidity will be experienced by some cancer survivors. This means that as well has there being more able-bodied cancer survivors, there will also be more people living with the consequences of cancer, or cancer treatment, who also have other health conditions or disease, all of which increases the complexity of care planning and delivery.
Chart 2 below shows cancer incidence rates per 100,000 of the population in the South East of Scotland cancer planning region, by age-band. There is a clear increase in incidence with older age. Incidence data shown is for 2011, which is the most recent period of published data.

Significant improvement in survival has been seen over the last few decades. Appendix 2 to this document shows trends in cancer survival in Scotland over this period. We know that better survival prospects are associated with:

- Earlier presentation by patients
- Participation in screening programmes (where screen detected cancers are often found at an earlier stage)
- Improvements in specific treatments

Conversely, survival is worst in patients presenting with advanced stage disease, often as emergencies, and for cancers for which current treatments are less effective (such as lung, brain, and pancreatic etc).

Over the entire South East of Scotland cancer planning area the picture of changing incidence, prevalence and survival is common. All highly specialist cancer care is provided to these patients in NHS Lothian. Where possible, assessment and diagnosis is undertaken locally in the NHS Board of patient's residence. Some patients from other South East of Scotland NHS Boards will however be referred to NHS Lothian for clinical assessment and diagnosis of suspected cancer. Some treatment services in the South East of Scotland such as radiotherapy and complex
chemotherapy provision are exclusively provided by NHS Lothian as provider Board for the Edinburgh Cancer Centre. Healthcare planning and subsequent capacity delivered needs to take due account of the patient volumes and patient pathways followed across the whole of the South East of Scotland region.

2. PRIORITISE PREVENTION, REDUCE INEQUALITIES AND PROMOTE LONGER HEALTHIER LIVES FOR ALL

Preventing Cancer in Lothian

Public Health, Primary Care, and Health Improvement – Smoking is the single biggest risk factor for cancer, alongside poor diet, lack of physical exercise, and alcohol misuse. A public health based strategy, and focus on health improvement is fundamentally required as a central component to any effective cancer strategy. Primary care has a key role to play in preventing cancer through for example action on smoking, lifestyle, diet, physical activity, and alcohol.

The Lothian health improvement strategies, many flowing from areas with HEAT targets associated with them, are vital. The HEAT framework, which outlines performance standards and targets agreed each year between NHS Lothian and the Scottish Government Health Directorates, has diet, physical activity, smoking cessation, obesity, and health inequalities as a central focus, alongside cancer access and quality standards. All of these domains of work are central to the cancer programme in Lothian and need to increasingly align with specific cancer programme workstreams and operational delivery.

Public health also has a crucial role to play in supplying data and information to planners and service providers across Lothian and nationally, to guide priorities and help to assess delivery and performance.

Reducing the damage caused by the use of tobacco – NHS Lothian is implementing its Smoke Free Lothian Vision. This strategy is aligned to the Scottish Governments 2013 tobacco control strategy ‘Creating a tobacco-free generation - a tobacco control strategy for Scotland’. The national strategy has a headline aim of creating a tobacco free generation of Scots by 2034. The headline outcome measure is achieving an adult smoking prevalence below 5% by 2034. In Lothian, in 2011, smoking prevalence is recorded at 18.7% (with significant variation across our most disadvantaged to our most affluent communities and populations).

Lothian’s Smoke Free vision is being pursued currently via focussing work in three major domains:

Tackling health inequalities and focussing on specific groups – via joint work with Lothian Local Authorities and the voluntary sector. Focussing for example on young people’s health behaviour and their health education, and working with vulnerable young people such as looked-after children and young offenders, as well as building effective alliances to tackle the availability of illicit tobacco.

Improving Health protection – offering advice on creating smoke free homes, working with specific organisations such as the Scottish Prison service to plan smoke free
prison facilities, and implementing our ‘Smoke Free NHS Lothian’ plan from May 2014, ensuring enforcement and compliance by March 2015.

Supporting smoking cessation – by continuing to develop and deliver our Smoke Free services, and target programmes for example to increase the number of women referred, and successfully quitting, by ensuring effective care pathways for smoking in pregnancy.

**Tackling obesity, improving diets, and increasing physical activity** - we will do this by:

- Supporting staff to promote healthy lifestyles, by encouraging health eating and regular physical activity, and improving training opportunities for staff i.e. in the delivery of brief intervention / brief advice.

- Increasing the awareness of recommended levels of physical activity and understanding of food and diet to maintain healthy weight.

- Developing and implementing specific initiatives to increase physical activity and promote healthy eating, and become an exemplar organisation in promoting health improvement.

- Supporting effective local and national programmes that aim to increase physical activity and promote healthy eating.

- Use our Sustainability Strategy, and the Green Travel Plan, to promote active travel and dissuade people from using cars, and promote walking or cycling including the development of secure cycle parking for NHS staff and patients on our sites.

- With partners in Local Authorities and the third sector we will provide appropriate evidence based interventions for people who are overweight and obese through our Lothian Weight Management Services.

- By continuing to develop “Get Going!” our innovative weight management programme aimed at children and young people. The programme aims to develop young people’s interest in exercise, recreation and health-related issues to increase opportunities for them to participate in physical activity within their local communities.

- Developing our catering strategy, and become an exemplar organisation in the provision of food on our premises, and through participating in the ‘Food for Life’ programme with partner organisations.

- Supporting the free school meals programme, led by Lothian Local Authorities, and developments in the curriculum on healthy living. National guidance exists for both nutritional content of meals and the health promotion activities within schools.
**Tackling alcohol misuse** - We will do this by:

- Supporting the specialist Alcohol Problems Service, and dedicated Drug and Alcohol Action Teams within each local authority area in Lothian.

- Work with Local Licensing Boards to map the provision of alcohol sales outlets in Lothian, and oppose any over provision.

- Expanding our programme of alcohol brief interventions by continuing to train staff to deliver these throughout the NHS.

- Supporting the Lothian and Edinburgh Abstinence Programme (LEAP). LEAP offers an alternative choice and opportunity for those with alcohol problems to change drinking habits.

**Human Papillomavirus (HPV) and Hepatitis C** – protecting against the cancer risk factors associated with HPV and Hepatitis C is part of the work of the NHS Lothian Health Protection team. Both areas are subject to specific programmes of work and action plans for health improvement, including the HPV immunisation programme, and the Lothian Hepatitis C Managed Care Network.

**Tackling Cancer Inequalities**

We know that the incidence of cancer is higher, and cancer outcomes poorer, in our most deprived communities – including differences in the pattern of cancer in some ethnic groups. Socio-economic status is an important independent prognostic factor for most common cancers in adults.

Socio-economic differences in the stage of disease at diagnosis, and in access to and participation with optimal diagnostic and treatment services may explain at least some of the association between deprivation and poorer cancer survival. Full explanations for differences in survival are not completely documented in research. However reasons that some groups may be disadvantaged can fall into 3 groups of underlying causes:

1. **Tumour factors** – late stage of detection; delays in seeking healthcare or delayed referral; ‘stage shift’ whereby cancers are classified and recorded as earlier stage than they actually are. This is possibly because some patient groups are not completing full staging investigations (and the extent of spread is thus not detected).

2. **Patient factors** – psychosocial factors such as lack of social support; unclear access or delay in seeking healthcare; perceived social stigma attached to cancer; individual perception of personal risk; poorer mental health; poorer communication with healthcare professionals. Co-morbidity may also reduce survival by adversely interacting with or limiting the range of treatment given for cancer.
3. Healthcare system factors – lower uptake of screening services; treatment differences (either options not offered, for example in more elderly or co-morbid patients, or options not taken-up for example follow-up appointments); emergency admissions; and the availability of medical expertise.

Our focus on health inequalities and health improvement is vital therefore to both cancer prevention and improving cancer outcomes. Through Lothian’s Detect Cancer Early programme we are seeking to tackle many of the potential underlying causes of poorer survival, as listed above. A focus on these areas will continue to be developed throughout all of our work on prevention, health improvement, treatment and service delivery.

The Health Promoting Health Service concept - ‘every healthcare contact is a health improvement opportunity’ – is based on person centred and effective practice, and will underpin our approach. We will do this by working in partnership, and adopting a focus on health improvement and tackling health inequalities via development, assessment, and implementation all of our policies and plans.

Managing the late effects of cancer
In tandem with building our focus on Transforming Care After Treatment, to support longer healthier lives we need to ensure that as we develop our cancer pathways the late effects of cancer are recognised and effective management is supported. Late effects may include the development of second cancers, and additional needs associated with cardiology, endocrinology, bone health, lymphoedema, and sexual health / gynaecology.

3. PUT IN PLACE ROBUST SYSTEMS TO DELIVER THE BEST MODEL OF INTEGRATED CARE FOR OUR POPULATION – ACROSS PRIMARY, SECONDARY AND SOCIAL CARE

Earlier detection of Cancer

The Detect Cancer Early Programme is an ambitious programme of work to improve survival for people with cancer in Scotland to amongst the best in other European countries by diagnosing and treating the disease at an earlier stage. The Detect Cancer Early programme was formally launched by the Cabinet Secretary on February 20, 2012. The NHS Lothian Detect Cancer Early (DCE) Programme is now established, focussed on breast, lung and bowel cancer. A Lothian Programme Board has been formed to develop and steer the programme over a three-year period (2012/13 – 2014/15), in line with the initial government investment period. Our approach is based on a review of the cancer inequalities evidence base, and on the national DCE programme framework. It focuses on tacking inequalities and identified ‘wicked-issues’ in cancer care, building-up our diagnostic and treatment capacity, integrating early detection into our existing service redesign work across Lothian, and increasingly focusing on targeted action in primary and secondary care to identify opportunities and service approaches to detect a higher proportion of cancers at stage 1 of disease.
In years one and two of the programme, investment has gone into primary care, diagnostic and treatment services providing care for patients with lung, breast, and bowel cancer, as well as cancer audit, e-health, and investment in cancer informatics.

Delivery of the Detect Cancer Early programme is measured via the HEAT performance framework. The programme target, at national level, is to increase the proportion of people diagnosed and treated in the first stage of breast, colorectal and lung cancer by 25% by 2014/2015. NHS Lothian’s baseline position (an average of the combined years 2010 and 2011) was 22.6% of all breast, lung and bowel cancers diagnosed at stage 1 of the disease. By the end of 2015 we need to be achieving 29%.

Over the next two years of the programme we will focus on a number of key areas including: progressing targeted initiatives in the bowel and breast cancer screening programmes and with primary care teams to increase screening participation and service capacity; develop our lung cancer pathway including building capability focussed on earlier detection and support, and redesign referral and initial diagnostic pathways, develop our referral and diagnostic assessment pathways for the 3 DCE tumour group areas across primary and secondary care to support referral at the earliest opportunity of people with signs and / or symptoms of suspected cancer; continue to improve our cancer intelligence strategy and deliver DCE programme reporting; invest further in diagnostic and treatment capacity; and support national and local awareness campaigns.

**Providing population Screening Programmes:**

**Bowel Screening Programme**

NHS Lothian’s participation in the National Bowel Screening programme commenced in May 2008, with our first two-year screening cycle running between May 2008 and April 2010. The administration of invitations to participate in screening, and the testing of returned screening kits, is undertaken by the national screening centre located in Kings Cross Hospital in Dundee. The rate of positive screening tests was 2.2% in Lothian (i.e. the proportion of tests that are positive from all samples returned for testing), compared to a Scottish average of 2.5%. NHS Lothian provides the clinical assessment, diagnostic and treatment pathway for all Lothian residents who return positive screening tests to the central laboratory.

The national standard for bowel screening uptake is 60%, and this is monitored by Healthcare Improvement Scotland. Uptake in Lothian in 2010 – 2012 was 53.5%, compared with a Scottish average of 54.9%. Uptake remains lower in areas of higher deprivation.

In Lothian, through the screening programme, 1,190 people have been diagnosed with an adenoma or an invasive cancer or polyp cancer. 172 of these were an invasive cancer or polyp cancer (based on screening programme data to 2012). Our yearly screening accounts for the detection of around 15-20% of all colorectal cancers in Lothian. Cancers detected through the screening programme show an earlier stage profile compared to those not detected through screening.
Our action plan for the Lothian Bowel Screening Programme includes exploring a greater use of nurse colonoscopists as part of the screening programme accredited endoscopy workforce, and exploring how radiology can be further used to support capacity in the programme, and more widely to support endoscopy capacity in Lothian.

In spring 2013, as part of the local DCE campaign, a breast and bowel screening pilot commenced with 10 GP practices in Lothian. The aim of the pilot is to identify and test ways to increase screening uptake. Additionally, the majority of GP practices in Lothian (110 of 126 practices) have signed up to take part in the new bowel screening Scottish Quality Outcomes Framework (SQoF) initiative (2013 – 2015) which will reward practices for increasing their bowel screening uptake.

**Breast Screening Programme**

The South East of Scotland Breast Screening Service is commissioned and funded by National Services Division (NSD) with the service hosted by NHS Lothian for the South East of Scotland region. Overall uptake of the breast screening programme in NHS Lothian is 72% (over the period 2008/09-2010/11). This figure is above the QIS standard of 70% and below the Scottish average of 75%.

The overall uptake level is similar for NHS Lothian, NHS Lanarkshire and NHS Greater Glasgow & Clyde – where the majority of appointments are offered at a static centre. Uptake rates tend to be higher in Board areas where the majority of screening is undertaken in mobile units.

Our lowest uptake groups are:
- Women new to screening (first invitation)
- Women who are invited outwith five years of last attendance – (i.e. previous non attendees)

In order to address these target groups we continue to work closely with colleagues in primary care, health promotion, community development and cancer charities to promote the benefits of screening. We so provide staff with training and information to ensure a higher, positive profile of the programme at primary care level. Specific actions include:

- Introducing changes to the appointments schedule to allow extended periods of screening for localities.
- Providing targeted visits to low uptake practices by colleagues in health promotion prior to the screening round in order to support staff in promoting screening to patients.
- Providing practices with additional information to identify defaulting or DNA patients.
- Liaising with the Learning Disabilities Service to provide additional specialist care to clients.
• Providing workshops for Lothian primary care staff to update knowledge and further promote the benefits of screening.

In Lothian, uptake levels vary across deprivation categories from 79% (least deprived) to 58% (most deprived). This pattern is reflected across Scotland. An ‘Immediate Action’ pilot has been established with the agreement of some practices to evaluate whether additional targeted primary care efforts can improve uptake at practice level.

The South East Scotland Breast Screening Programme (SESBS) has implemented 2-view mammography for all women attending for screening from April 2010. Implementation of 2 views has led to higher numbers of cancers diagnosed (up by approx 25% based on 2011/12 figures).

During 2011 the National Planning Forum commissioned NSD to undertake a review of Breast Screening Service in Scotland. The Review was prompted by concern regarding the sustainability of the programme in light of workforce pressures and the need to realise efficiency savings to fund the introduction of new technology. The Review’s findings were subject to a formal option appraisal. The Review has since recommended that the status quo in terms of the organisation and commissioning of breast screening be maintained but that efforts should be directed at achieving greater integration of the screening and symptomatic services. NSD will establish work streams to deliver the necessary service reconfiguration.

Over 2013 the South East Scotland Breast Screening Programme modernised mammography imaging by moving to digital mammography. This development is a key part of delivering the change required as part of the national service review, and will assist in improving the efficiency of the service and in supporting the earlier detection of breast cancer.

**Cervical Screening**

Overall the cervical screening programme in Lothian has been very successful. Age standardised incidence rates for Lothian have declined from 18.0 per 100,000 persons at risk in 1988 to 12.6 per 100,000 persons at risk in 2011. Lothian has seen a decrease in mortality from cervical cancer from 5.7 per 100,000 persons in 1986 to 3.1 per 100,000 in 2011 (25 to 15 deaths). Survival rates continue to improve for women diagnosed with cervical cancer. Five year survival is now 58.6% and one year survival is 78.6% (a 6.7% and 3.3% improvement over the last 20 years).

NHS Lothian laboratory process nearly 80,000 smears per annum. Laboratory turnaround times and overall reporting times are lower than the national average. Unsatisfactory rates are in line with practice across Scotland. The percentage of smears reported as negative is 89.1% which is slightly lower than the national average of 90.3%. Our data is quality assured by the national SCCRS laboratory group.

The cervical screening programme is at a time of transition and there is significant activity at national level to agree a new policy for future service delivery. Nationally uptake rates have been falling across Scotland over the last 5 years. Whilst there are many reasons for this the key driver is falling uptake in the 20-25 age group due to
confusion about risk perception. Furthermore emerging evidence now indicates that women in this age group should not be offered screening. With this in mind there are two major changes to policy on the horizon:

1) The age range and frequency thresholds will be changed from 2015 (women between 20-25 will not be called, and women 60+ will be offered screening 5 yearly)
2) HPV screening will be implemented from 2016 with cohort clinical pathways embedded.

As a consequence the screening programme will look very different and new performance measures (uptake) will have to be agreed.

NHS Lothian has been targeting certain groups of women to shift the pattern of attendance to be more in line with the evidence base, and future national policy. Therefore our uptake rates are lower in the 20-25 age group and higher in the 40+ age group. We will continue to work collaboratively to develop and improve the screening programme in line with national policy and implementation planning.

Primary Care, and the Primary Care cancer workplan

Many aspects of cancer care are managed in primary and community health service settings routinely across Lothian. Primary care has a key role to play in preventing cancer through for example assessing smoking status and providing advice and support regarding stopping smoking, supporting a healthy lifestyle and diet, physical activity (including the ability to prescribe exercise programmes), and advising on alcohol related issues and the provision of brief interventions, where necessary, on alcohol intake.

Primary care teams co-manage cancer care (alongside secondary care delivered treatment) at all stages of disease, and often this includes the management of patients with multi-morbidity over and above their cancer which may involve additional review and change to monitoring and clinical management plans. This impact is especially felt in areas of high social deprivation in Lothian where both the incidence of cancer and multi-morbidity is higher.

An increased demand (for example pre and post treatment bloods, PSA bloods) and changes to the pattern of work in primary care (for example variations to tasks undertaken by district nurses and general practitioners) may also be experienced as a result of clinical pathway developments, often arising in secondary care.

To support a focus on specific development work NHS Lothian and Macmillan Cancer Care support a GP Lead post and a Nurse Consultant post for Cancer & Palliative Care. This team, working with colleagues across the system, manage a programme of work which aims to support:

- Participation in the Detect Cancer Early Programme at local and national level including developing and implementing specific Lothian initiatives
- Improving access to diagnostic services to support earlier detection, including scoping the potential for pathway redesign and working alongside national improvement programmes
• Assist practices in improving their screening programme uptake, in particular supporting the bowel screening Scottish Quality and Outcomes programme initiative in 2013/14 and 14/15
• Supporting the improvement of cancer referral guidelines by working locally and nationally, and supporting their local implementation in liaison with referrals advisors and others
• Supporting the palliative care programme including supporting learning and development associated with the Palliative Care Directed Enhanced Service (DES), and supporting the Lothian Palliative Care Redesign Programme
• Assessment of redesign potential to improve follow-up, and participation in the Lothian Transforming Care After Treatment programme.

Supporting the GP diagnostic process is central and we will continue to develop work on referrals guidance for urgent suspected cancer, and on initial advice and access to diagnostic services that best support efficient and effective working and early detection. Continued support for the cancer and palliative care leadership posts in primary care is vital to this.

Supporting community based palliative and end of life care is a central objective to Lothian’s Palliative Care Strategy ‘Living and Dying Well in Lothian’ - section 5 of this document refers to this and to the Lothian Palliative Care Redesign Programme that is underway. The redesign programme will make recommendations to support capacity requirements for community management, and as such will support the emerging strategies of the planned Integration Joint Boards (see below).

A stronger collaborative approach to cancer pathway development, joint planning, and service redesign is required. The approach needs to be specified and agreed however opportunity exists around the establishment of the new Integration Joint Boards arising from the implementation of the Public Bodies (Joint Working) (Scotland) Bill. The new Integration Boards will take over the role of Community Health Partnerships and are required to strategically plan to meet the needs of their local populations. NHS Lothian is expecting that the four new Integration Joint Boards (one in each Lothian Local Authority area) will be established in the spring of 2015.

Additionally, we will seek to work with both secondary and primary care stakeholders as part of planning work to review cancer pathways and models of care in Lothian to be taken forward as part of the Cancer Centre reprovision programme. This will support joint consideration of the value, evidence, and priority for cancer pathway redesign and the consequential impact on workload, workforce and service requirements in secondary, primary, and social care settings.

**Lymphoedema**

The NHS Lothian Primary Care Lymphoedema Service provides a service for people living in Lothian with a diagnosis of primary or secondary lymphoedema e.g. non cancer and cancer related lymphoedema. The service also receives referrals and provides care for people who have a diagnosis of lipedema.
The NHS Lothian Primary Care Lymphoedema Service is provided on five sites (South & north Edinburgh, Mid, East and West Lothian) to facilitate care nearer to the patient’s home. All patients seen by the service (those with lymphoedema and those with lipoedema) have a comprehensive assessment, care options discussed, self care management, garment provision and treatment provided all of which tailored to meet the needs of the individual.

A secondary care based Lymphoedema service is also in place at the Western General Hospital for oncology patients with breast cancer related lymphoedema.

4. **ENSURE THAT CARE IS EVIDENCE-BASED, INCORPORATES BEST PRACTICE, FOSTERS INNOVATION AND ACHIEVES SEAMLESS AND SUSTAINABLE CARE PATHWAYS FOR PATIENTS**

**Better Treatment:**
Modernisation of cancer services requires a collaborative regional approach across the South East of Scotland, to ensure efficient, effective and quality care is provided as close to the patient as possible. This must incorporate all the aspects of service provision, technological development and improvement to the patient pathway. Effective local and regional arrangements to support the planning and management of cancer services in an integrated way across NHS Lothian services, and with all South East Scotland NHS Boards, is vital to achieving this.

**Scheduled care:**

**Radiotherapy**
Edinburgh Cancer Centre provides radiotherapy for patients from across the South East of Scotland. Radiotherapy provision is changing rapidly, and demand for radiotherapy is set to grow significantly over the next decade, and beyond.

Our strategic priorities include

- Providing evidence on the number and location for the future provision of linear accelerators.
- Keeping pace with current technology, and ensuring that patients have timely access to the appropriate, evidence-based advancements in radiotherapy.
- To ensure optimal efficiency of the use of the machines, and to allow patients to be treated at times more suited to their needs, we will work towards the provision of extended working days, and the potential for a 7-day service, keeping in line with planned capacity requirements.

**Chemotherapy**
Our strategic priorities include:

- To provide chemotherapy delivery as close to the patient’s home as possible, where it is safe and effective to do so.
- To ensure optimal efficiency of the use of capacity, and to allow patients to be treated at times more suited to their needs, we will work towards extended working and consider the potential for a 7-day service.
Cancer surgery

- Ensure the outcomes for surgical intervention are compliant with best practice.
- Services are provided at locations where expert intervention is provided, and, where the evidence supports such an approach, ensure optimum outcomes through focussing pathways to high volume services.

Clinical Radiology and Oncology Imaging

- The provision of imaging services should be strengthened on the site of the cancer centre to ensure complex imaging can be provided, and integration with other systems and image transfer is harmonised. This should also include the ability to link remote imaging from other Health Board areas to support efficient local and remote working.

PET scanning provision in the South East of Scotland

- In line with national planning for the provision of PET, we will continue to review the usage of PET scanning in SCAN, and ensure adequate provision for the future in conjunction with good cancer care and evidenced based medicine. PET provision in NHS Lothian should be considered alongside reviewing imaging provision to support cancer services on the Western General Hospital campus.

Unscheduled care:

Oncology Emergency Care – Effective Acute Cancer Services

Through the advancement of acute oncology services, the unscheduled element of care will continue to grow and will need to be effectively formalised across the region, maximising the contribution of services such as the cancer treatment helpline. Our strategic priorities include:

- Through safe treatment protocols and timely access to advice and interventions, to reduce as much as possible, emergency admissions for the complications of cancer therapies.
- Progressing and developing management arrangements for emergency presentations by the appropriate use of telehealth.
- Ensuring that all patients with cancer, who are managed outside of the Edinburgh Cancer Centre, are managed according to the best practice for their condition, including timely access to the same expertise as those managed in the Edinburgh Cancer Centre.

To support the development of a more formally agreed and co-ordinated system, the potential of telehealth should be assessed. This should consider, for example, improving arrangements for remote access to health records and clinical management advice such that clinicians seeing Oncology patients presenting anywhere in the region will have access to the same clinical data and could be discussed within a defined period of time of presentation with the on-call team at the Western General Hospital.
Cancer Modernisation and Innovation:
Over 2012/2013 and 2013/2014 we have invested in the modernisation of acute oncology, surgical oncology and radiotherapy services. We will seek to consolidate and build on the progress made in these areas. We will also seek to continue to build on the regional approach taken to date in some of our areas of specific modernisation initiatives, such as in radiotherapy and acute oncology.

South East of Scotland Non-Surgical Oncology Review
In 2010, the regional cancer network commissioned a review of non-surgical oncology services in the context of increasing demand as a result of increasing incidence, prevalence and detection of cancer and the increasing complexity of treatments.

The review concluded that the non-surgical oncology service is a highly efficient and successful service. It noted that a substantial amount of redesign work had already been undertaken but identified some scope to improve efficiency further. The review report emphasised that the recommended redesign programme, while capable of releasing some capacity, would not be sufficient to meet the expected increase in demand in the longer term and that boards would need to consider potential increases in expenditure in future if they wished to provide the same levels of service. It was estimated that implementing the redesign programme might delay the need for additional investment in non-surgical oncology services until 2014.

The review report envisaged a rolling programme of review and redesign and set out a series of recommendations grouped under seven key themes: team-based practice; acute oncology; clinical pathways, policies & guidelines; patient information; eHealth, telehealth and intelligence systems; managing interfacing and support systems; sustainability.

As a result of implementing the redesign programme, the regional boards have improved the efficiency of the non-surgical oncology service in its current configuration. Radical new approaches to service delivery will be required to meet increasing service demand and complexity over the next 5 years. Regional boards will need to exploit the opportunities offered by national and regional initiatives, such as the Edinburgh Cancer Centre Reprovision project, the development of a national strategy for radiotherapy workforce capacity, the Transforming Care After Treatment Programme (TCAT), implementation of Quality Performance Indicators (QPI), and implementation of Systemic Anti Cancer Therapy (SACT) CEL (30) 2012.

Colorectal Cancer Services Improvement
Over 2012 and 2013 NHS Lothian was one of 5 healthcare systems internationally to participate in the Colorectal Cancer Service Improvement Network. This data driven exercise adopted a pathway focussed approach to service improvement in colorectal cancer. As a result of participating in the network, ten priority value areas began to emerge across all 5 healthcare systems internationally. These were:

- Improving screening uptake in targeted populations
Our Health, Our Care, Our Future – Appendix 7

- Refining colonoscopy referral protocols for symptomatic patients
- Ensuring efficient use of existing endoscopy capacity
- Adopting best practice staging protocols for treatment planning
- Using multidisciplinary teams to consistently coordinate care
- Centralizing surgical treatment for rectal cancer
- Balancing palliative care and drug treatment in late-stage disease
- Firming up risk-adaptive follow-up surveillance protocols
- Reducing variation in access and outcomes across geographies
- Tracking population-level outcomes through end-to-end data integration

NHS Lothian’s top 3 improvement priorities have been identified as below, and are being pursued particularly through the Lothian Detect Cancer early Programme and in diagnostics capacity planning.

- Increasing the share of early-stage cancers to meet Detect Cancer Early goals
- Reducing the rate of emergency presentation through improvements in diagnostic pathway
- Finding more cancers with fewer colonoscopies with improved referral protocols

Cancer Multi-Disciplinary Meetings (MDM’s)
NHS Lothian will utilise and seek to adhere to the National Cancer Audit Team Standards for the management of cancer Multi-Disciplinary-Meetings (MDM’s). Recognising that this is a critical element of the patient pathway work is being undertaken to support clinical teams in delivering safe, efficient and effective MDMs. This will enable performance against the standard to be regularly monitored, and support governance issues in being identified and addressed to ensure the delivery of appropriate clinical treatment decisions.

NHS Lothian is currently implementing a programme of work to provide a TRAK MDM module to each MDM to support meeting administration, clinical decision making, and governance. This rolling programme of work will complete in 2015. The TRAK module dataset will support efficient working and improve quality, and will include capture of the cancer Quality Performance Indicators (QPI’s) for each tumour type, which NHS Lothian is obligated to collect and report on as part of the National Cancer Quality Programme. The TRAK MDM programme is supported as part of the Lothian Detect Cancer Early Programme implementation, as a key part of improving our use of cancer information and associated improvements in care co-ordination.

Access to Cancer Medicines
Access to existing and new cancer medicines within NHS Lothian sits within a transparent governance structure which ensures medicines are utilised safely, effectively and efficiently.

The Edinburgh Cancer Centre acts as a hub for the majority of this activity within SCAN, and multidisciplinary staff across the network work together to ensure relevant polices and procedures are implemented and maintained by all staff. NHS
Lothian cancer services ensure that the process encompassing patient access to medicines is efficient for both existing and new medicines. Staff are in full control of the medicine supply chain to ensure that marketed and clinical trial medicines are available, and that they meet quality standards.

New medicines are introduced subsequent to guidance from the Scottish Medicines Consortium and internal processes utilising the Lothian Joint Formulary. In addition, NHS Lothian acts as a hub for an agreed regional approach to the consideration and approval of applications for funding of non-formulary cancer medicines for patients across SCAN who are treated by ECC clinicians. This is formalised between SCAN Boards, and is managed by the cancer medicines management committee on behalf of NHS Lothian.

The amount of chemotherapy prescribed and administered within NHS Lothian is increasing which has led to a requirement for new services, more efficient medicine pathways, and also increased medicine budgets. In 2014 there may be changes to NHS Scotland’s system for accessing new medicines. Two changes involve:

1. A transformation of the Scottish Medicines Consortium approval process which will provide clinicians and patients a stronger voice on SMC decisions for life-limiting and rare conditions. This encompasses cancer.
2. The introduction of the Peer Approved Clinical System (PACS) which will replace the Individual Patient Treatment Request (IPTR) for assessing medicines not approved for regular use within NHS Scotland.

Assuming the policy change described above is approved and implemented nationally, these two changes will increase the number of medicines approved for use, and by association the basic medicine spend and requirement for increased services to administer and dispense them. The exact effects of these changes will become evident during 2014/15.

**Cancer Informatics**

NHS Lothian is a data rich system, and has comparatively an advantage over many other healthcare systems in terms of our existing data and information infrastructure and its reach across the whole system of care. We hold a vast amount information about cancer patients. A strategy for cancer informatics is required to support the integration of all related systems containing information about cancer patients and their treatment and to pull this data together in a way that best informs practice. An integrated cancer information system capability would allow reporting on patient pathways, care of specific groups of patients, anticipating care needs, and supporting the planning of services.

Under the Detect Cancer Early Programme NHS Lothian has invested in dedicated cancer analytical resource and further supported cancer audit and e-health systems development to support more efficient data capture. Furthermore, NHS Lothian Cancer Services will be appointing a Programme Manager in 2014 to undertake a review of the production, development and promotion of a range of information services, including statistical analysis, for cancer associated services within NHS Lothian and the Southeast of Scotland. The Programme will work alongside the Director of the Edinburgh Cancer Centre, strategic planning functions of S.E Scotland NHS Boards, and the Oncology Clinical Management Team to develop
long term plans and provide strategic direction for Oncology, Haematology and Breast Services. Early priorities will include the amalgamation of 2 existing teams into a single Cancer Information Service, and also the transfer of the existing Oncology database on to a new and more stable platform.

The programme will also seek to identify the linkages between NHS Lothian’s cancer management information requirements and those of university researchers – both current and future; ensuring that approved statistical analysis is available for a variety of stakeholders across all aspects of healthcare. It will seek to ensure close working and undertaking of collaborative clinical research projects with academic bodies including local universities, Chief Scientists Office, MRC, Cancer Research UK etc. enabling the Edinburgh Cancer Centre to derive full potential for data contribution within joint academic - NHS research projects, including medical informatics, analyses of clinically annotated tissues etc.

Essential to the informatics strategy is single entry, multiple use of clinical data. Accurate recording at the appropriate point of care will ensure reliable data which can be made available on a “need-to-know” basis across the care pathway, and allow collation of data to facilitate detailed planning of services, anticipation of complications, whether acute or chronic, and analysis of outcomes. A portal approach creating summary data on diagnosis and treatments to facilitate a patient centred view of each cancer journey will enhance communication between the many different health care professionals involved at all stages of cancer care delivery.

**Robot-assisted surgery for urological cancers**

Across the South East of Scotland prostate cancer will see the greatest percentage increase in incidence over the next decade. Developing our approach to treatment and our capacity, including improving care after treatment for this group, is essential. In 2013 The Cabinet Secretary for Health & Wellbeing recommended that Scotland move to provision of radical prostatectomy being undertaken in high volume centres utilizing minimal access or laparoscopic techniques. High-volume is defined as at least 150 cases per year. At present NHS Lothian is the only Health Board in Scotland where at least 150 laparoscopic radical prostatectomies are performed. Partial nephrectomy and cystectomy are still performed as open procedures in NHS Lothian.

Across North America, Europe and England & Wales there has been widespread adoption of robot-assisted surgery for prostate cancer (in the USA 70%, and in England almost 50% of radical prostatectomies are currently performed using a robotic system). The robotic systems are also widely used to undertake partial nephrectomy for renal cancer and radical cystectomy for bladder cancer. In England NICE has recommended that commissioners consider commissioning robot-assisted radical prostatectomy only where at least 150 cases per annum are performed, in order to ensure economic efficiency.

As the use of such technology becomes more common across the rest of the UK and Europe the training opportunities in laparoscopic radical prostatectomy in super-specialist units performing >400 cases per year will almost certainly disappear as these super high-volume centres move exclusively to robotics.
At present there are no robotic systems in Scotland. Two charities are actively raising funds to purchase systems for use in NHS Scotland (UCAN specifically for Aberdeen with the explicit support of NHS Grampian; Prostate Scotland for the central belt with support from NHS Scotland). NHS Lothian will assess the value and advantage of robot-assisted surgery, to help develop our capacity in line with national planning and developments. This will include consideration of the whole pathway of care for prostate cancer, the potential skills development for surgical staff, and imaging requirements.

Over 2014 / 15 there is therefore a requirements to work regionally to ensure that for laparoscopic prostatectomy care is being delivered in line with National Planning Forum recommendations. NHS Lothian must also assess the value and advantage of robot-assisted surgery, and assess the potential advantages, costs and risks associated with adoption or non-adoption in Lothian.

5. DESIGN OUR HEALTHCARE SYSTEMS TO RELIABLY AND EFFICIENTLY DELIVER THE RIGHT CARE AT THE RIGHT TIME IN THE MOST APPROPRIATE SETTING

Teenage Cancer

For young people with cancer, the provision of a dedicated teenage cancer unit makes the cancer pathway more bearable, makes it easier to engage with treatment, easier to keep going and easier to maintain existing social and support networks. NHS Lothian is working with the Teenage Cancer Trust (TCT) to achieve this. The TCT aims to ensure that every young person with cancer and their family receive the best possible care and professional support throughout their cancer journey. The Trust also empowers young people through education and advocacy.

In the East of Scotland our joint goal is to have age appropriate units at:
- The new Royal Hospital for Sick Children, Edinburgh, for 13-16 year olds (a refurbished unit opened at the RHSC in 2010, and this unit is included in re-provision plans for the new children’s hospital)
- The Western General Hospital, Edinburgh, for older teenagers and young adults aged 16 – 24 years (with a new unit opened in 2013, which will be further considered in the reprovision of the Edinburgh Cancer Centre).

The overall benefits associated with the provision of a dedicated unit for teenagers and young adults with cancer are:
- treatment can be delivered in a suitable environment, at appropriate times and an appropriate location
- enables the delivery of specialist care that has been demonstrated to significantly benefit this patient group
- peer support for teenage and young adults with cancer
- provide areas for patients, siblings and friends of teenagers and young adults with cancer to meet and support each other
Our Health, Our Care, Our Future – Appendix 7

Children and Young Adults – Managing Transitions in Care Provision

From the Patient Experience Programme staff in both paediatric and adult neuro-oncology services identified the need to design a better transition between services for the increasing number of teenage patients who are being seen in age inappropriate environments. The enthusiasm of key clinical staff to be involved in the design of a transition process created an ideal situation for a small scale project to begin the project work, and also demonstrated a commitment to working with hard to reach patient population groups.

Parents and teenagers feel safe and supported by their consultant and teams at Sick Children’s and express anxiety about transition to adult services. The move from children’s services should occur when the individual patient is ready and the decision should be agreed by staff in partnership with patient and parents. An outcome from the teenagers and young people’s experiences in neuro-oncology project was to create a transition clinic for current young patients and for newly diagnosed patients in this age group, which can be replicated in other specialities. Alongside the change in physical surroundings changes in practice must occur such as the young people being encouraged to see the clinicians alone as well as with their parents so that they take ownership of managing their health as they mature.

As part of the national programme of revision to referral guidelines for urgent suspected cancer a guideline for the referral of children and young people will be produced. This will support the service and locally, once available, the guidance will be built into the Lothian e-referral system.

Transforming Care After Treatment

The Transforming Care After Treatment (TCAT) programme is a collaboration between Macmillan Cancer Support and NHS Scotland and aims to ensure that people diagnosed with cancer are prepared for and supported to live with the consequences of the diagnosis and its treatment. With more people living longer after cancer treatment and incidence also increasing, by 2030 there are likely to be around 360,000 people living with or after cancer treatment in Scotland. Health services need to consider how care and support should be delivered after the initial management phase of treatment is complete to support and enable people affected by cancer to live as healthy and as good a quality of life for as long as possible.

TCAT is a major component of the Scottish Cancer Taskforce Workplan, which will be delivered in partnership with the Scottish Government, Regional Cancer Networks, Health Boards, Local Authorities and the Voluntary Sector. Macmillan Cancer Support is providing £5 million over 5 years to facilitate the development and implementation of models of care that:

• Enable people affected by cancer to play a more active role in managing their own care.
• Provide services which are more tailored to the needs and preferences of people affected by cancer.
• Give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment.
• Improve integration between different service providers and provide more care locally.

The principles for future practice which should be integral elements of all new models of cancer care after treatment are risk stratification, personalised care planning, information to meet individual needs, care coordination across care settings and rapid access to appropriate health or care professional when problems arise. We want to promote a culture shift towards shared decision making and supporting self management. The wellbeing of people affected by cancer will be greater and their demand for services lower if they get the support that is relevant to their particular needs.

In December 2013 NHS Lothian’s TCAT proposal “Developing a recovery-based approach to cancer care in Lothian” was approved, securing Macmillan funding for a 2-year development project. The overall aim of this scheme is to evaluate the immediate and intermediate benefits of a recovery-based approach to care in patients treated for prostate, breast, gynaecological, anal/rectal and lung cancer. Needs assessment, and End of Treatment Assessment Clinics will be delivered.

The specific objectives of the scheme, to be delivered over 2014 – 2015, are:
1. To prepare and inform people about what to expect after completion of treatment including follow-up, offering tailored advice on what they can do for themselves and how to access further sources of support;
2. To evaluate the implementation of Holistic Needs Assessment and care planning and/or specific interventions to support the identified needs of patients at 6-12 weeks post treatment;
3. To evaluate the implementation of an end-of-treatment review about care and treatment received, possible treatment toxicities and/or late effects, ongoing management plan and any actions/goals to support recovery which would inform both the patient and the primary care teams;
4. To evaluate the benefits of conducting a supportive end-of-treatment approach to recovery from the perspectives of both patients and health care professionals;
5. To evaluate the feasibility of embedding this service in everyday care;

A secondary objective will be to review the key concerns raised by patients and assess whether there are common themes for all patients or within specific tumour groups. This data may help inform future intervention work.

Phase-2 of the programme, during 2014, will see the development of the TCAT initiatives further with the involvement of Lothian Health and Social Care
Partnerships. This brings the opportunity to extend the improvement in care to Local Authority and NHS provided community based services.

**Breast Service Redesign**

NHS Lothian is the host Board for The South East Scotland Breast Screening Programme (SESBSP) which is commissioned by National Services Division (NSD). The service provides screening and diagnostic services for the NHS Lothian, NHS Fife (except North-East Fife), NHS Forth Valley and NHS Borders region. Breast Screening services are located at Ardmillan House, in South West Edinburgh. Symptomatic Breast services are provided at the Western General Hospital (WGH). Patients diagnosed with breast cancer in the screening pathway are referred to the breast service at the WGH for further assessment and treatment.

The screening static centre at Ardmillan carries out routine screening for over 50% of the City of Edinburgh eligible population; along with follow-up assessment. The screening service currently operates 5 mobile units to cover the eligible population of South-East Scotland.

Over the course of October and November 2013 digital screening was introduced into the screening programme (the first region in Scotland to be fully digitised). This removes the requirement to store films in the future, and is a major step forward in terms of image quality and diagnostic capability. It is anticipated that the introduction of digital screening will lead to the detection of more early stage breast cancers, including more DCIS (Ductal Carcinoma In Situ).

The screening population served is predicted to increase by 14% over the next 3 screening rounds. It is likely that with the anticipated increase in eligible population, increasing uptake from the 71+ age bands and marketing campaigns designed to increase attendance that within 5 years demand will exceed capacity available in the breast screening service.

The Mammography Department at the WGH also provides breast diagnostic imaging services for symptomatic women in Edinburgh, with localisation services for patients with impalpable lesions from across Lothian, Fife, Borders, and half of Forth Valley regions. Long-term follow-up screening service for patients who have been treated for breast cancer is also provided.

Increasingly the screening and symptomatic services work in an integrated way and planning for redesign and modernisation of the breast service pathway includes consideration of the total breast pathway. As we further consider service capacity requirements, and link this work to planning for a new cancer centre, the co-location of breast symptomatic and screening services needs to be reviewed to determine if the advantages of full co-location can be achieved in the context of potentially taking forward a major cancer services capital programme on the Western General Hospital site.

In early 2011 the National Planning Forum commissioned NSD to undertake a major review of the Breast Screening Programme across Scotland. The review group concluded that the screening service should retain a six-centre model, but pursue further integration with symptomatic breast services.
Work is underway in Lothian to assess and plan redesigned services, particularly at this stage associated with the Detect Cancer Early Programme. NHS Lothian, alongside other NHS Boards in Scotland which host breast screening services, will work with NSD and other partners as the implementation plan following the national review is rolled-out.

**Palliative and End of Life Care**

The Lothian Palliative and End of Life Care strategy was approved by the NHS Board, and our partner agencies involved in co-developing the strategy, in 2010.

Our vision is for high quality Palliative and End of Life care available in all settings, utilised by all who require it, and prioritised according to the patient’s need, rather than medical condition. By 2015 clinical teams in all settings across Lothian will be reliably identifying and assessing patients as they reach a palliative phase of their illness, and developing and updating integrated care plans for them and their carers, based on patients and family preferences.

Our aim is to ensure access to high quality Palliative Care to all who need it, irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and socio-economic status.

Public and professional feedback alike highlighted the importance of supporting choice for people with palliative and end of life care needs. Based on this, the goals of strategic implementation in relation to supporting choice focus on action to:

- Identify people who would benefit from palliative care, and to develop care plans with people which include establishing preferred place of care and preferred place of death
- Maximise the time spent in people’s preferred place of care (home, care home, and community hospital)
- Minimise emergency admissions where these could be avoided by good anticipatory care planning
- Support realistic choice of place of death (taking into account a holistic assessment of patient, family and carer needs)

We are taking forward a model of palliative care which seeks to support the integration of disease modifying treatment and palliative care. Our approach breaks down palliative care planning and delivery into 3 tiers:

- Working with people with **Long Term Conditions** to make sure that the need for palliative care is identified as part of routine care at the earliest stage appropriate, helping people to plan, direct and be actively involved in their own care.

- Adopting the **Palliative Care Approach** from as early a stage as is agreed appropriate. The palliative care approach seeks to maximise quality of life, by maintaining good symptom control, offering holistic assessment including
family and carers needs, and seeks to agree choices around treatment options, place of care and preferred place of death.

- Planning for and managing end of life care in the last days of life in a tightly co-ordinated and structured manner.

As a result of development work in recent years, there is now a stronger platform from which to make further service improvement, however our strategic indicators show that progress towards overall goals and strategy outcomes is not being made quickly enough. There is therefore a need to re-focus on the main pathways of care in palliative and end of life care to achieve better and more reliable co-ordination of care within and across service settings. All partners recognise the need for more of an emphasis on integrated community based care.

To support the necessary redesign, NHS Lothian and Marie Curie UK are jointly sponsoring the Lothian Palliative Care redesign programme, with the participation of all stakeholders. The development phase of the programme runs over 2013 and 2014, with change initiatives being delivered thereafter. In summary the programme aims to:

- Assist in taking further the community based model of palliative care in place across Lothian, and to accelerate progress in shifting the balance of end of life care towards greater community based care

- To improve co-ordination of care, within and across settings, to support patients and families with complex and unstable palliative and end of life care needs

- To increase capabilities to identify patients and to plan care in anticipation and in advance of needs

- To enhance education, and support greater recognition of non-cancer palliative care identification and planning requirements

- To increase community based care service provision


Bereavement Care in NHS Lothian

death and dying from the point of view of the bereaved, developing staff training and support, considering ways of improving the advice and guidance given to bereaved people following a death, and developing links with other stakeholders.

To support achievement of these recommendations NHS Lothian employs a designated Bereavement Co-ordinator within Lothian Acute Hospitals. This post was the first of its kind in the NHS in Scotland, and has been used as the model for the type of coordinated service recommended within CEL (2011) 9. This post, and our Shaping Bereavement Care action plan, is managed in Spiritual Care & Bereavement Services.

The management of elderly patients with complex needs
Fifty percent of the increasing incidence in cancer is in the retired population. Building on pilot work being undertaken in haematology to consider the additional needs associated with elderly cancer patients with complex needs, we need to further consider pathways and clinical management arrangements for older patients. A systematic analysis of need is required to support the development of pathways and protocols across the region.

Tumour specific Group issues:
Tumour Specific Groups (TSGs) are in place as part of the South East Scotland Cancer Network. Groups are in place for the following: Breast, Colorectal, Gynaecology, Haematology, Lung, Skin, Upper GI, Head & Neck and Urology.

The work programme of all of the TSG’s includes common features supporting the achievement of reliable and high quality care delivered in the right setting. Features such as:

- Identifying best practice and supporting evidence based care into practice
- Allowing regional clinical management collaboration to support and achieve new standards of care across regional units
- Participation in the development and implementation of the new Cancer Quality Performance Indicators
- Participation in cancer clinical audit
- Development of guidelines and protocols to support clinical management
- Pathway development specific to the tumour type
6. INVOLVE PATIENTS AND CARERS AS EQUAL PARTNERS, ENABLING INDIVIDUALS TO MANAGE THEIR OWN HEALTH AND WELLBEING AND THAT OF THEIR FAMILIES

Cancer patients input to service programmes and the Better Together Patient Experience Programme
Patient involvement has been, and will continue to be, a fundamental element of the planning and development of Cancer Services within NHS Lothian.

NHS-24 Cancer Treatment Helpline
Within the Acute Oncology Programme, NHS Lothian has participated as an early implementer of the NHS-24 Cancer Treatment Helpline (CTH). Lothian patients were closely involved in the planning of this national development via the SCAN (South East of Scotland Cancer Network) Patient Forum. The views and experiences of patients accessing this service continue to be sought from patients accessing this service via telephone interviews undertaken by the CTH team in Lothian. This feedback is being used to further inform service change as implementation within the other Health Boards is undertaken.

Transforming Care After Treatment (TCAT)
Other major programmes which have had local patient involvement from the start include the Transforming Care After Treatment (TCAT) Programme. NHS Lothian patients have been involved in the discussion and selection of potential projects from all SCAN Boards. The successful projects in each phase of this 5 year programme will be managed by a local steering group where active involvement from patients will be sought. Indeed the first project to be undertaken has been developed with direct input from the Lothian Prostate Cancer Support Group.

Patient Experience Cancer Quality Performance Indicators (QPI’s)
The first collection of Patient Experience Quality Performance Indicators (QPIs) will be undertaken in 2014. These were developed during 2013 with contribution from the SCAN Patient Involvement Manager, and duly ratified by the national group in December 2013. The local delivery plan for monitoring against these indicators is currently being devised and will include patient involvement via the Tumour Specific Groups (TSGs).

Tailored Information for People of Scotland (TIPS)
September 2013 saw the launch of Tailored Information for People of Scotland (TIPS). This is a web based service which aims to guide patients towards the information that may be useful to them at a specific point in time. It seeks to avoid ‘information overload’. The design and development of this website has involved patients from its’ inception. The information chosen to support the Chemotherapy section is taken directly from patient information leaflets developed within the Edinburgh Cancer Centre.

Better Together Patient Experience Programme
NHS Lothian will continue to strive to improve services based on patient feedback such as those seen in recent years. Many of these were a direct result of the Better Together
Programme launched in 2008 by the Scottish Government Health Department. Projects include:-

- Development of Head and Neck specific section on SCAN website, including a DVD for patients
- A neck lump clinic set up in 2012 to ensure timely access to appropriate diagnosis
- Development of a transition clinic for young adults, as they move between paediatric and adult services.
- Redesign of chemotherapy booklet for patients, based on individual experiences
- Creation of the Teenage Cancer Trust Unit on WGH site, which opened in July 2013.
- Ongoing development of One Stop Breast Clinics at St John’s Hospital, following the Breakthrough Breast Cancer Service Pledge to patients
- Expansion of the Mammography Unit at WGH
- Recorded conversations in Urology consultations now commonplace (following on from the innovative Decision Navigator Study)
- Improvement in provision of snacks for those undergoing chemotherapy treatments
- Development of visual information to use with patients with learning difficulties in respect of Cancer treatments

SCAN Patient Forum

NHS Lothian is represented in each SCAN Tumour Specific Group. These groups now all have patient representation, thus ensuring patient involvement in all discussion around clinical developments.

The establishment of a Bladder Cancer Support Group has resulted from some of these discussions within the SCAN Urology TSG. This has a Patient and Carer reference Group as a sub group – the first of its kind in SCAN and developed to support patients and carers together. There is an aspiration to roll this out to the other TSGs, particularly Gynae and Breast.

Undertaking patient satisfaction / experience surveys will be a core part of service delivery. Following a pilot in December 2013, the ECC will be undertaking a regular programme of patient experience work within their own local quality strategy.

A national patient satisfaction survey relating to radiotherapy treatment will be completed between March and June 2014.

In undertaking the Edinburgh Cancer Centre Re-provision Programme patient involvement will be initially supported via use of the SCAN Patient Forum. Thereafter individual contribution will be built into the relevant workstreams, as required by the programme.
Our Vision for Cancer Care Delivery: Cancer Centre Reprovisioning and the Western General Hospital

The Western General Hospital is Lothian’s Cancer Services campus, providing oncology services for Lothian and the South East of Scotland region. The cancer service provided is greater than Edinburgh Cancer Centre (ECC) direct provision, for example it includes acute care provided both directly by ECC and by acute services, surgical oncology, and physician led cancer care in various specialties. As such, elements of oncology care pathways are provided all across most services at the Western General Hospital (and indeed the other Lothian main acute sites). This multi-disciplinary approach is how cancer pathways operate, supported by co-ordinated care managed by the cancer multi-disciplinary meetings. These clinical linkages and dependencies need to be recognised and developed to support the delivery of high quality cancer care across Lothian, and to achieve a focus for cancer care at the Western General Hospital as Lothian’s principal cancer site.

Our previous planning work on visioning and the potential for reprovisioning of the Edinburgh Cancer Centre confirmed the Western General Hospital as the preferred site for a new cancer centre. A long list of eight options were considered (including looking at the Lothian main acute sites, other Lothian sites, doing nothing / minimum, and phased development on the existing Cancer Centre). Of these options the preferred option, based on a limited (non financial) options appraisal was for a ‘New build on the Western General Hospital development zone (DCN) – New co-located cancer centre capable of meeting 2025 activity’. This was based on consideration of the best strategic fit, service integration and clinical effectiveness, physical environment, sustainability, and deliverability.

Critically the Western General Hospital is supported in its potential to become Lothian’s designated cancer campus because of the presence of key services, capabilities and facilities, for example:

- Clinical Genetics services
- Colorectal Surgery provision in Lothian centralised on the site
- Urology
- The potential to develop leading expertise and integrated provision of complex pelvic surgical services by bringing together gynaecology, colorectal surgery, urology, and oncology for joint procedures and integrated planning and management
- The Lothian Bowel Screening Service is co-ordinated from the Western General Hospital
- Breast cancer symptomatic assessment, diagnostic and treatment services are based on the site with further potential to integrate with breast screening services
- Specialist Palliative Care services are provided
- Significant cancer imaging is undertaken, with the potential to further develop and redesign imaging services to support cancer pathways
• The Maggie’s Centre is on the Western general Hospital Site
• The University of Edinburgh, Edinburgh Cancer Research Centre is on the campus

To further progress service improvement and the delivery of co-ordinated pathways of care we will take forward throughout 2014 a ‘Model of Care’ workstream as part of the planning programme for the new cancer centre. This will consider, for each tumour group area, key clinical linkages and dependencies, pathways, and the model of care required to support effective service arrangements in each area.

The planning programme for the new cancer centre will focus around the principal workstreams of radiotherapy, workforce, accommodation, and models of care. Key cross-cutting principles such as delivery of care closest to a patients’ home without loss of quality, access or efficiency, and maximising the role and involvement of primary care will be central. In designing plans for the new centre, integration of ambulatory care facilities, acute assessment and inpatient beds will be specifically considered, as well as other key issues such as the co-location of our breast screening and symptomatic services. Maximising the potential benefits telemedicine can bring will also be key. Working with regional partners our concept will be to build a South East of Scotland Cancer Centre as the hub of a regional cancer service, with strong links to imaging, pathology and surgical services across the region.

eHealth and Cancer in Lothian

Section 4 of this document rehearses our plan to develop cancer informatics.

Our e-health developments include, for example:

• Developing the TRAK system to support cancer patient pathway management by using this system both for cancer tracking and, increasingly, to support multi-disciplinary groups (MDM’s).

• Increasingly utilising the Clinical Portal system to integrate clinical systems and support collaborative working between clinical teams, whether that be within Lothian, across the South East of Scotland Cancer Network, or nationally.

• Providing e-referral systems including cancer specific referrals guidance in line with nationally agreed cancer referral guidelines.

• Testing and further considering telehealth and telepresence technology to potentially allow remote consultation and collaboration between professionals.

• Using the C-PORT system in chemotherapy to assist with capacity and demand modelling and scenario planning. We are also utilising and further developing the CEPAS system to support prescribing.
• Using the R-PORT system to support radiotherapy department level capacity planning.

• Developing a South East of Scotland cancer e-health strategy to support all regional Boards.

• In palliative and End of Life care we are utilising the Key Information Summary (KIS) system to record and communicate palliative care anticipatory care plans across in and out-of-hours services. We are also planning to establish secure data connections between the NHS Lothian Network and the two Lothian Independent Hospices to allow electronic referral via Gateway and to support greater clinical communication.

Access to Cancer Care in Lothian
There are two headline national cancer waiting times’ targets in Scotland:

• 62 days from urgent referral with suspicion of cancer (and referrals from the national screening programmes) to first treatment
• 31 days from decision to treat to first treatment (irrespective of route of referral)

NHS Lothian’s performance against both of the headline targets in recent years has been either over the required standard or, where dips in performance in 62-days have been experienced, close to the 95% standard required. Lung cancer 62-day performance is being further scrutinised in 2014 and an action plan for improvement in lung cancer will be developed, including review and redesign of the lung cancer pathway. Lung cancer, Head & Neck Cancers, and Lymphoma are the pathways where compliance with the 62-day pathway requires ongoing support.

NHS Lothian has consistently met the standards for acute leukaemia and for children’s cancers, both of which are subject to a separate reporting mechanism to the 62 and 31 day standards.

The leukaemia target is a maximum wait from urgent referral to treatment for acute leukaemia of one month

The children’s cancer target is a maximum wait from urgent referral to treatment for children's cancers of one month

Cancer Research
If we aspire to optimise outcomes, incorporating clinical research as a core service is essential. Research should be embedded into the clinical service across the region, as there is a growing body of evidence that those hospitals that conduct clinical research deliver better outcomes for all their patients, not just those enrolled into clinical trials. Support departments (imaging, nursing, diagnostics, portering etc.) all have a key role to play in facilitating and maximising research activity.
8. **STRATEGY MEASUREMENT**

**Routine measures**
Cancer services in Lothian are subject to continuous measurement and reporting, all of which contribute to service scrutiny and improvement. The main areas of routine measurement are noted below.

<table>
<thead>
<tr>
<th>Area</th>
<th>Measure</th>
<th>Published</th>
<th>Description</th>
<th>Source</th>
<th>Lothian Performance</th>
<th>Scotland Performance</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening programmes</strong></td>
<td>Bowel Screening</td>
<td>Uptake</td>
<td>Annually Bowel Screening Key Performance Indicator report which includes 28 indicators.</td>
<td>ISD</td>
<td>53.5%</td>
<td>54.9%</td>
<td>60%</td>
</tr>
<tr>
<td></td>
<td>Breast Screening</td>
<td>Uptake</td>
<td>Annually Report on the KC62 Health Board Standards. This includes a number of indicators around breast screening including uptake.</td>
<td>ISD</td>
<td>71.7%</td>
<td>74.5%</td>
<td>80%</td>
</tr>
<tr>
<td></td>
<td>Cervical Screening</td>
<td>5.5 year Uptake</td>
<td>Annually Data covering uptake, workload, processing, turnaround and reporting.</td>
<td>ISD</td>
<td>75.5%</td>
<td>78.1%</td>
<td>80%</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td>Cancer Access Standards</td>
<td>62-day referral to treatment</td>
<td>Quarterly 95% of those referred urgently with a suspicion of cancer to begin treatment within 62 days of receipt of referral</td>
<td>ISD</td>
<td>96.9%</td>
<td>94.5%</td>
<td>95%</td>
</tr>
<tr>
<td></td>
<td>31-day decision to treat</td>
<td>Quarterly</td>
<td>95% of all patients diagnosed with cancer to begin treatment within 31 days of decision to treat</td>
<td>ISD</td>
<td>99.6%</td>
<td>98.1%</td>
<td>95%</td>
</tr>
<tr>
<td>Area</td>
<td>Measure</td>
<td>Published</td>
<td>Description</td>
<td>Source</td>
<td>Lothian Performance</td>
<td>Scotland Performance</td>
<td>Target</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------------------------------------</td>
<td>-----------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------</td>
<td>---------------------</td>
<td>----------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>DCE HEAT Target</td>
<td>Proportion of cancers detected at stage 1 (HEAT</td>
<td>Annually</td>
<td>To increase the proportion of people diagnosed and treated in the first stage of breast, colorectal and lung cancer by 25% by 2014/2015</td>
<td>ISD</td>
<td>10.20%</td>
<td>4.30%</td>
<td>Local: 28.3% National: 25%</td>
</tr>
<tr>
<td></td>
<td>target H10.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking Cessation</td>
<td>Successful Quits (HEAT target H6.1)</td>
<td>Quarterly</td>
<td>NHS Scotland to deliver universal smoking cessation services to achieve at least 80,000 successful quits (at one month post quit) including 48,000 in the 40% most deprived within-Board SIMD areas over the three years ending March 2014</td>
<td>ISD</td>
<td>7,779</td>
<td>48,396</td>
<td>Local: 7,011 National: 48,000</td>
</tr>
<tr>
<td>Cancer Quality</td>
<td>Various - Yet to be published</td>
<td>Annually</td>
<td>The QPIs have been developed collaboratively with the three Regional Cancer Networks, Information Services Division (ISD), and Healthcare Improvement Scotland. QPIs will be kept under regular review and be responsive to changes in clinical practice and emerging evidence. They include small sets (approximately 10-15 indicators) of tumour specific and generic national quality performance indicators (QPIs).</td>
<td>HIS/ISD</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Performance indicators</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incidence</td>
<td>Incidence</td>
<td>Annually</td>
<td>Incidence statistics by cancer type, sex, network and health board. The data is also split by age group at network level and above.</td>
<td>ISD</td>
<td>Total: 4,614 EASR: 445.1</td>
<td>Total: 30,125 EASR: 425.2</td>
<td>-</td>
</tr>
</tbody>
</table>
### Mortality

Mortality statistics by cancer type, sex, network and health board. The data is also split by age group at network level and above.

<table>
<thead>
<tr>
<th>Source</th>
<th>Total: 1,113</th>
<th>Total: 15,787</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISD</td>
<td>EASR: 179.4</td>
<td>EASR: 198.6</td>
</tr>
</tbody>
</table>

### Survival

The National Cancer Intelligence Network (NCIN) produces a cancer e-Atlas tool that includes incidence, mortality and survival indicators for the whole of the UK.

<table>
<thead>
<tr>
<th>Source</th>
<th>Currently being revised</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCIN</td>
<td>Currently being revised</td>
</tr>
</tbody>
</table>

### Quality Report – Clinical Governance

A yearly cancer quality report is produced in NHS Lothian. Clinical effectiveness measures presented include: mortality rates, smoking cessation outcomes, uptake of the three screening programmes and primary care review of patients newly diagnosed with cancer. The QOF indicator used for the final measure requires that patients are reviewed in primary care within six months of the practice receiving confirmation of the cancer diagnosis.

<table>
<thead>
<tr>
<th>Source</th>
<th>96.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoF Calculator</td>
<td>-</td>
</tr>
</tbody>
</table>

### Palliative Care Indicators

#### Occupied bed days

Reduction in the number of occupied bed days in last year of life (for deaths in domiciliary and care home settings)

<table>
<thead>
<tr>
<th>Source</th>
<th>Lothian Performance</th>
<th>Scotland Performance</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>LAS</td>
<td>26,923</td>
<td>-</td>
<td>22,603</td>
</tr>
</tbody>
</table>

#### Deaths/year

10% reduction in deaths/year in acute hospital settings between 2008 and 2015

<table>
<thead>
<tr>
<th>Source</th>
<th>Lothian Performance</th>
<th>Scotland Performance</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>LAS</td>
<td>-0.3%</td>
<td>-</td>
<td>-10%</td>
</tr>
</tbody>
</table>

#### Quality Outcome Measure 10

Percentage of last six months of life spent at home or in a community setting

<table>
<thead>
<tr>
<th>Source</th>
<th>Lothian Performance</th>
<th>Scotland Performance</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISD</td>
<td>92.0%</td>
<td>91.2%</td>
<td>-</td>
</tr>
</tbody>
</table>
9. STRATEGIC RESOURCING

NHS Lothian’s operating budget for oncology in 2013 / 14 was £43.85m (covering breast screening, oncology services including breast services and palliative care, and haematology). We manage a strategic budget of £4.3m to commission hospice care in Lothian and support the palliative care strategic programme, including the managed clinical network (MCN). Specific aspects of the strategic programme such as the Detect Cancer Early Programme and the cancer modernisation programme bring additional allocations which are used to support specific services and initiatives across the system. The NHS Lothian Detect Cancer Early Programme was allocated £1.5m in revenue and £0.3m in capital in 13/14, and will be subject to further (variable) income allocations in 14/15 and 15/16 to support the programme. Cancer modernisation in NHS Lothian was allocated £0.5m in 13/14 (with 0.3m of this for regional radiotherapy modernisation), with further investment to come in 14/15. Other specific allocation routes also support the provision of cancer care in Lothian, such as for key diagnostic capacity and development (for example PET provision), and via primary care funding routes such as the GP contract / Scottish Quality and Outcomes Framework, which are for example currently being utilised nationally to further support local Detect Cancer Early Programmes and screening programmes.

Cancer pathways operate across the whole system of care. As an example, lung cancer care will include a GP or Emergency Department presentation and onward referral, initial diagnostic imaging, respiratory medicine assessment and related endoscopic diagnostics, may include thoracic surgery, and most cases will necessitate assessment, planning and treatment in oncology (radiotherapy, chemotherapy or a combination treatment), and may require palliative and end of life care. Such co-ordinated care happens across specialties and settings of care, and often across NHS Board boundaries. We do not have an accurate mechanism to determine the full costs of cancer care across the whole system. The development of the Integrated Resource Framework (IRF) in Lothian may assist in achieving a better estimate of cancer pathway costs.

At the South East of Scotland regional level the shared costs of cancer care (cross charging other South East of Scotland NHS Boards for specialist care provided by NHS Lothian) are managed via service level agreements across the region. Under this model, recovery of costs is based on annual average case volumes and costs per case.

Section 7 of this strategy outlines our ambition to develop the Western General Hospital as Lothian’s cancer campus and the base for a new South East of Scotland Cancer Centre. In order to support this ambition the associated business case needs to be completed locally and submitted into the national capital programme for consideration and prioritisation. Production of an Initial Agreement and, subject to approval, an Outline Business Case will be taken forward during 2014/15.
This appendices provides two schematics. The first shows the organisation of the national cancer programme and the South East of Scotland regional arrangements. The second shows the Lothian cancer and palliative care programme in the context of the NHS Lothian strategic planning arrangements.
## APPENDIX 2 – TRENDS IN CANCER SURVIVAL 1983-2007

All malignant neoplasms excluding non-melanoma skin cancer (ICD-9 140-208 excl. 173; ICD-10 C00-C97 excl. C44)

Trends in survival by age group and period of diagnosis

Observed and relative survival (%) at 1, 3, 5 and 10 years; patients diagnosed 1983-2007.1,2

### All Persons

<table>
<thead>
<tr>
<th>Age group</th>
<th>Period</th>
<th>Number of cases analysed</th>
<th>Observed survival (%) at</th>
<th>Relative survival (%) at</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-44</td>
<td>1983-1987</td>
<td>7,237</td>
<td>1 yr: 82.6</td>
<td>5 yr: 63.5</td>
</tr>
<tr>
<td>1988-1992</td>
<td>7,818</td>
<td>84.4</td>
<td>67.2</td>
<td>60.6</td>
</tr>
<tr>
<td>1993-1997</td>
<td>8,115</td>
<td>87.6</td>
<td>72.1</td>
<td>66.2</td>
</tr>
<tr>
<td>1998-2002</td>
<td>8,290</td>
<td>89.4</td>
<td>80.1</td>
<td>75.8</td>
</tr>
<tr>
<td>2003-2007</td>
<td>8,487</td>
<td>90.4</td>
<td>81.8</td>
<td>77.6</td>
</tr>
<tr>
<td>45-54</td>
<td>1983-1987</td>
<td>9,744</td>
<td>1 yr: 65.9</td>
<td>5 yr: 47.3</td>
</tr>
<tr>
<td>1988-1992</td>
<td>10,554</td>
<td>70.9</td>
<td>56.2</td>
<td>41.7</td>
</tr>
<tr>
<td>1993-1997</td>
<td>11,889</td>
<td>74.7</td>
<td>60.1</td>
<td>54.7</td>
</tr>
<tr>
<td>1998-2002</td>
<td>12,223</td>
<td>78.1</td>
<td>64.3</td>
<td>58.9</td>
</tr>
<tr>
<td>2003-2007</td>
<td>12,560</td>
<td>81.0</td>
<td>68.8</td>
<td>63.6</td>
</tr>
<tr>
<td>55-64</td>
<td>1983-1987</td>
<td>22,274</td>
<td>1 yr: 57.2</td>
<td>5 yr: 36.1</td>
</tr>
<tr>
<td>1988-1992</td>
<td>22,086</td>
<td>58.2</td>
<td>41.9</td>
<td>35.3</td>
</tr>
<tr>
<td>1993-1997</td>
<td>22,593</td>
<td>63.8</td>
<td>48.0</td>
<td>41.5</td>
</tr>
<tr>
<td>1998-2002</td>
<td>23,092</td>
<td>68.0</td>
<td>52.4</td>
<td>46.0</td>
</tr>
<tr>
<td>2003-2007</td>
<td>25,133</td>
<td>71.6</td>
<td>57.3</td>
<td>51.7</td>
</tr>
<tr>
<td>65-74</td>
<td>1983-1987</td>
<td>30,446</td>
<td>1 yr: 45.4</td>
<td>5 yr: 29.0</td>
</tr>
<tr>
<td>1988-1992</td>
<td>32,063</td>
<td>48.3</td>
<td>31.9</td>
<td>25.2</td>
</tr>
<tr>
<td>1993-1997</td>
<td>35,819</td>
<td>52.8</td>
<td>36.0</td>
<td>29.1</td>
</tr>
<tr>
<td>1998-2002</td>
<td>34,357</td>
<td>57.7</td>
<td>40.7</td>
<td>33.6</td>
</tr>
<tr>
<td>2003-2007</td>
<td>34,970</td>
<td>62.1</td>
<td>45.7</td>
<td>38.9</td>
</tr>
<tr>
<td>75-84</td>
<td>1983-1987</td>
<td>23,669</td>
<td>1 yr: 36.3</td>
<td>5 yr: 21.0</td>
</tr>
<tr>
<td>1993-1997</td>
<td>27,953</td>
<td>44.8</td>
<td>27.4</td>
<td>19.5</td>
</tr>
<tr>
<td>1998-2002</td>
<td>29,067</td>
<td>46.8</td>
<td>29.3</td>
<td>21.7</td>
</tr>
<tr>
<td>2003-2007</td>
<td>30,581</td>
<td>48.9</td>
<td>31.3</td>
<td>23.3</td>
</tr>
<tr>
<td>85-99</td>
<td>1983-1987</td>
<td>5,537</td>
<td>1 yr: 26.8</td>
<td>5 yr: 12.4</td>
</tr>
<tr>
<td>1988-1992</td>
<td>7,183</td>
<td>29.9</td>
<td>14.4</td>
<td>7.9</td>
</tr>
<tr>
<td>1993-1997</td>
<td>9,183</td>
<td>33.5</td>
<td>17.0</td>
<td>9.3</td>
</tr>
<tr>
<td>1998-2002</td>
<td>9,695</td>
<td>34.4</td>
<td>17.0</td>
<td>9.7</td>
</tr>
<tr>
<td>2003-2007</td>
<td>10,072</td>
<td>34.9</td>
<td>17.2</td>
<td>9.9</td>
</tr>
<tr>
<td>95-104</td>
<td>1983-1987</td>
<td>69,701</td>
<td>1 yr: 54.5</td>
<td>5 yr: 38.4</td>
</tr>
<tr>
<td>1988-1992</td>
<td>72,521</td>
<td>58.6</td>
<td>42.9</td>
<td>36.5</td>
</tr>
<tr>
<td>1993-1997</td>
<td>78,416</td>
<td>62.9</td>
<td>47.4</td>
<td>41.0</td>
</tr>
<tr>
<td>1998-2002</td>
<td>77,962</td>
<td>67.3</td>
<td>52.1</td>
<td>45.8</td>
</tr>
<tr>
<td>2003-2007</td>
<td>81,150</td>
<td>70.9</td>
<td>56.7</td>
<td>50.8</td>
</tr>
<tr>
<td>105-114</td>
<td>1983-1987</td>
<td>98,907</td>
<td>1 yr: 48.8</td>
<td>5 yr: 32.8</td>
</tr>
<tr>
<td>1988-1992</td>
<td>105,498</td>
<td>52.2</td>
<td>36.5</td>
<td>29.8</td>
</tr>
<tr>
<td>1993-1997</td>
<td>115,552</td>
<td>56.4</td>
<td>40.3</td>
<td>33.4</td>
</tr>
<tr>
<td>1998-2002</td>
<td>116,724</td>
<td>59.6</td>
<td>43.5</td>
<td>36.8</td>
</tr>
<tr>
<td>2003-2007</td>
<td>121,803</td>
<td>62.5</td>
<td>47.1</td>
<td>40.5</td>
</tr>
</tbody>
</table>

**Directly standardised**

<table>
<thead>
<tr>
<th>Age group</th>
<th>Period</th>
<th>Number of cases analysed</th>
<th>Observed survival (%) at</th>
<th>Relative survival (%) at</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-44</td>
<td>1983-1987</td>
<td>69,701</td>
<td>1 yr: 54.7</td>
<td>5 yr: 38.5</td>
</tr>
<tr>
<td>1988-1992</td>
<td>72,521</td>
<td>58.6</td>
<td>42.9</td>
<td>36.5</td>
</tr>
<tr>
<td>1993-1997</td>
<td>78,416</td>
<td>62.9</td>
<td>47.4</td>
<td>41.0</td>
</tr>
<tr>
<td>1998-2002</td>
<td>77,962</td>
<td>67.3</td>
<td>52.1</td>
<td>45.8</td>
</tr>
<tr>
<td>2003-2007</td>
<td>81,150</td>
<td>70.9</td>
<td>56.7</td>
<td>50.6</td>
</tr>
<tr>
<td>45-54</td>
<td>1983-1987</td>
<td>98,907</td>
<td>1 yr: 47.9</td>
<td>5 yr: 32.1</td>
</tr>
<tr>
<td>1988-1992</td>
<td>105,498</td>
<td>51.6</td>
<td>36.0</td>
<td>29.5</td>
</tr>
<tr>
<td>1993-1997</td>
<td>115,552</td>
<td>56.2</td>
<td>40.2</td>
<td>33.5</td>
</tr>
<tr>
<td>1998-2002</td>
<td>116,724</td>
<td>59.5</td>
<td>43.5</td>
<td>36.9</td>
</tr>
<tr>
<td>2003-2007</td>
<td>121,803</td>
<td>62.4</td>
<td>47.1</td>
<td>40.7</td>
</tr>
</tbody>
</table>

---

1. Cases diagnosed in 2005-2007 do not have 5 years' follow-up and cases diagnosed in 2000-2007 do not have 10 years' follow-up.

2. Cases diagnosed in 1983-1996 are coded to ICD-9 scheme and cases diagnosed in 1997-2007 are coded to ICD-10 scheme.

3. These rates are standardised to the European Cancer Patient Population (EUROCARE-4).

---

Source: Scottish Cancer Registry, ISD
Data extracted: June 2010