CANCER IN SCOTLAND ACTION FOR CHANGE



BOWEL CANCER FRAMEWORK FOR SCOTLAND











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ISBN 0 7559 4151 9

Published by Scottish Executive St Andrew's House Edinburgh

Produced for the Scottish Executive by Astron B34558 4-04

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FOREWORD

Bowel cancer is an important health issue worldwide and, in Scotland, it represents a major problem. It is the second most common cause of cancer death in this country, and the incidence, which is currently 53.5 per 100,000 of the population, increased by 12% in men and 2.1% in women between 1991 and 2000 (Information and Statistics Division).

Although the outcome of treated bowel cancer has improved over time, five-year survival is still in the region of 40%. If continuing improvements are to be made, a range of initiatives and actions are required across a range of areas and specialties, from prevention, through earlier detection, treatment, palliative care and ongoing research.

In this framework, the key components of a national bowel cancer service programme are outlined, under the headings of Basic Elements, Service Implications and Research Implications.

Significant work is already underway throughout NHSScotland to improve bowel cancer services. However, a formal over-arching framework would provide a national focus and add value in terms of collaboration and consistency. That is why this framework is being published. It brings together various elements aimed at improving bowel cancer services and ultimately outcomes for patients with bowel cancer in Scotland.

Cancer continues to be a top priority for the Scottish Executive and for NHSScotland. Working together with clinicians across cancer networks, the voluntary sector and patients, significant strides have been made in improving cancer services.

Of the additional £60m investment supporting implementation of the cancer strategy, *Cancer in Scotland: Action for Change* (SEHD, 2001), which has enabled more than 300 additional staff to be employed, in the community, in secondary care and in specialist cancer centres, £18m has been invested in earlier detection, £17m in improving treatment services so that waiting times are reduced and a continuous quality improvement ethos is embedded within day-to-day practice. This includes £4m for bowel cancer services that has been directly invested from *Cancer in Scotland* and a further £5.8m from New Opportunities Fund to support improvement in prevention, investigation and treatment.

A second bowel cancer network development workshop will be held on 23 April, focusing on the period up only to diagnosis. As the subject is so big it is planned to hold a second workshop later in the year focusing on the treatment and care of patients with colorectal cancer.

A great deal of additional effort and resource is also being invested in programmes of prevention and education aimed at lifestyle interventions that are known to make a difference to people's health.

The Cancer Challenge, or as it is more commonly known, the bowel cancer screening pilot, underway in Fife, Tayside and Grampian is now in its second round. The formal Evaluation Report on the UK Colorectal Cancer Screening Pilot in July 2003 confirmed the potential benefits of colorectal cancer screening. The Minister for Health and Community Care Mr Malcolm Chisholm, re-affirmed on 4 September 2003, and subsequently, the Scottish Executive's commitment, to introduce a national bowel cancer screening programme. The planning process to support the screening programme is expected to take some time and will be taken forward in conjunction with the service and will take into account advice from the UK National Screening Committee.

Endoscopy capacity is recognised across the country as a significant challenge for earlier diagnosis and investment is either being put in place or is planned in a number of NHS Board areas. This framework highlights the issues surrounding training and workforce planning as well as capacity and demand.

The purpose of this framework is not to draw conclusions, but rather to set a direction of travel. We need to bring together screening and symptomatic diagnostic services in order to plan in a co-ordinated way for the future. It is proposed that a new national steering group will be established to map out an agreed approach over the next three to five years to ensure that bowel cancer services are ready to support a national screening programme as well as meeting qualitative standards and targets, including waiting times.

As far as research is concerned, an additional £1m has supported the establishment of the Scottish Cancer Research Network and more than £2m is being invested by the Chief Scientist Office in the two Scottish National Translational Research Centres in Dundee and Glasgow (working together as a virtual centre) and in Edinburgh where there is a major research interest in the genetic aspects of bowel cancer.

Services for people at risk of or diagnosed with bowel cancer in Scotland are improving, but significant challenges remain. There is a national consensus that there are significant opportunities to enhance that progress. This framework provides a platform to do that.

Dr E M Armstrong Chief Medical Officer

&M Brothing

April 2004

PREVENTING CANCER

The Scottish Executive's policies to support improvements in the health of Scottish people are set out in a variety of published documents (see reference list at end).

Of these, perhaps improving diet and exercise can have the most impact on incidence of, and mortality from, bowel cancer in Scotland.

It is not intended to provide a comprehensive status report on these various initiatives here, however, a summary is provided that clearly demonstrates a wide range of actions being taken by the Scottish Executive and NHSScotland who are continuing to work in partnership to help achieve, among others, the overall cancer mortality target of a 20% reduction in deaths from cancer in the under 75s by 2010 (1995 baseline). In 2002 there were 22.8 deaths from cancer per 100,000 of population, which is a fall of 16% compared to the 1995 baseline.

ISD statistics show that in 2000 bowel cancer was the third most frequently diagnosed cancer in both sexes. Incidence was higher in males with a statistically significant increase of 12% over the period 1991 to 2000. However, the 2.1% increase in females was not statistically significant. Mortality fell for males (–12.4%) and females (–23.8%) over the period from 1993 to 2002.

The effects of unhealthy lifestyles and deprivation have long been recognised, although more work is needed to better understand the complex biological interactions that may influence individual and population health.

The government is committed to closing inequality gaps and, in the health area, is setting up a Centre for Population Health Studies in Glasgow, as set out in *A Partnership for a Better Scotland: Partnership Agreement* (2003).

PREVENTING CANCER

Basic Elements

- Lifestyle Intervention
 - Chemoprevention
- Population Screening and Surveillance of High Risk Groups

What is required? What		
Service Implications	What is already happening?	Next steps
Lifestyle Intervention • Scorification • Creation • Creation • A tologoup • A tologoup • A tologoup • Court • Sourt • Sourt • Share • Share	Scottish Executive Improving Health in Scotland – The Challenge provides a strategic framework to deliver health improvement • Creation of NHS Health Scotland to provide a national focus for improving health • A tobacco control action plan "A Breath of Fresh Air for Scotland" was launched in January 2004. The Action plan offers a broad-based programme of action aimed at: - accelerating reductions in smoking and smoking prevalence: - further extend smoking cessation services: - an additional £1m this year and £5m in 2005/06 allocated for smoking cessation services - Zyban/Nicotine Replacement Therapy available on prescription and free to those least able to afford it - £900k for 11 new initiatives designed to support smokers to give up - Tobacco Advertising and Promotion Act bans tobacco advertising - Reducing through legislative and other action, the availability and attractiveness of cigarettes particularly to children and young people; and - Sponsoring a public debate on action to minimise the impact of second-hand smoke - Sound Ayrshire Schools Tobacco Awareness Project (NOF funded) - Smoking cessation in South Glasgow (NOF funded) - Towards a smoke-free Highland (NOF funded) - Pharmacy smoking cessation services in North of Scotland (NOF funded) - Smoking and Young people in Tayside (NOF funded) - Tobacco policy programme in Dumfries & Galloway (NOF funded)	Establishment of Centre for Population Health Studies in Glasgow New smoking cessation targets will be set for each NHS Board this year A new Ministerial Working Group will guide the implementation of the action plan and help to shape the future direction of national tobacco control policy in Scotland

)iet

- Nutritional standards for school meals (Hungry for Success) were introduced, backed by a major investment (£63.5m) and detailed monitoring and inspection programme. Implementation underway across Scotland
- Free fruit for all primary 1 and 2 pupils introduced
- Food industry moving to support policy changes in Scotland. In response to Hungry for Success, Coca-Cola removed branded vending machines from all Scottish schools and agreed to provide water and healthier choices
- Product specifications, developed by Food Standards Agency Scotland, set levels for fat, salt and sugar in processed food for Scottish school menus. In response, suppliers and manufacturers, including Brakes, developed new healthier ranges
- The healthyliving campaign has kept awareness of healthy eating messages high. Campaign has made its presence felt in a big way supporting the work of health boards and
 - Great deal of activity at local level driven by local authorities and health boards. Increased investment is driving the development and implementation of local nutrition action plans throughout Scotland stimulated by the Health Improvement Challenge communities in both local and national press
- Eating more fruit and vegetables project in Ayrshire & Arran (NOF funded)
- Dietary prevention of bowel cancer a patient-focused education programme
 - University of Edinburgh (NOF funded)
- Community Action on Food in Clydebank (NOF funded)
- Pollock Fresh Fruit and veg "community kitchen" (NOF funded)
- Community Food initiatives in North of Scotland (NOF funded)
- Healthy eating in Orkney (NOF funded)
- Fruit for early years in Shetland (NOF funded)
- Pre-5 healthy eating initiative in Edinburgh (NOF funded)

Alcohol

- harmful drinking by children and young people. The plan seeks to kick-start a cultural change Problems. The two key priorities of the Plan are to reduce binge drinking and to reduce In January 2002 the Scottish Executive published a national Plan for Action on Alcohol in current harmful drinking patterns
- The Executive has also launched a national communications strategy, published the Alcohol Problems Support and Treatment Services Framework, and set up the National Alcohol Information Resource
- Local Alcohol Action Teams have been strengthened and have produced three-year plans for local delivery of the national Plan and the Executive has announced an injection of specific funding to £8m between 2004-05 and 2005-06 to support this local action

ncidence of cancer and other nutritional status, lifestyle and Investigation into Cancer and established including one on Research on Cancer (IARC), designed to investigate the The European Prospective chronic diseases. To focus working groups have been consumption and iron and Nutrition (EPIC) is a study, environmental factors and meat, fruit and vegetable bowel cancer looking at International Agency for research efforts several relationships between coordinated by the ibre intake • The responses to the Nicholson Committee's Report on the Review of Liquor Licensing Law in Scotland have been independently analysed and are being considered by Ministers. The Scotlish Executive will publish a White Paper in due course and this is expected to lead to new liquor licensing legislation for Scotland

What is required?	What is already happening?	Next steps
Service Implications		
		• A sub-group of the Scottish Ministerial Advisory Committee on Alcohol misuse has been set up to lead a review on the progress in delivering the Plan for Action on Alcohol Problems and in determining future priorities. Action flowing from the Nicholson review, the consultation on anti-social behaviour proposals and the English Alcohol Harm Reduction Strategy will have a significant bearing on how we take future action forward
	 Physical activity Publication of national strategy Let's Make Scotland More Active Appointment of National Physical Activity Coordinator Physical activity advice included in second phase of healthyliving campaign Investment in local infrastructure to support the establishment of local Paths to Health walking groups £24m investment to develop and expand the Active Schools programme National Walking initiative being developed Funding the development and delivery of training for physical activity specialists/deliverers Helping to build capacity among community planning partners for developing active travel as an integral part of their physical activity plans Widening opportunities for employers to provide physical activity opportunities for their staff in partnership with Scotland's Health at Work (SHAW) and Jogscotland 	
	 Voluntary sector Colon Cancer Concern aim to raise awareness and reduce deaths from bowel cancer through the provision of information, support and advice, education programmes for healthcare professionals and research into long-term solutions 	

Chemoprevention	 Chemoprevention seminar in October 2002 looking at the current position and issues Bowel cancer and folic acid trials NSAID use and bowel polyp/adenoma incidence 	 Maintain a watching brief on developments and review in 2004-05
Population Screening and Surveillance of High Risk Groups	 See section on early detection 	
Research Implications		
Lifestyle Intervention • Development of effective lifestyle modification techniques	 Evidence about what works in this area is patchy Requires innovative thinking and evaluation through the Health Improvement demonstration projects such as the Cancer Challenge (Bowel Cancer screening) 	 Continued research and evaluation of projects A cancer portfolio steering group has been set up to identify priorities for any additional expenditure within the Chief Scientist Office (CSO) cancer budget that would impact on cancer research in Scotland and add value to existing funding streams
Chemoprevention • Development of effective chemoprevention • Performance of chemoprevention trials • Identification of populations that would benefit	 CSO is spending ~E0.5million per year in support of project grants related primarily to the genetic determinants of colorectal cancer, ways of improving the FOB test, chemoprotective effects of NSAIDs, surgical reliability and immunotherapy CSO is spending £0.5m per year in support of translational cancer research carried out by the Edinburgh and Glasgow/Dundee National Translational Research Centres (NTRAC). Both workplans build on existing strengths in colorectal cancer research and aim to apply advances from laboratory research to clinical care 	 Support Scotland to participate in national and international trials (Scottish Cancer Research Network) Two Scottish Translational Cancer Research Centres (Glasgow/Dundee combined and Edinburgh)
Population Screening and Surveillance of High Risk Groups	• See section on earlier detection	

02. DETECTING AND TREATING CANCER EARLY

The best way to reduce mortality from bowel cancer in Scotland is to ensure earlier diagnosis and treatment. This means more rapid access to services as well as trying to ensure that patients seek advice earlier whenever they have symptoms suggestive of cancer. There is clear evidence that the earlier the stage of disease at presentation the better are the chances of cure.

Bowel cancer awareness raising programmes as set out above, such as the West of Scotland Cancer Awareness Project (WOSCAP) and the joint Lanarkshire/Forth Valley Bowel Cancer Awareness Project (BCAP) initiative have a clear role to play in helping people understand the signs and symptoms of bowel cancer.

A Cancer Genetics service is well established with clear referral and risk stratification protocols in place (Guidance available on *Cancer in Scotland* website at www.cancerinscotland.scot.nhs.uk). The Scottish Cancer Group's Cancer Genetics Sub-group is currently updating the guidance in light of new developments and emerging new evidence.

Cancer in Scotland: Action for Change (2001) confirmed the Scottish Executive's strategy for preventing as many cancers as possible (see section on Cancer Prevention above). It also stated that, "The next best strategy is to detect and treat cancer early and national population screening programmes aim to do that."

New screening programmes are introduced only after rigorous assessment to ensure that they are effective in doing what they set out to do, according to nationally agreed criteria. The UK National Screening Committee was established in 1996 to advise UK Health Ministers about the introduction of new screening programmes. The advice of the Committee is taken into account in the Scottish Executive's consideration of screening issues.

The Scottish arm of the pilot bowel screening programme – The Cancer Challenge – undertaken in Fife, Tayside and Grampian NHS Board areas, completed its first two-year round of screening in 2002 and is now in its second round. The evaluation report published in July 2003 confirmed that population screening for bowel cancer using Faecal Occult Blood testing was feasible.

European Union health ministers backed a plan in December 2003 calling on member states to implement more effective screening programmes for breast, colon and cervical cancer. The Council of the European Union recommended the introduction of faecal occult blood screening for bowel cancer in men and women aged 50–74.

The Minister for Health and Community Care has reaffirmed the Scottish Executive's commitment to introduce a bowel cancer screening programme, taking into account the recommendations of the UK National Screening Committee. As a first step NHS Boards have been asked to start planning for the introduction of such a programme. It is expected that the planning process will take at least five years as further consideration requires to be given to a range of issues including the appropriate upper age range for screening.

There are significant resource and workforce implications for NHSScotland and it is important that symptomatic services are able to absorb the impact of patients being referred from screening programmes. The estimated target screening population (based on the age range 50–69) is around 1.1m – approximately 557,000 a year. If a decision is taken to screen up to the age of 74 (in line with the EU recommendation) the target population each year would rise to around 660,000 people that are likely to be involved in a nationwide call-recall system for bowel cancer screening. Based on a number of predictions (from the evidence of the pilot) i.e. screening uptake, positivity rate of the returned tests, and the number of people who will go on to have diagnostic tests it is estimated that the

number of colonoscopies each year will be around 6360 (based on screening age range 50–69). As will be seen in the next chapter, the pressures on endoscopy/colonoscopy services are already severe. However, much can be learned from the experiences in the bowel cancer screening pilot area (Fife, Tayside and Grampian).

The following pages set out the current position and the actions that need to be taken in readiness for the introduction of a national bowel screening programme in due course.

To help plan towards that and to ensure an agreed approach across the country, the Scottish Executive Health Department will set up a National Steering Group to map out next steps and agreed approach to build capacity and ensure services are ready to support a national screening programme over the next three to five years.

Further guidance about a colorectal cancer screening programme is expected to issue later this year.

DETECTING AND TREATING CANCER EARLY

Basic Elements

- Early reporting of symptoms
- Prompt, high quality investigations
 Population screening and Surveillance of High Risk Groups

What is required?	What is already happening?	Next steps
Service Implications		
Early reporting of symptoms • Patient, GP and Community Pharmacist education • Development of referral criteria • Implementation of Scottish Referral Guidelines for Suspected Cancer • Reduce time between GP referral and patient receiving appointment	 West of Scotland oral and bowel cancer awareness campaign (NOF funded) Forth Valley and Lanarkshire Bowel Cancer Awareness Project (NOF funded) SCAN Cancer Information Network for patients and professionals (NOF funded) Lanarkshire Cancer Information Service (NOF funded) Scottish Referral Guidelines for Suspected Cancer published May 2002 and circulated throughout Scotland A joint initiative between South Glasgow hospitals and South East Glasgow LHCC has redesigned referral pathways for patients with colorectal symptoms resulting not only in reduced waiting times for access to diagnostic procedures, e.g. barium enema, flexible sigmoidoscopy and colonoscopy but also more effective use of investigative services 	Improving healthcare for people most in need – pilot projects backed by £15m investment over the next two years are to be set up in three NHS Board areas in order to improve access to healthcare for those in Scotland's poorest communities
Population screening and Surveillance of High Risk Groups Introduction of a national screening programme Protocols for the surveillance of high risk groups	 Population screening Scottish arm of UK bowel screening pilot now in second round of screening (in Fife, Tayside and Grampian) Evaluation report confirmed potential benefits of bowel cancer screening and that faecal occult blood (FOB) testing was feasible Colorectal Cancer Screening Pilot Project Board established to oversee and co-ordinate second round of screening and to assist with the roll out of the screening programme Public awareness campaign already taking part in some parts of the country (see prevention above) 	Scottish Executive Health Department to set up National Steering Group to map out next steps and agree approach over the next three to five years to build capacity and ensure services are ready to support a national screening programme Guidance on screening

	 Surveillance Protocols for the surveillance of high risk groups are already available from the latest SIGN guidance on Bowel Cancer High risk (HNPCC and FAP) genetics programme in place nationwide 	• Further work needed on the impact on primary and secondary care services, workforce and training requirements and upper age range for invitation • NHS Boards/Health Promotion Departments may wish to consider role of public awareness campaigns Surveillance Audit/evaluation of high risk programme under consideration by Cancer Genetics Sub-Group (Scottish Cancer Group)
Research Implications		
Prompt, high quality investigations	 As above What is the cost-effectiveness of endoscopy undertaken by nurses? – a multi-institution nurse endoscopy trial (MINUET), Professor J G Williams, Centre for Postgraduate Studies, (End date: 31/10/2004) 	Report awaited
Population screening and Surveillance of High Risk Groups Research into improving the sensitivity and specificity of the test Research into improving uptake while providing informed choice Research into the identification of high risk groups	 Trials of flexible sigmoidoscopy Immunological test research See section on prevention 	Report awaited Findings awaited

03. RAPID ACCESS TO DIAGNOSIS AND TREATMENT

"To increase the probability of treatment success while at the same time minimising patient anxiety and stress, delays in investigation, diagnosis and subsequent treatment of cancer must be eliminated wherever possible." *Cancer in Scotland: Action for Change* (2001).

Feedback from patients has frequently confirmed that waiting for appointments to be seen at out patient clinics, waiting for appointments for investigations, waiting for results and waiting for treatment adds considerably to their anxiety and stress. Moreover, speed of access is considered to be one of the main reasons for dissatisfaction with the NHS. The Scottish Executive is therefore committed to a programme of national targets that are designed to alleviate patient and public concerns and to improve diagnosis and treatment services by driving down waiting times for everyone with cancer. Every part of the patient pathway, from referral, through investigation, diagnosis and subsequent treatment requires to be carefully examined and appropriate changes made to secure real and lasting improvements.

In planning to meet the target that, "By 2005, the maximum wait from urgent referral to treatment for all cancers will be two months", NHS Boards also need to take into account the possible impact of the introduction of a national bowel screening programme. Local Health Plans are a public statement of each Board's plans for their local health services. National waiting times targets are monitored and for the 2005 target systems are currently being put in place to assess performance against it.

In the three years since publication of *Cancer in Scotland*, £18m additional investment has brought significant reductions in waiting times across the country. However, to assist further an additional £1m, over and above that, has been invested in the Cancer Service Improvement Programme (CSIP) that aims to accelerate the pace of change and bring further improvements to existing systems and processes across the three regional cancer networks.

In both the West of Scotland and the North of Scotland CSIP facilitators are working with bowel cancer networks to look at further sustainable improvements that can be made across their respective regions. It is anticipated that services will be reorganised and/or altered in a variety of ways that will enhance patients' experiences and further reduce waiting times. A redesign programme is also underway in West Lothian.

As noted elsewhere in this framework, the provision of endoscopy/colonoscopy services and workforce shortages represent significant challenges both for symptomatic and for potential screening services. Waiting times for colonoscopy are variable across Scotland. Innovative approaches to the delivery of these services are required if the range and type of services required are to be delivered for patients and for the well population eligible for screening.

The Centre for Change and Innovation is planning to hold a national convention in September to facilitate clarification of, and consensus on, the immediate, medium- and longer-term priorities including options for increasing capacity and training provision within NHSScotland.

So as to avoid unnecessary duplication of effort and to ensure a collaborative approach, these are issues that need to be considered at three levels; locally, regionally and nationally involving clinicians, workforce planning and NHS Education for Scotland colleagues.

RAPID ACCESS TO DIAGNOSIS AND TREATMENT

What is required?	What is already happening?	Next steps
Service Implications		
Prompt, high quality investigations Development of investigation protocols based on symptom complexes Provision of adequate endoscopy services across the country with appropriate investment in training, staff and equipment Provision of structured endoscopy training Provision of structured endoscopy training Provision of structured endoscopy training Family and equipment in training services through redesign	Endoscopy services • Almost E4m from Cancer in Scotland over 2001-04 has been invested in endoscopy equipment, staffing and additional sessions, for example: • Outreach diagnostic service in Grampian • Increase capacity and improve services in Argyll and Clyde to support West of Scotland Bowel Cancer Awareness Campaign • Colonoscopy equipment and additional sessions in Lothian • Establishment of a bowel unit in Fire (NOF funded) • Forth Valley – training for radiographer-led ultrasound and barium enema examinations (NOF funded) • Forth Valley – training for radiographer-led ultrasound and barium enema examinations (NOF funded) • North Glasgow – endoscopy staffing, training and equipment (NOF funded) • North Glasgow – endoscopy suite, facilitate supervision and training of new endoscopists and extend role of nurse colonoscopy (NOF funded) • South Glasgow – endoscopy suite, facilitate supervision and training of new endoscopists and extend role of nurse colonoscopy (NOF funded) • South Glasgow – endoscopy suite, facilitate supervision and training of new endoscopists and extend role of nurse colonoscopy (NOF funded) • South Glasgow – endoscopy suite, facilitate supervision and training of new endoscopists and extend role of nurse colonoscopy (NOF funded) • South Glasgow – endoscopy suite, facilitate supervision and training of new endoscopists and the theoretical part of the course with clinical practice being supervised in their workplace • Provision of training • There is a training course in England for nurses for endoscopy/Colonoscopy training covering the theoretical part of the course with clinical practice being supervised a Colonoscopy Training Report which includes proposals as to how such training might be carried out Redesign • West of Scotland and North of Scotland Cancer Service Improvement Programme (CSIP) facilitators supporting staff to implement guidelines and make changes which will result in as much as 2 weeks' reduction in waiting times across the patient journey	 Scottish Executive, NHS Boards, Regional Planning Groups and Regional Cancer Advisory Groups to consider what further action may be necessary to support symptomatic and screening services for the future Access to, and availability of, endoscopy/colonoscopy services represent considerable challenges and will be a significant feature of such consideration Collaboration with local, regional and national workforce planning and NHS Education for Scotland (NES) The Centre for Change and Innovation are planning to hold a national convention in September to facilitate clarification of and consensus on the immediate, medium- and longer-term priorities including options for increasing capacity and training provision within NHSScotland

What is required?	What is already happening?	Next steps
Service Implications		
	Robust Support Services, e.g. Radiology and Pathology • A meeting has been organised jointly by the SEHD. Royal College of Radiologists. Scottish Radiological Society and the Society of Radiogaphers the role of radiology in the patient pathway and review experiences across Scotland. This will include an interactive workshop on understanding and using capacity and demand theory in radiology or SEIP has identified areas for improvement in radiology and pathology in some areas, e.g. reducing time for pathology reports. Introduction of declared weekly, CT stols • Workforce development arrangements being put in place at national, regional and local level • 24 additional radiology and 16 additional pathology training posts have been established between 2001 and 2003 • Investment in 2004 to support PathAlba, the Scottish pathology telemedicine network that allows microscopic images of pathological samples to be examined by colleagues in other parts of the country	Cancer in Scotland investment to pump prime a managed clinical network for pathology initially in North East Scotland – the aim is to extend the network across Scotland to facilitate, among other things, enhanced sharing of expertise and role redesign

04. IMPROVING CANCER TREATMENT AND CARE

Cancer in Scotland (2001) reaffirmed patients' right to access clinically effective treatment, delivered safely and with minimum disruption to their lives and that to achieve this effective multi-professional and multi-disciplinary team working was essential.

The three regional cancer groups have made much progress over the last three years. Multi-disciplinary team working and tumour specific cancer networks are in place for most cancers and in most geographical areas. This is true for bowel cancer, with all regions having recognised groups of clinicians working together across institutional and geographical boundaries, in line with the accepted definition of a managed clinical network (NHS HDL (2002) 69).

All three networks audit their services and outcomes in accordance with the requirements of NHS Quality Improvement Scotland (NHS QIS) (previously Clinical Standards Board for Scotland (CSBS)) bowel cancer standards. This emphasis on improving quality is recognised throughout the world as having the potential to improve outcomes for patients, as well as bringing improvements in services.

As part and parcel of the continuous quality improvement cycle that is the founding principle of managed clinical networks, it is the role of Scottish bowel cancer networks to ensure that patients have access to the best possible diagnostic and treatment services with consistency of approach in the management of bowel cancer, including evidence-based aftercare and rehabilitation.

NHS QIS has developed a Quality Assurance/Accreditation Framework for cancer services. Each of the three regional networks are planning for NHS QIS accreditation during the summer of 2004. This QA/Accreditation process will further define the improvements expected by each of the bowel cancer networks.

For any cancer service a highly trained and effective surgical workforce is essential. It is known that the quality of surgery in Scotland is already high. However, there is always room for further improvement and Royal Colleges, along with NHS Education for Scotland and workforce planning and development colleagues may wish to consider whether there is a need to plan for a programme of training in highly specialised surgical techniques unique to bowel cancer, for example meso-rectal excision.

Currently, arrangements are being put in place in England to support such a programme. Laparoscopic surgery is also a highly specialised field (although not unique to bowel cancer). Training in bowel surgery is already available in several units across Scotland. However, to ensure that training programmes continue to support surgical services as they grow and develop, the Surgical Royal Colleges have been debating changes to surgical training which would probably mean strengthening of specialist training in colorectal surgery. This has also been discussed at the Joint Committee on Higher Surgical Training and the Senate of Surgery for Great Britain and Ireland and will be discussed further at a meeting to be held in the spring. Although the outcome is awaited, there are a number of Scottish surgical units that are well placed to support any new models of advanced bowel surgical training that may subsequently emerge.

Capacity and demand modelling will help inform need for HDU beds and other specialised care that is essential for patients undergoing bowel surgery.

Planning for radiotherapy provision for the longer term is currently being reviewed by a dedicated working group set up by the Scottish Executive Health Department. It is anticipated that this work will take approximately one year.

As far as chemotherapy provision is concerned, following the recommendations of the Scottish Medicines Consortium (SMC) and National Institute for Clinical Excellence/NHS QIS guidance it is a matter for Regional Cancer Advisory Groups, regional planning groups and their constituent NHS Boards to plan appropriately for the introduction of new drugs.

NHS Boards must ensure that drugs or treatments recommended by SMC are made available to meet clinical need within three months of the publication of that advice or within the timeframe specified within any national implementation plan for that drug or treatment.

This advice does not override or replace the individual responsibility of health professionals to make appropriate decisions in the circumstances of their individual patients, in consultation with the patient and/or guardian or carer.

Where the SMC consider that a drug is unique and innovative NHS Boards must make provision for this drug to be made available also according to clinical need. This is in line with HDL (2003) 60.

IMPROVING CANCER TREATMENT AND CARE

Basic Elements

- Good technique and appropriate patient selection
- Short waiting times for surgery
- Functional multi-disciplinary teams (MDTs)
- High quality radiotherapy
- High quality chemotherapy
- Short waiting times for treatment

What is required?	What is already happening?	Next steps
Service Implications - Surgery	Surgery	
Good technique and appropriate patient	Waiting times Work ongoing to enable reporting of performance against the 2005 target	 Workforce planning and development implications

selection

- Appropriately trained and accredited
- programme increasing accreditation Training and surgeons
 - Waiting times for surgery in line with 2005 target laparoscopic surgery and NHS QIS (CSBS) may be required emphasis on standards
- Sufficient numbers of trained surgeons
- Sufficient numbers of ward and HDU beds
- process from diagnosis to surgery Eliminate delays in

- CSIP facilitators in North and West of Scotland working with networks to implement changes resulting in a reduction in the number of steps in the process

Nationwide surgical audit

Scottish Audit of Surgical Mortality (SASM)

Waiting times

discussing possible changes

to surgical training

Surgical Royal Colleges

assessment

OIS (CSBS) standards and performance against NHS national target for 2005 Assessment of MCN

- Sufficient staffed theatre

What is required?	What is already happening?	Next steps
Research Implications -	- Surgery	
Good technique and appropriate patient selection		Research into defining technique that is associated with good outcomes – this includes operative technique and post-operative care Continued trials of laparoscopic surgery
Service Implications - N	MDT	
Audit of MDT activity	Audit of bowel cancer ongoing in all three bowel cancer networks. Audit data published in West and South East Scotland annual reports	First national report across three regional networks published April 2004
Service Implications - C	Oncology	
High quality radiotherapy Appropriately trained Clinical Oncologists Appropriate access to radiotherapy Sufficient numbers of LinAcs High quality chemotherapy Appropriately trained Clinical/Medical Oncologists Appropriate use of effective drugs – requires urgent reassessment of NICE/NHS OIS guidance Short waiting times for treatment	SIGN/Royal College of Radiologists guidelines Chemotherapy SIGN/Joint Council for Clinical Oncology (JCCO) guidelines and Scottish Executive Guidance Maiting times Assessment of MCN performance against NHS QIS (CSBS) standards Work ongoing with ISD to support routine reporting of performance against the 2005 target	Radiotherapy Scottish Executive supporting ongoing Radiotherapy Equipment modernisation programme that has seen more than £33m committed since 1997 with state of the art linear accelerators now in place in all five Scottish Cancer Centres Scottish Executive Radiotherapy Activity Planning Project underway for period to 2010-14, that includes workforce and capacity planning and modelling Chemotherapy Updating HDL (2002) 22 on the safe administration of intrathecal cytotoxic chemotherapy

	Role of the developing Scottish Cancer Research Network in building portfolio of trials and doubling patient participation in trials National Translational Research Centres (NTRAC) established in Scotland (one Dundee/Glasgow virtual centre and one in Edinburgh) Co-ordination of SCRN/NTRAC activities	
- Oncology	Establishment of Scottish Cancer Research Network (NCRN) and National Cancer Research Institute (NCR) Inks with National Cancer Research Network (NCRN) and National Cancer Research Institute (NCR) The NCRN Process See section on prevention	
Sufficient staffing, for example Clinical and Medical Oncologists, Pharmacists, Therapy Radiographers, Cancer Nurses and Radiation Physicists Research Implications -	High quality radiotherapy Research into appropriate use of radiotherapy – clinical trials of adjuvant and palliative radiotherapy Research into individualising treatment on the basis of tumour/ patient parameters High quality chemotherapy Research into the appropriate use of chemotherapy – clinical trials of adjuvant and palliative chemotherapy Development of new chemotherapy Development of new chemotherapies Research into individualising treatment on the basis of tumour/patient parameters	

PALLIATIVE CARE

It is recognised that palliative care is an integral part of all clinical practice that takes as its starting point the quality rather than the quantity of life remaining. Palliative care needs can arise at any stage of a patient's care, and embrace psychosocial, emotional and spiritual issues surrounding life-threatening illness as well as the management of pain and other distressing symptoms.

Everyone, patients and carers, should be aware of services from which they might benefit. Clinicians across the spectrum of patient care should be alert to the needs of patients (and their carers) for appropriate support over and above immediate clinically required treatment.

The report on the NHS QIS (CSBS) assessment of bowel cancer services was published in 2002. This clearly sets out the NHSScotland performance against core palliative care standards generic to all cancer services.

Here again, significant improvements have been made over the last three years. In addition NHS QIS has recently published its report on the assessment of specialist palliative care services in Scotland (January 2004). This has demonstrated the commitment, dedication and hard work of the staff involved in providing specialist palliative care services. It also clearly demonstrated that these services seek, wherever, possible, to be responsive to patient needs and that a number of innovative service developments were evident. The importance was emphasised of taking into account needs for specialist palliative care when planning services.

A "mapping exercise" of palliative care provision is currently being undertaken by the Scottish Partnership for Palliative Care.

PALLIATIVE CARE

Basic Elements

- Good communication between palliative care and hospital service
- High quality hospice care
- Good home support

What is required? What is already happening? Next steps Service implications Good communication between pallative care and toxolidate services in 2001-04. for example: The and toxolidate services and toxolidate services and toxolidate services and toxolidate services. The and toxolidate services and toxolidates services and toxolidates services and toxolidates services. The service services in 2001-04. for example: The services in the process of undertaking a needs assessment and toxolidates services by the scontain the MDIS which services in the process of undertaking a needs assessment and example of pallative care ether undertaken or are in the process of undertaking a needs assessment and one pallative care are in the community (NOF funded). A mapping exercise' of pallative Care and the undertaken or are in the process of undertaking a needs assessment and example accord bronze care with a pallative care are in the community (NOF funded). A mapping exercise' of pallative care are and individuals requiring a needs assessment and example accord bronze care with a pallative care are in the community (NOF funded). A mapping exercise of a mapping exercise and a mapping and a mappin	eood nome support		
Over £5m from Cancer in Scotland invested in palliative care services in 2001-04, for example: - Training of nurses in primary care in Highland to become palliative care key workers - Additional Consultant in Palliative Medicine in Fife - Primary care crisis response team in Ayrshire & Arran • Most Boards have either undertaken or are in the process of undertaking a needs assessment • Development of palliative care networks • Gold Standards Framework in Scotland - to improve the care of individuals requiring palliative-cancer care in the community NOF funded) • Review of NHS QIS specialist palliative care standards in 2003 – report published January 2004	What is required?	What is already happening?	Next steps
• Over £5m from Cancer in Scotland invested in palliative care services in 2001-04, for example: - Training of nurses in primary care in Highland to become palliative care key workers - Additional Consultant in Palliative Medicine in Fife - Primary care crisis response team in Ayrshire & Arran • Most Boards have either undertaken or are in the process of undertaking a needs assessment • Development of palliative care networks • Gold Standards Framework in Scotland – to improve the care of individuals requiring palliative/cancer care in the community (NOF funded) • Review of NHS QIS specialist palliative care standards in 2003 – report published January 2004	Service Implications		
	Good communication between palliative care and hospital service • Efficient networking through the MDTs High quality hospice care • Appropriate access to good hospice care with adequate staffing Good home support Palliative care nursing support	Over £5m from Cancer in Scotland invested in palliative care services in 2001-04, for example: - Training of nurses in primary care in Highland to become palliative care key workers - Additional Consultant in Palliative Medicine in Fife - Primary care crisis response team in Ayrshire & Arran • Most Boards have either undertaken or are in the process of undertaking a needs assessment • Development of palliative care networks • Gold Standards Framework in Scotland – to improve the care of individuals requiring palliative/cancer care in the community (NOF funded) • Review of NHS QIS specialist palliative care standards in 2003 – report published January 2004	A "mapping exercise" of palliative care provision is being undertaken by the Scottish Partnership for Palliative Care

CONTINUOUS QUALITY IMPROVEMENT

Continuous quality improvement is essential for the delivery of the best quality of treatment and care possible and is the *raison d'être* of NHS QIS. Regional cancer networks have a responsibility for ensuring continuous quality improvement is at the heart of their day-to-day working as set out in NHS HDL (2002) 69 and NHS HDL (2001) 71. To be able to assess services against evidence based clinical standards and guidelines, all services should have in place robust arrangements for clinical audit, including data collection and analysis and agreed reporting arrangements to NHS Boards/operating divisions. All cancer networks are required to publish annual reports of their activities and performance (NHS HDL (2001) 71) and *Cancer in Scotland: Action for Change* confirmed that "prospective audit is the platform on which monitoring will be based and is the key for local (MCN) continuous assessment".

The Scottish Executive, RCAGs and NHS QIS are working together to establish a Quality Assurance/Accreditation Framework for cancer services.

Each of the three regional cancer network organisations will seek accreditation during the summer of 2004.

Cancer in Scotland recognised the pressing need to harness the power of information technology and provide better information to patients and to improve communication between clinician and patients. To take this forward a National Cancer IM&T Plan was published in December 2002 whose basic foundation was to exploit ECCI and SCI to support the patient journey. Since then the Cancer eHealth Sub-Group has been piloting the plan in four areas across Scotland and in February 2004 hosted a national workshop to review outcomes from the pilot, share examples of good practice and to reach consensus on a way forward.

Scotland's Health White Paper *Partnership for Care* further recognised the urgent need for an eHealth culture driven by clinical leaders and set the goal to deliver an integrated care record. To drive this forward the eHealth Programme Board was established under the chairmanship of the Minister for Health and Community Care and has produced a National eHealth Strategy.

In line with the National eHealth Strategy move forward with a national procurement of a generic patient pathway system using cancer as a demonstration project.

Cancer in Scotland recognised that there is significant evidence that outcomes are improved for those patients treated in environments where research is the norm or for those patients who are involved in cancer trials. Throughout this framework research implications are noted but we need to bear in mind that as of 1 May 2004, cancer research involving a clinical intervention with medicinal products will require to be carried out under the EU Clinical Trials Directive. While the Directive aims to protect the rights, safety and well-being of those participating in clinical trials, it is appreciated that the organisation and management of cancer clinical trials will be more challenging, particularly in the transitional phase.

CONTINUOUS QUALITY IMPROVEMENT

Basic Elements

- Uniform, comprehensive, independent data collection based on agreed minimum core dataset and definitions
- National comparative data reporting
- NHS QIS Framework for Quality Assurance/Accreditation of cancer networks

Next steps			First national comparative report April 2004	NHS QIS Accreditation for regional cancer networks summer 2004	
What is already happening?		National (SIGN) Dataset agreed, with definitions published by ISD	Data collection Information from three regional networks collated by ISD for pilot report on waiting times nationwide as platform for routine reporting against 2005 target		
 What is required?	Service Implications	Uniform, comprehensive, data collection	National comparative data reporting Collection of uniform	minimum data set, linked with cancer registration	

POLICIES AND DOCUMENTS

A Partnership for a Better Scotland: Partnership Agreement (2003)

A Breath of Fresh Air for Scotland Improving Scotland's Health: The Challenge Tobacco Control Action Plan Scottish Executive (2004)

Cancer Scenarios: an aid to planning cancer services in Scotland in the next decade ISD, NHSScotland, Edinburgh (May 2001)

Cancer in Scotland: Action for Change Scottish Executive (2001)

Cancer in Scotland: Action for Change: Regional Cancer Advisory Groups (RCAGs) NHS HDL (2001) 71, September

Eating for Health: A Diet Action Plan for Scotland Scottish Office (1996).

Improving Scotland's Health: The Challenge Scottish Executive (2003)

Let's Make Scotland More Active: A Strategy for Physical Activity Scottish Executive (2003)

National Overview: Colorectal Cancer Services NHS Quality Improvement Scotland (2002)

Reducing Smoking and Tobacco Related Harm: A Key to Transforming Scotland's Health NHS Health Scotland/ASH Scotland (2003)

Specialist Palliative Care - National Overview NHS Quality Improvement Scotland (January 2004)

Our National Health: A Plan for Action, A Plan for Change Scottish Executive (2000)

Promoting the development of managed clinical networks in NHSScotland NHS HDL (2002) 69, September

Scottish Health Statistics 2004 - ISD, NHSScotland, Edinburgh

Management of Colorectal Cancer Scottish Intercollegiate Guidelines Network (2003)

Scottish Referral Guidelines for Suspected Cancer HDL (2002) 45, May

Smoking Kills - A White Paper on Tobacco HMSO (1998)

Smoking, drinking and drug use among young people in Scotland in 2000: Scottish Executive

The NHS and Labour's battle for public opinion. British Social Attitudes 18th Report, Sage, London – Mulligan J, Appleby J (2001)

Towards a Healthier Scotland Scottish Executive (1999)

Plan for Action on Alcohol Problems Scottish Executive (2002)

The Nicholson Committee: Review of Liquor Licensing Law in Scotland Scotlish Executive (2003)

Useful web addresses

Cancer in Scotland: www.cancerinscotland.scot.nhs.uk

Information and Statistics Division: www.isdscotland.org/cancer

Scottish Executive Health Department: www.scotland.gov.uk

Scottish Health on the Web www.show.scot.nhs.uk

The Scottish Executive Health Department is not responsible for the undernoted sites and cannot guarantee the accuracy or currency of any of the material you may find there.

Bowel Cancer Awareness Project (BCAP) NHS Lanarkshire and Forth Valley - www.show.scot.nhs.uk/bcap

Colon Cancer Concern www.coloncancer.org.uk

West of Scotland Cancer Awareness Project - www.woscap.co.uk

South East of Scotland Cancer Network (SCAN) Cancer Information Network – www.scanweb.hw.ac.uk/cgi-bin/WebObjects/SCANweb

West of Scotland Managed Clinical Networks - www.show.scot.nhs.uk/woscan/Default.htm

Lanarkshire Cancer Information Service – www.lcis.org.uk/

National Institute for Clinical Excellence – www.nice.org.uk/

NHS Quality Improvement Scotland – www.nhshealthquality.org/

Scottish Medicines Consortium – www.scottishmedicines.org.uk/

If you want to comment on any of the issues in *Cancer in Scotland: Action for Change* or make suggestions about how these can be taken forward, you can contact a member of the Cancer Team at:

Scottish Executive Health Department St Andrew's House Regent Road Edinburgh EH1 3DG

e-mail: cancer@scotland.gsi.gov.uk

Useful web addresses:

Cancer in Scotland:

www.cancerinscotland.scot.nhs.uk

Scottish Executive Health Department:

www.scotland.gov.uk

Scottish Health on the Web:

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