

Cancer Reform Strategy

Maintaining momentum, building
for the future – first annual report

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Letter from Professor Mike Richards, National Cancer Director

Dear Secretary of State

CANCER REFORM STRATEGY – MAINTAINING MOMENTUM, BUILDING FOR THE FUTURE

The Cancer Reform Strategy (CRS) committed the National Clinical Director to deliver annual reports on progress to Ministers. I am very pleased to submit the first such report.

The Strategy also said that an advisory board of stakeholders would be convened to provide input to each annual report. I would like to thank all the members of the CRS Advisory Board who have very helpfully contributed to this annual report.

I would also like to take the opportunity to thank the wide range of stakeholders who have worked with us over the past year on implementation of the Strategy. We cannot implement the Strategy without their help and support and we hope that they will continue to work with us in the year ahead.

In this report, I have quite systematically gone through the CRS to report on: where progress has been made, our priorities for the future, and any developments over the past year which need to shape future implementation of the CRS. In this covering letter, I would like to highlight some of the most important issues within these categories.

First, I will draw attention to the further considerable progress with reducing cancer mortality. The latest data (the average for 2005-07) indicates that the England cancer mortality rate has fallen by 18% since 1995-97 and the

inequalities gap has narrowed by 13%. This means that nearly 9000 lives will have been saved in the under 75s in 2007 compared with the 1996 baseline.

In terms of moving forward this year with implementing the CRS, highlights have been:

- the introduction of the HPV vaccine, which protects against two strains of HPV that cause over 70% of cervical cancer cases
- the successful further rollout of bowel cancer screening – so far, nearly 2000 cancers have been detected
- the launch of the National Awareness and Early Detection Initiative – late diagnosis has been a major factor in poor cancer survival rates, and this initiative should begin to tackle this problem
- the launch of the National Cancer Survivorship Initiative – we know that there are now about 1.6 million cancer survivors in England, and this initiative aims to ensure that they receive the integrated, quality services that they need
- the establishment of the National Cancer Intelligence Network – better information on cancer services and outcomes will drive up quality and underpin stronger commissioning
- the launch of the Cancer Commissioning Toolkit, which provides the information that commissioners need to commission effectively for their populations.

Following discussion with the CRS Advisory Board, I would identify the following as particular priorities for us for the year ahead:

- ensuring that primary care is fully engaged – in particular in the challenge of ensuring early diagnosis
- tackling the issues raised by the National Confidential Enquiry Patient Outcome and Death (NCEPOD) report on systemic anti-cancer therapy
- ensuring that radiotherapy capacity is being developed in line with the requirements of the 2010 waiting time standard
- using implementation of the Improving Outcomes Guidance and peer review as levers to improve quality
- making sure that patients have the information that they need – building on existing good work on patient information pathways and linking with NHS Choices
- putting patient experience at the heart of our measurement of quality of services, particularly by moving forward on the patient experience survey programme
- continuing the very impressive work that is under way in transforming inpatient care, which will avoid unnecessary emergency admissions and reduce length of stay
- moving forward on a range of training issues, for example, the more widespread use of laparoscopic surgery for colorectal cancer
- local implementation.

There have been many developments since the CRS which are relevant to the development of cancer services, but here I will highlight three:

- *High Quality Care For All*, the final report of the Next Stage Review (NSR), in June 2008 – the emphasis on quality should provide an important boost for delivering the CRS objectives and there are many important individual elements, for example the

emphasis on comprehensive wellbeing and prevention services, promoting personalised care plans for those with long-term conditions and empowering patients. But there needs to be effective coordination at local level between the work on the NSR and the work on implementation of the CRS

- the publication of the *End of Life Care Strategy*, in July 2008 – this tackles improving quality of care for people approaching the end of their lives, and we are working closely with those implementing the Strategy to ensure consistency of approach
- my report, in November, on improving access to medicines for NHS patients.

Of course we would all like to have seen more and faster progress on implementation of the CRS, but I am satisfied that considerable and significant progress has been made, and that we are well positioned for further progress next year.

The National Cancer Team – which supports the implementation of the CRS – consists of a number of different organisations, including the Department of Health, the National Cancer Action Team, NHS Improvement, NHS Cancer Screening Programmes, the National Cancer Intelligence Team and the National Cancer Service Analysis Team. I would like to record my thanks for their work over the past year and I look forward to working with them – and colleagues throughout the NHS, social care and the private and voluntary sectors – over the year ahead.



Prof Mike Richards CBE

Chapter 1: The challenge of cancer

Introduction

1.1 This progress report generally uses the same headings as were used in the Cancer Reform Strategy (CRS), in order to report systematically on progress over the past year. This chapter, however, simply presents some new figures around incidence, mortality, prevalence and survival after one year – which demonstrate that improvements continue to be made in outcomes, but the challenge in terms of rising demand for services and resources also continues.

Incidence

1.2 The incidence of cancer continues to rise due to the ageing population. Cancer incidence figures for 2006 were published in October 2008 and they showed:

- there were 242,200 new cases of malignant cancer (excluding non-melanoma skin cancer) registered in England in 2006 – 121,600 new male cases/120,600 new female cases

– compared to around 239,000 in 2005 and 223,500 in 2000

- the age-standardised cancer incidence rate increased by less than 1% for both males and for females between 2005 and 2006
- the four most common cancers – breast, lung, colorectal and prostate – accounted for over half of all new cases
- breast cancer accounted for one in three newly diagnosed cases of cancer among women
- prostate cancer accounted for one in four newly diagnosed cases of cancer among men.

1.3 The incidence figures since 2000 are set out below. Incidence is predicted to increase by around a third between 2001 and 2020, and hence the importance of services planning to meet this extra demand.

Cancer Incidence in England

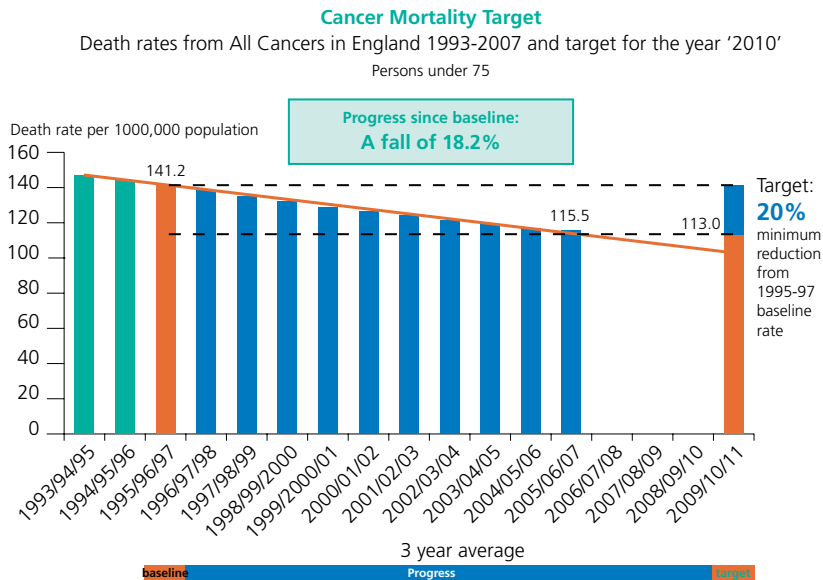
Year	Number of new cancer cases	Males	Female
2006	242,200	121,600	120,600
2005	239,000	119,600	119,400
2004	233,600	117,800	115,800
2003	227,400	112,700	114,700
2002	223,800	112,600	111,200
2001	224,600	112,500	112,100
2000	223,500	111,500	112,000

Source: ONS Cancer Registration Statistics for England
Figures have been rounded up to the nearest hundred

Mortality

1.4 As the table below shows, cancer mortality continues to fall. The latest figures, which were published in October 2008, showed that the three-year average mortality rates for

cancer (ages under 75) for England have fallen by 18.2% since the baseline. We are on course to meet our target of a reduction of at least 20% in cancer death rates in people under 75 by 2010.



Rates are calculated using the European Standard Population to take account of differences in age structure. ICD9 data for 1993 to 1998 and 2000 have been adjusted to be comparable with ICD10 data for 1999 and 2001 onwards. Source: ONS (ICD0 140-209; ICD10 C00-C97)

Prevalence

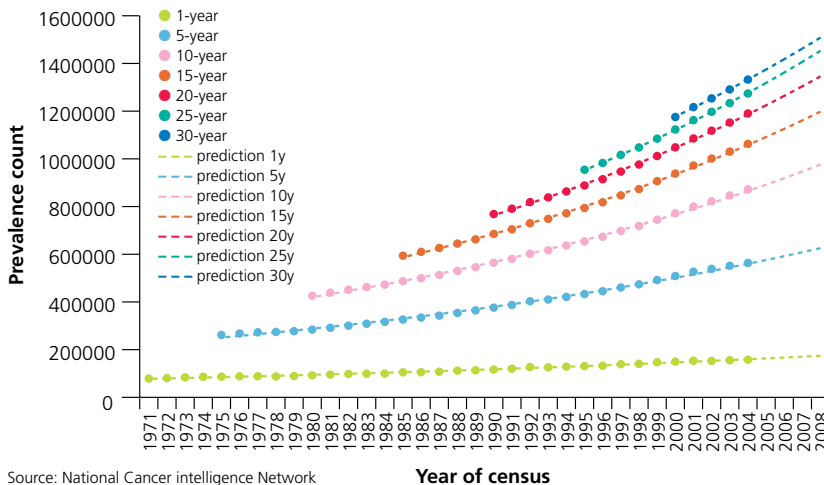
1.5 Cancer prevalence refers to the number of people who have previously received a diagnosis of cancer and who are still alive at a given point in time.

1.6 Information about prevalence was published for the first time in July 2008.

This shows that there are about 1.6 million cancer survivors in England; 10% of people aged 65+ are cancer survivors; and the number of cancer survivors is increasing by 3.2% each year. Detailed information is available on the National Cancer Intelligence Network (NCIN) website (www.ncin.org.uk), but the table below sets out how prevalence is changing over time.

Trends in prevalence of all malignant neoplasms (ICD-10 C009-C97 excl. C44)

England, 1971-2004 (with predictions to 2008)



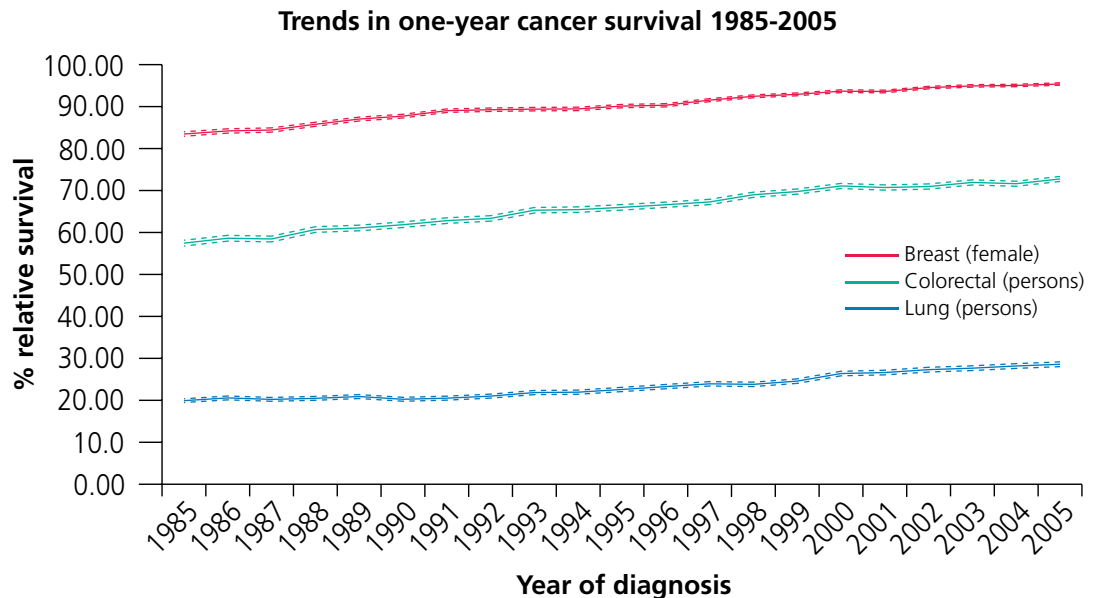
Source: National Cancer intelligence Network

One-year survival

1.7 Recently published data on one-year survival shows that there is a consistent improvement in one-year survival over the 20 years up to 2004. For 15 of the 22 site groups, the improvement was statistically significant and was seen for types of cancer with underlying poor (eg pancreatic increasing from 12.3 to 15.8%), intermediate (eg colorectal increasing from 63.1 to 71.9%) and good (female breast increasing from 88.9 to 95%) one-year prognoses. Of the eight remaining cancer site groups, three (lung, testis and leukaemia) do show clear but modest improvements in survival that are not statistically significant. Three cancer

site groups (cervix, the combined group of "eye, brain and central nervous system" and Hodgkin's disease) show no change in survival. In the coming year, attention will need to be given to those cancer sites for which there has been no or limited improvement.

1.8 The figure below shows trends in one-year survival rates for three common cancers between 1985 and 2005. For each cancer type (breast, colorectal and lung) there has been a steady increase in one-year survival. Further detailed analyses are available on the National Cancer Intelligence Network website (www.ncin.org.uk).



Dotted lines show 95% confidence intervals

Data source: National Cancer Information Service accessed November 2008

Chapter 2: Preventing cancer

Progress:

- January 2008 – launch of *Healthy Weight, Healthy Lives: A Cross-Government Strategy for England* – with funding of £372m
- May 2008 – consultation on the future of tobacco control
- Emphasis in Next Stage Review on prevention and promoting well-being
- Introduction of the HPV vaccine, which protects against two strains of HPV that cause over 70% of cases of cervical cancer
- Sunbed survey
- National awareness survey

Priorities for the coming year:

- New strategy for tobacco control
- More work at local level on prevention

Introduction

2.1 We know that over half of all cancers are potentially preventable, and the Cancer Reform Strategy (CRS) set out a range of actions to promote cancer prevention.

2.2 The past year has seen an increasing focus on prevention – both at national and local level. In this chapter we report on progress and the challenges ahead.

Tobacco and Cancer

2.3 Smoking remains the single largest preventable cause of death from cancer, accounting for around one third of all cancer deaths and up to 90% of lung cancer deaths. It is the primary reason for the gap in healthy life expectancy between rich and poor.

2.4 As a result of the government's focused action on tobacco, overall adult smoking prevalence has been reduced in England over the past decade from 28% in 1998 to 22% in 2006. The Department of Health (DH) is on target to reach the Public Service Agreement (PSA) objective of reducing adult smoking rates to 21% or less by 2010.

2.5 Smoke-free legislation, implemented since 1 July 2007, has been very effective and received widespread popular support. Independent research has shown that not only are bar workers protected from second-hand smoke, but around 400,000 additional smokers have taken the opportunity to stop smoking because of the smoke-free law.

2.6 In May of this year, the DH published the *Consultation on the Future of Tobacco Control*, which is the first step in developing a new national tobacco control strategy. It covered four main areas: reducing smoking rates and health inequalities caused by smoking; protecting children and young people from smoking; supporting smokers to quit; and helping those who cannot quit. About 96,000 comments have been received – and most of them were very supportive of further tobacco control measures. The DH plans to publish the new strategy in 2009: from the Cancer Programme’s perspective, we will be feeding into the development of that strategy in the hope that we can achieve further reductions in smoking, which will help reduce cancer deaths from smoking.

Obesity, diet and physical activity

2.7 Obesity has links with certain cancers, particularly endometrial, breast and colon. 10% of all cancer deaths among non-smokers are related to obesity (30% of endometrial). The CRS highlighted that the planned strategy to tackle obesity would be important in cancer prevention.

2.8 In January 2008, the government published *Healthy Weight, Healthy Lives: A Cross-Government Strategy for England*, with £372 million in funding. This laid out the government’s ambition to be the first major nation to reverse the rising tide of obesity and overweight in the population, by enabling everyone to achieve and maintain a healthy weight. The initial focus will be on children: by 2020, the government aims to reduce the proportion of overweight and obese children to 2000 levels.

2.9 The Strategy set out a framework for action in five main areas: promoting children’s health; promoting healthier food choices; building physical activity into our lives; supporting health at work and providing incentives more widely to promote health; and providing effective treatment and support when people become overweight or obese. It is still early days in terms of delivering outcomes, but this is a significant strand of work for reducing the risk of cancer. In November 2008, the government launched the Change4Life coalition.

It is a lifestyle revolution involving thousands of local organisations and charities which will help families eat well, move more and live longer. Under the banner Change4Life, the government is aiming to galvanise support from everyone in the country from grass roots organisations to leading supermarkets and charities.

2.10 Physical activity is associated with a reduction in overall risk of dying from cancer. For example, physical activity has a protective effect on colon cancer, with an average risk reduction of 40-50%. The DH is working across government to develop a new strategy for physical activity, which builds on the commitment for 2 million more active adults by 2012 contained in the 2012 Legacy Action Plan. The DH is also working on a Physical Activity Care Pathway to embed the promotion of activity in General Practice, through the identification of inactive patients and signposting individuals to community-based opportunities for physical activity.

Alcohol

2.11 Regular drinking above recommended daily limits (2-3 units for women, 3-4 units for men) increases the risk of a number of cancers, such as cancer of the mouth and throat, the digestive system, the liver and breast. Public understanding of these risks is low, when compared with awareness of harms such as liver cirrhosis.

2.12 In May 2008, the DH launched its Know Your Limits “Units” campaign, to help people understand how many units are in the alcohol they drink and the link between alcohol consumption and their health, including cancer risks. The government has an agreement with the alcohol industry that they will include health and unit information on all alcoholic drinks labels by the end of 2008. Interim monitoring of implementation has been disappointing and the government has just completed a public consultation (*Safe, Sensible, Social – consultation on further action*) asking whether the government should take the next steps to make it a legal requirement to include health and unit information on all bottles and cans. The consultation also asks what else could be done

and by whom to support people who find it difficult to cut down on their drinking.

2.13 A social marketing campaign, including direct-mail, is targeting heavier drinkers. Support is available through the Drinkcheck website, the Drinkline phone service and the NHS.

2.14 A new methodology has been applied to estimate the proportion of hospital admissions to which alcohol consumption contributes. This provides data for 48 conditions, including some seven varieties of malignant neoplasm, that are wholly or partly attributable to alcohol. Previous statistics did not attribute these cancer admissions to alcohol. This data underpins the Vital Signs Indicator (from April 2008) to measure change in the rate of hospital admissions for alcohol-related conditions – the first ever commitment to monitor how the NHS is tackling alcohol harm. This indicator is included in the Home Office PSA to reduce drug and alcohol harm and in the Communities and Local Government National Indicator List for local authorities and their partners.

2.15 The indicator is expected to encourage earlier identification of people who drink too much and to encourage the provision of advice and support for them from GPs or hospitals. This has been shown to be an effective way of reducing the levels of “everyday” drinking which over time leads to alcohol-related cancers and other problems. The indicator is also likely to promote the provision of accessible treatment for the heaviest drinkers who are at greatest risk of such harm in the long term.

2.16 The DH has commissioned an independent review of the relationship between alcohol price, promotion and harm, by the School of Health and Related Research at the University of Sheffield (SchARR). Phase 2 of this comprehensive review will map risk functions and model the relationship between alcohol consumption and various harms and conditions including cancers.

Excessive ultraviolet exposure

2.17 As the CRS noted, melanoma incidence is increasing rapidly and a commitment was made to increase funding for awareness programmes.

2.18 An additional £1m will be spent on skin cancer prevention this year. This funding is being allocated to both national and local work. At national level, there is continuing work through the Sunsmart campaign and a survey to understand better the use of sun beds by young people (see box 1). At local level, a number of Cancer Networks are running initiatives to understand and address the local reasons for the high rates of skin cancer (see box 2). Examples include outreach services to ensure high-risk communities have access to information and services – on the beach, through health buses, and in communities where there is high use of sun beds.

2.19 Priorities for the programmes in 2009 will be to:

- test how local Cancer Networks can work more effectively under the umbrella of the national Sunsmart Campaign
- ensure awareness-raising initiatives are firmly linked to other primary care services providing efficient pathways of care and treatment
- bring together good practice for other Cancer Networks and Primary Care Trusts (PCTs).

2.20 A key development in 2009 will be the publication of the National Institute for Health and Clinical Excellence (NICE) review of skin cancer prevention guidance.

Box 1: Use of sun beds by young people

A scoping study on the use of sun beds by young people has been completed. The sample size for the scoping study was small, and the results therefore need to be viewed with caution, but they were enough to prompt us to commission a larger survey to probe some of the results. This survey will report in 2009. The headline results from the scoping survey were:

- around a quarter of adults across Great Britain have used a sun bed (around 32% of women and 15% of men)
- around 6% of young people (11-17 year olds) have used a sun bed (around 9% of girls, 2% of boys)
- around 18% of young people said they had not yet used sun beds but would consider doing so in future
- around 16% of young sun bed users reported having used a sun bed in an unsupervised setting
- in the city populations examined, around 11% of 11-17 year olds had used sun beds
- variation in use was recorded across the six cities studied – in Liverpool, for example, around 22% of 11-17 year olds questioned had used a sun bed; another 15% had not used a sun bed but would consider doing so in future
- generally, the prevalence of sun bed use was significantly higher in 15-17 year olds compared to 11-14 year olds; in Liverpool around 39% of 15-17 year olds had used a sun bed compared to around 10% of 11-14 year olds.

Box 2: Tackling skin cancer

Merseyside and Cheshire Cancer Network launched their Cancer Early Detection and Prevention Strategy in January 2008. The Strategy focuses on 5 key themes: social marketing, staging, screening, healthy schools and symptom awareness.

The main progress on the project is as follows:

- all PCTs signed up to improve skin cancer prevention and to reduce mortality
- development of an e-learning healthy schools project on use of sun beds by young people – in collaboration with a range of interested stakeholders, including Cancer Research UK, local authorities, National Cancer Action Team, Health Protection Agency and Healthy Schools coordinators
- use of social marketing techniques to identify populations to target for skin cancer prevention messages
- working in partnership with Cancer Research UK to pilot a SunSmart campaign across Merseyside and Cheshire.
- developing a Health Bus initiative that targets areas of need within the Network: the project raises awareness of cancer symptoms and risks, with an emphasis on skin cancer prevention, to a variety of groups within the community and workplace.

Awareness of general risk factors

2.21 Researchers funded by Cancer Research UK have developed a tool to measure public awareness of the risk factors and symptoms of cancer (see also chapter 3). The awareness tool has been used to undertake the first national survey of awareness, and the tool will soon be available to Cancer Networks and PCTs wishing to survey their own populations, to obtain a more detailed local picture.

2.22 The data from the use of this tool will enable those planning interventions or

campaigns to raise awareness of risk factors to understand the level of public knowledge before an intervention and, when the survey is re-run after an intervention, to assess whether the intervention had the intended result.

2.23 An example of a local survey run by the Healthy Communities Collaborative, which helped inform testing of the awareness tool, was published on 29 August 2008 in the British Journal of General Practice – see box 3.

Box 3: Survey of patient awareness of risk factors

A survey was carried out in eight general practices in Northern England. Adult patients attending in December 2007 or January 2008 were asked to select six from twelve possible risk factors. As well as the six risk factors, six false ones were included. 1556 questionnaires were returned. The mean number of risk factors selected was 5.6.

Putative risk factor	Number marking this factor increases cancer (n=1,556)	Percentage marking this factor increases cancer
<i>Risk factors associated with cancer</i>		
Smoking	1,486	96
Exposure to sunlight	1,288	83
Being overweight	1,082	70
Excessive alcohol	1,054	68
Lack of fresh fruit/veg.	654	42
Not taking regular exercise	619	40
<i>Risk factor debatably associated with cancer</i>		
Exposure to traffic fumes	813	52
<i>Risk factor with little or no scientific support</i>		
Exposure to microwaves	554	36
Lack of iron in the blood	487	31
Lack of vitamin C	405	26
Eating spicy food	142	9
Drinking very hot drinks	105	7

Our results suggest publicity about smoking has worked. Similarly, excess sun exposure, excess alcohol use and being overweight are now generally recognised as risk factors. Less encouraging was the relatively low level of knowledge about diet and exercise. This suggests a new direction for cancer prevention campaigns. A significant proportion considered both traffic fumes and microwaves to be risk factors. Although scientific evidence does not support these, both have also had considerable media coverage.

Reference: Knowles, J, Hamilton W; Knowledge of risk factors in cancer. BJGP, 2008, 58, 650-651

2.24 *High Quality Care For All* said that: “every primary care trust will commission comprehensive wellbeing and prevention services, in partnership with local authorities, with the services offered personalised to meet the specific needs of their populations. Our efforts must be focused on six key goals: tackling obesity, reducing alcohol harm, treating drug addiction, reducing smoking rates, improving sexual health, and improving mental health.” Implementation of this will be an important part of the prevention agenda.

Vaccination and cancer

2.25 The Human Papillomavirus (HPV) vaccination programme, which protects against two strains of HPV that cause over 70% of cases of cervical cancer, commenced in September 2008 for girls aged 12-13. A major publicity campaign utilising TV/radio adverts, magazines and newspapers is currently underway.

2.26 The cost savings derived from choosing cervicalix over gardasil as the vaccine for the national programme enabled the implementation of a three year catch up programme. The catch-up programme commenced in September 2008 and will offer the vaccine to other older girls aged 13-18.

2.27 The CRS Advisory Board has brought to our attention the need to link a person’s HPV vaccination status with the cervical screening programme records. This is an issue that DH will be taking forward over the coming year.

Genetic predisposition and cancer

2.28 The CRS said that we wanted people who were concerned about their family history of cancer to have access to cancer genetic services with high quality risk assessment and counselling services and that, following evaluation of pilot sites, the DH would provide guidance to commissioners on how to commission these services.

2.29 A BMJ Learning Module has been developed. The module, entitled *Cancer and genetics: an up-to-date guide*, is designed to give GPs, practice nurses, hospital consultants, and doctors in training a basic understanding of

cancer and genetics. The module was launched in October 2008 – see box 4.

Box 4: Advice to clinicians on genetic predisposition

“I have worked as a GP and as a primary care geneticist based in a regional genetics department. As a GP I felt uncertain about how to deal with patients who were concerned about a family history of cancer. As a primary care geneticist I realised that generalists could develop the skills to deal with these patients.”

Fred Kavalier, author of BMJ Learning Module *Cancer and genetics: an up-to-date guide*

2.30 A “Community of Practice” has been established to learn and share best practice. This Community of Practice for Family Cancer History Services has been set up with Macmillan Cancer Support to share the learning from the pilots. Membership stands at around 40, comprising of clinicians from the pilot studies, service users, senior figures in the national cancer genetics field and DH and Macmillan colleagues. Actions for 2009 are:

- developing and sharing widely the professional and organisational knowledge gained from the Macmillan/DH pilots programme
- influencing and accelerating improvement in family cancer history services nationally, through connecting with local, regional and national professional and other networks, including NHS commissioning
- increasing the personal professional effectiveness of individual Community of Practice members as service practitioners.

2.31 A chapter on services for people with a genetic predisposition to cancer is being developed for inclusion in the Cancer Commissioning guidance which will be published shortly – see chapter 9. We are working with

experts in the field to develop the chapter, which will be available in early 2009.

Research in cancer prevention

2.32 Several important initiatives are underway to strengthen research in cancer prevention and build an evidence base to inform policy and support the implementation of effective interventions to reduce cancer risk and encourage behaviour change.

2.33 The CRS reported on the National Prevention Research Initiative (NPRI), a UK-wide initiative made up of government bodies, research councils and major medical charities that are working together to encourage and support research into chronic disease prevention, including cancer prevention. NPRI-funded studies are exploring a range of approaches to promoting positive health behaviour, to encourage people to avoid habits that increase their risk of cancer and to follow a healthy diet and physical activity programme.

2.34 The CRS also outlined plans by the major funders of public health research (under the auspices of the UK Clinical Research Collaboration – UKCRC) to fund a number of Public Health Research Centres of Excellence in the UK. Five successful Centres across the UK have been awarded funding:

- North East Centre of Excellence for Translational Research in Public Health, Newcastle University – directed by Professor M White
- Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement, Cardiff University (in collaboration with Swansea University and Bristol University) – directed by Professor L Moore
- UKCRC Public Health Research Centre of Excellence, Queens University Belfast – directed by Professor F Kee
- Diet and Physical Activity Public Health Research Centre, Cambridge, University of Cambridge – directed by Professor N Wareham
- The UK Centre for Tobacco Control Studies, University of Nottingham – directed by Professor J Britton.

Chapter 3: Diagnosing cancer earlier

Progress:

- Pilots developed to look at how to increase the uptake of cervical screening among younger women
- Guidance sent out on 14-day turnaround for cervical screening and pilots underway
- Further improvements in quality of testing for cervical cancer
- Nearly 2,000 bowel cancers detected by screening so far
- National Awareness and Early Diagnosis Initiative launched
- National survey of awareness of symptoms
- Ovarian cancer key messages launched
- Audit of diagnosis of cancer in primary care under way

Priorities for the coming year:

- Piloting of extension of breast cancer screening
- Digital mammography to be introduced nationally
- Further rollout of bowel cancer screening
- Revised informed choice packs to be launched for prostate cancer
- Further work to promote better awareness of symptoms
- Completion of first round of audit of diagnosis in primary care, and then further engagement with primary care to help achieve earlier diagnosis
- More local work on raising awareness of symptoms
- More work to improve GP access to diagnostics

Introduction

3.1 Evidence suggests that later diagnosis of cancer has been a major factor in the poorer survival rates in the UK compared with other countries in Europe. The Cancer Reform Strategy (CRS) set out a range of actions to promote earlier diagnosis of cancer, and this chapter reports on progress and on the plans for the future.

Improving cervical screening

3.2 The CRS set out a plan of action to increase uptake of screening, to minimise the time taken to get results back to women and to use new technologies.

3.3 To tackle problems around uptake of screening, six Primary Care Trusts (PCTs) have been selected to work with the NHS Cervical Screening Programme and the Improvement Foundation (IF) to develop and test initiatives which aim to improve the uptake of cervical screening in women aged 25-35 in these local communities. They are using social marketing techniques and, once the different possible initiatives have been evaluated, the results will be disseminated.

3.4 To incentivise services to encourage higher coverage, the decision has been taken to have a tariff for cervical screening (along with breast and bowel screening).

3.5 To help reduce the time taken to get results back to women, guidance to the NHS on achieving the 14-day turnaround time was issued in April 2008, in preparation for delivering the required turnaround by 2010. NHS Improvement is now working with ten areas on how best to streamline the pathway from initial test to getting the results. This is part of a three-year programme of work which will involve improvements across the whole of the cervical screening pathway to enable women to get their results sooner.

3.6 As the CRS reported, prior to the introduction of new technology (liquid based cytology – LBC), rates of inadequate samples were over 9% resulting in about 300,000 women a year being screened again. In October 2008, rollout of LBC across the country was completed. As LBC was rolled out, the rate of inadequate samples has fallen every year and is now at a record low of just under 3% or fewer than 100,000 women (last year's figure was 4.7%). This means that in 2007/08, 200,000 women did not have to have a repeat test because their original sample could not be read, with all the anxiety that entails.

3.7 In terms of making the best use of new technologies, we have now moved forward into the implementation phase of Human Papillomavirus (HPV) triage for women with borderline and low-grade abnormalities using HPV testing. Work has begun in six screening services. We will be able to deliver health

services targeted more appropriately, reducing the need for significant numbers of repeat tests.

Improving breast screening

3.8 The CRS set out plans to maintain and extend this country's excellent record on breast screening.

3.9 In terms of the age extension of breast screening to women aged 47-73 years, arrangements have been made with six breast screening centres to pilot the rollout. Activity will commence in these sites from January 2009. These areas will meet strict quality and performance criteria and will also act as a learning platform to enable remaining services to model their rollout plans.

3.10 The NHS is committed to conversion to direct digital mammography for use throughout the NHS Breast Screening Programme. This equipment is now available in a number of sites and a national framework agreement has been negotiated to enable easier acquisition of this equipment by the remaining services. Advice to the service on digital mammography and all the CRS breast screening initiatives will be issued shortly. The CRS Advisory Board has expressed its concern to ensure that the funding provided for digital mammography is used for that purpose, and the Board will be considering progress with its introduction in the Spring of 2009.

3.11 The following are being taken forward to improve surveillance of women identified as being at high risk:

- guidance on quality assurance for magnetic resonance imaging (MRI) is in development by the Royal College of Radiologists Breast Group and the NHS Breast Screening Programme Quality Assurance Radiologists Group: this will include good practice standards to be achieved and workload criteria
- a functional specification is being prepared for a new module on the National Breast Screening System in order to manage these women

- the detailed protocol to implement the National Institute for Health and Clinical Excellence (NICE) guidance on familial breast cancer is being refined.

Improving bowel screening

3.12 The CRS's main focus in this area was on the continuing rollout and extension of the bowel screening programme. Eventually, all men and women from age 60 to 75 will be invited for screening.

3.13 As at November 2008, 40 screening centres were operational. 107 PCTs (70%) have 100% rollout. Nearly 1.3 m kits had been returned, with nearly 2000 cancers detected. Over 7000 people have, as a result of screening, had polyps removed.

3.14 We have already begun the phased expansion of the bowel cancer screening programme to people aged 70-75, starting in six sites.

Screening for other cancers

3.15 As highlighted in the CRS, we are revising the informed choice packs for prostate cancer. In order fully to take on board the opinions and ideas of key stakeholders, the revision has been slightly delayed and the new Prostate Cancer Resource Management Programme pack will be launched early in 2009.

3.16 In terms of research into screening other cancers, major trials into prostate cancer screening are underway nationally and internationally, and are due to report in the next two to four years. The UK National Screening Committee, the body that keeps screening for prostate cancer closely under review, will be carefully monitoring the results of the trials. A major national trial of screening for ovarian cancer – the UK Collaborative Trial of Ovarian Cancer Screening – is due to report its main findings in 2012. The Department of Health (DH), through its National Institute for Health Research (NIHR) Health Technology Assessment Programme, has funded research on the feasibility of a UK trial of computed tomography (CT) screening for lung cancer.

Raising public awareness of cancer symptoms and encouraging people to seek help early

3.17 The CRS included a commitment to establish a National Awareness and Early Diagnosis Initiative (NAEDI), to coordinate a programme of activity to support local interventions to increase cancer symptom awareness and encourage earlier presentation. NAEDI is co-chaired by Harpal Kumar, Chief Executive of Cancer Research UK, and Mike Richards, the National Cancer Director, and was formally launched in November 2008.

3.18 There are currently seven work streams:

- review of evidence base on awareness and early diagnosis
- measuring awareness
- interventions to promote early presentations by patients
- interventions in primary care
- international benchmarking
- prospective research
- key messages.

3.19 As reported in the CRS, to support the initiative, researchers funded by Cancer Research UK have developed a generic and modular assessment tool to assess public levels of awareness of cancer symptoms (along with risk factors, see chapter 2). The DH has funded the Office for National Statistics to use the general tool to carry out the first national cancer symptom awareness survey – see box 5 for the first results. The survey will be repeated every two years, and the results published. This will enable change over time to be monitored and impact of interventions to be evaluated.

3.20 As explained in chapter 2, the plan is for the NHS locally to use the tool to assess risk and symptom awareness, as a benchmark for local work and in order to monitor improvements.

Box 5: Awareness of cancer symptoms – survey results

Professor Jane Wardle of UCL, in collaboration with Dr Joan Austoker, Professor Amanda Ramirez, Dr Una Macleod, Dr Kathryn Robb, Dr Jo Waller and Sarah Stubbings, has developed a validated measure of public awareness of cancer to be used for surveillance, examining gender, socioeconomic, ethnic and geographic inequalities, and evaluating the impact of interventions. The Cancer Awareness Measure (CAM) assesses knowledge of “warning signs” for cancer, anticipated time to seek medical advice, barriers to seeking medical advice, knowledge of risk factors, and awareness of cancer incidence and national cancer screening programmes.

Formal psychometric procedures were followed to create a validated measure. The existing literature was reviewed and expert advice sought to create an item pool, which was reduced through iterations of expert consultation and informal testing. Cognitive interviewing was used to check face validity, with subsequent modification to phrasing of some items. Reliability was assessed by repeating the measure on two occasions one week apart; and it was high. External validity was checked by demonstrating that test scores were significantly higher in cancer experts than equally-senior, non-medical academics. Sensitivity to change was demonstrated by showing that test scores in a volunteer sample increased significantly following a simple educational intervention.

Data from a population-representative sample are being collected as part of the Office of National Statistics Omnibus Survey, and ethnic differences are being examined through a survey conducted by Ethnibus. Preliminary results from the first half of the population data reveal low awareness of “warning signs” and significant socioeconomic inequalities. The most prominent barriers to seeking medical advice included fear about the results and worries about wasting the doctor’s time. Awareness of risk factors indicated continuing high awareness of the risk of smoking, improved recognition of cancer risks associated with overweight and sun exposure – perhaps related to recent campaigns, but low awareness of other risk factors, along with continuing social inequalities.

3.21 The CRS mentioned the importance of having key awareness messages for different cancer types which could be used to support stakeholders when they are developing awareness campaigns, for example during Lung Cancer Awareness Month. Over the past year, the DH has been working with stakeholder groups to review the key messages for lung cancer, and develop a new set of messages for ovarian cancer. The ovarian cancer key messages were launched on 6 October – see box 6.

3.22 The Improvement Foundation (IF) has been running a Healthy Communities Collaborative on cancer awareness in ten pilot areas for the past year, and have now started work with a further ten areas. All of the sites, which are based in Spearhead PCTs, have been undertaking targeted interventions to improve awareness of the signs and symptoms of breast, bowel and lung cancer, and to encourage those with symptoms to visit their GP.

3.23 Early signs suggest that there has been a better uptake of bowel screening in the PCTs running a Healthy Communities Collaborative, compared with other Spearhead PCTs. This may be a reflection of the fact that many of the sites targeted the rollout of bowel screening in their local area in their work.

Box 6: Ovarian cancer – key messages for members of the public

Ovarian cancer is the fourth most common cancer in women, but to put this in perspective, the average GP sees only one case of ovarian cancer every five years. The risk of ovarian cancer does increase with age and particularly after the menopause.

Cervical screening tests -sometimes known as smear tests -will not help to detect ovarian cancer.

The good news about ovarian cancer is that if diagnosed at an early stage, the outcome is good. However, because some of the symptoms of ovarian cancer are similar to those seen in more common conditions, it can be difficult to diagnose. Most women are not diagnosed until the disease has spread, which is why it is important that women know about the symptoms, so that they can seek advice as early as possible.

Ovarian cancer was once known as a “silent” disease in that the symptoms can be vague, but evidence now shows that any of the following three symptoms, if they occur on most days, can suggest ovarian cancer. This has led for the first time to some of the UK’s leading cancer charities, scientists and doctors agreeing that the following three symptoms are more frequent in women diagnosed with ovarian cancer:

- persistent pelvic and abdominal pain
- increased abdominal size/persistent bloating – not bloating that comes and goes
- difficulty eating and feeling full quickly.

Occasionally other symptoms such as urinary symptoms, changes in bowel habit, extreme fatigue or back pain may also be experienced on their own or at the same time as those listed above. Again, it is most likely that these symptoms are not ovarian cancer, but may be present in some women with the disease.

If you regularly experience any of these symptoms, which are not normal for you, it is important that you see your GP. It is unlikely that your symptoms are caused by a serious problem, but it is important to be checked out. You should also mention if there are two or more cases of ovarian or breast cancer in your close family, as ovarian cancer can sometimes run in families. If you have already visited your GP and the symptoms continue or worsen, it is important to return and explain this to your doctor – you know your body better than anyone.

Remember, ovarian cancer is uncommon and early diagnosis may save lives.

3.24 Evidence on the effectiveness of these collaboratives is inconclusive at this stage. The IF will continue to collect and analyse data from the sites. This will set out the impact that the local interventions have had on the key measures.

3.25 The initial ten sites showcased their work at a Healthy Communities Collaborative event in Blackpool in September 2008 – see box 7

for information about what the “Marketplace” demonstrated.

3.26 The Football Foundation have developed a pilot to raise awareness of the signs, symptoms and risk factors of bowel, lung and prostate cancer in men aged over 55. The pilot, supported by funding from the DH, will be delivered in football clubs and community-based projects delivering football activity through the Football Foundation’s local engagement work.

Box 7: What did the Healthy Communities Collaborative Marketplace demonstrate?

- huge enthusiasm and creativity
- projects in multiple venues: bingo halls, post offices, mosques, amusement arcades, sheltered accommodation, community halls/centres, working men's clubs, workplaces, a city centre marquee, pubs, reading groups, betting shops, supermarkets, a DIY store
- projects were targeted at different groups: men, older people, black and minority ethnic groups, people with learning disabilities
- engaging others: MPs, councillors and (importantly) patients influencing GPs
- key roles for volunteers, project managers and health trainers
- using people's own agendas (focus groups and surveys to design the projects)
- partnerships with other agencies: PCTs, NHS Trusts, councils and charities (eg Age Concern and Macmillan Cancer Support)
- engaging people through: snakes and ladders, lassoing, quizzes, mannequins with breasts and bowels, smoothies, hand massage
- the importance of humour/fun.

3.27 Cancer Networks, with PCTs, are using the information available to understand their local picture related to the early diagnosis and detection of cancer. Key indicators for local use include one-year survival rates, uptake of screening programmes, referral rates, emergency admissions and health inequalities. Using their local analyses, some Cancer Networks and PCTs, working with local authorities and others, are developing action plans in this area. The CRS Advisory Board has commented that the real challenge now is to turn this early interest into proven interventions across the whole country to promote better awareness of symptoms and earlier diagnosis of cancer.

Working with primary care professionals to diagnose earlier

3.28 To promote earlier diagnosis of cancer, the DH is funding the Royal College of General Practitioners to carry out an audit of cancer diagnosis in primary care. This audit will:

- provide a baseline understanding of which patient groups are experiencing the greatest delays in primary care
- provide insights into the primary care diagnostic process

- help construct an audit tool which can be used nationally to generate large scale data.

Improving access to diagnostics

3.29 The CRS said that improving access to diagnostics was the single most important priority in primary care to improve the early diagnosis of cancer.

3.30 In terms of diagnostics generally, there have been very significant improvements as part of the 18 weeks programme. In 2005, the DH set out milestones for the NHS to reduce waits for diagnostic tests to a maximum of 13 weeks by March 2007 and to six weeks by March 2008.

3.31 The reduction of diagnostic waiting times for all patients means that those who subsequently prove to have a cancer diagnosis but do not present with "red-light" symptoms, and are therefore not on a two-week pathway, are not disadvantaged in terms of waiting for a diagnosis and treatment.

3.32 The DH has published waiting time data for diagnostic tests since April 2006. Data is collected monthly on 15 key high volume diagnostic tests (eg MRI scans, CT scans, colonoscopy) and quarterly for all

other diagnostic tests. In addition, waiting times data for all other diagnostic tests are collected through a quarterly census.

3.33 The NHS has made excellent progress in reducing waits for diagnostics over the past two years. For example in April 2006, based on the 15 key tests, there were 404,000 six week plus waits. In March 2007, this had reduced to 243,000 and based on the latest published data for September 2008, has fallen to 6,600. The median waiting time for a diagnostic test has decreased to 1.6 weeks in September 2008, from 6.1 weeks in April 2006 when data were first published.

3.34 Commissioning world class imaging services is fundamental to providing high quality care to patients. To support PCTs in this aspect of their role, and as part of the 18 weeks programme, the National Imaging Board has developed an interactive toolkit to support commissioners of imaging services. The toolkit aims to bring together a number of resources about diagnostic imaging eg workforce, clinical governance, safety and radiation etc in one easy and convenient reference tool: <http://www.18weeks.nhs.uk/Content.aspx?path=/achieve-and-sustain/diagnostic/imaging/commissioning-guidance>.

3.35 In addition to the web based world class commissioning tool, a dedicated imaging services web forum has also been established. The forum is designed to allow PCTs to share best practice with colleagues across the country, and share ideas and experiences on service redesign.

3.36 Despite these very significant improvements in diagnostics, the CRS Advisory Board is of the view that further improvements can be made in GPs' access to the necessary diagnostics. As the CRS said, greater access is needed both to diagnostic tests for initial investigations, mainly to exclude cancer, and to specialist diagnostic services for patients with a high chance of cancer. In response to this concern it has been agreed that cancer diagnostics should be added as an eighth work stream within the National Awareness and Early Diagnosis Initiative.

Chapter 4: Ensuring better treatment

Progress:

- Cancer waiting times: preparation for new standards and new data collection methodology
- Further increase in uptake of cancer drugs and reductions in geographical variations in drug usage
- Further training for laparoscopic surgery for colorectal cancer launched
- Radiotherapy action plans

Priorities for the coming year:

- Delivery of new waiting time standards
- Transfer to new local and central data collection methodologies
- Further implementation of the Improving Outcomes Guidance
- Building up radiotherapy capacity and workforce
- Tackling problems related to quality and safety of chemotherapy services

Introduction

4.1 As the Cancer Reform Strategy (CRS) emphasised, treatment for cancer has improved considerably over the past decade. The CRS built on that progress with a series of actions to deliver faster and better treatment. This chapter reports on further progress and on the challenges ahead.

Going further on cancer waits

4.2 Latest figures (Q2, 2008/09) show that the current standards for cancer waiting times are delivering the following:

- 99% of patients are seen within two weeks from urgent GP referral to outpatient appointment

- 99% of patients are treated within 31 days from diagnosis to treatment for breast cancer
- 97% of patients are treated within 62 days from urgent GP referral to treatment for all cancers.

4.3 This is a significant achievement, representing a great deal of hard work by NHS staff. However, as set out in the CRS, the aim now is to extend the benefits to a wider range of patients. The new commitments are:

- the two week wait standard will apply to all patients referred with breast symptoms, who will be seen within two weeks, whether cancer is suspected or not
 - *to be implemented from the end of 2009*

- the 31 day standard will apply to all treatments for cancer, including after a recurrence
 - *to be implemented from the end of 2008 for surgery and drug treatment, and from the end of 2010 for radiotherapy and other treatments*
- the 62 day standard will apply to all patients
 - referred from NHS Cancer Screening Programmes (breast, cervical and bowel)
 - deemed urgent by their consultant as well as those referred urgently by a GP
 - *to be implemented from the end of 2008.*
- reduce the burden of data collected for non-clinical purposes
- streamline the data collection process for treatment providers
- bring cancer waiting times data into the mainstream of NHS performance data processes (ie under the 18 weeks model)
- support patient choice and clinical autonomy (not every patient wants to be treated within the standard time, and not every patient can be).

4.4 Since publication of the CRS, the NHS has been working to implement these standards. The National Cancer Action Team (NCAT) is supporting Strategic Health Authorities (SHAs) to ensure delivery of the extended standards. In terms of the new standards for December 2008, the data to show whether they have been met will be published in May 2009, but there will be some tracking data in advance of that which will indicate the direction of travel.

4.5 The Department of Health (DH), Connecting for Health and the NCAT are developing a new performance recording and reporting system to support the new standards. Cancer treatment providers will no longer have to collect information about the intervals when cancer patients are unfit to undergo procedures or when patients take time to consider treatment decisions, in order to make adjustments to the calculated waiting times (this change has been assured by the Information Standards Board for Health and Social Care and communicated via DSCN 20/2008). When these changes are implemented from 1 January 2008, these adjustments will no longer be used to calculate performance against the cancer waiting time standards. This will bring cancer waiting times data into line with 18 weeks data and:

4.6 Because the data collection rules will be more consistent with the 18 weeks data collection rules, there will need to be a change in the operational standards for both the current and new waiting time standards, in order to preserve time for patients to consider treatment options and to reflect good clinical practice (ie the fact that some patients cannot be appropriately treated within these timescales). Reported performance against the current standards will change because of the new rules:

- performance against the existing two-week standard (for urgent referral to a specialist) is 99+%, against an operational standard of 98% – we expect reported performance will move to about 93%
- performance against the existing 31 day standard (from diagnosis to treatment) is 99+%, against an operational standard of 98% – we expect reported performance will move to about 98%
- performance against the existing 62 day standard (from referral to treatment) is 97+%, against an operational standard of 95% – we expect reported performance will move to about 86%.

4.7 The changes are designed to reduce the burden of information collection on the NHS. The standard remains that, as previously, 100% of cancer patients **who are willing and able to do so** will be treated within the timescales set out in the CRS (and the *NHS Cancer Plan*).

4.8 The cancer treatment waiting times standards are designed to highlight and eliminate unnecessary waits from the system, whilst supporting patient choice and clinical priority.

4.9 NHS Improvement will be producing an improvement guide for going further on cancer waits in the New Year, and will be providing support to SHA leads through Cancer Network service improvement teams.

Improving Outcomes Guidance implementation

4.10 The CRS emphasised the importance of implementing the Improving Outcomes Guidance (IOG), in order to see further improvements in the outcomes of complex cancer surgery.

4.11 Action plans for implementation have been developed in several phases, as part of the Local Delivery Plan process. The first four services (gynaecology, upper gastro-intestinal, urology and haematology) were due to be fully implemented by December 2007. The overall summary of progress by December 2007 confirmed good progress had been made with the exception of a small number of health economies, where support is now being provided by the NCAT. For haematological malignancies, a particular problem was identified in relation to the development of specialist haematopathology services in line with the relevant IOG. During 2008, most Cancer Networks appear to have developed good processes and put plans in place to deliver this element of the service. The NCAT is working with the Royal College of Pathologists to ensure sustainable services are developed in all SHAs.

Box 8: Major surgery for prostate or bladder cancer – progress on specialisation 1997/98–2006/07:

- the number of major surgical procedures (prostatectomy or cystectomy) has more than doubled over the past nine years (from 2041 in 1997/98 to 4532 in 2006/07): this is very largely due to the increasing incidence of prostate cancer
- the number of Trusts undertaking either of these procedures has decreased from 145 to 119
- the number of Trusts undertaking fewer than ten procedures per annum has fallen from 65 to 22 – and the percentage of all major surgical procedures undertaken in these “low volume” Trusts has fallen from 17% to 2%
- in contrast the number of Trusts undertaking at least 40 major procedures per annum has increased from five to 54 and the percentage of all such procedures undertaken in these high volume Trusts has increased from 12% to 77%.

Prostatectomy or cystectomy for cancer

	1997/98	2006/07
● number of Trusts undertaking (per annum):		
1-9 procedures	65	22
10-39 procedures	75	43
40+ procedures	5	54
● % of procedures taking place in Trusts undertaking (per annum):		
1-9 procedures	17%	2%
10-39 procedures	71%	21%
40+ procedures	12%	77%

4.12 Progress on implementation can be monitored through inspection of Hospital Episodes Statistics. For example, progress on centralising urological cancer services is shown in box 8. It is important to note that the most recent national figures available are for 2006/07 and considerable further progress has been made since then.

4.13 Specialist teams for head and neck cancers which treat more than 100 new patients each year with improved community support services are due to be in place by the end of December 2008. Four Cancer Networks have implemented their plans ahead of the deadline and a further 19 have confirmed that they expect to be compliant by the due date. Work will continue to reduce the risk with the remaining plans.

4.14 Commitment was given in the CRS for full implementation of the National Institute for Health and Clinical Excellence (NICE) guidance on supportive and palliative care (SPC) for adults with cancer. The intention had been for this guidance to be fully implemented across the country by December 2007. However, this guidance is particularly complex and wide ranging and the initial timetable for implementation has overlapped with the development of other national strategy areas, such as end of life care and the Department of Health's (DH) Common Assessment Framework, which needed to be taken into account as Cancer Networks took forward implementation of the SPC guidance. It was confirmed in the CRS that the deadline would be extended by 12 months to December 2008. Networks will be reporting on partial compliance by this date, with full implementation by December 2009.

4.15 For the remaining IOGs, NCAT has been working closely with Specialised Commissioning Groups (SCGs) across the country and good progress has been made in developing services for penile and testicular cancers that serve populations of four and two million respectively. There has been significant progress made in consolidating pancreatic surgery into fewer centres, but four SHAs do not yet have agreed plans. For skin cancer, most Cancer Networks now have agreed plans. For sarcoma, eight out

of ten SHAs have plans in place to consolidate services, and there is confidence that these will all be fully implemented by December 2010.

4.16 Principal Treatment Centres for children's cancers have now been approved by all SCGs except one where there is a review process under way. It is expected that services for young people (aged 16-24) will be established in the same cities. Guidance has been developed for SCGs and Cancer Networks to ensure that all young people aged 16-19 years benefit from being referred for treatment in a designated Principal Treatment Centre for young people, and that all young people aged 16-24 years inclusive should be notified to a teenage and young adult multi-disciplinary team (MDT), to be based at these Principal Treatment Centres.

4.17 The initial mapping of brain and central nervous system services has been completed. However, issues have been identified by Cancer Networks that require further clarification with the IOG development group, after which further advice will be issued to the service.

Laparoscopic colorectal surgery

4.18 The CRS said that, in order to increase the use of laparoscopic surgery for colorectal cancer, a pilot training programme would be established which would be fully evaluated for potential national rollout.

4.19 A network of ten centres – including a total of 16 hospitals – has been established to take this forward, with support from the relevant professional bodies. A clinical lead has been appointed and a coordinating centre has been set up to provide project support and business management to all training centres. Imperial College London are developing an educational platform to support the training that includes coordination of training methods, provision of integrated education material and competence-based assessment against agreed criteria.

4.20 To date 30 surgeons have been recruited on to the programme and a further 30 have expressed interest. The programme is being extended to include the potential for cadaveric training prior to attending the main training.

An enhanced recovery training programme will also be provided.

4.21 The waiver of full implementation of the 2006 NICE technology appraisal related to laparoscopic colorectal surgery will be reviewed in 2009. Trust Chief Executives are being made aware of the benefits and impact of laparoscopic surgery for colorectal cancer and are being urged to allow surgical teams to attend the training as the waiver is likely to be lifted once the capacity to deliver laparoscopic surgery has been increased through the programme.

Radiotherapy

4.22 One of the major commitments in the CRS was to deliver a step change in radiotherapy capacity to deliver a world-class service, with a first key objective of meeting the new 31 day waiting times standard for radiotherapy by the end of 2010.

4.23 In response to this, Cancer Networks were advised to prepare plans for increasing radiotherapy capacity in line with the goals set in the CRS. In assessing the challenges for the future, the CRS Advisory Board highlighted that the long lead-in time for commissioning new radiotherapy facilities means that action is needed now to deliver the 2010 standard. Most SHAs and their Cancer Networks have shared their plans with the NCAT. Feedback will be given during December 2008.

4.24 A radiotherapy capacity planning tool (R-PORT) is being developed to help service departments assess capacity and to model working patterns effectively. This is being piloted in three radiotherapy departments before being offered to all centres in Spring 2009.

4.25 It is the intention that, from April 2009, radiotherapy fraction information will be routinely collected, following full standard assurance by the Information Standards Boards for Health and Social Care (ISB HaSC) and subsequent approval being granted by the Review of Central Returns (ROCR) (this information is collected voluntarily at present). This will allow Primary Care Trusts (PCTs) to track

how access to radiotherapy is improving for their populations.

4.26 The size of the radiotherapy workforce is increasing, but more needs to be done in order to keep pace with the increasing demand for radiotherapy. The CRS asked SHAs to develop long-term workforce strategies, including an urgent review of workforce supply, demand and skills mix to identify the investment needed in both staff numbers and types of training commissions. The DH and NCAT will shortly be reviewing the progress being made by SHAs, so that further support can be provided if necessary.

4.27 The CRS highlighted the importance of improving learning experiences for therapeutic radiographers. Virtual Environments for Radiotherapy Treatments (VERT) are being introduced in radiotherapy training sites with the aim of reducing the current high attrition rates amongst trainee therapeutic radiographers. The impact of this new approach on attrition and recruitment will be evaluated by October 2009. A small working group has been established – chaired by the DH's Chief Scientific Officer – to look at the role of healthcare scientists in radiotherapy, with the intention of this initiative supporting the development of the radiotherapy workforce.

Proton therapy and other technological advances

4.28 The CRS said that, from April 2008, proton therapy for certain cancers would be commissioned from overseas by the National Commissioning Group. This is now happening. It also said that the DH would consider options for providing modern proton therapy services in this country. Work is being undertaken to establish an agreed set of clinical indications for this treatment and work up an outline service specification. A Proton Therapy Advisory Group has been established to provide expert clinical and scientific advice. We plan to have a draft outline business case setting out the options for the procurement of proton therapy services against this specification early in 2009.

Drug treatments

4.29 Several major strands of work have been undertaken over the past year to improve access to new cancer medicines and to improve the quality and safety of chemotherapy services. Some of these are already bringing benefits to patients and further major improvements can be expected over the next year. The key work strands are:

- a further update on the use across the country of cancer drugs approved by NICE
- changes to the process by which cancer drugs are appraised by NICE to give more timely advice to the NHS
- better local planning of chemotherapy services
- improving access to medicines for NHS patients
- publication of *Chemotherapy Services in England: Ensuring quality and safety*.

Update on the use of cancer drugs approved by NICE

4.30 The first report on usage of cancer drugs approved by NICE was published in 2004. This showed unacceptable variations in usage between Cancer Networks. This variation was not due to funding not being made available by PCTs but was considered to be largely due to variations in forward planning for chemotherapy and to variations in clinicians' perceptions of the effectiveness of the drugs. A second report issued in September 2006 showed a significant increase in uptake of NICE approved drugs across the country as a whole, together with reduced variation in usage between Cancer Networks.

4.31 A third analysis has now been undertaken, as promised in the CRS, based on drug usage in 2007/08 and using the same methodology as before. There are 14 NICE approved drugs and four comparator drugs for which uptake figures were included in both the second report and latest evaluation. For 13 of the 14 NICE approved drugs an increase in overall usage has been observed (median 72% increase,

range 4% to 286%). For seven drugs utilisation has increased by 50% or more (trastuzumab, oxaliplatin, docetaxel, temozolamide, topotecan, vinorelbine and capecitabine). Usage has decreased for only one of the NICE approved drugs (fludarabine -18%). This is likely to be due to other drugs, such as rituximab, being used in preference. Usage has increased for three of the four comparator drugs (carboplatin 15%, cisplatin 31%, epirubicin 15%), whole usage of doxorubicin has fallen by 4%.

4.32 Variation in usage across the 30 Cancer Networks in England was once again assessed using the ratio of the 90th percentile to the 10th percentile of the distribution of usage by Networks (in milligrams per head of population) ie for each cancer drug the 30 Cancer Networks were ranked by their usage from highest to lowest, and the usage for the Cancer Network at the 90th percentile (10% of Networks lie above this point) and 10th percentile (10% of Networks lie below this point) were compared. This method excludes the results of Networks at each extreme (ie very high and very low users). A higher 90th/10th percentile ratio indicates greater variation in usage across Networks.

4.33 In 2005, variation in uptake was observed to have decreased for all NICE approved drugs and was generally quite similar to the variation in usage of the four comparator drugs (which had 90th:10th percentile ratios of 2.1-2.5). Variation in the usage of comparator drugs has remained broadly static in 2007/08 (1.9-2.4).

4.34 Further reductions in variation in usage have been observed from 2005 to 2007/08 for nine of the 13 NICE approved drugs, which now have a variation of 1.6 to 3.2 (capecitabine, docetaxel, gemcitabine, imatinib, oxaliplatin, pegylated liposomal doxorubicin, rituximab, temozolamide and trastuzumab). The largest reductions in variation in usage were for trastuzumab (44%), pegylated liposomal doxorubicin (46%) and temozolamide (66%).

4.35 For two drugs variation has remained stable (irinotecan 2.5, paclitaxel 3.2). There was a small increase in variation of usage for fludarabine (from 2.2. to 2.5). Variation in the usage of

vinorelbine has increased from 3.1 to 5.0 despite an overall increase in usage of 72%.

4.36 The CRS also mentioned action to improve the information available to help understand variations. The DH, with the National Cancer Intelligence Network (NCIN) and other partners, continues to work on the development of a chemotherapy dataset. In terms of encouraging the use of e-prescribing to facilitate introduction of Healthcare Resource Group 4 (HRG4, the latest national currency system) for chemotherapy payment, during 2006/07 Connecting for Health provided some capital to allow NHS Trusts/Cancer Networks to purchase a system ahead of the IT solution. Sixteen bids were successful and these are being implemented. A financial module that maps to HRG4, developed as part of the Chemotherapy Planning Oncology Resource Tool (C-PORT) project, is currently being tested within a Cancer Network with a view to rolling this out to all Trusts using C-PORT during 2009.

Cancer drug appraisal by NICE

4.37 The CRS made the commitment that all new cancer drugs and significant new licence indications would be referred to NICE for appraisal provided that there was a sufficient patient population and evidence for NICE to undertake an appraisal. The CRS also reflected the government's existing commitment to ensure that new cancer treatments are appraised promptly, using the faster Single Technology Appraisal (STA) process where appropriate.

4.38 The DH has developed with NICE a process to deliver the CRS commitment of the "default" position on NICE's appraisal of new cancer drugs. The default option is that all new treatments will be appraised in parallel with the licensing process as far as is possible.

4.39 Revised processes include changes to NICE's arrangements for consultation on cancer appraisal topics and handling of Ministerial sign off. Cancer drugs included in the 19th work programme for NICE are the first to be handled under the revised topic selection process to implement the CRS commitment. By 2010 draft or final guidance for all new cancer drugs will

be available within six months, on average, of a drug being licensed.

Supporting better local planning for chemotherapy

4.40 The CRS reported on the development of the C-PORT, which should help Trusts to ensure that they plan for the safe introduction of new drugs in a thorough and cost-effective way. C-PORT is currently in use in 22 Cancer Networks, though they are all at different stages of implementation. There are plans to work with the remaining Cancer Networks and this will start during 2009. An event is being planned for Spring 2009 which will show case the benefits that teams have found from using the tool. A number of Trusts are already starting to use it to determine which services they may be able to move to alternative settings, and as a way to support business cases for additional resources.

Improving access to medicines for NHS patients

4.41 In June 2008 the Secretary of State for Health invited Professor Mike Richards to lead a review to examine current policy relating to patients who choose to pay privately for drugs that are not funded on the NHS. Professor Richards' report *Improving access to medicines for NHS patients* was published in November 2008. The 14 recommendations made in his report have been accepted by the Secretary of State and draft guidance on their implementation has been issued to the NHS. Alongside Professor Richards' report, NICE has proposed a new scheme for the appraisal of drugs licensed for use in patients with conditions which are uncommon and which carry a poor prognosis.

4.42 These new initiatives should bring very considerable benefits to cancer patients. In particular, access to new medicines will be improved by:

- improving the processes used by PCTs to assess new drugs and to evaluate exceptional circumstances. This will be taken forward through the work on the NHS Constitution.

- ensuring appraisals undertaken by NICE are more timely. Action is already being undertaken on this (see paragraphs 4.37-4.39 above).
- promoting more flexible approaches to the pricing of new drugs. This has recently been agreed with the pharmaceutical industry as part of the Pharmaceutical Price Regulation Scheme (PPRS).
- broadening the cost effectiveness criteria used by NICE in the appraisal of drugs used near the end of life.
- investigating the extent and causes of international variations in drug usage.

4.43 Although these measures should improve access to cancer medicines very considerably, there are limits to what the NHS can reasonably be expected to pay. However, in response to the Richards Review the government has made it clear that no patient will lose their entitlement to NHS care they would otherwise have received, simply because they opt to purchase additional treatment for their condition.

4.44 The draft guidance from the DH sets out how this will be achieved by delivering privately funded care and NHS care separately. Alongside this, commitments have been made to ensure that written information is always available, giving patients a balanced view of the benefits, potential toxicities and likely costs of new treatments. The DH will also commission a training programme for clinicians to enhance the quality of discussion about these difficult issues. A national audit of the use of unfunded drugs will also be commissioned.

Quality and safety of chemotherapy services

4.45 During the course of 2008 concerns about the quality and safety of chemotherapy services have been raised from three different angles. First, the National Patient Safety Agency (NPSA) issued a Rapid Response Report in January 2008

relating to the risks of incorrect dosing of oral anti-cancer medicines. Second, the national overview report of the cancer peer review programme (2004-2007) highlighted variations in compliance with the chemotherapy measures set out in the Manual for Cancer Services (2004). Third, the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published a report *For better or worse* in November 2008 which reviewed the care of patients who died within 30 days of receiving systemic anti-cancer therapy.

4.46 Taken together these reports highlight the need for urgent action to improve the quality and safety of chemotherapy services. In response to these concerns draft guidance from the National Chemotherapy Advisory Group (NCAG) was published by the DH in November 2008, alongside the NCEPOD report. This guidance is open for consultation until 4 February 2009.

4.47 The draft NCAG report *Chemotherapy Services in England: Ensuring quality and safety* sets out proposals for the actions that will be required at each step in the chemotherapy care pathway:

- referral, assessment and decision to treat
- prescribing, verification and dispensing
- delivery
- information, education, support and advice
- urgent assessment and management of complications
- knowledge and recording of toxicity
- end of treatment record and subsequent care plan.

4.48 The draft NCAG report draws particular attention to the need for improvements in acute services for cancer patients, including those receiving chemotherapy. Patients may be

admitted to hospital as an emergency, and in some cases to a hospital different to the one where chemotherapy was delivered. Good coordination between emergency medicine, general medicine, clinical oncology, medical oncology and haemato-oncology services is essential.

4.49 Following consultation final guidance on chemotherapy services will be issued to the NHS in 2009.

Chapter 5: Living with and beyond cancer

Progress:

- Advanced Communications Skills Training programme is fully developed and has been rolled out to the Cancer Networks
- 11 national cancer patient information pathways have been developed
- National Cancer Survivorship Initiative launched
- 16 communities testing new approaches to survivorship care

Priorities for the coming year:

- Patient Experience Survey
- Putting patients' experience at the heart of measures of performance
- Autumn 2009 – vision and plan for National Cancer Survivorship Initiative

Introduction

5.1 By the end of this year, there will be around 1.6 million people in England alive having had a diagnosis of cancer. Chapter 5 of the Cancer Reform Strategy (CRS) was about improving the experience of these people living with and beyond cancer. This chapter considers what progress has been made towards that objective, and looks ahead to the further work planned.

Information, communication, decision-making and choice

Face-to-face communication

5.2 The CRS set out actions to improve and extend communication training for senior healthcare professionals.

5.3 The Advanced Communications Skills Training programme (ACST) is fully developed and has been rolled out to the Cancer Networks.

The course has been developed from a sound evidence base and uses experiential learning to promote behavioural change in the participants. The course lasts three days and includes intensive role play sessions using actors as simulated patients/carers or colleagues. The role play is video recorded and participants receive constructive feedback and a secure environment to help them explore alternative communications processes and styles.

5.4 The course is now referred to as Connected, the national communication skills training programme. A dedicated website for the programme (www.connected.nhs.uk) has been launched. The site will not only promote the course to clinicians, but will also provide an interactive workspace for facilitators and course participants to develop communication skills further.

5.5 Some 275 course facilitators have been trained in the Connected programme with 50% of those currently fully approved to deliver the course. The balancing 50% can deliver training while mentored by an approved facilitator. All Cancer Networks have some capacity to deliver the national programme and approximately 150 courses are planned for the current financial year. This will deliver training to some 1500 cancer practitioners.

5.6 The CRS also said that we needed to ensure that general and community-based clinicians and other healthcare staff who treat and support cancer patients have access to good communication skills training. Pilot programmes have been run in a number of areas including in heart disease and children and young people's (CYP) services. The programme is currently also being reviewed as part of the End of Life Care Strategy implementation plan and a number of pilots will be undertaken in 2009.

5.7 Meanwhile, the more focused work on communication with CYP is progressing. Train the Trainer programmes are scheduled for December 2008 and February 2009. In addition the West Midlands Strategic Health Authority (SHA) have allocated funds to develop materials to support delivery to CYP.

5.8 New peer review measures will enable Primary Care Trusts (PCTs) to identify that all members of the multi-disciplinary team (MDT) who have contact with patients are trained in advanced communications skills.

Information products, pathways and prescriptions

5.9 Major progress has been made over the past year on providing high quality information to cancer patients at each step in the care pathway.

5.10 The National Cancer Action Team (NCAT), with Cancer Networks across England and over 13 cancer charities, has been working to develop national cancer patient information pathways to support the delivery of information prescriptions to cancer patients. The national pathways along with "bite-sized" chunks of information will provide the content for cancer patient information prescriptions. To date eleven

national cancer patient information pathways have been developed: breast, bowel, prostate, lung, womb, ovarian, cervical, vaginal, vulva, palliative care, and generic information for all cancer types.

5.11 A first stage of pilot testing a prototype cancer information delivery system and ten draft national pathways took place from May to August with five trusts covering:

- breast cancer
- bowel cancer
- gynaecological cancers
- palliative care
- generic information about cancer.

5.12 The first stage pilot demonstrated that a national tool storing a wide range of information which is available at the point of need, which supplies the patient with a permanent record of the information received and which is dispensed at the consultation was beneficial for both health care professionals and patients. The prototype system made a wide library of content available to health care professionals, so that patients had a choice of information to take away with them to support treatment decisions and the effects of living with cancer.

5.13 A second wave of early adopter sites will begin shortly. Thirty nine trusts have applied to take part across twelve Cancer Networks, covering all developed national pathways, for six months. These pilots will be testing:

- prescribing and dispensing of patient information by clinical nurse specialists
- prescribing of patient information by consultants
- dispensing of patient information prescriptions by information centres
- prescribing of information by community nurses

- self prescribing by patients.

5.14 There are plans in early 2009 to look at a primary care module of the cancer patient information delivery tool for GPs and other community staff, to help them to ensure that patients living with cancer have access to high quality coordinated information.

5.15 Another version of the tool will be available, in 2009, which will allow health care professionals to develop bespoke information prescriptions with patients supported by information from the national cancer patient information pathways, with additional features such as emailable information to patients and carers.

5.16 In discussing the information needs of patients, the CRS Advisory Board highlighted the very important role that NHS Choices does and can play in providing the right information. They suggested that the Cancer Programme should work more proactively with NHS Choices. This will be taken forward in 2009.

National Cancer Survivorship Initiative

5.17 Chapter 5 of the CRS covered a range of other issues which affect people living with and beyond cancer, including the need to ensure that patients experience good continuity of care, the importance of psychological support for cancer survivors and the role of clinical nurse specialists. These and many other issues are being taken forward as part of the National Cancer Survivorship Initiative (NCSI) which, following the CRS, was established to support the survivorship agenda.

5.18 The NCSI is co-chaired by Ciaran Devane, Chief Executive of Macmillan Cancer Support, and Mike Richards, National Cancer Director, with a steering group overseeing the delivery of the agenda. The CRS said that there would be a think tank event about how to take the survivorship agenda forward, and the work programme is based on the recommendations arising from that event, which was held in March 2008.

5.19 Work streams have been established on the following:

- assessment, care planning and immediate post treatment approaches to care
- managing active, progressive and recurrent disease
- late effects of treatment
- survivors of childhood and young people cancers
- work and finance
- self-care and self-management
- research.

5.20 Each work stream has also been asked to consider issues relating to information, commissioning and workforce. Once the work of the individual work streams is more advanced, cross-cutting groups will be established.

5.21 Sixteen test communities have been identified to map their current adult survivorship pathway, identify opportunities for improvement and to test the opportunities within their community. For children and young people's services, ten test sites are being launched in January 2009. NHS Improvement are overseeing and managing this process.

5.22 The NCSI as well as the work streams and test sites were officially launched on 11 September 2008. The plan is for the work streams to have reached initial conclusions in time for a vision and implementation plan to be published in the autumn of 2009.

Box 9: Project in Yorkshire to test feasibility and acceptability of a new supportive care model of follow-up for breast cancer patients

Standard practice after potentially curative surgery for breast cancer is regular hospital follow-up visits. The value of this resource intensive practice is constantly being questioned. It is acknowledged that routine hospital visits cause significant stress to the patient and, more importantly, most symptoms attributable to local recurrence are first identified by the patient. Many clinicians believe that time spent following up essentially well women is not clinically beneficial or cost effective. Inevitably these routine visits lengthen waiting times for new referrals and may compromise the efficiency of individual diagnostic services.

This pilot – which started in June 2008 – involves women who have recently undergone potentially curative surgery for breast cancer. A model of follow-up based on supportive care, which will replace routine hospital appointments, with a package of self-help in the form of a “prescribed” training course. It is provided through collaboration between the NHS and Breast Cancer Care. Telephone support and access to specialised clinics for all patients will be provided as required.

The pilot study is being carried out over a two-year period. All consenting patients will attend the course. Following this, patients will be randomised to either the trial arm with open access but no routine visits or the standard arm with routine follow-up in outpatients. All patients will complete quality of life assessments and phone interviews at regular intervals to assess their experiences.

Box 10: The Service Pledge for Breast Cancer: a tool for patient involvement and service quality improvement

Breakthrough Breast Cancer has collaborated with fifteen breast units in England and Wales to produce a local Service Pledge for Breast Cancer. At each unit, Breakthrough has worked with healthcare professionals and patients to review the existing service and identify specific areas for improvement. This results in the publication of a local Service Pledge for Breast Cancer, listing the standards of care patients should expect to receive and the chosen improvement goals.

Goals already achieved include:

- a photographic guide to surgery and reconstruction at The Royal Surrey County Hospital
- a drop-in clinic run by the nurse specialists at The Friarage Hospital

Longer term pledges include a new breast care unit (previously housed in a portakabin) for Pilgrim Hospital.

The Service Pledge is designed to enable patients to speak up about what matters most to them. Breakthrough coordinates a patient survey at each unit and sends trained patient advocates to carry out interviews with a number of patients that have used the unit.

Each unit also recruits patient representatives to work closely with healthcare professionals on the drafting of the local Service Pledge.

A staff member, usually a breast care nurse, leads the Service Pledge team. Breakthrough supports each Pledge site and enables and encourages the Pledge leads across the country to learn from each other.

An independent evaluation in 2008 confirmed the value of the Service Pledge approach to improving services:

- patients and healthcare professionals regard it as a distinctive and sound approach to bringing about improvements in breast services through patient involvement
- patients find their local Service Pledge a useful information tool, clarifying what they should expect from their unit
- the Service Pledge facilitates team working and unites multi-disciplinary teams around common, patient-centred goals.

Breakthrough will work with twelve more hospitals in 2008/09.

5.23 There have been a number of developments outside of the CRS programme which have been supportive of the survivorship agenda. These include:

- in June 2008 the Government launched a new strategy to support, help and improve the lives of carers. The Carers Strategy is underpinned by £255 million to implement some immediate steps alongside medium and longer term plans.
- in July 2008, the final report of the Next Stage Review was published. This report sets out a range of plans relevant to improving care and support for survivors, such as improved information for patients and personal care plans for all those with long-term conditions.
- in October 2008, the government announced that all prescriptions for patients with cancer will be charge-exempt from April 2009 – this will be beneficial for those patients for whom payment of charges has been a financial pressure.

5.24 While the CRS Advisory Board was generally pleased with progress on the survivorship agenda, they highlighted that a top priority needed to be achieving coordinated, integrated care for cancer patients. This aspect of the work will receive a particular focus in the year ahead. The Advisory Board also suggested that the Cancer Programme needed to ensure that cancer patients benefited from the expansion and development of psychological therapies, and this is something that will be considered further in the year ahead.

Measuring patients' experience

5.25 The CRS said that there would be a new NHS Cancer Patient Experience Survey Programme.

5.26 This Survey Programme will build on experience from the large-scale cancer patient experience surveys carried out in 2000 and 2004. A Cancer Patient Experience Survey Programme Advisory Group is taking forward important preparatory work for the survey programme to begin in 2009/10. This includes:

- considering key principles for the underpinning of the survey programme
- working with clinicians to learn how to get better engagement with the survey at a local level and use results to drive service improvement locally
- learning lessons from existing local surveys (eg see box 11 from Sussex Cancer Network), other DH patient surveys and the cancer patient experience surveys from 2000 and 2004.

Box 11: Sussex Cancer Network (SCN) Patient Experience Surveys 2008

The SCN Partnership Group has developed four surveys building on the National Patient Survey (1997) to enable multidisciplinary teams (MDTs) and tumour groups to receive feedback from patients about their experience. As a result of the reports, the MDTs identify any changes which need to be made and are implementing those changes. The results are discussed in each of the tumour group to enable sharing of best practice. The surveys carried out in 2007/08 reviewed the experience of patients from GP referral to diagnosis.

To date 352 urology, haematology, head and neck, colorectal and breast patients have responded to the survey. Overall, the feedback from patients has been overwhelmingly positive and has been a great endorsement of the multi-disciplinary collaboration in the MDTs.

These endorsements included:

- over 80% of patients receiving sufficient information about their investigations, diagnosis, treatment options and treatment
- over 94% of patients feeling they had been listened to, treated in a friendly and courteous manner, enabled to discuss any fears and worries and told their diagnosis in a sensitive way by the MDT doctors and nurses
- over 92% of patients stated that overall the quality of the care they received was good.

There were some consistent shortfalls in the standards expected, such as:

- between 37% and 51% of patients referred under the 2-week wait system stated that their GP had not warned them that they were being referred to rule out or confirm a possible cancer diagnosis
- lack of generic information such as finances, diet, complementary therapies, psychological support, body image, support groups and family history risks
- less than half of patients being offered a “permanent record of significant consultations” or being advised to bring someone with them when they were told their diagnosis.

Box 12: North London Cancer Network – Picker Survey of cancer patients' experiences

As part of the peer review process, each multidisciplinary team (MDT) is required to undertake an annual survey of patients' experience. To date these surveys have been locally developed often with poor analysis and limited impact on service improvement. National peer review data shows that although 62% of MDTs had undertaken a survey, 42% had presented and discussed results and only 35% had acted on the results.

In response to this, the North London Cancer Network has worked with local patients, clinicians, managers and commissioners to develop a network approach to surveying the experience of care of cancer patients. The benefit of conducting a network wide survey has meant that the network will be able to:

- provide a systematic approach to assessing the patient experience that allows us to benchmark our MDTs
- understand the experience of care across the patient pathway and identify areas of good and poor experience
- provide reports at a Trust and Network level
- provide reports to PCT commissioners on local providers.

The Network has worked with the Picker Institute to develop, distribute, analyse and provide reports back to Trusts and commissioners so that there is robust data to input into Trusts' quality and patient experience strategies. The first reports are due in March 2009.

5.27 In assessing progress in implementing the CRS, Advisory Board members said that they considered that one of the top priorities for the future is to develop a culture where there is more of a focus on outcome measures rather than process measures, and where patient experience is seen as a key outcome measure. Progress on the patient experience survey will be one of the top priorities for next year.

backed by new funding (£286 million over two years).

5.29 Progress on implementation of the *End of Life Care Strategy* will be monitored by an external advisory group and an annual report to Ministers on progress will be published.

End of Life Care Strategy

5.28 End of life care is not covered in any detail in this report, as progress will be monitored elsewhere. In July 2008, the DH published the first ever comprehensive *End of Life Care Strategy* for this country. This covers end of life care for all conditions and in all settings, but will of course benefit cancer patients. The aim is to bring about a step change in the quality of services and to enhance choices relating to care for people approaching the end of life. Particular emphasis is being put on improving community services and coordination of care. The Strategy is

Chapter 6: Reducing cancer inequalities

Progress:

- Further reduction in inequality gap in mortality rate
- June 2008 – launch of *Health Inequalities: progress and next steps*
- Development of the National Cancer Equality Initiative

Priorities for the coming year:

- Ensuring that the cancer programme is fully integrated into broader work on tackling inequalities
- Dissemination of good practice in relation to tackling inequalities in cancer care and outcomes
- Embedding action on health inequalities throughout all strands of the Cancer Reform Strategy implementation
- Publication of incidence and mortality figures by ethnicity, to provide evidence base for future action
- National BME Cancer Patient Advisory Panel established

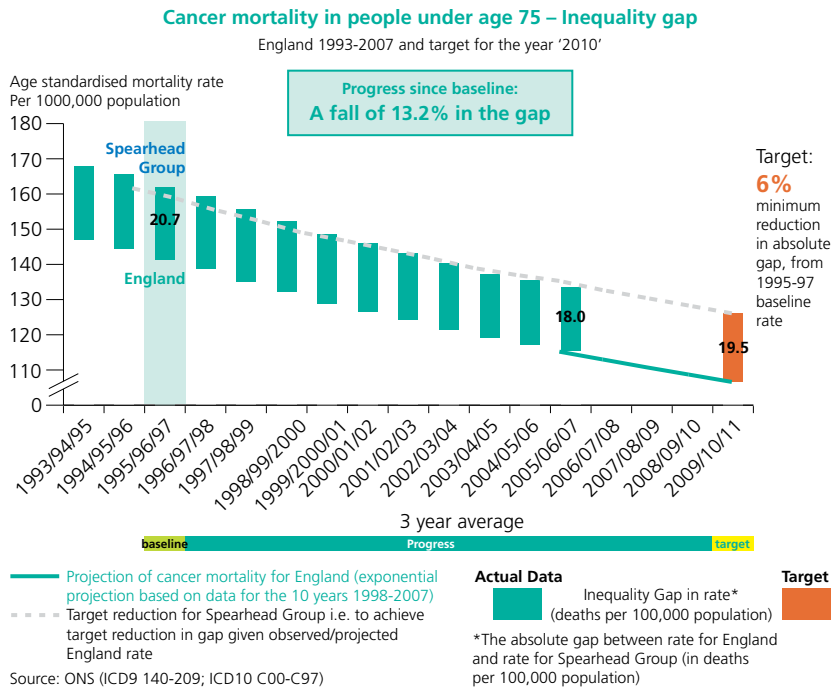
Introduction

6.1 The Cancer Reform Strategy (CRS) contained a number of actions to help reduce inequalities, and this chapter reports on progress and plans for the future.

gap in mortality has reduced to 18%. The challenge for the future is to decrease it further.

Mortality

6.2 The latest mortality figures (see below) demonstrate a further reduction in the inequality gap for cancer mortality for people under the age of 75. This graph shows that in the baseline years (1995/97) cancer mortality was 20.7% higher in Spearhead (deprived) Primary Care Trusts (PCTs) than in England as a whole. Over the past decade, mortality has fallen both in Spearhead and other PCTs, but the inequality



Health inequalities: progress and next steps

6.3 In June of this year, the government launched a document outlining its plans to increase action on the 2010 health inequalities Public Service Agreement (PSA) targets, assessing what has worked and setting the direction of travel beyond 2010. This document sets out how the government will tackle health inequalities by promoting health and wellbeing, by strengthening efforts to tackle the wider determinants of inequality and by making sure that everyone can access the services they need in a way that is convenient to them and by promoting direct support and tools for delivery organisations. Much of this action will be very significant in tackling inequalities in cancer outcomes, but this chapter focuses particularly on the work flowing from the CRS.

National Cancer Equality Initiative

6.4 A National Cancer Equality Initiative (NCEI) Advisory Group is taking forward a series of actions to reduce inequalities in cancer care. The NCEI is co-chaired by Joanne Rule, a member of the CRS Advisory Board, and Mike Richards, the National Cancer Director. The actions include:

- a survey of Cancer Networks and community groups to identify good practice in reducing

inequalities in cancer care. The aim is produce advice to the service on best practice in Spring 2009.

- charging the other major CRS initiatives with embedding equality and action on inequalities into their workstreams. The NCEI has already sent detailed ideas on reducing inequalities to the National Awareness and Early Diagnosis Initiative (NAEDI) and National Cancer Intelligence Network (NCIN) and plan to communicate similar ideas to other CRS initiatives (eg survivorship, patient experience survey, research).
- recognising that individuals may fall into more than one equality strand, developing a human rights programme, *Know Your Rights*, in partnership with Macmillan Cancer Support and the Department of Health (DH) Equality and Human Rights Group.

6.5 Cancer has also been identified as a priority in the second wave of the DH Pacesetters programme. Pacesetters is a partnership between local communities with significant health inequalities, the NHS and the DH. The overall aim of the programme is to deliver equality and diversity improvements and innovations.

Box 13: Wave 1 of the Pacesetters Programme: breast cancer screening and people with learning disabilities in Walsall

Walsall Integrated Learning Disability Service (ILDS) realised that they had some significant work to do to improve the uptake of breast screening by women with a learning disability. The key aim of the project was to provide improved access and uptake to breast screening services in Walsall for women with a learning disability.

A collaborative approach was taken between key partners – The Health Facilitation Team and community nurses from Walsall ILDS and radiographers from the breast screening unit at Walsall Manor Hospital NHS Trust.

Engagement took place between female service users through the user group, “Making our Choice”, to find out what the barriers were to accessing screening services. Simple, practical steps rather than complex interventions were identified that users felt could make a real difference. These included:

- awareness training for breast screening staff
- “easy read” invitation letters and information material
- health promotion groups
- pre-familiarisation visits to help users overcome fear of the unknown
- collaborative clinics facilitated by community learning disability nurses to support users and screening staff.

Both qualitative and quantitative data were collected as part of the evaluation of the project.

So what was the outcome? In 1997, 62 women with a learning disability were eligible for breast screening but only 19 (31%) were screened. Following the project, in 2007-08 the uptake for screening by women with a learning disability, able or wanting to be screened increased to 100% (54 successful screenings undertaken).

The challenge now is to embed the lessons learned, maintain the improvement and share the learning with other learning disability Trusts in the NHS.

6.6 As part of Pacesetters Wave 2, the following cancer issues have been identified to help reduce inequalities:

- breast screening in the over 70s
- breast screening in BME women
- cervical screening for lesbians
- screening for trans-men and trans-women
- palliative care for cancer patients from faith groups.

Local action

6.7 Cancer Networks, with PCTs, are reviewing the percentage change in mortality rates since 1997, in order to assess their contribution to achieving the 2010 PSA targets: to reduce cancer mortality and health inequalities in cancer and to improve life expectancy. Understanding progress and variations between Cancer Networks and PCTs will underpin how they, with PCTs, agree challenging goals for reducing cancer mortality in every Network area by 2012.

6.8 An example of action is set out in box 14 below:

Box 14: Inequalities in early detection and prevention: experience in Merseyside and Cheshire

Context:

Inequalities exist in cancer incidence, survival and mortality

- incidence of common cancers such as lung cancer, vary more than twofold with social and economic advantage
- survival for common cancers such as bowel cancer is worse in poorer areas
- death rates from cancer are much higher in cities in the North West

And in how much different people take advantage of cancer screening

- for example, people with mental health problems or learning disabilities are less likely to be invited, and need more support, to participate in cancer screening.

One Cancer Network in England invested in a Health Inequalities Manager in 2005, and engaged with Directors of Public Health to commission strategic public health leadership in the Cancer Network team.

These individuals worked together to propose and deliver a strategy to reduce inequalities in cancer incidence and survival. The strategy was designed by the Network's stakeholders including patients, clinicians and managers.

The strategy prioritised six cancers where inequalities are significant. These were breast, lung, bladder, cervix, bowel cancer and malignant melanoma.

Five themes were chosen. These were screening, healthy schools, social marketing, symptom awareness and risk, and staging.

The strategy is being delivered through numerous organisations and people. Local NHS organisations have signed up at the highest level to support the strategy. We have a two year action plan which is being delivered by task and finish groups.

For example, PCT screening leads have agreed to tackle inequalities in performance between different general practices, and to target the never screened, because they are most likely to benefit.

The Network is committed to continuing wide stakeholder involvement. It has decided to manage performance through annual stakeholder reviews, the first of which occurred in October 2008.

Existing programmes and local initiatives have been extended across the Network area, and some important new ideas have been tested and implemented.

For example, the Network has developed and shared a DVD about bowel screening in several languages including British Sign Language. The Network has commissioned a social marketing team to develop a cancer specific approach that will influence lifestyle behaviours and choices.

Ethnicity

6.9 The eight Cancer Registries in England have worked with the National Cancer Services Analysis Team and the Public Health Observatories to examine, evaluate and exploit the use of patient-level coded ethnicity data, which is held in the Hospital Episodes Statistics (HES) data held by the NHS Information Centre.

6.10 The National Cancer Intelligence Network (NCIN) funded the development work to undertake national-level data linkage, to link cancer registry and HES data for the latest ten years of data (up to 2005). The resulting work has been fed back to all the eight regional Cancer Registries, which are uploading the ethnicity data into their data systems.

6.11 Through the NCIN, routine access to all prospectively recorded ethnicity data will be available to all eight Cancer Registries, to ensure that where ethnicity data is recorded in hospitals, this data is electronically routed to the registries, through the HES dataset.

6.12 The Thames Cancer Registry has done several studies of cancer incidence, care and outcomes in relation to ethnicity and reports from the studies are due to be published in 2009. The studies focus particularly on breast and prostate cancer and will help to show the incidence and survival rates in different BME groups, mainly Black and Asian people. In general terms, the studies show that in South East England:

- Asian and black women have a lower incidence of breast cancer than white women
- young women have more similar rates than older women (suggesting a migration effect with convergence towards the local rate)
- black women have significantly worse survival than white women (this is attributable to deprivation and stage differences)

- prostate cancer incidence is generally consistent with international patterns of variation
- black men have rates twice those in white men while Asian men have lower rates
- survival is similar in white and black men, and Asian men have higher survival.

6.13 The National Cancer Action Team (NCAT) working with Cancer Black Care and other BME cancer charities are developing a National BME Cancer Patient Advisory Panel. The panel will provide BME cancer patients and their carers with an opportunity to voice their experiences of cancer services across England in a facilitative way. It will also provide a space for feedback from BME patients and carers, to be used by service providers to improve the way services are provided and developed for diverse groups of cancer patients and carers.

6.14 The Panel builds on a BME cancer charities meeting held in January 2008 and addresses the under-representation of BME patients and carers in traditional methods and modes of engagement with the NHS. It will provide a national voice to this group of patients and provide a much needed vehicle for the NHS to engage with diverse groups of cancer patients and carers.

Clinical trials

6.15 In line with a commitment in the CRS to encourage recruitment of older people into clinical trials, a joint project between the National Cancer Research Network, the Northern and Yorkshire Cancer Registry and the NCIN has started to pilot the linkage of clinical trials data with Cancer Registry data. This will allow the monitoring of entry rates into clinical trials (both randomised and observational) to compare the demographics and tumour characteristics against underlying population based incidence. This work will examine geographic, age, ethnic and socio-economic characteristics of patients in trials, comparing characteristics of trial entrants with those of non-entrants.

6.16 The project will additionally:

- produce an evaluation of the potential for following up patients who have been in clinical trials over long periods
- assess the quality, reliability and reproducibility of data available in the NHS datasets against the data collected in clinical trials.

Chapter 7: Delivering care in the most appropriate setting

Progress:

- Establishment of NHS Improvement project to transform inpatient care for cancer patients

Priorities for the coming year:

- Significant improvements in inpatient care
- Improving MDT working

Introduction

7.1 New models of care can bring significant advantages to patients and release resources for other developments. The Cancer Reform Strategy (CRS) set out a number of actions to deliver care in the most appropriate setting, and this chapter reports on progress.

Inpatient care

7.2 The CRS identified that:

- little attention had been given to cancer inpatient care to date
- England had higher bed utilisation for cancer than other countries and that this accounted for a large proportion of total cancer expenditure
- over 14,000 cancer patients were in hospital at any one time
- this equated to around 29 occupied beds per 100,000 population and around 435 for a Network with a population of 1.5 million
- 60% of these beds were occupied by patients admitted non-electively

- inpatient care for cancer patients accounted for 12% of all inpatient bed days
- most people diagnosed or suspected to have cancer had at least one admission into hospital.

7.3 Previous testing work carried out by NHS Improvement and the National Cancer Action Team (NCAT) identified opportunities to improve the quality of the inpatient experience and improve the efficiency and effectiveness of the elective and emergency inpatient pathway. The learning from this early work led to a national programme being established with a specific focus on transforming inpatient cancer care.

7.4 The Transforming Inpatient Care programme covers six major work streams:

- patient experience – to commence with a baseline assessment
- new models of care
- commissioning
- research and evaluation

- new clinical approaches
- information/data performance including the impact of service improvement.

7.5 The programme is supported by NHS Improvement and the NCAT, working with users, charities, professional bodies and partners in health and social care. It was launched in October 2008.

7.6 The new models of care work stream aims to focus on testing new ideas to reduce length of stay, avert emergency admissions, deliver care in the most appropriate setting and develop models of care delivery that improve quality and value the patient's time.

7.7 To date the work stream involves:

- 34 organisations
- covering over 58 geographical sites
- 22 sites testing new ideas
- 15 sites spreading the winning principles (see box 15)
- 26 sites testing sustainability of tested improvements
- further specific pilots focused on haematology & oncology.

Box 15: The NHS Improvement four winning principles

1. Unscheduled (emergency patients) should be assessed prior to the decision to admit. Emergency admission should be the exception not the norm.
2. Patients should be on defined inpatient pathways based on their tumour type and reasons for admission.
3. Clinical decisions should be made on a daily basis to promote proactive case management.
4. Patient and carers need to know about their condition and symptoms to encourage self-management and to know who to contact when needed.

7.8 Examples of the type of changes that have been achieved are set out in box 16 below:

Box 16: Improving inpatient care examples

Winning Principle 1. Sherwood Forest Hospital NHS Foundation Trust

The Trust reduced the average length of stay by 25% for lung cancer patients by developing and testing a Recurring Admission Patient Alert System (RAPA) and identified the potential to release 560 bed days per annum. The success of this approach has now been implemented across the whole hospital and won the 2007 Medical Innovation Futures Award.

“RAPA is a simple communication solution that ensures that everyone knows their patient is there. It has worked successfully in cancer and now the idea is used across other specialties.”

Winning Principle 2. Sandwell & West Birmingham Hospital NHS Trust

The Trust reduced the average length of stay for breast cancer patients undergoing elective surgery (including mastectomy patients) from 6.6 days to 23 hours. Approximately 300 patients a year will benefit. All breast cancer patients are now treated in the treatment centre. Changes in clinical practice have supported this development with robust pre-operative screening and wound drains are no longer inserted. Current medical audit of this approach has shown a reduction in hospital acquired infection and patients' satisfaction with this new model of care has been very positive.

“The 23 hour stay was universally popular with patients from all backgrounds.”

Winning Principle 3. Improving bed utilisation of oncology beds – Brighton and Sussex University Hospitals NHS Trust and the Sussex Cancer Network

The second half of 2007 and early 2008 saw the team at Brighton and Sussex University Hospital participating in the national Cancer Collaborative “Inpatient Experience” work stream to identify what makes a difference to the cancer inpatient experience. As one of the national pilot sites the team, supported by a service improvement facilitator from the Sussex Cancer Network, set out to test the following principle: could “timely decision making” improve access and reduce length of stay? The focus was oncology inpatients in Howard 1 ward.

Baseline – there were two areas identified where it was felt improvements could be made. One related to “access”, where only half of elective patients were normally admitted on their original planned date (“clinical priority” patients were among those deferred). The other related to patient discharge, where about a third of elective patients stayed beyond their planned discharge date. The average overstay was around half a day. The baseline measure for average stay was 2.92 bed days per patient.

Changes – with support from the oncologists, several changes were implemented, which have now become normal working practice:

“Admission Priorities criteria” were produced, with a reference chart to automate the decision-making process, ensure admission based upon clinical priority, to help forecast and manage patient flow and help take emotion out of the decision making.

Benchmark length of stay periods by treatment were established and processes introduced to use the benchmarks for improved discharge management. This involved the setting up of a weekly inpatient review meeting involving oncologists, including the patients' planned discharge date on shift handover sheets, daily “paper” ward round attended by the ward team, and an escalation procedure if discharge overstay is likely.

Outcome – the changes produced significant improvements in both areas of access and discharge and an informal review in February 2008 (post-pilot) indicated an encouraging level of sustainability.

The number of all elective patients normally admitted on their original planned date rose from 58% to 81%. The priority patients went from 64% to 93%. For the patients that were deferred, the average wait reduced from 3 days to 1 day.

The proportion of patients exceeding their planned discharge date reduced from 29% to 5%. The average overstay reduced from half a day to virtually zero and the average stay was 2.4 bed days per patient.

Recognition – the team's achievement was recognised by winning the South East Coast Strategic Health Authority Health & Social Care Regional Award 2008 for the Improving Inpatient Care category. The success can be put down to excellent examples of leadership, commitment and enthusiastic support from all involved.

Winning Principle 4 – Blackpool, Fylde & Wyre Hospitals NHS Foundation Trust

Tested multiple approaches involving patients and clinicians to reduce mortality and length of stay through developing an emergency pathway for the management of emergency patients with neutropenic sepsis. This work included development of a DVD about neutropenic sepsis featuring patients.

Winner of the 2007 Blackpool Fylde & Wyre Innovation Award

The approach to improving the emergency pathway for patients with Neutropenic Sepsis is underpinned by an agreed Neutropenic Sepsis Management Policy, listening and using the views of our patients.

This DVD is a good idea verbal information and leaflets don't really sink in because it is such a difficult time. You can't take it all in it is a bit too much, but I think the DVD will stick in people's minds. Husband of a patient

Thanks for the DVD which I found very powerful. Every patient on chemo should have a copy. Diana's statement that "I didn't want to be any trouble, because they are so busy" rang very true to me and it could have been my late wife speaking. Husband of a patient

I do think it is important that it is patients that feature on the DVD. I thought I knew better and didn't follow all the written advice but that's what patients need to do. Patient

The patients' stories in the DVD are very powerful and make much more impact on other patients and carers understanding of the importance of presenting early. Lead cancer nurse

Neutropenic Sepsis - Reduce mortality - Reduce length of stay (LOS)

<p>Late emergency presentation</p> <p>High risk of mortality</p>	<p>Aim</p> <p>Improve patient awareness/promote early presentation, self management and patient's confidence</p> <p>Save lives</p>	<p>Tested solutions</p> <p>Promote self management and confidence in the system</p> <ul style="list-style-type: none"> • Patient held alert card • 24 hour help line • Patient experience DVD created by patients for patients 	<p>Impact</p> <p>Cancer Partnership Group undergoing audit of patient views - positive feedback</p> <p>Divisional audit on neutropenic sepsis to include presentation times</p>
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<p>Multiple emergency access points</p> <p>Only 42% of patients go to the right place first time</p>	<p>Aim</p> <p>Right place, first time</p> <p>Improve patient, primary and secondary care awareness</p>	<p>Tested solutions</p> <ul style="list-style-type: none"> • One entry point • Direct admission to ward • Awareness campaign to GPs • Press release • Direct admission policy • Neutropenic sepsis management policy 	<p>Impact</p> <p>100% admitted went to designated ward</p>
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<p>Delay in treatment</p> <p>Only 8% of admissions received antibiotics within an hour of admission</p>	<p>Aim</p> <p>Improve door to treatment time for 100% of patients</p>	<p>Tested solutions</p> <ul style="list-style-type: none"> • Patient group directive for antibiotics given at point of entry by nurse 	<p>Impact</p> <p>55% of patient's received antibiotics within an hour of arrival</p> <ul style="list-style-type: none"> • No deaths
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Box 17: Andy's reflections

My name is Andy Millward. I am a 55 year old man who was diagnosed in October 2004 with metastatic prostate cancer, a form of cancer that was so advanced that I was only given eighteen months to two years to live. I am very fortunate in that I have thus far been able to defeat that timetable and prognosis, but the majority of my subsequent treatment has been successfully managed whilst at home, which is very much where I, along with many others on similar cancer journeys, wish to be. I have had two hospital admissions since then, both via the emergency pathways at my local hospitals and both admissions related primarily to severe pain. The process of accessing in-patient care was both difficult and traumatic for both my wife and I and unnecessarily burdensome, as we had to negotiate very different processes and locations to eventually arrive at the oncology ward that could attend to my specific difficulties.

I cannot fault the level of care offered as an inpatient (and in line with many of the audits that I know have been carried out, some of my time was spent unnecessarily on general medicine wards). However, whilst recognizing that staff who have responsibility for us have serious considerations of risk and clinical governance to consider, I think we as patients could be given more responsibility and innovative resources to manage more at home. From experience, I do also believe that I could very easily have been discharged sooner, thereby shortening my length of stay. This is the real challenge for all of us and I therefore warmly welcome the launch of the national strategy on in-patient care and potential likely alternatives to managing cancer journeys like my own away from hospital. We also need to ensure that even if acute admission is absolutely necessary – and not just a default position of the system – that treatment and care in hospital is kept to an absolute minimum.

7.9 It is important to emphasise that the patient's needs and wishes are at the centre of the improvements to the work on delivering care in the most appropriate setting. Box 17 sets out one cancer patient's view about his experiences with inpatient care.

Multidisciplinary team working

7.10 The CRS noted that, while multidisciplinary teams (MDTs) were now well established as the core model for cancer service delivery, more needed to be done to ensure that they were working effectively. The NCAT is leading a new project to determine "what makes a good MDT". The aim of this project is to:

- identify domains/themes that are essential for a good/high performing MDT
- agree how best to measure an MDT against each domain/theme
- provide support/tools to help MDTs to reach and maintain a high level of performance in each domain/theme.

7.11 The project is starting by seeking views from stakeholders (including all cancer MDTs) about what makes a good MDT and the support needed to achieve this. A company has been commissioned to run the questionnaire process, which should begin shortly and report early in 2009.

7.12 It is intended to hold workshops in the Spring of 2009 to discuss the outcome of this exercise and identify potential next steps. A programme of action for 2009/10 will then be agreed.

7.13 In addition the *Manual for Cancer Services* includes a series of measures relating to MDT structures and processes which Networks are assessed against as part of the national cancer peer review programme (see chapter 9).

Integration of satellite centres

7.14 The CRS said – with the increasing development of service models to provide care outside of hospital settings – commissioners should ensure that any satellite services

should be fully integrated with other services within the Cancer Network. To support such integration, the NCAT have developed a tool that consists of a Commissioning Framework, Service Specification and Patient Pathway. In addition, a further tool is being developed which will support Networks and commissioners in analysing the requirements to meet their current and future population needs. Taken together, the tools will ensure that services developed within a Network are planned and appropriate.

Other issues

7.15 In discussing progress in terms of delivering care in the most appropriate setting, Advisory Board members raised a number of important issues:

- as highlighted above, most cancer patients are keen to spend as little time as possible in hospital, and so delivering on this agenda is very much part of improving the patient experience
- primary care engagement is central to avoiding unnecessary admissions
- the linkages between this programme of work and the rest of the CRS programme, particularly in terms of early diagnosis and the survivorship agenda
- the role of local authorities in enabling people to leave hospital as quickly as possible
- the need for care trackers to help people navigate their way through complex care systems
- the links between delivering care in the most appropriate setting and much of the Next Stage Review agenda.

7.16 The national cancer programme will take account of each of these points over the coming year.

Chapter 8: Information to improve quality and choice

Progress:

- The National Cancer Intelligence Network has been established

Priorities for the coming year:

- Maximising the potential of the National Cancer Intelligence Network

Introduction

8.1 Better information on cancer services and outcomes enhances patient choice, drives up service quality and underpins stronger commissioning. Improved data collection, analysis and feedback was identified as one of the key drivers for implementation of the Cancer Reform Strategy (CRS). To achieve this, the CRS set out a range of actions to improve information, and this chapter reports on progress.

Establishment of the National Cancer Intelligence Network

8.2 To underpin the information requirements set out in the CRS, the National Cancer Intelligence Network (NCIN) was launched in June 2008 at a conference in London attended by over 450 people from the NHS, charities, patients, carers and other stakeholders.

8.3 The core objectives of the NCIN are:

- promoting efficient and effective data collection throughout the cancer journey
- providing a common national repository for cancer datasets

- producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
- exploiting information to drive improvements in standards of cancer care and clinical outcomes
- enabling use of cancer information to support audit and research programmes.

8.4 Although the NCIN is funded by the Department of Health (DH), it is managed as part of the wider National Cancer Research Institute. This maximises opportunities for research on cancer services and enables NCIN to contribute to UK-wide projects. A lead clinician has been appointed, to drive the work of the NCIN forward with clinical and professional groups, with a Scientific Advisory Group to oversee and ensure the scientific merit of NCIN outputs.

8.5 While NCIN will have its own organisational identity and infrastructure, many NCIN outputs will be a product of collaborations with partner organisations for example, with the National Cancer Action Team (NCAT), NHS Improvement, individual Cancer Registries, the United Kingdom Association of Cancer Registries, Cancer Research UK, the Office for National Statistics as well as academic groups

(eg the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine).

National repository

8.6 Working with the Cancer Registries, the NCIN has developed a new national repository of cancer data, which for the first time has linked data on incidence (routinely available from cancer registries) with activity (data collected by NHS Trusts and available through Hospital Episode Statistics). A series of workshops have explored the potential of this combined data, which covers the most recent 10 years of available data. Cancer Registries and NCIN partners will develop work plans to produce key national and local analyses in specific tumour and cross-cutting areas.

National Cancer e-Atlas launched

8.7 In July 2008 the NCIN launched the online National Cancer e-Atlas, a collaboration between NCIN, the cancer registries and the public health observatories. Available free on the internet, the e-Atlas provides quick and easy access to cancer statistics, using a simple point and click approach. We have already seen significant use of the tool and have received interest from outside the UK in extending this into international data. (www.ncin.org.uk/eatlas)

National Cancer Information Service

8.8 The Cancer Registries have developed a new National Cancer Information Service, aimed at NHS clinicians and clinical teams. This NHS-only (because of patient confidentiality issues) online system makes available cancer incidence, mortality and survival information for England and by Strategic Health Authority (SHA), Primary Care Trust (PCT) and Cancer Network, covering all major tumour types, with trend data from 1985.

Publication of incidence and mortality rates by Cancer Network

8.9 In 2008 the NCIN produced its first report on incidence and mortality for the major types of cancer (together with all malignancies combined for all age groups, children and teenagers and young adults). This included information from all four nations within the United Kingdom, analysing 2005 cancer incidence and mortality rates for the 30 Cancer Networks in England with comparable information from the seven Cancer Networks in Scotland, Wales and Northern Ireland.

Cancer Commissioning Toolkit

8.10 An electronic toolkit, bringing together information on cancer in an accessible and usable way to enable the benchmarking of services and to inform commissioning, has been developed. For more information, see chapter 9.

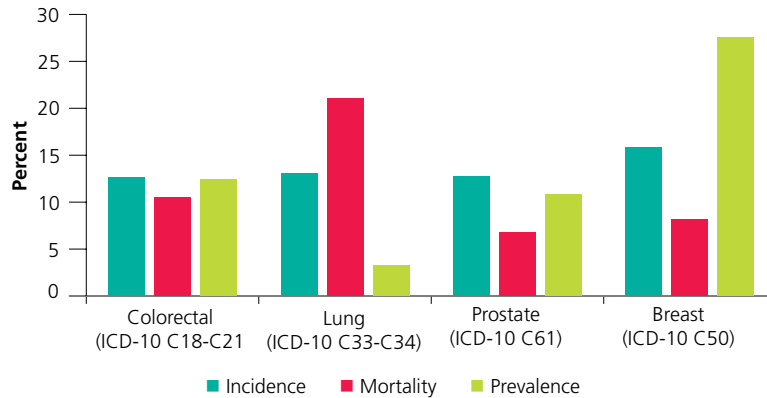
Publication of one-year survival by Cancer Networks

8.11 The NCIN has published analyses of the trends in one-year survival rates for different cancers, for all the Cancer Networks in England. One-year survival has always been thought of as a proxy indicator for early/late diagnosis. As the collection of reliable pre-treatment staging data becomes a reality more sensitive clinical outcomes analyses will be feasible.

Understanding cancer prevalence

8.12 Having already published new national analyses of cancer incidence and mortality for 2005 by Cancer Network, the NCIN, working with Macmillan Cancer Support and the Thames Cancer Registry, have published new analyses which describe the overall prevalence of cancer in the UK. The understanding of the number of those living with cancer is essential for the planning of cancer and support services, and further work is under way with Macmillan and the Thames Registry to extend this work to provide additional detail and projections of future numbers.

Burden of disease from four major cancers
Proportion of total incidence, mortality and prevalence contributed to by each of the four major cancers in England, 2004



Note: Incidence and mortality figures obtained from the National Cancer Information Service

Supporting effective data collection

8.13 One of the key commitments in the CRS was that datasets (eg for staging, radiotherapy and chemotherapy) should be defined and that collection of these datasets should be mandated. An ongoing work programme has been established with the eight English Cancer Registries and 30 Cancer Networks to implement this, in collaboration with all multidisciplinary teams (MDTs). During 2008, all organisations are reviewing the overall data requirements, examining where these data exist within hospital systems and the most appropriate way to collect, collate, utilise and export these (this will be done with the involvement of the Information Standards Board for Health and Social Care).

8.14 All Trusts and Cancer Registries are working towards the provision of data electronically, with appropriate key data items provided electronically by 2009. As all eight Registries and the provider Trusts within the 30 Networks are at different stages with regard to electronic data capture and transfer, this will be a phased but focused approach.

8.15 To ensure that the required cancer data are not perceived as separate from other NHS data requirements, the data will be incorporated where feasible within standard commissioning datasets and flows for payment by results (PbR). This definitional work is being undertaken in collaboration with the NHS Information Centre and Connecting for Health.

8.16 The radiotherapy dataset will begin to be collected from April 2009 (see chapter 4). To ensure the data is able to “flow” in line with other NHS activity, the radiotherapy data has been incorporated within the Outpatient Commissioning Dataset which feeds PbR.

8.17 Work is underway with a group of clinicians to agree a dataset for chemotherapy. The contents of the National Cancer Dataset have been benchmarked against the two main providers of e-prescribing systems. It is planned that a draft dataset is produced before the end of 2008/09 which will be shared with the National Chemotherapy Advisory Group before going out for consultation.

8.18 Once the dataset has been approved by clinical teams, consultation will then take place during the first half of 2009, with the aim of implementation in 2010.

Supporting MDTs in improving data collection

8.19 The NCAT and the NCIN have held a series of events to discuss the provision of key data collected at the MDT meeting to cancer registries, clinical audits and for cancer waits. All Cancer Networks and cancer registries are involved in this work. The NCIN will continue to coordinate this programme with six monthly reviews in each region.

8.20 In addition, the NCAT and the NCIN are supporting the national MDT Coordinators Taskforce to understand the optimal mechanisms by which data can be recorded as part of MDT working and made available in an efficient manner. Working closely with the Going Further on Cancer Waits work stream, work is underway to utilise existing national data flows to “carry” this key data from MDTs, and to make this available for audit and analysis, by local clinical networks and, through the Cancer Registries, by the NCIN.

8.21 NCIN clinical reference groups are being established for each tumour group. Their remit will include the review of all potential data items to ensure any additional data collection is kept to an essential minimum and to eliminate duplication of existing data collection processes.

Planned analyses from the NCIN

8.22 The NCIN is already working on the production of incidence and mortality data according to deprivation and analyses of PCT cancer spend against incidence/mortality. Other specific analyses which are already in progress, both within NCIN and with NCIN partners, include:

- prevalence (30-year) as at 2005, England and by SHA and Cancer Network – all major sites (Thames Cancer Registry and Macmillan Cancer Support)

- ethnicity cancer statistics (Cancer Research UK, NCIN, Thames Cancer Registry and Northern and Yorkshire Cancer Registry and Information Service)
- teenage and young adult cancer statistics (Cancer Research UK and the North West Cancer Information Service)
- statistics for rarer cancers (Cancer Research UK and Rarer Cancers Forum).

Making Information available

8.23 All the information that has been produced by NCIN is available through NCIN and partner organisations.

8.24 The NCIN will continue to work with its partners to ensure that analyses which are produced will be accessible through a wide range of media, including printed output and the web. A dedicated press office is in place to ensure all enquiries are handled quickly and effectively, and to ensure the work of the NCIN is made available to the widest audience possible.

First year progress

8.25 While there is much more work to be done, the CRS Advisory Board noted in particular the very important work being carried out by the NCIN in its first year and looked forward to its future work.

Chapter 9: Stronger commissioning

Progress:

- Launch of Cancer Commissioning Toolkit
- National Cancer Peer Review results for 2004/2007 published June 2008

Priorities for the coming year:

- Cancer Commissioning Guidance to be available shortly
- Further work to promote stronger commissioning
- Promoting user involvement in commissioning
- New peer review process

Introduction

9.1 Stronger commissioning was identified as a second major lever (alongside better information) for driving up the quality of cancer care. The Cancer Reform Strategy (CRS) set out central and local actions to improve commissioning of cancer services, and this chapter reports on progress.

Enabling stronger cancer commissioning

9.2 The National Cancer Action Team (NCAT) is working with the Department of Health (DH) World Class Commissioning (WCC) Team to support the step change that Primary Care Trusts (PCTs) and their Cancer Network teams will want to make in commissioning cancer services. Draft Cancer Commissioning Guidance (CCG) has been issued to Cancer Networks and a final version will be available shortly. The CCG is in two parts:

- the first section highlights aspects of the WCC Assurance Framework, including the organisational competences that those

involved in cancer commissioning will want to focus on

- the second section sets out key issues and key questions commissioners/network teams will want to take into consideration when assessing health needs; reviewing services; developing their contract service specifications and monitoring performance.

9.3 In addition, a web-based Cancer Commissioning Toolkit (CCT) is available. The toolkit provides an easily accessible “one stop” source of cancer information. This overcomes the challenge that national information on cancer, although publicly available, is currently held in several different places (cancer registry, cancer screening service, hospital episode statistics, cancer peer review, programme budgeting, bespoke national analyses etc). The CCT brings this together into a single, web based product. Metrics have been selected and benchmarked to answer key commissioning questions. The aim is to support commissioners/Cancer Network teams in their strategic planning and prioritisation,

enabling them to lead change and innovate locally, based on best clinical evidence. The benchmarked information will inevitably prompt further questions, but it is hoped that it will act as a catalyst for intelligent discussion between commissioners, local providers and the local population.

9.4 The NCAT and National Cancer Intelligence Network (NCIN) will support PCTs, Cancer Networks and other stakeholders to use the toolkit and will continue to work with them on further refinements and developments. It is hoped that by making more use of the information that is available, data accuracy will improve year on year. Significant support in developing the information has come from the National Cancer Service Analysis Team, as well as the Cancer Registries and the NHS Cancer Screening Programmes.

9.5 A further important strand of work being led by Cancer Network teams is the development of model service specifications for each cancer pathway, which will be available on the Map of Medicine (MofM). Map of Medicine offers high quality clinical information, linked to the NHS IT programme. The Network Development Programme recommended colorectal pathway is already on the MofM and this, together with an

overall methodology and governance framework, has been developed by North East London Cancer Network and MofM and supported by the National Institute for Health and Clinical Excellence (NICE). It is anticipated that model disease pathways and service specifications for the main cancers will be available on the MofM by December 2008 to support the next round of contracting. Individual Cancer Networks are leading on the development of different pathways, within an agreed framework for sign-off that includes NICE.

9.6 Throughout the CCG and CCT there are links to policy and guidance documents as well as to the NHS Improvement website to ensure that PCTs and Networks have ready access to best practice examples of service innovation.

9.7 In discussion with the CRS Advisory Board, it was pointed out that, although all Cancer Networks had plans to implement the CRS, those plans did not necessarily feed through into PCT commissioning plans. Further work is needed on this link. The NCAT will continue to work with Cancer Networks, PCTs and others to promote stronger commissioning. The PCT Chief Executives who act as chairs of the Cancer Networks plan to consider next steps in terms of promoting better commissioning of cancer services.

Box 18: Commissioning in North East London Cancer Network

In the North East London Cancer Network (NELCN), all PCTs will benchmark existing cancer pathways against the Network agreed clinically effective pathways and then identify differences and gaps which are prioritised for tackling. The locally agreed pathway is what is then commissioned.

There are some 30 Network pathways, with agreed audit metrics/key performance indicators. These have been developed by cancer site specific Tumour Advisory Boards (TABs) who will maintain and update them and who have also agreed the metrics against which they will now monitor compliance. These TABs are central to the pathway level clinical governance of the Network and the NELCN Service Specification for Cancer, together with National Peer Review measures, requires that providers make representatives of clinical teams available to attend these groups in the capacity of clinical advisors to commissioning.

The NELCN Service Specification for Cancer – which is used by all PCTs in their NHS Contracts – sets out clearly what is expected of providers. The Specification includes governing principles, criteria which should be met by any provider wishing to offer cancer services, generic pathway specifications and site specific service specifications. The Service Specification is being reviewed and updated, to set out what PCTs should include in the 2009/10 contracts. This will include the integration of national exemplar specifications for both chemotherapy and radiotherapy as they are published.

User involvement

9.8 The NCAT has set up a project to promote user involvement in commissioning.

9.9 In discussing user involvement in commissioning with the CRS Advisory Board, members made the point that it was very positive that user involvement was a core WCC competence. As part of the promotion of user involvement, the patient representatives on the Advisory Board have offered to review Cancer Network plans for user involvement.

Peer review

9.10 The Cancer Peer Review Programme provides an important mechanism for assessing individual teams and services against measures which are linked to service quality. Feedback from peer review provides a useful stimulus to providers to enhance the quality of the care they provide. Comparisons of the quality of local services with national benchmarks is likely to be of value to commissioners.

9.11 The national overview report on the Peer Review Programme 2004/07 was published in June 2008. This covers all the Cancer Networks in England; 1069 multidisciplinary teams (MDTs) (breast, colorectal, lung, gynaecology, upper GI and urology), 1051 cross cutting services (imaging, pathology, radiotherapy, chemotherapy, specialist palliative care) and eight Cancer Registries. A great deal of good practice was observed, but also wide variation in compliance with measures.

9.12 The peer review team has identified and congratulated the best services, and followed up with those services where there were some concerns – recognising that things may well have moved on since the peer review assessment.

9.13 For the future, there will be a 3-staged approach to peer review with:

- the first stage being validated self assessments completed annually by all teams and cross cutting services such as chemotherapy and radiotherapy

- the second stage to be an external verification of a sample of the self assessments
- the third stage to be a programme of targeted peer review visits using agreed selection criteria and following discussion with the appropriate cancer networks.

9.14 This new approach will mean that more teams and services will be reviewed, and will be reviewed more frequently, while keeping the burden of review within reasonable limits.

9.15 The first phase of implementation of the new approach to peer review will begin in January 2009.

Ensuring that tariffs support service improvements

9.16 The CRS said that the funding mechanism for cancer services should recognise and incentivise appropriate and effective care.

9.17 PA Consulting Group was commissioned to assess whether amendments are needed to payment by results so that it fully supports future cancer services. They reported in January 2008 and identified six priority issues:

- improving coding quality and consistency
- ensuring fair payment for MDTs
- ensuring the structure of tariffs for chemotherapy drugs work in practice
- separation from tariff of investment cost of radiotherapy bunkers
- a separate cancer outpatient tariff in key specialties
- fair payment for highly complex cancer procedures.

9.18 The Information Centre (IC) has also recently re-established its Cancer Expert Reference Panel. The NCAT is fully engaged with the process and has worked closely with colleagues within radiotherapy and

chemotherapy services to develop improvements around coding and other principles. There are working groups across these two areas co-ordinated by the NCAT which have made recommendations to the IC group. Members of each of the groups are drawn from clinical teams from Trusts and also their finance colleagues. To date these groups have agreed revised definitions of services and are supporting the development of guidance that goes out to the service.

9.19 Forty Trusts providing radiotherapy services have established a benchmarking club to accelerate the development of an appropriate tariff. There are also plans to develop a small benchmarking group for chemotherapy services.

9.20 Further work is under way and this will need to be prioritised in 2009.

Chapter 10: Funding world class cancer care

10.1 The Cancer Reform Strategy (CRS) reported an increase in cancer expenditure over the previous three years, as measured by programme budgeting. The figure for 2006/07 had been published a few weeks before the launch of the CRS and showed a 27% increase in expenditure over three years. Because of changes to the reference cost system, figures for 2007/08 have not yet been published. It is therefore not possible to provide an update. However, when the figures are available, further detailed work will be commissioned to explore reasons for variations in expenditure on cancer by Primary Care Trust.

Chapter 11: Building for the future

Introduction

11.1 While the Cancer Reform Strategy (CRS) set out a wide range of actions to improve cancer services and outcomes, it also recognised that the changing cancer environment meant that we would need to continue to assess progress and amend our approach in the light of developments. This chapter looks at issues for the future.

A skilled and flexible workforce

11.2 As the CRS said, in general, workforce development and the commissioning of training programmes is the responsibility of Strategic Health Authorities and Primary Care Trusts. However, where it makes sense to identify and commission training pilots at a national level, this would be done. For example, the Department of Health (DH) and the National Cancer Action Team (NCAT) have taken forward nationally the programme to pilot, evaluate and roll out surgical master classes relating to the treatment of prostate cancer. Other workforce developments have been reported in previous chapters. The DH and the NCAT will continue to have a national role when appropriate.

Develop environmental quality mark for good cancer facilities

11.3 Macmillan Cancer Support have appointed a project manager to oversee this piece of work. As a first step, a literature review is being undertaken to provide the evidence base for the impact of environments on patients and outcomes. Stakeholder events are planned to be held between January and April 2009. It is anticipated that a baseline assessment of current facilities will be undertaken in volunteer networks. A tool to assess facilities against

a standard will be developed with a view to piloting it before the end of the year. Links are being made with the DH Estates and Facilities teams, as an update of the Health Building Note on Cancer Facilities is currently being undertaken, and with Breakthrough Breast Cancer and their work on Service Pledges for Breast Cancer which also address environments.

Good horizon scanning

11.4 Two of the expert groups – prostate and breast – established to develop the site-specific visions for cancer services in 2012 have met again, and their discussions have fed into the implementation of the CRS and into thinking around this annual report. The DH plans to revisit the visions systematically for the future.

High quality cancer research

11.5 The DH is a key member of the National Cancer Research Institute (NCRI). The NCRI is a partnership of the UK's major funders of cancer research including government, charities and industry, together with patient representatives. Its purpose is to ensure a national strategic approach to cancer research. The DH is a major financial contributor to NCRI initiatives such as: the NCRI Prostate Cancer Collaboratives; the NCRI Supportive & Palliative Care (SuPaC) Collaboratives; the National Prevention Research Initiative; and initiatives in response to the NCRI report on Lung Cancer Research. The NCRI Strategic Plan for 2008-2013 includes new initiatives on survivorship; earlier diagnosis; and inequalities.

11.6 The National Institute for Healthcare Research (NIHR) Cancer Research Network continues to provide coordinated NHS infrastructure (staff and other NHS costs)

embedded in the cancer service networks to support later-phase clinical trials and other well designed studies in cancer. The latest information shows that about 11% of cancer patients in England are entering clinical studies – this is the highest percentage in the world.

11.7 The 15 NIHR/Cancer Research UK Experimental Cancer Medicine Centres (ECMCs) in England are together carrying out over 300 early-phase trials of new interventions for cancer. Their aim is to speed up the development of new therapies by evaluating novel drugs and biomarkers, thus individualising patient treatment. This year, the DH has committed an additional £8.5 million to the ECMCs, and other centres, in the form of NIHR capital funding for cancer equipment including imaging.

11.8 The NIHR has created twelve Biomedical Research Centres within our leading NHS and University partnerships to drive progress on innovation and translational research in biomedicine. The Royal Marsden Hospital/Institute of Cancer Research partnership has won NIHR Specialist Biomedical Research Centre status in cancer involving funding of £46 million over five years.

11.9 NIHR Senior Investigators are the most prestigious health and social care researchers. They make the most outstanding contribution to patient and people-focused health research. Twenty three of the first hundred NIHR Senior Investigators are cancer researchers.

Annual report for 2009

11.10 This first report on progress on implementation of the CRS necessarily focuses on the key commitments which require national coordination, together with some examples of progress at Cancer Network level. As the report shows, a great deal of progress has been made both nationally and locally. At Cancer Network level, one of the main priorities during 2008 has been to assess how best to incorporate new priorities from the CRS into local cancer strategies and commissioning plans. At the request of the CRS Advisory Board, the annual report for 2009 will have a greater focus on local implementation.

Annex

RELEVANT DOCUMENTS PUBLISHED SINCE THE PUBLICATION OF THE CANCER REFORM STRATEGY

- Transforming Inpatient Care Programme for Cancer Patients, The Winning Principles, NHS Improvement, April 2008
- NHS Cervical Screening Programme: Achieving a 14 day turnaround time for results by 2010, Department of Health, April 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/theweek/DH_084378
- Ensuring PbR supports delivery of effective cancer services. PbR final assessment – Recommendations and findings – final report, May 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086877
- Project Plans for Increasing Radiotherapy Capacity, National Cancer Action Team, August 2008 – www.cancer.nhs.uk/radiotherapy/commissioning.htm
- National Cancer Peer Review Programme 2004-2007. Overview of the findings from the second round of peer reviews of cancer services in England, National Cancer Action Team, June 2008 – www.cquins.nhs.uk/
- End of Life Care Strategy: Promoting high quality care for all adults at the end of life, Department of Health, July 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085307
- Health Inequalities: Progress and Next Steps, Department of Health, June 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- High quality care for all: NHS Next Stage Review, Department of Health, June 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
- Updated national guidance on the safe administration of intrathecal chemotherapy. HSC 2008/001, Department of Health, August 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_086870
- Key Messages for Ovarian Cancer, Department of Health, October 2008 – www.nhs.uk/Livewell/cancer/Pages/Ovariancancer.aspx
- Transforming Inpatient Care Programme for Cancer Patients – Meeting the Challenge together....delivering care in the most appropriate setting – supporting delivery, NHS Improvement, October 2008 – www.improvement.nhs.uk/cancer/documents/inpatients/Inpatients_Meeting_the_Challenges.pdf
- Improving access to medicines for NHS patients – A report for the Secretary of State for Health by Professor Mike Richards CBE, November 2008 – www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089927

- End of Life Care Strategy: Quality Markers Consultation, Department of Health, November 2008 – www.dh.gov.uk/en/Consultations/Liveconsultations/DH_090077
- Chemotherapy Services in England: Ensuring quality and safety – a report from the National Chemotherapy Advisory Group, November 2008 – www.dh.gov.uk/en/Consultations/Liveconsultations/DH_090150
- Cancer Commissioning Toolkit – www.cancertoolkit.co.uk/PublicPages/Login.aspx?ReturnUrl=%2fDefault.aspx&AspxAutoDetectCookieSupport=1

NCIN publications, available at www.ncin.org.uk:

- Publication of Incidence and Mortality by Cancer Network, June 2008
- Launch of the National Cancer e-Atlas, July 2008
- Publication of Cancer Prevalence in the UK, July 2008
- Publication of Incidence and Mortality for all UK Cancer Networks, October 2008
- Publication of 1 Year Survival by Cancer Networks, October 2008
- Publication of Trends in 1 Year Survival, October 2008
- Launch of the National Cancer Information Service (NCIS), October 2008



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