



# Improving cancer outcomes:

An analysis of the implementation  
of the UK's cancer strategies  
2006–2010



*Together we will beat cancer*

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## Foreword

The World Health Organisation asserts that each nation should have a cancer plan<sup>1</sup>: to highlight the burden of cancer in a given nation, to set policy direction, to oversee the allocation of resources for services and to help the workforce plan and deliver policy intentions.

Each UK nation and region currently agrees with this assertion and has a cancer strategy or plan aimed at improving cancer services and, ultimately, cancer outcomes.

Each plan was developed at a slightly different time and is at a different stage of implementation. The English *Cancer Reform Strategy*<sup>2</sup> was published in December 2007 and is now being refreshed by the Coalition Government. The current Scottish Strategy, *Better Cancer Care, An Action Plan*, was published in October 2008 and is being implemented. In Wales, *Designed to Tackle Cancer* was published in 2008 and is due to run until 2011. Finally, the Northern Irish *Cancer Control Programme* was published in 2007. A more detailed Framework is in development and is due to be published later in 2010 and, as such, this report does not consider the impact of the Cancer Service Framework, other than when it was referred to by research participants.

In each nation, the current cancer plan is a follow-up to previous plans or dedicated initiatives aimed at improving the way cancer services are formulated and delivered. Though the current plans are intended to be the strategic driver in cancer services, they do not operate in isolation, and there are a plethora of different plans, standards and guidance that complement the cancer strategies. For example, separate tobacco control plans and end of life strategies exist across the UK, which overlap and link with the current cancer plans.

This report seeks to critically appraise the implementation of the UK's cancer strategies, and to identify both gaps in the individual plans and differences between the nations – in terms of development and delivery – which might have an impact on future patient outcomes. We hope that it will facilitate the sharing of best practice in the delivery of cancer services and treatment between the nations and in particular that it will assist the Coalition Government in Westminster in developing some of the policy objectives set out in the recently published White Paper *Equity and Excellence: Liberating the NHS* and the Cancer Reform Strategy which is currently being updated.

Throughout our research, and as documented in this report, we have aimed to:

- Demonstrate how the UK governments are meeting commitments made in their national cancer strategies and highlight barriers to delivery and models of good practice;
- Monitor the progress of implementation of the four strategies in England, Scotland, Wales and Northern Ireland;
- Hold to account the responsible government where progress is shown to be slow;
- Identify changes in outcomes over the strategy periods, where possible; and
- Develop targeted recommendations for further action on issues seen as gaps in the plans.

<sup>1</sup> World Health Organisation (2002) *National Cancer Control Programmes: Policies and Managerial Guidelines* WHO: Geneva

<sup>2</sup> Department of Health (2007) *Cancer Reform Strategy* HM Stationery Office: London

To inform our thinking, we have undertaken qualitative research with relevant policy experts, senior managers, commissioners, academics, cancer network staff and multi-disciplinary team (MDTs) members including oncologists, surgeons, pathologists, nurses and GPs. We have also reviewed the relevant literature.

Our report argues that cancer plans are important to help drive improvements in cancer outcomes. In order for maximum effectiveness, we believe it is crucial that the cancer community comprehends and supports the strategy, and feels enabled, via the provision of sufficient guidance, levers and resource, to deliver its aims.

The report is intended to assist policy-makers and those responsible for allocating resource at local level to ensure that cancer services remain a priority during a financially challenging period for the NHS. In particular we hope the report will assist the Secretary of State for Health and the Minister for Cancer Services in England in drafting the refreshed Cancer Reform Strategy. The ultimate aim of the revised strategy, and any future strategies in the other nations, should be to ensure that the UK's outcomes are among the best in the world in the coming years.

### Structure of the report

In line with Cancer Research UK's organisational strategy, we have been particularly keen to understand what progress has been made at the beginning and middle of the patient pathway. We therefore collected more evidence about developments in the prevention, early diagnosis and treatment of cancer. We have reported less analysis about survivorship and progress in end of life care. The qualitative nature of our analysis also means that on some issues our recommendations are more detailed than others. This reflects the evidence we gathered and organisational expertise.

We do not comment on research policy, other than where research participants raised the need for further research to aid a particular service development. From our perspective, it should be a given that a thriving and well maintained research base is crucial to support excellent cancer services.

The report starts with a summary of findings and recommendations. We have included an overview of the findings from our fieldwork with health professionals. We follow with a chapter about the drivers of change. We briefly examine different tools put in place to support the development of cancer services, for example, multi-disciplinary teams, and assess their value. We then work through the patient pathway, beginning with cancer prevention, to summarise what the respective plans set out to achieve, what they have achieved to date, and what those we spoke to think about these achievements.

## Executive summary and recommendations

All four UK nations now have cancer plans which clearly set out aims, targets and solutions to improve cancer services. Each nation outlines different timelines for these improvements, and this report has critically appraised the implementation of cancer policy and identified gaps in the plans between the devolved nations which might have an impact on future patient outcomes. The plans in England and Scotland are more comprehensive than those in Wales and Northern Ireland.

The plans have achieved success in some areas. Overall, there is momentum among those working in cancer services and there is recognition that cancer services have improved significantly in recent years. The increase in resources has been welcomed. Standardisation in the delivery of treatment has taken place and there is increasing specialism in patient care.

However, the NHS must deliver efficiency savings and will need to improve quality, innovation, productivity and prevention to deliver the level of savings required to meet the increasing demands on the NHS and demographic pressures. This was an issue which was evident in many of the interviews undertaken as part of this research; how extra demand on services will be resourced was seriously questioned.

Some progress on cancer prevention has been made across the UK, most notably with the introduction of tobacco control measures, but it is also a challenging area, with corporate, political and social barriers to overcome. Other lifestyle factors that influence the risk of developing cancer, such as obesity, are perceived to be more difficult to influence. Many do not see it as within their remit to try. The plans have helped raise the profile of cancer prevention among the cancer workforce. However, there needs to be political will to take heed of the evidence in this area and to regulate where necessary. There must also be further work to reduce cancer inequalities.

The UK has world-class screening programmes of which we should be proud. There have been significant improvements to the screening programmes in recent years but concerns remain about national differences between the programmes in terms of the age at which some programmes are offered. We need to maintain our tradition of funding excellent research in this area and rapidly adopting new technologies and screening interventions where the evidence supports this.

Familiarity with the National Awareness and Early Diagnosis Initiative (NAEDI) in England is reasonably widespread. Some clinicians are involved in the Primary Care Audit as part of this and there is an expectation, especially in Cancer Networks, that this will yield very valuable data. Scotland, Wales and Northern Ireland need to prioritise the early diagnosis of cancer.

Improving cancer treatment has been a focus for a number of years and is seen as a strong component in the patient pathway. Chemotherapy has developed rapidly in recent years, offering new hope to many more patients. However, the increase in the use of chemotherapy has put a degree of stress on the services delivering it, and there is debate about the delivery of ambulatory chemotherapy and the use of mobile units. Radiotherapy capacity is even more of a concern; the building of new units is a major undertaking, and there remains a shortage of trained staff in many areas. There is a problem with access to new technologies, such as intensity modulated radiotherapy treatment (IMRT), in some parts of the country, which is a consequence of workforce planning issues. Surgery has become increasingly specialised, though new cancer surgeons are not receiving the same training time as their predecessors.

The commissioning of cancer services is a complex area and this research has not fully explored the associated complexities, but it is clear that for robust commissioning to be in place there is a need for better data, as well as more analytical capability to effectively make use of the data. The commissioning of new treatments and chemotherapy activity is a specialist activity; Cancer Networks should be better utilised to advise on the commissioning of new treatments and technologies. Commissioners need robust and detailed information on outcomes to assist them in commissioning services. The National Cancer Intelligence Network plays a crucial role in delivering this.

Living with and beyond cancer has sometimes been seen as a neglected area but it is now receiving more attention, not least because more people are surviving cancer. However, as a 'softer area' it could potentially be vulnerable to the challenging economic climate. In particular, there is considerable concern about follow-up appointments, which will very soon exceed system capacity.

Cancer Networks are operating with dedication and energy, but are not always seen to be as useful by the clinical workforce as they feel themselves to be. Notwithstanding this, if clinicians are heavily engaged, they tend to better understand the value they can add.

Overall the picture is one of dedicated, professional health service staff providing generally very good cancer services for the increasing number of cancer patients. The cancer pathway is complex, and over many care and treatment issues different perspectives about the appropriate way forward were voiced. The closer health professionals are to patients' experiences the more challenging it seems to be to work out a rigid 'what's best' strategy, and yet it would seem that certain targets and standardisation are of undoubted benefit to the population as a whole. **To continue to improve cancer outcomes, and to make our outcomes among the best in the world in the coming years, we need to maintain comprehensive cancer plans that set national direction, incentivise action and dedicate resource to beating cancer.**

### Overarching recommendations

**1 Cancer Plans are important and useful. They set direction and make the best use of resources to reduce cancer incidence and mortality. To continue to improve cancer outcomes, and to make our outcomes among the best in the world in the coming years, we need to maintain comprehensive cancer plans that incentivise action and dedicate resource to beating cancer.**

**2 A more comprehensive plan should be developed to ensure consistent delivery, implementation and integration across Wales.**

**3 Northern Ireland should finalise and publish its Service Framework as a priority.**

**4 Scotland should review progress against Better Cancer Care, address the gaps identified, such as promoting awareness and early diagnosis of cancer, and begin preliminary consideration of an updated plan.**

### Chapter specific recommendations

#### Prevention

**1** In order to reduce the incidence of smoking related cancers and see cancer mortality fall, we should continue to promote comprehensive tobacco control measures. This should include:

- a)** A strong commitment to the World Health Organisation's Framework Convention on Tobacco Control.
- b)** The development and ongoing monitoring of a tobacco control programme by each nation in the UK.

**2** We welcome the legislation in England, Scotland and Wales to regulate the use of sunbeds. Supportive regulations should be developed and implemented in England and Wales to ensure maximum effectiveness of the measures. In addition, there should be further work to communicate with the public about the dangers of sunbeds and the link between their use and skin cancer. The Northern Ireland Assembly should pass and implement the Sunbeds Bill.



3 The roll-out of the HPV vaccination programme has been a notable success to date. We support the continuation of a school-based vaccination programme, reaching girls before they are likely to be at risk of infection.

4 Any future strategies to prevent obesity and promote physical activity should be multi-faceted. They should include initiatives to increase physical activity, improve dietary quality, reduce energy intake and develop clear, consistent and evidence-based messages on healthy eating.

5 Any future strategies to tackle alcohol should include:

- a) Measures to increase the cost of alcohol
- b) Further restrictions on the marketing of alcohol
- c) Investment in information campaigns to raise awareness of the long-term health risks associated with cancer and other diseases.

### Awareness and early diagnosis

6 The National Awareness and Early Diagnosis Initiative (NAEDI) needs to maintain momentum and deliver change in England. Best practice in promoting awareness and early diagnosis needs to be replicated in each of the other UK nations. Though we know of some relevant work underway in other nations, the priority given to encouraging early diagnosis should be increased.

7 GP access to the appropriate diagnostic tests should be improved. To make progress in this area, we need to better understand current access levels. Appropriate follow-up is also critical.

8 Anecdotal evidence suggests that clinical leadership at a local level is a helpful driver for progress in promoting early diagnosis; some Cancer Networks have appointed short-term clinical leads. We think there could be value in formalising these arrangements.

9 Information to help health professionals is vital. First, referral guidelines for different cancers should be regularly updated. Second, work to develop decision-support tools to help referral in primary care has not progressed as quickly as hoped. We would welcome further work in this area. This may help to address a lack of continuity in primary care, for example, patients not always seeing the same GP.

10 Research should be undertaken across the UK to understand more about the pathways of non-urgent referrals, for example, for those patients admitted as emergencies. This research should explore whether or not patients had experienced symptoms and/or previously presented to a health professional.

11 Coordinated work should be undertaken to engage health professionals, particularly pharmacists, to promote early diagnosis. This should be especially targeted to lower socio economic groups as we know that people living in deprived areas are less likely to survive common cancers than those living in more affluent areas<sup>3</sup>.

12 We must continue to build the evidence base and incentivise the better measurement of important indicators to assess the progress we are making. For example, the mandatory collection and reporting of staging data would be a useful driver to encourage the earlier diagnosis of cancer.

### Screening

13 Northern Ireland's bowel screening programme was delayed due to financial constraints. This is being addressed and the programme is beginning to roll out. This must be completed as a matter of urgency.

14 Recent research<sup>4</sup> has shown that flexible sigmoidoscopy (or 'flexi-scope') can prevent a third of bowel cancers and reduce deaths from bowel cancer by up to half. As well as the potential to save lives, incorporating the flexi-scope test into a national bowel cancer screening programme would result in long-term cost savings due to the reduced costs of bowel cancer diagnosis, treatment and follow-up years later<sup>5</sup>. We strongly recommend the introduction of the flexi-scope test into a national screening programme for bowel cancer.

3 Ellie L, Rachet B, Shah A, Walters S, Coleman M (2009) Trends in cancer survival in Spearhead Primary Care Trusts in England, 1998-2004. *HealthStat Q 41*: 7-12

4 Atkin et al (2010) *Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial* *Lancet*; 375: 1624-33

5 Tappenden et al (2007) Option appraisal of population-based colorectal cancer screening programmes in England *Gut* 56: 677-684.

**15** Take-up rates for bowel cancer screening are low, which may be due to the fact that it is a relatively new programme. This may also be because the test requires a more active role by the participant than the breast or cervical screening tests and because people may find the test unpleasant. Uptake is lower among men, more deprived groups and among certain minority ethnic groups, such as people from the Indian sub-continent. Steps should be taken to address inequalities in uptake and ensure that as many people as possible are taking up the offer of bowel cancer screening. This includes developing messages that are tailored to the UK's diverse communities.

### Surgery

**16** Laparoscopic surgery has improved the quality of cancer surgery, is less invasive than other forms of traditional surgery and should lead to lower morbidity and speedier recovery rates for patients, as well as cost savings for the NHS. Further progress should be made in rolling out new surgical techniques such as laparoscopic surgery across the UK.

**17** Our research highlighted that there has been political intervention regarding the choice of location for surgery for Welsh patients. This would be of great concern if it means surgery is not being carried out in places that can deliver the best outcomes. Cancer patients in Wales should have access to good quality surgical treatment regardless of location.

**18** The reduction in training time for new surgical oncologists is worrying. The EU Working Time Directive is stopping junior surgeons from receiving the requisite experience. Trainee surgeons should have dedicated time to receive the appropriate level of surgical training to overcome the constraints of the Working Time Directive.

### Chemotherapy

**19** Where drugs have been referred to NICE for appraisal, they should be appraised quickly and as close to licensing as possible.

**20** The expertise of Cancer Network staff must be better used to improve the commissioning of chemotherapy treatments in the NHS.

**21** UK spending on new cancer therapies still lags behind the rest of Western Europe. Major cancer medicines are still being prescribed in the UK at under two-thirds of the European average, five years after licensing. Healthcare providers should encourage doctors to use these new drugs when treating cancer patients.

**22** There must be a continued commitment from local providers that all patients across the UK should have access to the appropriate treatments for their condition, regardless of where they live. Local providers should be reminded of their requirement to provide approved treatments.

### Radiotherapy

**23** All UK governments should introduce datasets for the reporting of fractionation, waiting times, access, and patient outcomes. The routine collection of benchmarked radiotherapy data should be obligatory for radiotherapy services across the UK.

**24** All UK governments should produce a rolling ten-year plan, setting out a vision and strategy for future radiotherapy services, which should be revised every few years. These plans will include detail about how quickly patients are being seen and whether services are reaching all patients who should be receiving radiotherapy as part of their treatment.

**25** Radiotherapy techniques which have become established practice in other countries for a number of years such as intensity modulated radiotherapy (IMRT) and proton therapy should be introduced and implemented in the NHS as quickly as possible to ensure that all patients who may benefit can get access to these new technologies.

**26** The UK governments must ensure that the UK is equipped with sufficient numbers of linear accelerators (LINACs) and that these machines are able to deliver the most up-to-date techniques. This needs careful planning to address future need, as cancer incidence rises and more patients are being offered radiotherapy.

**27** More work needs to be done to ensure that measures to improve workforce capacity, such as the four-tier skills model for radiotherapy, are fully implemented.

### Information

**28** Tailored information for patients from hard to reach groups should be developed and appropriately targeted.

**29** All patients should have access to high-quality information at all relevant points along the patient pathway to ensure that they can make fully informed choices about their care.

**30** Healthcare professionals also need to be provided with accurate and up-to-date information about the choices available to their patients, and how best to communicate with patients to ensure the choices they make are fully informed.

**31** Information on additional support from healthcare providers should be discussed before patients are discharged from hospital treatment.

**32** Healthcare professionals should, as part of their ongoing career development, receive training in communication skills, with a focus upon harder to reach communities.

**33** It is important to carry out patient experience surveys across all nations and at Cancer Network level to accurately assess patients' views of their treatment and care. The National Cancer Patients Experience survey in England and similar surveys in Scotland, Wales and Northern Ireland should be carried out on a bi-annual basis.

**34** The collection and analysis of cancer information and data is an integral part of delivering world-class cancer services. The UK governments must develop methods to collate good quality cost and quality metrics to ensure cancer services and treatments are properly commissioned and planned.

### Survivorship

**35** Survivorship is an important and emerging policy area, which should be fully embedded in the patient care pathway.

**36** Wales and Northern Ireland should develop a survivorship initiative.

### Palliative care

**37** Palliative care strategies should be fully implemented for maximum effectiveness.

**38** Further work about how the intent of palliative care treatment is communicated to patients should be undertaken.

**39** Support for patients who wish to self-manage their cancer and die at home can be good for patients and will reduce the burden on the NHS, and require fewer bed days in hospital. Work in this area should be accelerated.

### Cancer networks

**40** Cancer Networks are helpful vehicles for planning and implementing cancer services on behalf of their populations. They also have a key role in commissioning cancer services. The incentives for Networks should be focussed around improved outcomes for cancer patients rather than equality of services, which might lead to services being reduced to the lowest common denominator.

**41** Cancer Networks should play an important role in assisting GPs by acting as advisers in the commissioning of cancer services and treatment in England. Advice provided should include: needs assessment and demand profiling, prioritisation within the cancer agenda, service design and improvement, quality assurance and peer review, pathway and provider performance, patient experience and value for money.

### Multi-disciplinary teams (MDTs)

**42** The Department of Health should review the operation of MDTs and put in place a programme to ensure that cancer patients have equal access to high quality care and co-ordination provided by MDTs.

### Commissioning

**43** Cancer services should be commissioned by NHS staff who have expertise and skills including risk analysis, health economics, procurement and data management.

### National standards

**44** National standards are one way of driving improvements to cancer services and removing variation in access to those services. They are useful for benchmarking services and monitoring changes to see whether they lead to improvements. Further national standards are needed in some areas of the cancer patient pathway, such as the provision of radiotherapy and surgery, and in dealing with less common cancers.

### Incentives

**45** The government should review the points along the patient pathway where Primary Care can be more involved in cancer care, and propose a range of new measures for inclusion in the Quality and Outcomes Framework and other relevant incentive schemes to encourage this.

**46** The Quality and Outcomes Framework should include an incentive for GPs to collect staging data for all newly diagnosed cancer patients, to find out where improvements in earlier diagnosis could be made.

**47** We should continue to drive improvements in cancer services via the use of relevant incentives – both financial and quality-enhancing.

### Leadership

**48** National leadership to help drive improvements in cancer services is seen as important by the workforce. The National Clinical Director for Cancer in England and Chief Medical Officers in Scotland have played key roles in cancer service planning; these roles should be maintained and replicated where appropriate.

### Funding

**49** Sustained investment in cancer services is critical to achieving excellent cancer outcomes. The UK governments should commit to a continuing programme of long-term investment in cancer services. Governments should continually review the efficiency, effectiveness and value for money of services, and make comparisons of different pathways of care with our European and other international comparators.

## 01

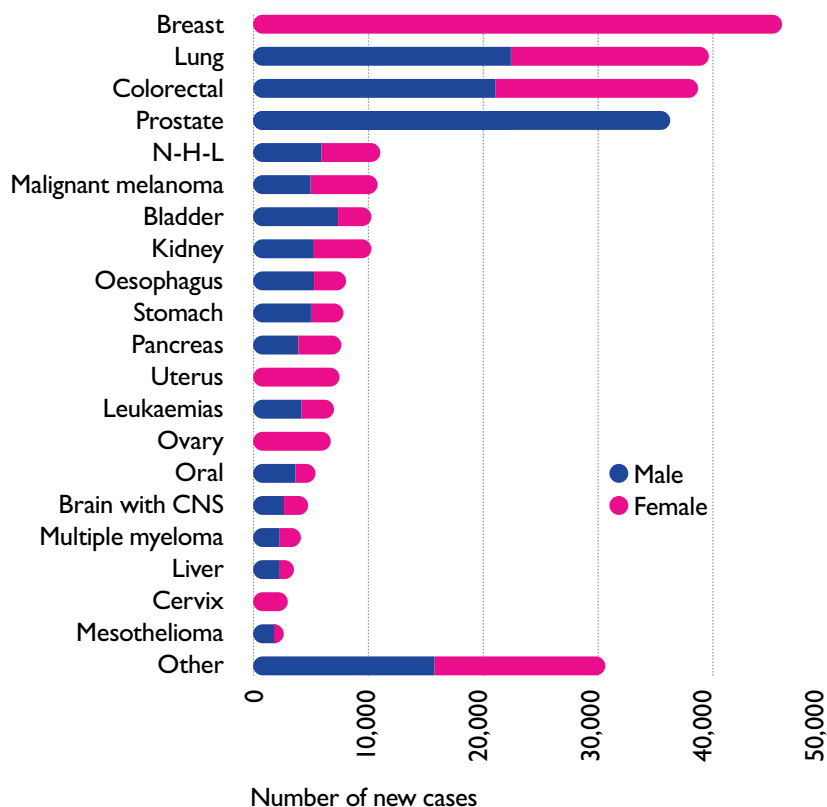
## Introduction

**Key cancer facts**

More than one in three people will develop cancer during their lifetime, and cancer causes one in four of all deaths in the UK. In 2007, the most recent year for which we have statistics, in the UK, 297,991 people were diagnosed with cancer, about the population of a city the size of Nottingham or Belfast.

Below: a graph showing the number of men and women who were diagnosed with cancer in 2007. (Excluding non-melanoma skin cancer).

The 20 most commonly diagnosed cancers (excluding non-melanoma skin cancer), UK, 2007

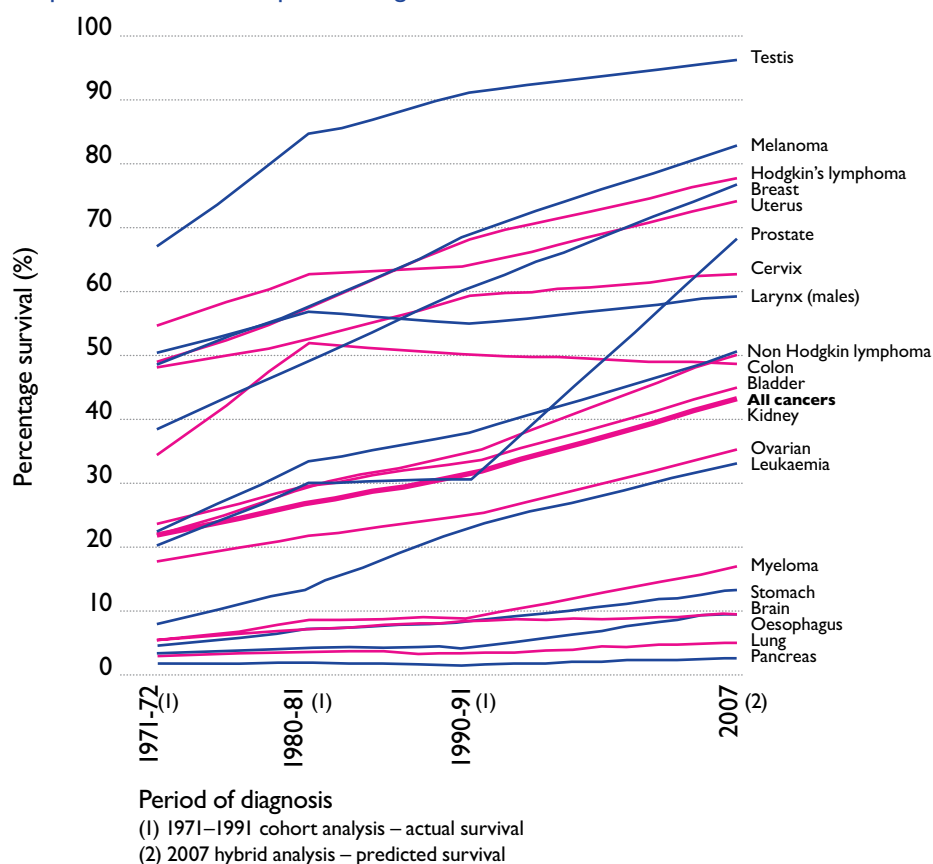


Source: Cancer Research UK

We know that the UK's current cancer survival rates lag behind those of the best performing countries in Europe. Whilst the average ten year cancer survival rate has doubled since the 1970s, for some cancers there has been very little headway. For example, we have made little progress in improving outcomes for lung, pancreatic and oesophageal cancer.

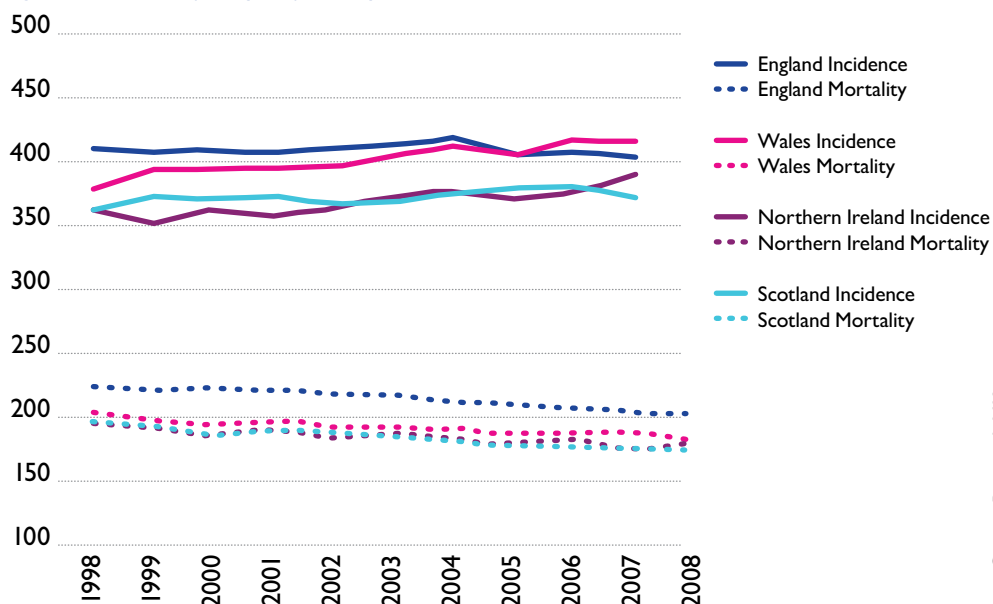
Next page: showing ten year survival rates of adults, improving in most cancers between 1971 and 2007

Ten year relative survival for adults diagnosed with cancer during 1971–2001, and predicted survival for patients diagnosed in 2007



Because of the delay in reporting cancer incidence, survival and mortality figures, we cannot yet tell the overall impact of the current UK cancer strategies on cancer outcomes as the diagram below demonstrates. However, we can report objective progress or lack of progress in some areas, and seek to do so throughout this report wherever possible. Moreover, the qualitative analysis that we have undertaken should give policy-makers a good idea of how things are being implemented at the local level. We hope that they will act where there is serious concern about delivery or progress in an area.

Cancer incidence and mortality trends in persons in the countries of the UK, age standardised (European) rates per 100,000, 1998–2008



Cancer services are the third largest area of expenditure by the Department of Health in England, with almost £5 billion spent in 2007/08 (5.6% of NHS expenditure in England). However, spending per capita on cancer services remains low compared to some other European countries. Spending on cancer in England is £80 per capita, compared to £121 per capita in France and £143 per capita in Germany. Overall, France and Germany spend half as much again of their public healthcare budget on cancer at 7.7% and 9.6% respectively than England which spends 5.6% of its public healthcare budget on cancer.

Although investment in cancer has certainly increased in recent years, it has not increased more rapidly than a number of other disease areas, and a perception, voiced by some commentators, that cancer has had a disproportionate amount of resource, is unfounded.<sup>6</sup> In 2008/09, Local Health Boards in Wales spent a total of £358.9m on cancer.<sup>7</sup> Unfortunately, we have not been able to source comparative cancer expenditure figures for the rest of the UK.

### Cancer policy since 1995

The mid-1990s provided a watershed moment in the planning of cancer services. Below, we very briefly summarise the different UK initiatives.

Published in 1995, *The Calman–Hine Report*<sup>8</sup> for England and Wales, and the comparative Scottish report, published in 1996,<sup>9</sup> recommended a new structure for the delivery of cancer services.

The reports recommended the establishment of generalist Cancer Units and specialist Cancer Centres, with multi-disciplinary teams for the co-ordination of cancer care for individual patients. They also proposed the establishment of Cancer Networks to provide a framework for planning cancer services across geographical localities.

#### England

In 2000, the Cancer Plan was published in England. This first national plan covered a range of issues, including the introduction of waiting time targets to promote earlier diagnosis and treatment, the extension of cancer screening programmes and targets for the reduction of smoking as set out in the White Paper *Smoking Kills*,<sup>10</sup> which was published in 1998. It announced the creation of the post of National Cancer Director; included plans for significant investment in equipment, staff and specialist palliative care and emphasised the importance of good communication skills. It also created the National Cancer Research Institute (NCRI) and the Cancer Task Force (now the National Cancer Action Team), to coordinate research and some service delivery from the centre.

The 2007 Cancer Reform Strategy built on the 2000 Cancer Plan by identifying areas in cancer policy that needed concerted action to improve patient outcomes in England. As well as announcing new legislation to further regulate tobacco products, it introduced a co-ordinated programme of work aimed at detecting and diagnosing cancer earlier; including making improvements to the three national screening programmes. It also proposed improvements in the treatment of cancer; through increased radiotherapy capacity, and new processes for assessing cancer drugs. It identified patient information, commissioning and investment as key drivers in achieving the aims of the strategy and highlighted the importance of research and survivorship.

#### Scotland

In 2001, *Cancer in Scotland: Action for Change* was published. This plan included the introduction of waiting times for cancer treatment and extension of the breast screening programme. The plan also outlined the role of the Scottish Cancer Group in monitoring implementation, the establishment of regional cancer networks, and coincided with the appointment of a new Lead Cancer Clinician for Scotland (this post was abolished in 2006).

6 Department of Health (2010) *Estimated England level gross expenditure by Programme Budget* Department of Health: London. Available at: <http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/index.htm> (Accessed 2 July 2010)

7 Welsh Assembly Government (2010) *NHS Programme Budget by Local Health Board 2008/09* Welsh Assembly Government Cardiff. Available at: <http://www.statswales.wales.gov.uk/TableViewer/tableView.aspx?ReportId=6109> (Accessed 2 July 2010)

8 Calman K, Hine D (1995) *A policy framework for commissioning cancer services: a report by the expert advisory group on cancer to the chief medical officers of England and Wales*. pp 34. London: Department of Health

9 Scottish Cancer Co-ordinating and Advisory Committee (1996) *Commissioning Cancer Services in Scotland: report to the Chief Medical Officer*, SODoH pp 39. Edinburgh: The Scottish Office

10 Department of Health (1998) *Smoking Kills: A White Paper on Tobacco* The Stationery Office: London

In 2004, an update, *Cancer in Scotland: Sustaining Change*, was published, outlining achievements to date and setting out plans for the next three years. The plan was backed by £25 million recurring investment, ring-fenced until 2005/06.

*Better Cancer Care* is the Scottish government's current action plan for cancer, published in October 2008. It established the Scottish Cancer Taskforce to succeed the Scottish Cancer Group in driving implementation.

### Wales

In 2005, The Welsh Assembly Government (WAG) published the *National Cancer Standards*, which cover the organisation of cancer services, patient care, time to diagnosis and treatment. The standards should have been achieved by March 2009; however, unfortunately, many of the standards have not been met. In May 2010, the Welsh Assembly Government released an all-Wales analysis of compliance with the National Cancer Standards<sup>11</sup>. The report shows that there are many areas of non-compliance in almost all areas of Wales and that all but one Local Health Board (LHB) (Betsi Cadwaladr University Health Board) achieved less than 50% compliance with the cancer-specific standards. One trust achieved only 38% compliance.

*Designed to Tackle Cancer in Wales* was published in December 2006, setting out the Welsh Assembly Government's policy aims and strategic direction to tackling cancer at a national and local level across Wales for delivery by 2015. *Designed to Tackle Cancer* covered services from 2006-2008. A further *Designed to Tackle Cancer in Wales: 2008-11 Strategic Framework* was published in July 2008 and went into considerably more depth about how the Assembly Government will tackle the cancer challenge in Wales. However, some of the targets set out in the Framework appear to be slipping. Work will begin in the autumn on a third Strategic Framework, setting requirements for the period 2011-15.

### Northern Ireland

The *Cancer Control Programme for Northern Ireland* was published in 2006. A Service Framework for Cancer Prevention, Treatment and Care is currently being developed. The Framework prioritises the recommendations coming out of the Cancer Control Programme and sets out standards in respect of the prevention, diagnosis, treatment, ongoing care, rehabilitation and palliative and end of life care. The publication of the Service Framework has been significantly delayed, but is due some time in 2010.

The Cancer Control Programme set out to build upon the progress made in cancer service provision since *The Campbell Report: Investing for the Future*<sup>12</sup> was published in 1996. The intervening years saw significant investments in cancer services, including the new regional cancer centre at Belfast City Hospital, and the establishment of the Northern Ireland Cancer Network (NICaN).

<sup>11</sup> Cancer Services Coordinating Group National Cancer Standards Compliance Report, 2009

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=47547>

<sup>12</sup> Department of Health and Social Services (1996) *Cancer Services: Investing for the Future* Belfast: The Stationery Office. Available at: [http://www.cancerni.net/files/ph\\_cancer\\_services\\_investing\\_for\\_the\\_future\\_\(the\\_campbell\\_report\).pdf](http://www.cancerni.net/files/ph_cancer_services_investing_for_the_future_(the_campbell_report).pdf) (Accessed 5 July 2010)



## 02

## An overview of findings from fieldwork with health professionals and cancer network staff

To inform this report we have collated a wealth of information from interviews with healthcare professionals. Overall, they told us that there is a strong sense of momentum among those working in cancer services. There is recognition that cancer services have improved markedly in recent years, not least because there has been significant and justifiable investment. They reported that standardisation and a reduction in the variation of treatment type continues to take place, and treatments are moving forward apace. They also felt that increasing specialism is a prominent feature of the changing workforce and pattern of delivery of cancer services.

Healthcare staff are dedicated and provide good cancer services for the increasing number of cancer patients. Cancer Networks are functioning but not always seen to be as effective to external observers as they perceive themselves to be. However, if clinicians are involved with networks, they have a greater understanding of the value they can add.

There is, however, acute awareness of shifting into a different economic climate, where cuts are imminent, or already biting. Cancer incidence is projected to increase further, in line with our ageing population, but how the extra demand on services will be resourced is seriously questioned.

### I Knowledge of the strategies

Knowledge of the cancer strategies is patchy among clinicians. Many healthcare professionals interviewed for this report highlighted concerns about resources and wondered how quality could be maintained, let alone improved, for an increasing number of people with cancer, at the same time as budgets are tightened.

The cancer pathway is complex; as a consequence, the closer health professionals are to patients' experiences, the more challenging they often find it to identify the best approach to patient care. However, it would seem that targets and standardisation have reaped many benefits for patients, although there is room for improvement.

#### England

*It's fantastic – all the early diagnostic stuff wasn't addressed in the Cancer Plan, neither was end of life addressed very well, or survivorship and living with and beyond – the CRS covers all of that*

Network Nurse Director, England

Healthcare professionals welcomed the role of the National Cancer Director, the leadership provided by Professor Sir Mike Richards in that position and the work that he has done to drive improvements in cancer services in England.

The Cancer Reform Strategy (CRS) is perceived by the workforce and Cancer Networks as the strategic driver for services. It is very well regarded and positively acknowledged as it covers the whole pathway.

*The initial focus was on specialist services, fast tracking into them, getting the configurations right. The CRS helped to broaden the focus – not forgetting things for the longer term – prevention, survivorship...*

Network Associate Director, England

Quality standards and investment have helped to prioritise cancer within the NHS and bring about change. Where there has been slow or disappointing progress, lack of resource or standards in treatment of care were cited by healthcare professionals as contributing factors in many cases. Setting standards alone was seen by health professionals as too crude, and they recommended that the workforce was involved in the development of any new standards that they were being tasked with delivering.

*In principle the hospitals are sorted now, they've got functioning MDTs, proper clinical pathways, and the Improving Outcomes Guidance is more or less complied with. The CRS focuses on the pre-hospital and the post-hospital*

CN Medical Director, England

An increased emphasis on the quality of care is welcome and popular. It is vital to improve compliance with waiting time standards, but this should not be done in isolation from the patient experience. Many health professionals view the quality of the experience and the provision of holistic, continuous care as crucial.

*The CRS doesn't suggest a way of solving the problem – but it gives a good analytical framework. It's there to suggest direction for how things should travel; that's what it does very well. The upshot is that there's been a lot of green shoots, in different directions, of very good work...*

Primary Care Lead, England

However, some interviewees stated that whilst the strategy provides specific solutions in some areas, other aspects are vaguer. There is also general concern that the Cancer Reform Strategy was drawn up in times of high investment. This will need to be taken into consideration in the refreshed Cancer Reform Strategy which is due to be published in late 2010.

*The challenge for Mike Richards has been – he published the CRS just as we were going into financial collapse, as a country, and yet it had been written on the back of a period of financial growth*

Commissioner, England

### Scotland

Better Cancer Care, An Action Plan is well regarded and has been translated into tangible actions by the new Cancer Taskforce. There is familiarity across the service with its key aims of better patient care and better team work. Its focus on the quality of care has also been welcomed by healthcare professionals.

*Better Cancer Care was well received because it focused more on the quality agenda where there had been a very high focus on waiting time, and that was very welcomed by clinicians on the ground... I think for the networks it strengthened their roles... we're now working with the Taskforce at a national level about how we take that forward*

Regional Network role, Scotland

In Scotland, there is strong evidence of a cooperative spirit and shared determination to deliver the plan among healthcare professionals. This manifests itself in problem-solving team work and a high level of engagement. Current structures for the delivery of cancer services are perceived to be effective and the workforce has learnt to work regionally, with success.

*Scotland is quite small, you tend to know who the main people are in each Board and a lot of the project work links across Boards*

Cancer Nurse Consultant, Scotland

Scotland's success can be attributed to a unique combination of factors including a smaller population than England, more resources per capita spent on health,<sup>13</sup> a feeling of national pride in wanting to make cancer services better; the strong clinical leadership of Dr Harry Burns (the Chief Medical Officer), and a long history of MDT working and auditing practices. Some policy-makers and healthcare professionals also stated that Scotland has stayed much closer to the NHS ethic than other nations, and this has helped contribute to improvements in cancer services.

<sup>13</sup> HM Treasury (2010) *Public Expenditure and Statistical Analyses* HM Stationery Office: London. Available at: [http://www.hm-treasury.gov.uk/d/pesa\\_2010\\_chapter10.pdf](http://www.hm-treasury.gov.uk/d/pesa_2010_chapter10.pdf) (Accessed 6 July 2010)

## Wales

Interviews conducted in Wales demonstrated a markedly different picture. Healthcare professionals and policy-makers felt that cancer has not been given enough priority in Wales.

*The Assembly gave £4.5 million to implement the 2005 Cancer Standards, which across Wales is not very much really*

Commissioner, Wales

There has been a preoccupation with waiting times and concern that they are still not being met.

*Our MDT isn't NICE IOG (Improving Outcome Guidance) compliant by any stretch of the imagination... we haven't got a key worker or the infrastructure for this. We're all doing it out of the kindness of our hearts. If you want a NICE IOG compliant service, cost it, give us the money and we'll do the job*

Oncologist, Wales

There is also a perception of insufficient performance management.

*In England performance management is being done by the Strategic Health Authority and we don't have that... now we don't have commissioning, I'm not sure where the performance management role lies. Who is going to make the new Health Boards in Wales do things?*

Network employee, Wales

*Designed to Tackle Cancer isn't quite the same as the CRS; it hasn't put in targets*

Breast Oncology Nurse Specialist, Wales

Healthcare professionals stated that distracting organisational change had created uncertainty and declining morale. Although some interviewees for this report welcomed the Welsh Assembly Government's hands-on approach to managing the NHS, others felt that Wales is lagging behind the rest of the UK in terms of waiting times, radiotherapy capacity and some non-compliant MDTs.

## Northern Ireland

*I want the patient involvement ethos translated into standards, and an understanding that it is worthwhile*

Network employee, NI

The Cancer Control Programme, published in 2007, was not sufficiently robust according to the workforce and policy-makers and the Cancer Service Framework (CSF) is currently still in development. The CSF is the second part of the Regional Strategy, and will include a range of standards that patients can expect to be met during the clinical pathway. The development of the Cancer Service Framework has involved engagement across the service and is perceived to have vigour which was missing from earlier strategic initiatives. There is also optimism about what can be delivered under the Cancer Service Framework.

*It [CSF] was billed as a great opportunity for ground level staff to say where they think the services need to be developed... the problem is, it's taken so long that those standards are out of date now – like for radiotherapy... it's continuously playing catch up*

Oncologist, NI

There is a sense that some cancer services are less well developed than in the rest of the UK though a feeling that other parts of the service are working well. Healthcare professionals stated that organisational change and the review of public administration had been distracting to the service.

In the following sections we outline what the respective plans said they would do in certain areas, what has been achieved to date, analysis of what the workforce thinks about this and recommendations for future action.

## 2 Staff in Cancer Networks

Cancer Network staff see their role as multi-faceted, including to get and keep cancer high on the agenda, to work regionally to standardise within the region and perform well against other regions, to coordinate and reconfigure services where necessary, to support and advise commissioners and providers, to help procure funding, to lead on and support projects and, importantly, to support the clinical network groups. Some Networks, with employees who sit on key committees, consider they have some influence on national policy.

*The first cancer plan focused very much on speedier access and better treatment... it was about investment, more; this one feels a lot more about 'reform'. There is a particular re-orientation on early detection and prevention... And health inequalities was also flagged – probably for the first time – in a strategic way*  
Network mini group, England

Reported Network achievements include a number of standardisation initiatives, encouraging relevant parts of their workforce to prioritise the early diagnosis agenda and engage with the National Awareness and Early Diagnosis Initiative (NAEDI) in England.<sup>14</sup> They also reported gathering comparative data and sharing audit information, helping to implement an e-prescribing system in Scotland, reconfiguring gynaecological services in Wales, securing funding for projects such as (in London) *Vision to Survivorship* and 'skilling up' pharmacists.

The Networks know that clinicians do not necessarily view them as positively as they view themselves, partly because there is an emphasis from the networks on meeting standards, which is not always a popular function. They also imagine that many clinicians are not aware of their exact purpose. Clinicians do in fact have mixed views of the Networks. Some are unclear about their purpose, or in some cases are unaware that they exist. Others work more closely with them and have correspondingly greater respect for the work that they undertake.

## 3 Healthcare professionals' views of Cancer Networks

**a) Primary care workers** often feel quite remote from their Network, unless working with them specifically. Most GPs interviewed for this report had not heard of their Network, or their strategy. Other primary care workers often had little awareness of the strategy or Network, unless they are appointed 'Leads' in their local areas.

**b) Surgeons** reported having full but manageable workloads and a degree of autonomy. Some have roles within the Clinical Networks and tend to be fairly positive about their Cancer Network, but are not sure how much it would be missed if it was removed.

**c) Oncologists** reported feeling burdened and struggling with an extremely heavy workload, and not always invited to be part of the Clinical Networks. They tended to be very vocal about questioning where resources to meet strategy demands are going to come from; few know much about the strategy in detail.

**d) Histopathologists** knew little about their Cancer Network or their respective strategy and did not necessarily see the need to have an in-depth knowledge. Although their job has become much more integrated into the team, via MDTs, they still felt distanced from much of the cancer workforce, and felt this was mostly appropriate.

**e) Nurses** and those in nurse-related roles have very variable levels of awareness of their cancer strategy, with some knowing the strategy, or parts of it, thoroughly, and others not at all. Some of the nurses we interviewed are working closely with their Network, or are currently employed by it.

**f) Commissioners** know their strategy well and tend to have close links with the Cancer Network. They tend to be highly focused on evidence and data, and often frustrated at the inadequacy of it. Currently, commissioners are preoccupied with the extra pressure on their role in the light of imminent funding cuts.

## 03

## Levers, incentives and tools to drive change

Across the four UK nations, there is a general sense of momentum in cancer services dating back to *The Calman-Hine Report*. There is recognition that cancer has been a priority area in recent years and that services have improved. There has been progress in the development of new treatments and patients have benefited from more standardisation across services, with developments like the introduction of the two week wait target for suspected cancer.

The inception and development of multi-disciplinary teams has in the main been strongly welcomed. They are seen as an effective way to organise treatment and to safeguard high quality care for patients. Increased specialisation among the workforce is a reality. This has driven service improvement, but can lead to a concern about deskilling among some in the workforce.

The NHS is entering a very challenging financial climate. Healthcare professionals interviewed for this research were aware of this, stating that there was a feeling that cuts were imminent or had already started to take effect. Some healthcare professionals stated that they felt overloaded and demoralised by bureaucracy.

This section focuses on the different levers, incentives and tools that are used in the strategies to try to drive change.

### 1 Multi-disciplinary Teams

The formalisation of multi-disciplinary teams (MDTs) has been very welcome. There is a strong feeling among healthcare professionals and policy-makers that MDTs do deliver patient benefit by better coordinating care and improving services. The 2010 guidelines for MDT working are timely and need disseminating, perhaps via Cancer Networks.<sup>15</sup>

Healthcare professionals consider MDTs to offer patients better care and help to build relationships among professionals. Healthcare professionals also believe they are interesting and educational and the audiovisual systems can allow attendance without travel.

*I learn so much – it's vital for head and neck patients to be clear, before you see them, what's happening; so if a patient asks me, I know more*

Oncology Nurse Specialist, Anglia

However, there are challenges with this way of working. MDT meetings are time-consuming. They can be disorganised, poorly chaired, with no agenda or clear timings, and people join by links at different times during meetings. In some cases, no-one has seen the patient and there are reports of some health professionals signing in and then leaving. Current technology is sometimes not wholly satisfactory.

### 2 Cancer Networks

Responsibility for implementing national policy on cancer at local level currently lies with Cancer Networks. Their role is to apply national directives to their localities in full partnership with commissioning and provider organisations. Cancer Networks have a key role to play in modernising cancer services and improving patient care. They are dependent on investment decisions by PCTs in England which currently hold a large proportion of the NHS budget. This can lead to a significant amount of time engaged in negotiations with commissioning PCTs about the implementation of national guidance.

Healthcare professionals interviewed for this report outlined very varying views of Cancer Networks. Some networks offer an excellent local and regional perspective on national plans. They practically translate national policy to local activity, targets and planning and are valued by the local workforce. Others are not so well perceived or regarded and their value in a challenging economic climate has been questioned.

Cancer Networks do not have statutory status, role or budget and this is a cause for concern. They are not taken as seriously as they might be because of their more informal and virtual status. However, healthcare professionals reported that Networks can be dynamic drivers of change. They can offer the valuable expertise that is needed at local level to improve commissioning and to advise on local priorities. They can also deliver services.

Qualities of a successful Cancer Network include:

- The belief in and commitment to a regional approach.
- Appointing the right people in strategic roles, for example to gain the respect of the local workforce. It is important to have representatives with clinical backgrounds in some roles.
- There should be a closeness and good understanding between clinicians and non-clinicians. Some tensions arise when clinicians feel dictated to by non-clinicians and do not have the requisite levels of respect for them.
- Funding, for example access to service improvement funding, can be an important driver of local change.
- Successful and transparent communication of the Cancer Network's operations, effectiveness and achievements. It is important that the Network has a local profile. This helps raise awareness of their achievements.

### 3 Commissioning

There are very different approaches to the procurement of services across the four UK nations and the approach taken in the strategies.

In Northern Ireland, the Public Health Agency and the Health and Social Care Board are responsible for commissioning cancer services and this new system is still being implemented. In Wales, there was tension between Health Boards and Health Commission Wales.

*There's been a lot of tension between Health Commission Wales and Health Boards, about who commissions what and who leads on what*  
Commissioner, Wales

The purchaser/provider split in Wales has now been abolished and collective decision-making will be implemented in new unified health boards.

*From 1st April [2010], specialist services will be 'planned and procured' by a team called WHSST... The WHSS Committee, with representatives from seven local health boards, will make collective decisions. It will be difficult at first to rise above their local concerns, and look at things from an all Wales basis – this is the best option for patients*  
Commissioner, Wales

In Scotland, where the purchaser/provider split does not exist, there is a process of regional planning through Networks. Health Boards are accountable for the delivery of services.

In England, the Cancer Reform Strategy contains a specific chapter on commissioning for cancer services which states that Cancer Networks are expected to work with PCTs to commission services for a population of 1 to 2 million.

In all nations, healthcare professionals and experts stated that there needed to be more measures and better data in order to improve the planning and procurement of services. This was most strongly expressed in England, where good quality cost metrics are required to improve the quality of commissioning.

*You can't commission unless you can define – you have to define based on evidence, based on what patients say, based on good practice...*  
Network Associate Director, ex-commissioner, England

To facilitate more robust planning and commissioning, analytical capability at regional and local level must be improved. In practice this means ensuring that more public health consultants and health economists are analysing local data. Better measures, audits and data to facilitate improved commissioning are needed and these should show clearer links to outcomes. Additional work is needed to measure patient experience and then plan and make effective changes in this area. Clinical Nurse Specialist interventions would benefit from better measurement. Priorities need to be based on evidence of improved outcomes. The efficacy of peer review should be assessed as concern was expressed about the effectiveness of it in its current form. Generating better data will offer benefits for the public too. Accurate, reliable outcome data by hospital and clinical team would be of value to the public.

Many healthcare professionals perceive a shift from a quality and service improvement focus to a climate of cost cutting.

*It's about using health service data and making sense of it ... especially as we go into the next financial climate, because we need to be able to translate our health improvement, our early detection aspirations and plans, into pounds and pence*

Commissioner, England

#### 4 Measurement and communication

Communicating information to the workforce and the public can be a powerful driver of change.

Healthcare professionals interviewed for this project reported that there was some healthy competition about screening uptake between different areas. Some healthcare professionals praised a table in the Cancer Reform Strategy Annual Report where individual PCTs could rate themselves against others in terms of screening uptake.

*That table [Screening and Early Diagnosis of Second Annual Report] is incredibly powerful, and I think that's a really good example of how we can measure and make things happen – and that's something the CRS has made happen... the PCTs can see themselves ranked – you can't 'rank' yourself*

Network mini group, M&C

#### 5 Targets

Healthcare professionals welcomed the two-week wait for urgent referral in England. It has been embedded into the service and has highlighted the importance of rapid cancer diagnosis. However, the two-week wait is often described as both the best and worst example of a target. It has clearly driven faster access to diagnostics and cancer specialists and led to faster diagnosis in many instances. It does, however, lead to unintended consequences too. Those patients who are referred via a routine referral potentially have to wait longer for their diagnosis as a consequence of many being fast-tracked through the system on the two-week wait. Overall, health professionals felt strongly that this target should be retained. Policy makers and clinicians should strive to make any future standards as sophisticated and outcome focused as possible.

#### 6 Data

The Cancer Reform Strategy committed to improving information on cancer services and outcomes to drive up service quality and underpin stronger commissioning. The National Cancer Intelligence Network was established to bring together relevant stakeholders and act as a repository of cancer data as well as making Primary Care Trusts responsible for ensuring that information for datasets on patient was collated by multi-disciplinary teams and sent to cancer registries. Successes include clinical engagement, increased source utilisation, national data linkages and funded lead registry assignments. The NCIN has also produced innovative new analyses including ethnicity, routes to diagnosis, rurality studies, GP audit, inequalities and use of surgery by cancer and by age.

The NCIN has led to improvements in the collation of information about cancer services but there remains significant concern about the lack of good quality data and information to assist commissioners in commissioning services for a local population. Information about the needs of the local population, as well as good quality cost metrics, are both needed to improve the commissioning of services.

The speed of the start-up and outputs of the NCIN Site Specific Clinical Reference Groups (SSCRG) has been slow. Likewise, developing and managing relationships with the NHS Information Centre has been difficult. Further work is needed to improve the impact of the NCIN beyond England as well as improving the collation of information about staging data for cancer.



## 7 Delivering care in the most appropriate setting

The push to deliver care in the most appropriate setting for patients is an important aim of the Cancer Reform Strategy, and to a lesser extent, the other plans. Ensuring the delivery of care in the most appropriate setting is a complex issue and requires careful balance to ensure safe treatment for patients.

Interviewees were aware of an aspiration to 'deliver cancer care in the most appropriate setting'. Supported 'self care', where patients are increasingly based at home, was mentioned together with the idea of primary care pursuing a greater role in cancer service delivery in future.

*There is a component in Better Cancer Care to engage community services... cancer care delivery is more ambulatory -- even in surgery there is rapid recovery and discharge times so patients are spending a lot of time at home. A huge theme of that is supported self-care and how we deliver it*

Strategic nursing role, Scotland

Concern was raised about striking the right balance in this area.

*We've still got a fair way to go looking at how we begin to shift some of the balance to primary care and caring in local communities... there has been a move to more centralisation of some of the specialists there to concentrate expertise on greater numbers and improve outcome*

Regional Network role, Scotland

Some interviewees felt that the picture had in fact got worse in relation to care in the community.

*When the patient has had their primary treatment and are back in the community, they need support -- it's not there. In fact, it's much worse than it was 10 years ago*

GP group, London

Some healthcare professionals mentioned that they could provide follow-up appointments, using the phone as an alternative to face-to-face appointments.

*Traditional follow-up methods have been shown to be of little value, to say the least ... so there's a lot of work saying -- is this the best thing to do? We're looking at a phone follow-up after 6 months ... then let the patient take control. If they've got a problem, phone in -- Easy Access.*

CNS/Asst Director of Breast Nurses, England

Healthcare professionals stated that there was pressure to provide ambulatory care from squeezed secondary care. However, there was a strong sense that there is potential to reduce the length of in-patient stay for many cancer patients.

Integration of care and good links between tertiary, secondary, primary care and social services is crucial. Specialist nurses felt strongly that patients could feel neglected at the end of treatment unless appropriate support is provided.

A key senior oncologist stated that treatment closer to home can have unintended negative consequences, for example, it can rule patients out of clinical trials. He felt this reflected an inherent contradiction within the Cancer Reform Strategy.

*I think the public needs to understand that excellence and convenience are mutually exclusive*

Head of Oncology, England

Different regions had differing attitudes to travelling for treatment. Patients in Northern Ireland seemed to accept that Belfast offered the best specialist cancer services and that this would involve travelling. However, a satellite unit in the north-west of Northern Ireland is being planned. In London and Avon, Wiltshire, and Somerset, the biggest issue for patients was finding space in hospital car parks. Respondents from Merseyside and Cheshire sometimes resented having to cross the river (either way) to receive treatment. Anglia residents were unhappy about travelling, perhaps partly reflecting a big rural area with slow roads. In Wales, there was heavy reliance on charity volunteers and personal support networks for those without cars.



## 8 Funding and investment

Mostly, the current cancer plans do not dedicate significant 'new money' for the provision of services. There are some important exceptions. Many changes to the screening programmes – for example, the introduction of the bowel screening programme – have required additional resource. Where this has been made available in a timely fashion, it has quickly driven change and ensured that patients can benefit from new technologies or initiatives.

In addition, money can raise the profile of different parts of the pathway. The resource that has been made available to drive the early diagnosis agenda in England, combined with other factors such as strong leadership, has made a difference by raising the profile of diagnosis among the workforce and policy-makers. Initiatives for skin cancer prevention have also benefited from extra resource, political will and strong leadership.

## 9 Legislation

Interviewees felt that legislation introduced to ban smoking in public places had made a real difference and helped reduce the prevalence of smoking. This did pass before the current plans came into force, but implementation and monitoring of smokefree legislation is closely associated with current cancer prevention strategy. The use of legislation was also welcomed as a response to irresponsible use of sunbeds, particularly by young people. Although legislation was recognised as a tool to help achieve behaviour change, some interviewees stated that health professionals could do no more than offer standard advice, which might be ignored. It was also noted by interviewees that while change had occurred, there remained a section of the population who would remain very difficult to influence.

*Here [in England] it's very bitty... you get targeted money for smoking, but smoking's getting harder and harder. The people who were easy have given up; the hardened smokers are left – and they'll hang out in the cold and smoke.*

Primary Care Advisory Group

## 10 Central performance management

Central performance management of certain initiatives was often welcomed by the workforce. Interviewees stated that there was insufficient performance management in Wales, compared with England.

*We are way behind on waiting list targets... we haven't got payment by results, so although fingers will wag at us if we miss targets, we are still getting the money*

Oncologist, Wales

*In England performance management is being done by the SHA and we don't have that ... now we don't have commissioning, I'm not sure where the performance management role lies. Who is going to make the new Health Boards in Wales do things?*

Network employee, Wales

*It's more difficult in Wales than England – there hasn't been a strong performance management structure... and because it's a small country, you have to try and keep the clinicians on board, there isn't a ready pool of other people you can bring in if they don't play ball*

Commissioner, Wales

There was also a debate about incentivising improved palliative care and it was noted that the Quality and Outcome Framework had achieved some success in doing this.

*Without the palliative care Quality and Outcomes Framework we wouldn't have had half the improvements we've had in palliative care...*

Primary Care Lead, England

However, an interviewee from Northern Ireland stated that it was difficult to develop performance indicators for an area of medicine which was quite difficult to assess with traditional measurements.

*Putting performance indicators on palliative care can be quite tricky as the processes aren't really there to start with. One is the whole piece around communication and co-ordination, and having a keyworker in position...*

Network employee, NI

## II Leadership

Leadership is seen as critical to drive implementation of the plans and to motivate and engage the workforce.

In Scotland, interviewees stated that having a respected Chief Medical Officer and strong clinical leadership led to a buoyant co-operative spirit, mutual engagement and shared determination among professionals working in cancer services. This was evidenced by good cross-cutting working relationships and teamwork.

At a national level in England, Professor Sir Mike Richards, the National Director for Cancer, was praised for his work and the leadership he demonstrated in implementing the Cancer Reform Strategy and improving treatment and care for patients.

*I do think Mike Richards has achieved a lot for people being treated in less brilliant units – which is the majority of the population*

Head of Oncology, England

Many knew of Mike Richards, and there was reasonable awareness that he and the cancer strategy were connected. There was universal praise for his role; he was perceived as passionate, committed and inspirational. Even where there was some ambivalence in relation to the Cancer Reform Strategy and/or the Network, Mike Richards attracted admiration.

## Recommendations

### Cancer networks

- Cancer Networks are helpful vehicles for planning and implementing cancer services on behalf of their populations. They also have a key role in commissioning cancer services. The incentives for Networks should be focussed around improved outcomes for cancer patients rather than equality of services, which might lead to services being reduced to the lowest common denominator.
- Cancer Networks should play an important role in assisting GPs by acting as advisers in the commissioning of cancer services and treatment in England. Advice provided should include: needs assessment and demand profiling, prioritisation within the cancer agenda, service design and improvement, quality assurance and peer review, pathway and provider performance, patient experience and value for money.

### Multi-disciplinary teams (MDTs)

- The operation of MDTs should be reviewed and a programme put in place to ensure that cancer patients have equal access to high quality care and co-ordination provided by MDTs.

### Commissioning

- Cancer services should be commissioned by NHS staff who have expertise and skills including risk analysis, health economics, procurement and data management.

### Information

- The collection and analysis of cancer information and data is an integral part of delivering world-class cancer services. The UK governments must develop methods to collate good quality cost and quality metrics to ensure cancer services and treatments are properly commissioned and planned.

### National standards

- National standards are one way of driving improvements to cancer services and removing variation in access to those services. They are useful for benchmarking services and monitoring changes to see whether they lead to improvements. Further national standards are needed in some areas of the cancer patient pathway, such as the provision of radiotherapy and surgery, and in dealing with less common cancers.

*Incentives*

- The government should review the points along the patient pathway where Primary Care can be more involved in cancer care, and propose a range of new measures for inclusion in the Quality and Outcomes Framework and other relevant incentive schemes to encourage this.
- The Quality and Outcomes Framework should include an incentive for GPs to collect staging data for all newly diagnosed cancer patients, to find out where improvements in earlier diagnosis could be made.
- We should continue to drive improvements in cancer services via the use of relevant incentives – both financial and quality enhancing.

*Leadership*

- National leadership to help drive improvements in cancer services is seen as important by the workforce. The National Clinical Director for Cancer in England and Chief Medical Officers in Scotland have played key roles in cancer service planning; these roles should be maintained and replicated where appropriate.

*Funding*

- Sustained investment in cancer services is critical to achieving excellent cancer outcomes. The UK governments should commit to a continuing programme of long-term investment in cancer services. Governments should continually review the efficiency, effectiveness and value for money of services, and make comparisons of different pathways of care with our European and other international comparators.

## 04

## Prevention

*The public health people have been saying for years that if you take 90% of the budget used for treatment and transfer it to prevention, there wouldn't be a problem and I've got some sympathy for that*

Oncologist, Scotland

Each of the current strategies recognises cancer prevention as the most cost effective approach to saving lives. The improvement of public health is imperative not only to reduce cancer incidence, but to reduce the incidence of a raft of other chronic health conditions as well.

There is evident progress in preventing cancer in each of the four nations. This is most notably demonstrated through the introduction of smokefree legislation, though as detailed before, this legislation was passed before some of the current strategies were published. The strategies have helped increase the profile of cancer prevention among the workforce and political leadership has played a key role in the development and implementation of legislation to support the prevention of cancer. Governments should acknowledge evidence in cancer prevention and regulate where necessary, and further work must be undertaken to tackle and reduce cancer inequalities.

### Cancer Reform Strategy

The Cancer Reform Strategy dedicates a chapter to cancer prevention. It prioritises action to help people reduce their risk of developing cancer through improving awareness of lifestyle risk factors, encouraging a healthy lifestyle, and via a range of aspirational aims and plans. The Cancer Reform Strategy sets out action to tackle smoking, obesity levels, a poor diet, low levels of physical activity, alcohol consumption, excessive sun exposure, action to regulate the sunbed industry if deemed necessary and to encourage appropriate vaccination. It contains some new money, for example, for skin cancer prevention work, references legislation to be introduced and other prevention focused initiatives.

### Better Cancer Care, An Action Plan

Better Cancer Care shows a keenness to be thorough, bold and innovative in its approach to cancer prevention. It highlights a number of areas for health improvement including: tobacco, diet and obesity, physical activity, alcohol, Human Papilloma Virus (HPV) vaccination and excessive exposure to ultraviolet radiation. Prevention is the key area where the plan makes solid policy and funding commitments. Prevention measures are accompanied by a tangible target to achieve, a funding settlement or a separate strategic framework to address the issue.

A commitment to a consultation to inform a strategy is promised, but there is no timeline for this.

### Designed to Tackle Cancer

Designed to Tackle Cancer outlines an aspiration to 'reduce the incidence of cancer in Wales through primary prevention' and, in particular, to have comparable cancer incidence rates with the lowest European quartile by 2015. Despite this, there is a lack of firm commitment, substance or resource and it does not create any new initiatives to drive this activity forward or set new targets for the delivery of cancer prevention objectives. Specific commitments include: raising public awareness of the health risks of smoking; expanding smoking cessation services; promoting smokefree environments; encouraging healthy eating; promoting physical activity; promoting sensible drinking; encouraging sun protection behaviours.

## Cancer Control Programme

The Cancer Control Programme heavily references existing initiatives rather than setting up new programmes of work to deliver its cancer prevention aspirations. These include action on: tobacco, diet and nutrition, obesity, physical activity, alcohol, exposure to UV light (sunlight), exposure to radon and other sources of radiation, and sexual behaviour. The programme highlights the need for community based programmes supported by policies that work across health sectors and government departments and linking prevention to other disease areas such as coronary heart disease, stroke, diabetes and respiratory disease.

## Implementation of the strategies

### 1 – Tobacco control

Significant progress has been made across the UK with the implementation of several tobacco control measures. The UK compares favourably with the rest of the world in tobacco control terms.

The introduction of smokefree legislation has been led by supportive governments and resulted in high levels of compliance and popular support for the measure<sup>16</sup>, with 80% of the population in England supporting it three years on.<sup>17</sup> However, although significant advances have been made, there were 80,000 premature deaths in England in 2008 due to tobacco use. Around nine out of ten lung cancers and a significant proportion of other cancers are linked to smoking, so this trend will impact on cancer incidence in future.<sup>18</sup>

Across the UK, legislation has been introduced to raise the age of sale for tobacco, the introduction of picture warnings on cigarette packs, the passing of legislation to ban point of sale displays and to restrict the sale of cigarettes from vending machines, though these last two measures are yet to be implemented. In addition, money and support has been available for the maintenance of high quality smoking cessation services.

Although not all of the successes made in improved tobacco control can be attributed to the plans, there have been continued and sustained reductions in the prevalence of smoking. These include:

- Over the last 10 years, smoking prevalence in England has reduced by a quarter in adults from 28% to 21% in 2008.
- In England, smoking prevalence in 11 to 15-year-olds has halved between 1998 and 2008.
- Smoking prevalence in Scotland has dropped from 31% in 1999 to 25% in 2008.
- Smoking prevalence in Northern Ireland has fallen in recent years, from 25% in 2006/07 to 23% in 2007/08.<sup>19</sup>

Whilst these figures demonstrate the positive impact that the introduction of smokefree legislation has had on reducing smoking prevalence, it is too early to measure the full impact of many of the tobacco control measures outlined in cancer plans and related tobacco control strategies. However, there is strong evidence that a comprehensive and long-term strategy is needed to continue to see prevalence decline.

### 2 – Protection from the sun and skin cancer prevention

Rates of malignant melanoma, the most dangerous form of skin cancer, continue to rise steeply across the UK, with more than 10,300 cases of malignant melanoma diagnosed in the UK every year.<sup>20</sup> Alongside binge tanning on foreign holidays, experts believe that sunbed use accounts for rising rates of skin cancer. One estimate suggests that sunbed use is responsible for 100 deaths across the UK each year.<sup>21</sup>

Skin cancer prevention has received attention and this has led to a number of positive initiatives and legislation or the prospect of legislation across the UK. There has been progress on skin cancer prevention programmes and significant progress to discourage sunbed use, particularly by young people.

16 Haw S (2010) Second-hand smoke (In *Substance Misuse: the implications of research, policy and practice* ed, London: Joy Barlow Jessica Kingsley.  
17 Office for National Statistics (2008) *Smoking-related Behaviour and Attitudes*, 2007. Newport: HMSO.

18 Department of Health (2007). *NHS Cancer Reform Strategy*. London:HMSO

19 Department for Health Social Services and Public Safety (2009) *Review of Five Year Tobacco Action Plan 2003-2008*. DHSSPH: Belfast. Available at: [http://www.dhsspsni.gov.uk/tobacco\\_action\\_plan\\_review.pdf](http://www.dhsspsni.gov.uk/tobacco_action_plan_review.pdf) (accessed 2 July 2010).

20 Cancer Research UK (2007) *Cancer Incidence for Common Cancers: UK Statistics*. London: Cancer Research UK.

Available at: <http://info.cancerresearchuk.org/cancerstats/incidence/commoncancers/index.htm> (accessed 2 July 2010).

21 Diffey, B.L. (2003) A quantitative estimate of melanoma mortality from ultraviolet A sunbed use in the UK. *Br J Dermatol* 149(3): 578-81.

In Wales, there has been strong support for legislation to restrict sunbed use. The Health, Wellbeing and Local Government Committee Inquiry into the Use and Regulation of Sunbeds in Wales and successful research carried out by Cancer Research UK<sup>22</sup> positively influenced the bill that was passed in Westminster earlier in 2010 to restrict the use of sunbeds to over 18s in England and Wales. This was taken through as a Private Members' Bill with government support.

Legislation to restrict sunbed use and better regulate the sunbed industry in Scotland was implemented in December 2009. It is too early at the time of writing to formally evaluate implementation, but there have been no reports of concern about compliance. The Sunbeds Act 2010 is yet to be implemented in England and Wales, and work to develop the supporting secondary legislation is needed. A consultation on the regulations will be published in Wales in the autumn. Similar legislation is currently progressing through the Northern Ireland Assembly. Legislation restricting sunbed use, combined with strong skin cancer prevention campaigns, should lead to a drop in skin cancer rates, though any effect will take some time to become apparent.

The SunSmart campaign, funded by the UK health departments and coordinated by Cancer Research UK, has received additional funding. Tracking surveys have indicated that positive changes in sun protection behaviour were evident. Since 2003, year-on-year increases in SunSmart behaviour and attitudes have occurred. However, between 2007 and 2008 larger increases have been seen in relation to people limiting time spent in the sun and people understanding that fair skin is a risk factor for skin cancer.<sup>23</sup> It is too early to say if funding increases were attributable for these rises.

### 3 – Obesity

An England-wide obesity prevention strategy has been published and implementation is underway.<sup>24</sup> A key strand of this strategy has been a large, national social marketing campaign with significant local and partner involvement, *Change4Life*. The *Change4Life* programme has been running for over a year. Currently the level of central funding is being reduced and strategies are being revised. *Change4Life* has so far exceeded its initial published objectives, particularly in terms of brand awareness and the number of families joining the programme, and there are some indications that the year on year rise in childhood obesity is slowing.<sup>25</sup>

In Scotland, there have been initiatives to encourage the maintenance of a healthy weight and encourage physical activity. *Healthy Eating, Active Living: An Action Plan to Improve Diet, Increase Physical Activity and Tackle Obesity* (2008-2011) was published in 2008 and followed by *Preventing Overweight and Obesity in Scotland: A Route Map Towards Healthy Weight in 2010*. Scotland has one of the highest levels of obesity in OECD countries, with over a million adults and over 150,000 children obese. The latest available data show that the rate of increase in childhood obesity has slowed for the most recent period recorded. The proportion of children who are outside the healthy weight range increased to 33.6% in 2008, representing an annual rate of increase of 0.8% since 2003. The rate of annual increase is now lower than the previous 1.7% increase per annum between 1998 and 2003.<sup>26</sup>

In Northern Ireland, a programme to tackle obesity entitled *Inspiring Communities to Get Active Together* was published.

In Wales, Health Challenge Wales aims to help the public improve their own health by giving them tips on food and fitness. The MEND programme (Mind, Exercise, Nutrition Do-it) is also funded by the Welsh Assembly Government and is aimed at overweight and obese children aged 7 to 13 and their families. A consultation has also been published on the Obesity Pathway Strategy for Wales.

### 4 – Alcohol

There has been slow progress in each of the four nations on measures to reduce alcohol consumption. Strategies designed to tackle alcohol-related harm have focussed largely on the dangers of binge drinking (acute health risks and societal impact of alcohol), but little attention is paid to the consequences of sustained moderate levels of drinking over a long period.

22 Thomson CS, Woolnough S, Wickenden M, Hiom S, Twelves CJ. (2010) Sunbed use in children aged 11-17 in England: face to face quota sampling surveys in the National Prevalence Study and Six Cities Study. *BMJ* 340: c877.

23 Cancer Research UK, 2008, unpublished.

24 Department of Health (2008) *Healthy Weight, Healthy Lives* HM Stationery Office: London.

25 National Heart Forum (2009) *Obesity trends for children aged 2-11 years and 12-19 years* NHF: London

26 The Scottish Government (2009) *The Scottish Health Survey 2008* The Scottish Government: Edinburgh.

Available at: <http://www.scotland.gov.uk/Publications/2009/09/28102003/10> (accessed 2 July 2010).

In England, consumption is declining following a long upward trend from the Second World War until 2004,<sup>27</sup> but it is too early to tell if this is the start of a downward trend or just a blip. Awareness of the link between alcohol consumption and an increased risk of cancer remains relatively low.<sup>28</sup>

Scotland has advanced the most in efforts to introduce legislation to reduce consumption, including proposals for a minimum price per unit of alcohol. Alcohol consumption statistics show that patterns of drinking did not significantly change between 2003 and 2008.<sup>29</sup> An Alcohol Bill is currently being considered by the Scottish Parliament. The Fast Alcohol Screening Test (FAST questionnaire),<sup>30</sup> which measures alcohol consumption, and the Keep Well health check programme for 45 to 64-year-olds had been taken up with some enthusiasm by those interviewed in Scotland.

The Welsh Assembly Government is seeking additional legislative powers, and this could impact on the government's ability to make progress on some prevention policy areas, for example, to take legislative action to encourage reduced consumption of alcohol.

### 5 – Human Papilloma Virus

The HPV vaccine has the potential to prevent around 70% of cervical cancers.<sup>31</sup> The introduction and roll-out of the Human Papilloma Virus (HPV) vaccination has been a notable success in all four nations. A national vaccination programme has been successfully rolled out to 12 and 13-year-old girls with catch-up for 17 and 18-year-olds. Uptake and coverage have been high in Scotland,<sup>32</sup> England,<sup>33</sup> Wales and Northern Ireland.

### 6 – The role of health professionals in cancer prevention

Prevention was viewed by health professionals as a long-term priority, where changes in behaviour, in the event that they could be delivered, would take a long time to impact on cancer incidence.

Few interviewees felt that cancer prevention was their responsibility. However, Cancer Networks have been charged with developing cancer prevention plans and there are some good examples such as the Merseyside and Cheshire Cancer Network, which has prioritised cancer prevention and campaigned for tighter restrictions on sunbed use. However, we have no evidence that this good work has been replicated across the country.

The prevention of cancer was invariably acknowledged by interviewees as an 'ideal' focus and an integral part of any cancer strategy. However, GPs in England do not generally see cancer prevention, or indeed other disease prevention, as a core part of their role.<sup>34</sup>

Primary care workers had mixed views about stating that they were actively promoting disease prevention, which is good for cancer and other diseases,<sup>35</sup> but they could do no more than offer standard advice, which might be ignored, and that legislation would have most impact in changing health behaviours. Some voiced a concern about the difficulty of encouraging people to change their behaviour.

Those working in secondary care tended to view cancer prevention as the responsibility of primary care and believed that they did not have any expertise to offer.

However, there were a number of enthusiastic individuals who felt they were in a uniquely good position to encourage lifestyle change, and some GP practices had taken action on issues such as encouraging lower alcohol consumption, sometimes incentivised by enhanced service funding.

27 House of Commons Health Committee (2009) *Alcohol: First Report of Session 2009-10*. London: HMSO.

Available at: <http://www.publications.parliament.uk/pa/cm/cmhealth.htm> (accessed 2 July 2010).

28 Cancer Research UK (2009) *Perceptions of Risk Survey*. Cancer Research UK.

Available at: <http://info.cancerresearchuk.org/healthyliving/introducingcancerprevention/RiskSurvey/index.htm> (accessed 2 July 2010).

29 Office for National Statistics (2008) *Revised Alcohol Consumption Estimates from the 2003 Scottish Health Survey* Edinburgh: HMSO

30 The Alcohol Learning Centre (2009) *Fast Alcohol Screening Test (FAST)*. London: Department of Health. Available at: <http://www.alcohol-learningcentre.org.uk/Topics/Browse/BriefAdvice/SIPS/IdentificationTools/?parent=4448&chid=4570> (accessed 2 July 2010).

31 Cancer Research UK (2009) *Cervical Cancer Vaccine*. Cancer Research UK. Available at:

<http://www.cancerhelp.org.uk/about-cancer/cancer-questions/cervical-cancer-vaccine> (accessed 2 July 2010).

32 NHS National Service Scotland (2010) *HPV Immunisation Uptake Statistics*. Scotland: NHS National Service. Available at:

<http://www.isdscotland.org/isd/6153.html> (accessed 2 July 2010).

33 The Information Centre for Health and Social Care (2009) *NHS Immunisation Statistics England 2008/09*. London: The Information Centre for Health and Social Care. Available at: <http://www.ic.nhs.uk/statistics-and-datacollections/health-and-lifestyles/immunisation/nhs-immunisation-statistics-england-2008-09> (accessed 2 July 2010).

34 *Cancer Strategies Monitoring Project Qualitative Research Report*. CM Insight for Cancer Research UK. May 2009.

35 *Cancer Strategies Monitoring Project Qualitative Research Report*. CM Insight for Cancer Research UK. May 2009



Most encouragingly, the Scottish cancer workforce is strongly supportive of the need to prioritise cancer prevention and believes that working collaboratively to this end is important.

The workforce in Northern Ireland is supportive of cancer prevention activity but is concerned that progress in some areas has been slower than in other parts of the UK. In addition, stark health inequalities remain in Northern Ireland and interviewees felt that this issue must be tackled as a matter of urgency.

There is an expectation among the cancer community in Northern Ireland that the new Public Health Agency will provide drive and impetus to deliver change more rapidly, but broad concern was raised about the potential for loss of expertise through the restructure process.

### 7 – Political leadership and prioritisation of cancer prevention

Where political will to drive changes has been evident, legislation has been introduced or dedicated resource has been available to implement changes, progress on prevention has been quicker.

There has been a strong collective workforce and political will to prioritise public health and disease prevention in Scotland, which has driven many of the aims set out in Better Cancer Care. Though it is difficult to assess the impact that various initiatives are having on cancer incidence and outcomes to date, there are encouraging signs that progress is being made.

In other areas there has been less demonstrable progress and the workforce reported feeling both frustrated and disappointed by this.<sup>36</sup> Reorganisation of the health service in Wales has delayed some prevention activity in Wales.

Legislation has clearly had an impact in the areas of tobacco control and skin cancer prevention. It sends a strong signal from central government that action in an area is needed and that compliance is compulsory.

Where cancer prevention initiatives have been well funded, for example, the SunSmart campaign, or funded and carefully performance managed, for example, the introduction of the HPV vaccination programme, progress has been particularly pleasing.

In Northern Ireland, interviewees urged the Cancer Network to have access to more public health expertise. The involvement of public health consultants in the commissioning process was cited as a cause for hope.

## Conclusions and recommendations

Some progress on cancer prevention has been made across the UK, most notably with the introduction of tobacco control measures, but it is also a challenging area, with corporate, political and social barriers to overcome. Other lifestyle factors that influence the risk of developing cancer, such as obesity, are perceived to be more difficult to influence. Many do not see it as within their remit to try. The plans have helped raise the profile of cancer prevention among the cancer workforce. However, there needs to be political will to take heed of the evidence in this area and to regulate where necessary. There must also be further work to reduce cancer inequalities.

Assessing progress in public health and disease prevention is clearly a long-term task. Whilst positive soundings have been made everywhere in the UK, it will be important to maintain initiatives if we are to see objective progress.

### Cancer networks

- **In order to reduce the incidence of smoking related cancers and see cancer mortality fall, we should continue to promote comprehensive tobacco control measures. This should include:**
  - a) **A strong commitment to the World Health Organisation's Framework Convention on Tobacco Control.**
  - b) **The development and ongoing monitoring of a tobacco control programme by each nation in the UK.**



*Skin cancer prevention*

- We welcome the legislation in England, Scotland and Wales to regulate the use of sunbeds. Supportive regulations should be developed and implemented in England and Wales to ensure maximum effectiveness of the measures. In addition, there should be further work to communicate with the public about the dangers of sunbeds and the link between their use and skin cancer. The Northern Ireland Assembly should pass and implement the Sunbeds Bill.

*HPV vaccination*

- The roll-out of the HPV vaccination programme has been a notable success to date. We support the continuation of a school-based vaccination programme, reaching girls before they are likely to be at risk of infection.

*Obesity*

- Any future strategies to prevent obesity and promote physical activity should be multi-faceted. They should include initiatives to increase physical activity, improve dietary quality, reduce energy intake and develop clear, consistent and evidence-based messages on healthy eating.

*Alcohol*

- Any future strategies to tackle alcohol should include:
  - a) Measures to increase the cost of alcohol.
  - b) Further restrictions on the marketing of alcohol.
  - c) Investment in information campaigns to raise awareness of the long-term health risks associated with cancer and other diseases.

## 05

## Awareness and early diagnosis

*Awareness and early diagnosis... for a lot of PCTs it's not really in their mindset... if anything can get squeezed, that will be it*

Primary Care Lead, England

A key reason why our cancer outcomes lag behind the best performing countries in Europe is that we often diagnose cancer late in the UK. Estimates suggest that up to 10,000 deaths could be avoided each year if we diagnosed cancer earlier and ensured access to appropriate treatment.<sup>37</sup> This figure is based on an analysis of the number of deaths that could be avoided each year if survival in Great Britain matched the highest in Europe.<sup>38</sup>

Understanding why we diagnose cancer late in the UK in order that we can take steps to speed up diagnosis is complex. Awareness of the signs and symptoms of cancer among the general public is generally low,<sup>39</sup> there is often an extended interval between noticing a symptom and seeking help from a GP or another health professional,<sup>40</sup> GPs act as gate-keepers to NHS services and evidence suggests that access to some diagnostic tests is slow. System delays can also occur and the interface between primary and secondary care is often not as joined up as it should be.

Commitments to improve awareness and early diagnosis of cancer were contained in each of the plans. However, England has made significant progress to raise the profile of awareness and early diagnosis with the establishment of the National Awareness and Early Diagnosis Initiative (NAEDI). Interviews highlighted that the workforce understands the importance of early diagnosis and the impact this can have on treatment options and survival rates, but concern that this could be an area for financial constraint in light of efficiency savings. Comparative activity in Scotland, Wales and Northern Ireland has been patchy and must be given higher priority. There is much that we do not know about how to raise awareness of cancer signs and symptoms and how to encourage early diagnosis. Further research is needed, including into how patients are currently diagnosed.

### Cancer Reform Strategy

The Cancer Reform Strategy committed to creating NAEDI to promote the earlier diagnosis of cancer. The initiative is jointly chaired by the Department of Health and Cancer Research UK. The stated purpose of NAEDI was to coordinate a programme of activity to increase cancer symptom awareness and encourage earlier presentation. The activity included:

- Developing measurement tools for symptom awareness;
- Developing and testing new interventions to raise awareness;
- Supporting the roll-out and evaluation of local pilots of validated interventions and disseminating information about best practice.
- Encouraging PCTs to give appropriate priority to local initiatives to promote early presentation by people with symptoms of possible cancer.

37 Richards, M.A. (2009) The size of the prize for earlier diagnosis of cancer in England. *British Journal of Cancer* 101: S125-S129.

38 Abdel-Rahman, M., Stockton, D., Rachet, B., Hakulinen, T., Coleman, M.P. (2009) What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? *British Journal of Cancer* 101: S115-S124.

39 Robb, K., Stubbings, S., Ramirez, A., Macleod, U., Austoker, J., Waller, J., Hiom, S., Wardle, J. (2009) Public awareness of cancer in Britain: a population-based survey. *British Journal of Cancer* 101: S18-S23.

40 Macleod, U., Mitchell, E.D., Burgess, C., Macdonald, S., Ramirez, A.J. (2009) Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British Journal of Cancer* 101: S92-S101.

- Improving access to diagnostics
- More research to develop new tests and interventions; and
- Involving health professionals such as pharmacists and social workers in the development of NAEDI.

### Better Cancer Care, An Action Plan

Better Cancer Care focused on cancer screening as the main lever to increase awareness and early diagnosis. However, it did contain commitments to reduce system delays through the use of electronic referrals and redesigning patient pathways. Better Cancer Care made reference to audits undertaken in primary care to look at patient reporting of symptoms and referral timescales, but there were no clear plans to take these initiatives forward. Overall, Better Cancer Care lacked firm commitments in this area, representing a significant gap in the strategy.

### Designed to Tackle Cancer

Designed to Tackle Cancer aimed to improve survival rates by detecting cancer as early as possible through appropriate public education and stated that the Assembly Government could support the development of initiatives to promote symptom awareness. Specific commitments included a section on cancer awareness on the Chief Medical Officer's website.

### Cancer Control Programme

The Cancer Control Programme acknowledged that an increasing awareness of signs and symptoms could have implications for the workforce and adherence with waiting time standards, if more people presented with suspected cancer.

The Programme recommended that a pilot to raise awareness of the symptoms and signs of cancer and the benefits of early detection should be commenced by 2007 and that health professional awareness should also be improved through the development of regional referral guidelines. The Programme set no budget or other performance management mechanism for the delivery of these goals.

### Implementation of the plans and strategies

#### I – Establishment and roll-out of NAEDI

The early diagnosis agenda is front of mind amongst relevant health professionals in England. This has been a direct consequence of the Cancer Reform Strategy's focus and prioritisation of this issue. NAEDI is firmly established and has undertaken encouraging work to refine and communicate the evidence base and spread the message that early diagnosis is important to people 'on the ground'. There is widespread recognition of the importance of improving the awareness of cancer signs and symptoms and of encouraging early presentation/diagnosis at Cancer Network level and among GPs, even if they do not talk in the language of the Cancer Reform Strategy or NAEDI.

Specific examples of work include:

#### *a) Raising awareness*

The development of key messages for breast, bowel, lung, prostate, ovarian and cervical cancers is complete and an 'Ahead of the Game' project has been launched. Five football club community schemes across England are aiming to raise awareness of bowel, prostate and lung cancer in men over 55. PCTs and Cancer Networks across England are engaged in projects to raise awareness and promote earlier diagnosis of breast, bowel and/or lung cancer.

#### *b) Optimising clinical practice and systems*

In the first quarter of 2009, 92 general practices in the North of England Cancer Network completed significant event audit (SEA) reports for their most recent cases of lung cancer and teenager/young adult cancer in a project funded by the National Cancer Action Team and the Cancer Network.

Secondary analyses of the reports found that it was important to have processes in place to follow-up, manage and refer non-resolving symptoms. Plans for future Significant Event Audit analyses are under discussion.

#### *c) Improving GP access to diagnostics*

The previous government committed to give GPs quicker and easier access to diagnostic tests for those patients they suspect to have cancer. Work began to define the most appropriate diagnostic tests for different cancers ahead of the General Election, and post-election. Work in this area continues.

**d) Research, evaluation and monitoring**

A British Journal of Cancer supplement<sup>41</sup> was published in December 2009. The supplement brings together evidence underpinning activity in awareness and early diagnosis of cancer. A health economics study has been commissioned to establish the potential costs and benefits of earlier detection, focusing on breast, lung, colorectal, prostate and skin cancers. Early results suggest that achieving earlier diagnosis would be cost-effective.

**e) Primary care audit**

A primary care audit of cancer diagnosis by general practice has not been as well taken up as hoped. It could be that the poorer performing practices/Networks chose not to engage and this needs to be addressed.

**2 – Workforce engagement**

A significant proportion of the workforce in England is aware of NAEDI and recognises the importance of prioritising early diagnosis. Some have been financially incentivised to take part in the primary care audit though many have commented that the financial inducement is not equal to the amount of work they were asked to undertake.

Although the two-week wait standard was introduced before the development of the Cancer Reform Strategy, it is viewed as a powerful mechanism to encourage the quicker diagnosis of cancer. It is embedded in the English system, with many health professionals feeling passionate about its effects. Many interviewees felt it had encouraged earlier diagnosis in many instances. However, some believed that it led to unintended consequences for some patients, such as knock-on delays to non-two-week wait patients.

We were concerned to hear from some health professionals that there are in-built 'perverse incentives' not to refer patients to secondary care. In future, the NHS should always seek to encourage and incentivise early diagnosis.

**3 – Future work**

Although NAEDI has made significant progress to establish itself and support pilot interventions, there is much that we still do not know. NAEDI is seeking to combine action and research – building the evidence base at the same time as taking action to establish the optimal way to encourage earlier diagnosis. For example, we know that a significant proportion of patients are not diagnosed via the two-week wait; we need to understand more about the routes to a cancer diagnosis.

An International Cancer Benchmarking Partnership, currently underway, should also enable lessons to be learnt about diagnosis from comparative health systems.

**4 – Political leadership**

The vision and leadership of Professor Sir Mike Richards, the National Cancer Director, has been crucial in driving progress. Professor Richards has described the area of early diagnosis as 'the next big thing that needs to be tackled after smoking'.<sup>42</sup> The workforce reports feeling inspired by his leadership in this area. The available resource, good stakeholder engagement and international collaboration have also been important in rooting early diagnosis firmly at the centre of Cancer Network thinking.

**5 – Stakeholder engagement**

NAEDI has established four workstreams to drive progress in different areas, for example, to ensure that suitable research to support the NAEDI evidence base is developed in a timely way. Responsibility for different workstreams has been outsourced to a range of stakeholders, health professionals and academics. This model of delivery has ensured that the initiative is well supported by a range of expertise and has set clear boundaries for who is responsible for delivering different elements of the agenda. The joint leadership of NAEDI, provided by Cancer Research UK and DH, has also enabled progress to be driven forward in many areas.

As a consequence of concerted effort in this area, the evidence base is developing. It is inevitably difficult to assess what we now know as a direct consequence of the NAEDI initiative and evidence that has come to light since NAEDI was set up but may not have been driven by it. However, the developing evidence base should be considered a success.

41 British Journal of Cancer (2010) *Diagnosing Cancer Earlier: Evidence for a National Awareness and Early Diagnosis Initiative* Vol. 101(2).

42 Cancer Research UK (2008) *NAEDI Newsletter*, Vol. 1. London: Cancer Research UK. Available at: <http://info.cancerresearchuk.org/spotcancerearly/naedi/> (accessed 2 July 2010).

## 6 – Information

The provision of information has also helped to drive change. The publication of PCT data on one year survival in the Second Annual Review of the Cancer Reform Strategy has demonstrated the wide variation across the country and areas with very low one year survival. In future, more should be done to ensure this information is easily accessible to the general public.

## 7 – Implementation in Scotland, Wales and Northern Ireland

In early 2010, the Scottish Cancer Taskforce held a dedicated workshop on awareness and early diagnosis to investigate the issue, but action needs to be accelerated. We are aware of similar activity in Wales.

However, the focus on awareness and early diagnosis in Scotland, Wales and Northern Ireland has been patchy. Greater priority should be given to encouraging earlier diagnosis, notwithstanding the already excellent focus on screening.

## Conclusions and recommendations

Significant progress has been made in England to raise awareness of the importance of earlier diagnosis. The workforce is engaged and recognises the impact this could have on cancer outcomes. Implementation in Scotland, Wales and Northern Ireland has been patchy and should be given higher priority.

More research is needed in all four nations to understand how patients are diagnosed and to develop interventions to promote early presentation of symptoms.

- **The National Awareness and Early Diagnosis Initiative (NAEDI) needs to maintain momentum and deliver change in England. Best practice in promoting awareness and early diagnosis needs to be replicated in each of the other UK nations. Though we know of some relevant work underway in other nations, the priority given to encouraging early diagnosis should be increased.**
- **GP access to the appropriate diagnostic tests should be improved. To make progress in this area, we need to better understand current access levels. Appropriate follow-up is also critical.**
- **Anecdotal evidence suggests that clinical leadership at a local level is a helpful driver for progress in promoting early diagnosis; some Cancer Networks have appointed short-term clinical leads. We think there could be value in formalising these arrangements.**
- **Information to help health professionals is vital. First, referral guidelines for different cancers should be regularly updated. Second, work to develop decision-support tools to help referral in primary care has not progressed as quickly as hoped. We would welcome further work in this area. This may help to address a lack of continuity in primary care, for example, patients not always seeing the same GP.**
- **Research should be undertaken across the UK to understand more about the pathways of non-urgent referrals, for example, for those patients admitted as emergencies. This research should explore whether or not patients had experienced symptoms and/or previously presented to a health professional.**
- **Coordinated work should be undertaken to engage health professionals, particularly pharmacists, to promote early diagnosis. This should be especially targeted to lower socio economic groups as we know that people living in deprived areas are less likely to survive common cancers than those living in more affluent areas.<sup>43</sup>**
- **We must continue to build the evidence base and incentivise the better measurement of important indicators to assess the progress we are making. For example, the mandatory collection and reporting of staging data would be a useful driver to encourage the earlier diagnosis of cancer.**

<sup>43</sup> Ellie L, Rachet B, Shah A, Walters S, Coleman M (2009) Trends in cancer survival in Spearhead Primary Care Trusts in England, 1998-2004. *HealthStat* Q 41: 7-12.

## 06

## Screening

*Due to [bowel screening] I see more early cancers nowadays – we can offer better treatments... I'm confident it will affect the survival statistics. We have different kinds of treatment for the early cancers, not just surgery*  
Oncologist, England

Screening can detect cancer at an early stage and, for most cancers, early detection means that treatment is simpler and has a greater chance of success. Some screening programmes also prevent cancer: The cervical and bowel cancer screening programmes can detect and treat abnormal changes before they progress to full-blown cancer. Approaching 10% of cancers are detected via cancer screening.

The UK has an excellent track record of setting up and delivering screening programmes. We fund high quality screening research and have a tradition of delivering organised screening programmes.

### Overview of current screening programmes in the UK

#### Breast screening

	Age	Extensions	Time between screen
England	50-70	Extending age range to 47-73 by 2012	Every 3 years
Northern Ireland	50-64	Extending age range to 70 by March 2012	Every 3 years
Scotland	50-70*	No plans for further extensions	Every 3 years
Wales	50-70*†	No plans for further extensions	Every 3 years

\* Can be requested over 70

† Can be requested over 70 or under 50 if considered to be at risk)

#### Cervical screening

	Age	Time between screen
England	25-49	Every 3 years
	50-64	Every 5 years
	65+†	
Northern Ireland	25-49**	Every 3 years††
	50-64	Every 5 years
Scotland	20-60	Every 3 years
Wales	20-60	Every 3 years

† If history of abnormal smears or no smear since 50

\*\* 25-49 from January 2011

†† every three years from January 2011

### Bowel screening

	Age	Roll out	Time Extensions	between screen
England	60-69 Over 70s can request a kit	Over 90% of PCTs now covered	Extending age range to 70-75 by April 2010 Cancer Reform Strategy contains commitment to assess extension to below age 60	Every 2 years
Northern Ireland	60-69	Roll out began April 2010	Extending age range to include those aged up to 74 in 2012 if financial resources are available	Every 2 years
Scotland	50-74	Completed	No plans for further extensions	Every 2 years
Wales	60-69	Completed	Extending age range to 50-74 by 2015	Every 2 years

### Cancer Reform Strategy

The Cancer Reform Strategy set a number of targets for expanding and improving the screening programmes. These included:

- Extending the age range by 2012 for breast screening to provide nine screening rounds between 47 and 73 years.
- Introducing direct digital mammography by 2012.
- Responsibility for the management of surveillance for women at high familial risk of breast cancer to be taken over by the NHS breast screening programme.
- All women to receive the results of their cervical screening tests within two weeks by 2010.
- Action to tackle the falling participation in the cervical screening programme of younger women aged 25-35.
- Extension of the NHS bowel screening programme from 2010 to invite men and women aged 70-75 years.
- Scoping moving to an activity-based system to fund screening services.
- Encouraging NHS Cancer Screening Programmes to share best practice to improve the accessibility of screening for all groups.
- Introduction of new technologies including automation of cytology reporting and the use of Human Papilloma Virus (HPV) testing as and when the research evidence supports this.
- Possible roll-out of the bowel screening programme to people in their 50s by the end of 2010.
- Monitoring the emergence of potential new diagnostic markers as possible screening technologies of the future.

### Better Cancer Care, An Action Plan

Better Cancer Care committed to an evidence-based and best practice approach to screening, to raise public awareness of the existing screening programmes and to target those groups who are less likely to attend or complete a screening programme. Specific commitments included:

- Support for the roll-out of the Scottish Bowel Screening Programme by the end of 2009.
- £13.4 million to introduce two x-ray views of each breast from different angles at all breast screening appointments to be implemented by April 2010.
- The Scottish Government's Improvement and Support Team working in partnership with the Scottish Breast Screening Programme to redesign roles to support the introduction of two x-ray view breast screening.
- Recognition of the need to address the fall in uptake of cervical screening amongst women.

## Designed to Tackle Cancer in Wales

Designed to Tackle Cancer states that the national screening programmes for breast and cervical cancer should continue to improve detection rates. However, it does not set out how this will be achieved. Commitments included:

- The roll-out of a national bowel screening programme for men and women aged between 50 and 74. The screening programme was launched in 2008 for those aged 60 to 69, and this will be extended to those aged 74 by 2011 and down to age 50 by 2015.
- A review of the effectiveness of screening for other cancers, such as lung and prostate cancer, by the National Screening Committee.

Designed to Tackle Cancer outlines concerns that the future of Cervical Screening Wales is vulnerable because of a national shortage of histopathologists and cytologists and that the Breast Test Wales Programme was vulnerable due to a national shortage of breast radiologists, surgeons and radiographers leading to difficulties in expansion in the future. Although this is highlighted as a key area for concern, there is no action outlined to address these concerns.

## Cancer Control Programme

The Cancer Control Programme acknowledged that the uptake of cervical screening in Northern Ireland was lower than in other parts of the UK and contains a commitment to investigate and address the reasons for this poor take-up. Other commitments included:

- Extension of the Northern Ireland breast screening programme to women aged 64 to 70, to bring the programme into line with the rest of the UK.
- A continued effort to raise awareness of the breast screening programme in areas with lower uptake.
- Giving commissioners and providers responsibility to work at local level to improve uptake in areas of high deprivation.
- Roll-out of the bowel screening programme in Northern Ireland by 2009.

## Implementation of the plans and strategies

### I – Breast cancer screening

In England, some progress has been made on the extension of breast screening to women aged 47 to 49 and 71 to 73. Phasing in has been carefully considered and a proposal accepted to randomise the extension, with half randomised to invite women aged 47 to 49 and half to invite women aged 71 to 73. This is to ensure that the most useful epidemiological data can be gathered to inform future decisions about the programme. Ethical approval for randomisation has been granted and roll-out is underway in pilot sites.<sup>44</sup>

Implementation of digital mammography in England has been slow. Data in December 2009 suggested that a maximum of half of local programmes would have one digital set by 2010 and only six will be fully converted.<sup>45</sup> In Scotland, when Better Cancer Care was published the Scottish Breast Screening Programme was undertaking early planning for the introduction of digital mammography. It was anticipated that this would be introduced systematically by 2011.

Three early implementer sites for the surveillance of women at high risk have been identified in England and new IT software was released to them before end of 2009.<sup>46</sup>

Because of concerns about the over-diagnosis of breast cancer as a result of screening, the information leaflet for women in England is being revised and is due to be published shortly. The coverage of breast screening across PCTs in England still varies considerably between 42.3% and 83.5%.<sup>47</sup>

NHS Quality Improvement Scotland (QIS) published a status report in December 2006 on the Scottish Breast Screening Programme and made five recommendations including:

<sup>44</sup> Department of Health (2009) *Cancer Reform Strategy: Achieving Local Implementation – Second Annual Report*. London: HMSO.

<sup>45</sup> *Ibid.*

<sup>46</sup> *Ibid.*

<sup>47</sup> *Ibid.*



- Monitoring and reporting performance of radiologists and other film readers.
- Reducing the number of women recalled for assessment after their first screening appointment.
- Meeting the targets for issuing results.
- Encouraging each Scottish Breast Screening service to assess and manage the risks associated with breast screening so they can assure the clinical governance committee of their host NHS Board that risks are minimised.
- Recommending NHS Scotland to use the experience gained from breast screening to improve breast cancer services generally.

The Scottish Breast Screening Programme is to address these issues and to work with the Scottish government and NHS Boards to ensure workforce needs are met. It is commendable that there has been an evaluation of the Breast Screening Programme and that service problems are being addressed.

Breast Test Wales received nearly £1m in funding in June 2010 from the WAG to provide new mobile breast screening units. The service hopes the new units will speed up access to screening as well as help equalise access to screening services by providing facilities in local, convenient locations. Breast Test Wales has begun to work to make units accessible to those with physical disabilities. Additionally, pharmacies are running information campaigns about breast screening. The campaign will inform all eligible women when the Breast Test Wales mobile unit is in the area. Women aged 50 to 70, who will be routinely called for breast screening, will have a sticker placed onto their prescription bags. The campaign aims to reverse the falling number of women attending for their breast screening appointment.

## 2 – Bowel cancer screening

Northern Ireland is lagging behind the rest of the UK in the roll-out of its bowel screening programme, and roll-out needs to continue as swiftly as possible.

A range of standards has been published by NHS Quality Improvement Scotland (QIS), including a national target for 60% of those invited to participate in bowel screening to respond and complete a test. Better Cancer Care acknowledges that more needs to be done to encourage uptake, especially amongst men and Scotland's less affluent communities. Methods for doing so should be piloted and evaluated, and the findings acted upon.

Early indications from the bowel cancer screening programme suggest that men and those in the most deprived group are less likely to participate in screening than women and more affluent people. Efforts should be made across the UK to encourage men and people in the most deprived groups to take up bowel screening. Tailored messages should be developed which target groups with the lowest uptake rates.

Efforts to make progress in this area have been attempted in Wales, with pharmacies running awareness raising campaigns. During a recent Men's Health Week, Bowel Screening Wales became the first screening programme to run an information campaign through pharmacies. Evaluations highlighted greater public awareness of the screening programme as a result.

## 3 – Cervical cancer screening

In the wake of Jade Goody's death, there was a spike in cervical screening attendance, particularly among younger women.<sup>48</sup> This is encouraging as there had been a long-term decline in the numbers of younger women presenting for screening. However, whether this higher uptake can be maintained is another question.

In Scotland, a recent report outlines reasons for low uptake of screening and recommends an engagement strategy to improve uptake and address inequalities.<sup>49</sup> Following this report, a new suite of leaflets has been produced to encourage uptake of cervical screening, including one specifically targeting lesbian and bisexual women, and one designed to provide information to those women being invited for the first time.

<sup>48</sup> Ibid.

<sup>49</sup> Reid M (2009) *Report of a Study to Identify and Explore Attitudes Leading to Low Uptake of Cervical Screening in Scotland with a Particular Focus on How to Improve Uptake and Address Inequalities*. Edinburgh: NHS Health Scotland.

In England, prompted by public campaigning and a Ministerial Statement, a review of the age of first cervical screen was undertaken in 2009. This concluded that it remained appropriate for screening to start at age 25. However, it recognised that young women who presented with symptoms were sometimes given poor advice. Steps are being taken to increase health professionals' awareness in this area; young women presenting with symptoms should be referred straight to colposcopy.

In England, progress is also being made to achieve a 14-day turnaround time for the results of cervical screening. Liquid Based Cytology (LBC) is used for testing and an electronic Scottish Cervical Call/Recall system was introduced in May 2007.

In Northern Ireland, the Department of Health recently announced that from January 2011, the age of first screening would be raised to 25, in line with England, following a recommendation from the Northern Ireland Regional Advisory Group on Cervical Screening. In addition, women aged 25 to 49 will also now have the opportunity to be screened more frequently as the screening interval will be reduced from five years to three years.

#### **4 – The role of the workforce**

There was high awareness of the national screening programmes among health professionals. There was also awareness of relative strengths and weaknesses of different nations' programmes. For example, in Northern Ireland there was awareness that the introduction of the bowel screening programme was delayed compared to the rest of the UK. There was often a 'healthy competition' demonstrated between Networks about screening uptake.

In general, the workforce was very positive about the screening programmes, even when there had been controversy about the value of breast screening.

#### **5 – Uptake**

Tackling the complex issue of low uptake by some groups has been the responsibility of PCTs and Cancer Networks in England. They have mostly not had associated budget for this work and it has suffered as a result.

#### **6 – Introduction of new screening technologies**

As a rule, better progress has been made in service re-design and the introduction of new screening technologies across the UK than in encouraging uptake by hard to reach groups and reducing variation in uptake.

One reason why the strategies have had more success in encouraging new technology roll-out and service re-design is that these initiatives have been the subject of standards and have been performance managed, often at national level. This has undoubtedly quickened the pace of change in some areas.

#### **7 – Research into cancer screening**

Some members of the research community have questioned the plans' ambitions on cancer screening. Concern has been raised that the plans are too timid in their aspirations for screening and do not seek to radically change or improve the way that services are delivered. The research community argue that we also need to continue to invest in high quality screening research if we are to retain our reputation as a world leader in cancer screening.

Though there has been progress, there was a feeling that the strategies are predominantly service-orientated and short term. There is a reluctance to invest in demonstration and research projects looking at new screening techniques.

#### **8 – Performance management of screening in the NHS**

Some Cancer Reform Strategy progress has been made because of the incentives and levers deployed. For example, some aims set out in the CRS were incorporated into the NHS Operating Framework as a Vital Sign. This performance management and clear central direction has driven progress in some areas.

## Conclusions and recommendations

We have world-class screening programmes across the UK. Strong performance management has driven improvements across the service and, in turn, the service has generally responded well to the advent of new technologies and recommendations for service re-design.

The current UK cancer strategies, in different ways, seek to build on progress previously made in this area. They prioritise the roll-out of new technologies and service re-design, encouraging screening attendance by hard to reach groups and reducing variation in the uptake among different groups and between localities.

- Northern Ireland's bowel screening programme was delayed due to financial constraints. This is being addressed and the programme is beginning to roll out. This must be completed as a matter of urgency.
- The success in introducing new technologies should be repeated with the introduction of flexible sigmoidoscopy (or 'flexi-scope'). Recent research<sup>50</sup> has shown that flexible sigmoidoscopy can prevent a third of bowel cancers and reduce deaths from bowel cancer by up to half. As well as the potential to save lives, incorporating the flexi-scope test into a national bowel cancer screening programme would result in long-term cost savings due to the reduced costs of bowel cancer diagnosis, treatment and follow-up years later.<sup>51</sup> We strongly recommend the introduction of the flexi-scope test into a national screening programme for bowel cancer.
- Take-up rates for bowel cancer screening are low, which may be due to the fact that it is a relatively new programme. This may also be because the test requires a more active role by the participant than the breast or cervical screening tests and because people may find the test unpleasant. Uptake is lower among men, more deprived groups and among certain minority ethnic groups, such as people from the Indian sub-continent. Steps should be taken to address inequalities in uptake and ensure that as many people as possible are taking up the offer of bowel cancer screening. This includes developing messages that are tailored to the UK's diverse communities.

50 Atkin et al. (2010) Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial. *Lancet* 375: 1624-1633.

51 Tappenden et al. (2007) Option appraisal of population-based colorectal cancer screening programmes in England. *Gut* 56: 677-684.

## 07

## Surgery

*Over the next 5 to 10 years we're going to have real problems in that the younger people coming up don't have the time in the operating room to get to a really good standard before they become consultants... they have about 50% less exposure [mechanical practice] than guys coming off now*  
Surgeon, Scotland

For many cancers, surgery is the first line of treatment. Surgery cures more patients than any other type of treatment. Advances in surgical techniques mean that the quality of cancer surgery has improved, with more operations being carried out by specialist surgeons with expertise in particular procedures. However, there are concerns about training, specialisation of treatment, equipment and standard of theatres, and in Wales, concern that patients are not always being treated in the most appropriate location.

### The Cancer Reform Strategy

The Cancer Reform Strategy stated that cancer surgery will continue to improve and confirmed that a pilot training programme for laparoscopic bowel surgery would be established and evaluated for potential national roll-out.

The Cancer Reform Strategy also encouraged the full implementation of Improving Outcomes Guidance which recommends service reconfiguration to enable complex surgical procedures to be carried out by specialists.

### Better Cancer Care, An Action Plan

Better Cancer Care emphasised the need for clinical audit in surgical services, stated that surgical care should be offered at the highest standard and that demand for surgery should be understood in order to deliver this. BCC urged NHS Boards to work with the regional cancer networks to ensure the right facilities were in place to meet the future demands for surgical care.

Better Cancer Care recognised that further development and training of specialists would be necessary for the roll-out of laparoscopic colorectal surgery and sentinel node biopsy for breast cancer.

### Designed to Tackle Cancer

There is very little detail about the use of surgery as a treatment for cancer in the strategy. It is mentioned only twice. Designed to Tackle Cancer makes reference to some relevant National Cancer Standards which were published in June 2005 and should have been met by March 2009. However, this target has now slipped and has been pushed back to September 2010.

### Cancer Control Programme

The Cancer Control Programme highlighted surgery as the main treatment option for cancer patients and stated that there needed to be continual specialisation in cancer surgery for optimal care. The programme stated that all elective cancer surgery should take place within accredited services in designated sites by 2010.

### Implementation of the plans and strategies

Whilst researching this report, a similar picture across all of the nations emerged. This can be broken down into six areas including:

### 1 – Specialisation

Across the UK, there has been a shift towards greater specialisation in the delivery of surgery for cancer treatment. This is a result of research which shows that there is a close relationship between the volume of procedures and improved outcomes for patients.<sup>52</sup> For example, looking at surgery for prostate and bladder cancer in England it is clear that:

- a The overall number of prostatectomies and cystectomies has increased greatly, mostly due to the increasing incidence of prostate cancer.
- b The number of Trusts undertaking prostatectomies and cystectomies has fallen from 145 to 119, with the number of Trusts undertaking fewer than ten procedures per year (and so unlikely to have sufficient specialist expertise) falling from 65 to 22.
- c The number of Trusts undertaking at least 40 major procedures per annum has increased from 5 to 54, and the percentage of all such procedures undertaken in these high-volume Trusts has increased from 12% to 77%.<sup>53</sup> However, in certain areas, further progress must be made. For example, a recent study of oesophago-gastric cancer services found that 11 of the 30 cancer networks in England have still to centralise curative surgery for these cancers.<sup>54</sup>

Although there is a link between greater specialisation and improved outcomes, some patients are keen to receive their treatment close to their home and sometimes do not understand that having surgery to treat their cancer is best delivered in a specialist centre by a surgeon who has carried out a high volume of a similar or the same procedure.

Surgeons interviewed raised concerns about what they described as 'burn out' caused by carrying out the same or similar operations repeatedly. They also stated that they sometimes felt de-skilled, as specialising in one particular area of surgery meant that they could not maintain skills and expertise in other areas.

### 2 – Provision of surgical treatment

Not all patients that could benefit from surgery are offered it. This is partly a consequence of late diagnosis. Emerging research also suggests that age bias is an issue, with older patients less likely to be offered surgery to treat their cancer.

The National Lung Cancer Audit shows that only approximately 10% of patients with non-small-cell lung cancer receive surgical resection, when evidence suggests a rate of around 20% would be clinically appropriate.<sup>55</sup> Meanwhile, although active anti-cancer treatment (surgery and chemotherapy) is offered to 54% of patients with lung cancer, rates vary between Trusts from less than 10% to more than 80%.<sup>56</sup>

### 3 – Training

Young surgeons are not receiving the requisite number of hours of training because of the introduction of the EU Working Time Directive. This means that surgeons who are currently in training are receiving fewer hours during their training programme than their predecessors.

Concern was also expressed about how training standards would be maintained during the current economic climate and financial challenges facing the NHS.

Particular concerns were raised about ensuring surgeons were fully up to speed with new techniques such as robotic operations, and systems need to be developed to provide continuing professional development.

### 4 – Ageing workforce

Alongside training, it was noted that a number of senior surgeons are due to retire in the near future, which could compound the training issues facing this part of the cancer workforce.

52 Richards M (2009) The size of the prize for earlier diagnosis of cancer in England. *British Journal of Cancer* 101: S125–S129.

53 Department of Health (2008) *Cancer Reform Strategy: Maintaining Momentum, Building for the Future – First Annual Report*. London: HMSO.

54 Palser TR, Cromwell DA, Hardwick RH, Riley SA, Greenaway K, Allum W, van der Meulen JHP (2009) Reorganisation of oesophago-gastric cancer care in England. *BMC Health Services Research* 9: 204.

55 Department of Health (2009) *Cancer Reform Strategy: Achieving Local Implementation – Second Annual Report*. London: Department of Health.

56 NHS Information Centre (2009) *National Lung Cancer Audit* [online]. Available at: [www.ic.nhs.uk/canceraudits/lung](http://www.ic.nhs.uk/canceraudits/lung) (accessed 4 March 2010).

### 5 – Surgical theatres and equipment

Research participants noted that with improved surgical techniques and procedures, equipment and theatres also need to be updated and upgraded to ensure treatment is provided in an optimal setting. However, concern was raised that this could be problematic with the NHS facing a period of reduced investment.

### 6 – Surgery in Wales

Our research highlighted that there had been political intervention to encourage more surgery for Welsh patients in Wales. This is very worrying if it means that robust evidence on the importance of being treated by an experienced surgeon is being disregarded. Cancer patients in Wales should have access to good quality surgical treatment regardless of the location and this issue must be addressed as a priority.

## Conclusions and recommendations

There have been advances in cancer surgery in recent years which have led to specialisation and improving outcomes for patients. However, specialisation has led to some surgeons feeling deskilled. Pressures within the NHS sometimes mean that junior surgeons are not receiving the required level of training that their predecessors received.

- Laparoscopic surgery has improved the quality of cancer surgery, is less invasive than other forms of traditional surgery and should lead to lower morbidity and speedier recovery rates for patients, as well as cost savings for the NHS. Further progress should be made in rolling out new surgical techniques, such as laparoscopic surgery, across the UK.
- Our research highlighted that there has been political intervention regarding the choice of location for surgery for Welsh patients. This would be very worrying if it means surgery is not being carried out in places that can deliver the best outcomes. Cancer patients in Wales should have access to good quality surgical treatment regardless of location.
- The reduction in training time for new surgical oncologists is worrying. The EU Working Time Directive is stopping junior surgeons receiving the requisite experience. Trainee surgeons should have dedicated time to receive the appropriate level of surgical training to overcome the constraints of the Working Time Directive.

## 08

## Radiotherapy

*We have really got big capacity issues and consequently aren't wanting to implement specialist radiotherapy techniques.*

Oncologist, Wales

Radiotherapy uses radiation to treat cancer. It can be applied externally, most commonly using x-rays, or internally by drinking a liquid or insertion of radioactive material. This versatile treatment option is an integral part of many cancer patients' treatment plans.

A similar picture emerged across the nations in terms of access to, and the delivery of, radiotherapy. Shortages of both staff and units remain widespread. As a consequence, patients often have to travel long distances for their radiotherapy, despite a good practice recommendation in the plans that they should not have to travel for more than 45 minutes for treatment. The complexity involved in building new units was acknowledged by interviewees, given the requirement for bunkers, and the need for more than one machine in each location.

The provision of radiotherapy requires careful planning. Though much improvement work is underway, many believe that the NHS could do more to get the most out of its machines and measures to improve workforce capacity, such as the four-tier skills model for radiotherapy, should be implemented fully.

### Cancer Reform Strategy

The Cancer Reform Strategy accepted the recommendations contained in the National Radiotherapy Advisory Group (NRAG) report published in February 2007. This included local investment in both equipment and workforce, ensuring sufficient capacity to meet the widened 31 day waiting time standard for all radiotherapy by 2010 and ensuring that Network plans for the development of radiotherapy services were compatible with each other before increased levels of radiotherapy capacity or new services are commissioned.

Other commitments included the development of a long-term workforce strategy, including an urgent review of workforce supply, demand, and skill mix to identify the investment needed in both staff numbers and the type of training commissioned.

### Better Cancer Care, An Action Plan

Better Cancer Care reaffirmed a commitment made in the Radiotherapy Activity Planning 2011-2015 report which recognised the complexity of planning treatment in light of the likely increase and usage of newer techniques such as intensity modulated radiotherapy (IMRT) and image guided radiotherapy (IGRT).

Better Cancer Care also stated that the five cancer centres in Scotland providing treatment should cooperate in the provision of some treatments that may only be required infrequently; not all centres could or should provide all treatments. It also recommended that contingency agreements should be reached by all centres brokered by the Scottish Radiotherapy Advisory.

### Designed to Tackle Cancer

Designed to Tackle Cancer set out two specific aims. One was to ensure that patients undergoing radiotherapy would be treated within the maximum waiting times, as recommended by the Joint

Council for Clinical Oncology. It was also agreed that as part of the All-Wales Modernisation Programme, all radiotherapy equipment, MRI and CT Scanners should be up to date and their capacity increased to reduce patients' waits.

A framework for the review of radiotherapy services in Wales was also put in place early this decade. In 2002, the Cancer Services Co-ordinating Group (CSCG) submitted to the Welsh Assembly Government a strategic plan for cancer services, including a 12-year plan for radiotherapy services drafted by the Welsh Scientific Advisory Committee's Clinical Oncology Sub-Committee (COSC). In 2005, the COSC reviewed and updated its 2002 plan, and the following year the CSCG set up a Radiotherapy and Chemotherapy Advisory Group, to further support the initial work that had been undertaken, and to provide advice to inform strategic developments in Wales. The group's report, *Radiotherapy Equipment Needs and Workforce Implications 2006-2016*, was published in May 2006.

### Cancer Control Programme for Northern Ireland

The Cancer Control Programme stated that future radiotherapy planning should address: future capacity needs, equity of access, particularly for the population in the west of Northern Ireland, travelling times, further specialisation and advances in technology.

## Implementation of the plans and strategies

### 1 – Capacity

National planning reports on future radiotherapy requirements specified the increases in fractions, which are normally given on consecutive days with days off in between to recover, that are required to meet current and future demand, as set out below.

		England <sup>57</sup>	Scotland	Wales <sup>58</sup>	Northern Ireland <sup>59</sup>
Total	Current	1.5m (2007)	175,954 (in 2003) <sup>60</sup>	87,566 (2006?)	59,000 (2008)
	Required	2.5m immediately and 2.9m by 2016	Up to 534,000 (2011-15) <sup>61</sup>	174,000 by 2016	–
Fractions per million (Jan 2009) population (pmp)/year	Current	~30,000	39,584	30,161 (2005) <sup>62</sup>	34,951 (2005)
	Required	40,000 by 2010 or 54,000 by 2016	–	58,000 by 2016	–

### 2 – Provision

The problem of ensuring equitable provision of radiotherapy in and between the UK nations is an acute problem. In 2007, access rates ranged from 43% in Scotland to 32% in Northern Ireland, with 38% in England and 37% in Wales. All are significantly lower than the optimum level of 52%.<sup>63</sup>

There remain concerns about reduced capacity due to staffing issues in the more rural North Wales<sup>64</sup> and the current ability to serve the needs of people living in the western parts of Northern Ireland.<sup>65</sup>

<sup>57</sup> Department of Health (2007) *Radiotherapy: Developing a World Class Service for England*. London: HMSO.

<sup>58</sup> Radiotherapy & Chemotherapy Advisory Group (2006) *Radiotherapy Equipment Needs and Workforce Implications 2006–2016*. Cardiff: Cancer Services Coordinating Group.

<sup>59</sup> Cancer Research UK 2009 personal communication with Geoff Hill, 6 January 2009.

<sup>60</sup> The Scottish Government (2006) *Cancer in Scotland: Radiotherapy Activity Planning 2011–15*. Edinburgh: The Scottish Government.

<sup>61</sup> *Ibid.*

<sup>62</sup> Williams MV et al. (2007) Radiotherapy dose fractionation, access and waiting times in the countries of the UK in 2005. *Clin Oncol* (doi:10.1016/j.clon.2007.03.011).

<sup>63</sup> *Ibid.*

<sup>64</sup> Radiotherapy & Chemotherapy Advisory Group (2006) *Radiotherapy Equipment Needs and Workforce Implications 2006 – 2016*. Cardiff: Cancer Services Coordinating Group.

<sup>65</sup> Department for Health Social Services and Public Safety (2008) *Regional Cancer Framework, A Cancer Control Programme for Northern Ireland*. Belfast: DHSSPS.



There appears to be a greater variation of radiotherapy provision within England. Between Cancer Networks in England, the number of fractions per million population was estimated by NRAG to vary from around 17,500 to almost 48,000 – which represents a two and a half fold variation.<sup>66</sup> A report by the Conservative Party in November 2008 revealed that the current average number of fractions per linear particle accelerator (LINAC) per annum varied between NHS Trusts from 4,376 to 10,126.<sup>67</sup> Again, work is underway to address this, and the plans outline encouraging activity, but there is much still to do.

An added challenge is to accurately identify where patients are not receiving sufficient or timely access to treatment. Good, reliable data on radiotherapy activity are required to do this, and the National Cancer Intelligence Network (NCIN) has a key role in delivering this.

### 3 – Introduction of new technology

While there has been progress made on introducing some new radiotherapy technologies, notably IMRT, the UK lags significantly behind its neighbours in the provision of new technologies within the NHS. It seems that IMRT is still seen by many in the radiotherapy community as too difficult to implement.

### 4 – Workforce issues

The radiotherapy workforce is key to meeting future demand. However, there are shortfalls in radiotherapy workforce across all staff roles. A range of complex factors contribute to staff shortages. These include high attrition rates affecting retention of existing staff, recruitment issues and attracting sufficient students into training.

### 5 – Public awareness of radiotherapy

Public awareness of the role that radiotherapy plays in the treatment of cancer is low. Although radiotherapy is estimated to contribute to 40% of cases where cancer is cured, any review of media coverage in recent years would suggest that this message is not being widely conveyed. In addition, anecdotal evidence suggests that many patients are fearful of radiotherapy. Initiatives are underway to address these issues; progress should be closely monitored.

## Conclusions and recommendations

The delivery of radiotherapy services is a complex operation that needs careful planning to address future need, as cancer incidence rises and more patients are being offered radiotherapy. Planning should incorporate the need to replace radiotherapy machines once they have reached the end of their working life.

As new and more complex radiotherapy technologies are introduced into the NHS, sufficient resources will need to be available for training the radiotherapy workforce in using these techniques, and capacity issues, such as the need for greater numbers of radiotherapy physicists to implement Intensity Modulated Radiotherapy (IMRT), will have to be addressed.

Informing the public about radiotherapy treatment is particularly important in terms of patient choice, and also in ensuring that patients as advocates for local cancer services understand the importance of adequate funding for radiotherapy. An awareness raising campaign may also have a beneficial impact on recruitment into radiotherapy services.

- All UK governments should introduce datasets for the reporting of fractionation, waiting times, access, and patient outcomes. The routine collection of benchmarked radiotherapy data should be obligatory for radiotherapy services across the UK.
- All UK governments should produce a rolling ten-year plan, setting out a vision and strategy for future radiotherapy services, which should be revised every few years. These will include details about how quickly patients are being seen and whether services are reaching all patients who should be receiving radiotherapy as part of their treatment.

<sup>66</sup> Department of Health (2007) *Radiotherapy: Developing a World Class Service for England*. London: HMSO.

<sup>67</sup> Conservative Party (2008) Lansley: 9,000 cancer patients lost out on radiotherapy treatment last year [press release], 30 October.

- Radiotherapy techniques which have become established practice in other countries for a number of years, such as intensity modulated radiotherapy (IMRT) and proton therapy, should be introduced and implemented in the NHS as quickly as possible to ensure that all patients who may benefit can get access to these new technologies.
- The UK governments must ensure that the UK is equipped with sufficient numbers of LINACs and that these machines are able to deliver the most up-to-date techniques. This needs careful planning to address future need, as cancer incidence rises and more patients are being offered radiotherapy.
- More work needs to be done to ensure that measures to improve workforce capacity, such as the four-tier skills model for radiotherapy, are fully implemented.

## 09

## Chemotherapy and access to medicines

*At the end of the day the thing that's really helped the survival of cancer patients, although it's polyfactorial, is better drugs*

Oncologist, England

Improvements in research mean that treatment of cancer with the use of chemotherapy and other systemic agents is rapidly changing. The rate of introduction of new drugs is accelerating; the number of patients benefiting from such treatments is rising; patients are increasingly being treated closer to home and chemotherapy is becoming much more targeted and tailored to individual cancers.

These factors, coupled with growing cancer incidence and expected lower increases in annual settlements for the NHS, look set to place strain on the NHS budget. This strain will also increase as future best practice focuses on using combinations of the newer, more expensive treatments.

### Cancer Reform Strategy

The Cancer Reform Strategy made a commitment that all new cancer drugs and significant licence extensions would be referred by default to the National Institute for Health and Clinical Excellence's (NICE) technology appraisal work programme – provided that there was a sufficient patient population and evidence base for NICE to undertake an appraisal. Other commitments included:

- A requirement for chemotherapy service providers to collect and return an agreed dataset on all patients receiving chemotherapy.
- An expectation that providers would demonstrate to Primary Care Trusts plans for the safe introduction of new drugs in a thorough and cost effective way through the use of the Chemotherapy Planning Oncology Resource Tool (C-Port).<sup>68</sup>
- Reviews of the safety of chemotherapy services – especially those related to oral chemotherapy, workforce requirements, guidance for commissioners and out of hours management for patients receiving chemotherapy.

### Better Cancer Care

Better Cancer Care built on the clinical guidelines and protocols for the regional and national tumour-specific Managed Clinical Networks (MCNS) and announced that these should be developed further and evaluation of the use of second-line and subsequent chemotherapy should be co-ordinated. Other key points included:

- All Regional Cancer Advisory Groups (RCAGs) and NHS Boards had recently or were in the process of reviewing their chemotherapy services against the Guidance for the Safe Use of Cytotoxic Chemotherapy.
- The safe delivery of chemotherapy should be supported by IT systems, including the Chemotherapy Electronic Prescribing and Administration System (CEPAS).
- The Scottish Chemotherapy Advisory Group was charged with looking at how best to ensure that all parties involved in a patient's care were aware of the nature of the chemotherapy that had been received and how best to manage the side effects.

<sup>68</sup> <http://cport.co.uk/Home.aspx?ReturnUrl=%2fdefault.aspx>

<sup>69</sup> HDL (2005)29 *Guidance on the Safe Use of Cytotoxic Chemotherapy* Edinburgh: The Scottish Executive

- C-Port was also rolled out to improve current chemotherapy services and planning for the introduction of new treatments and regimens in the future.

### Designed to Tackle Cancer

Designed to Tackle Cancer made reference to the 2005 National Cancer Standards, detailing key elements of the treatment process that patients should expect to receive. Designed to Tackle Cancer stated that cancer services must comply with these guidelines by March 2009. This deadline has now been pushed back to September 2010. Cancer networks were also highlighted as responsible for leading the process of mapping and assessing current services against the Standards<sup>70</sup> and for developing action plans to address any areas that require attention.

### The Cancer Control Programme

The Cancer Control Programme tasked the Northern Ireland Cancer Network (NICaN) Chemotherapy Group with developing an optimal chemotherapy service with chemotherapy being delivered to patients in a variety of clinical settings such as hospital, facilities near to a patient's home or in a patient's home. The Regional Oncology and Haematology Drugs and Therapeutics Committee has responsibility for identifying priorities within the NHS and was tasked with developing standards for the delivery of chemotherapy across Northern Ireland.

### Implementation of the plans and strategies

#### I – Planning for chemotherapy services

##### a) Assessing demand

Participants at the expert group meeting in Wales suggested that there were problems in planning for the delivery of chemotherapy services. In particular, they suggested that there were problems in assessing demand for chemotherapy. Similar concerns were raised in Northern Ireland.

##### b) Information

The collation and use of robust information is central to the delivery of safe and optimal treatment. There was a reported need for better information to enhance knowledge about the demand for chemotherapy services and help staff plan for improved treatment.

##### c) Collaboration

It was suggested that some centres would come under increasing pressure to collaborate to deliver chemotherapy treatment from large specialised centres due to financial pressures within the NHS during the next few years.

#### 2 – Capacity issues

Some chemotherapy facilities are well designed, but some respondents reported that many were overcrowded. This might be due to rapid increases in workloads over recent years. For example, some interviewees reported a 40% rise in chemotherapy use in England since 2007 and a 74% increase in Northern Ireland over the past four years.

Interviews resonated with issues set out in the National Chemotherapy Advisory Group report<sup>71</sup> for England which suggested that some patients have to wait for long periods between arrival at a day case unit, having blood tests and starting treatment, largely because care processes have not been streamlined.

In Northern Ireland, it was reported that most outpatients came in for a full day; they waited patiently, often some hours, before their treatment started; and the few beds available for frailer patients were in fact usually full with emergency patients who had come in via the helpline. All in all, the increasing amount of chemotherapy treatment was not backed up by an equivalent increase in staff and hospital capacity.

70 Welsh Assembly Government (2005) National Cancer Standards. Cardiff: Welsh Assembly Government. Available at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=362&pid=9408> (accessed 2 July 2010).

71 National Chemotherapy Advisory Group (2009) *Chemotherapy Services in England: Ensuring Quality and Safety*. London: NCAG.

### 3 – Place of delivery of chemotherapy

A report from the National Confidential Enquiry into Patient Outcomes and Death,<sup>72</sup> published in November 2008, highlighted concerns about the quality and safety of chemotherapy services. In response to this the National Chemotherapy Advisory Group (NCAG)<sup>73</sup> published guidance in August 2009 which recognised both the increasing and changing use of chemotherapy and set out best practice for chemotherapy services including a new framework for commissioning, delivering and monitoring these services and introduced the concept of 'acute oncology'.

Interviewees stated that some patients are receiving chemotherapy as inpatients when this could be done on a day case basis and some are being treated at cancer centres when they could receive treatment closer to home. Experts in all the four nations commended the use of nurse-led or pharmacist-led chemotherapy within agreed working protocols. This offers great opportunities for increasing capacity and flexibility to reduce waiting times and to move at least part of the care closer to the home of the patient.

However, concerns were raised by clinicians in Northern Ireland about patients who experienced a reaction to their chemotherapy treatment and how they accessed services to reverse the situation. It was suggested that acute oncology services outside the traditional operating hours for chemotherapy suites needed improving.

Location was a source of debate in a number of interviews with clinicians. Ambulatory chemotherapy was referred to in most areas, with pros and cons articulated. While some patients very much welcomed the option, and it was felt to be part of the solution to reducing pressures on clinics, others did not want the actual chemotherapy 'in their home', and did not perceive this to be 'safe'.

One oncologist voiced his serious reservations about safety – the possibility of giving chemo to a patient with a low blood count at home and the potential for a lack of communication between hospital and nurse in the home environment, with neither party having the most up-to-date records, has the potential for a negative impact on the patient.

### 4 – Differences in the appraisal of and access to new chemotherapy treatments

Different appraisal mechanisms are used by the different nations to appraise the clinical and cost effectiveness of treatments in the NHS. This is leading to varied availability of medicines depending on where a patient lives.

#### England

The National Institute for Health and Clinical Excellence (NICE) was established in 1999 to end the so-called 'postcode lottery'. It was tasked with appraising the clinical and cost effectiveness of new and existing drugs and procedures and determining which should be routinely available on the NHS in England and Wales. NICE's technology appraisal guidance carries with it a legal obligation for all trusts to make requests for funding for these treatments available, within three months of publishing the guidance. The table below sets out the number of appraisals for cancer technologies carried out since 2000.

Recommendations for cancer appraisals	1 March 2000 to 31 May 2010 STA	1 March 2000 to 31 May 2010 MTA	1 March 2000 to 31 May 2010 Total	1 January to 31 May 2010
Yes	15 (65%)	48 (72%)	63 (70%)	0 (0%)
Optimised	2 (9%)	1 (1%)	3 (3%)	1 (50%)
Only in research	0 (0%)	6 (9%)	6 (7%)	0 (0%)
No	6 (26%)	12 (18%)	18 (20%)	1 (50%)
TOTAL	23(100%)	67(100%)	90 (100%)	2 (100%)

STA, single technology appraisal; MTA, multiple technology appraisal

72 National Confidential Enquiry into Patient Outcome and Death (2008) *For Better, For Worse? A Review of the Care of Patients Who Died within 30 Days of Receiving Systemic Anti-cancer Therapy*. London: NCEPOD.

73 National Chemotherapy Advisory Group (2009) *Chemotherapy Services in England: Ensuring Quality and Safety*. London: NCAG.

The introduction of NICE has led to greater clarity about what, in principle, is available on the NHS, and what is not. However, it has not eliminated variation in access to drugs. There is also concern that the existence of NICE has built in what one expert has described as a 'circle of conservatism', whereby clinicians are now less likely to recommend a new drug that has not yet been appraised by NICE. There is evidence that local implementation of NICE appraisals and clinical guidance is sometimes slow, because of resource and other constraints.<sup>74</sup>

Variations in the availability of drugs that are licensed but not yet appraised by NICE persist. Where NICE has not published recommendations on a particular treatment, Primary Care Trusts can come to their own decision about routine funding. Individual clinicians also have the opportunity to apply to an exceptional case committee with respect to a drug that has not been approved by NICE, and the PCT has decided not to routinely pay for, to make a case for their patient to access the drug on a named patient basis.

Where these requests for funding have been declined, some patients have successfully used legal challenges to reverse decisions. Following new guidance introduced in March 2009,<sup>75</sup> patients now have the option to pay for these drugs themselves, although this is not widely taken up.

The recent top-up review has also put in place a number of measures designed to speed up access to newly licensed drugs, in order to reduce the number of people unable to access the drugs they have been recommended. In 2009, the government published further proposals designed to speed up access to drugs before a NICE appraisal.<sup>76</sup> The coalition government has announced proposals to introduce a Cancer Drugs Fund, to enable patients to access drugs that their clinicians believe they could benefit from. An interim fund of £50 million will be available from October 2010, with the full fund being rolled out from April 2011. The government is positioning the fund as a step towards 'value based pricing', which it is committed to introducing from 2014.

Also, in response to Professor Richards' recommendations, NICE published guidance on a new 'end of life' criterion, by which drugs which increase survival in the last months of life are given greater weighting within their appraisal process.

### Scotland

The Scottish Medicines Consortium (SMC) evaluates the clinical and cost effectiveness of new medicines in Scotland and aims to prepare NHSScotland for the managed introduction of new medicines. However, NICE MTA recommendations, if endorsed by NHS Quality Improvement Scotland (QIS), will be adopted by NHSScotland.

In Scotland, the Scottish Medicines Consortium provides advice to NHS Boards and their Area Drug and Therapeutics Committees (ADTCs) across Scotland about the status of all newly licensed medicines, all new formulations of existing medicines and new indications for established products. Guidance provided by the SMC is 'advisory' and does not carry with it a mandatory requirement for funding to be awarded.

The Scottish Medicines Consortium is viewed positively by cancer clinicians. In particular, the Consortium is praised for providing guidance on the use of cancer medicines within six weeks of licensing and the constructive dialogue it undertakes with the pharmaceutical industry. It was also claimed that the Consortium is less expensive to operate and makes similar decisions to NICE.

In March 2008, following a petition from a patient, the Scottish Parliament's Public Petitions Committee launched an inquiry into the availability on the NHS of cancer drugs. This inquiry led to a reappraisal of various parts of the drug review process, including allowing patients to receive NHS care while paying privately for drugs not approved by the SMC in some circumstances; giving more detailed guidance to boards about making SMC approved medicines, or their comparators, available; and rewriting the guidance on exceptional case decisions.

74 House of Commons Health Committee (2007) *Patient and Public Involvement in the NHS* HC 278-I (2006-07). London: HMSO.

75 Richards M (2008) *Improving Access to Medicines for NHS Patients: A Report for the Secretary of State for Health by Professor Mike Richards*. London: Department of Health.

76 Department of Health (2009) *PCT Decision Making Process on Medicine*. London: Department of Health.

### Wales

The All Wales Medicines Strategy Group (AWMSG) brings together NHS clinicians, pharmacists, healthcare professionals, academics, health economists, industry representatives and patient advocates to provide advice on medicines management and prescribing to the Minister for Health & Social Services. The AWMSG appraises new high-cost, cardiac and cancer medicines for which no NICE guidance is expected for at least 12 months from the date of submission. NICE guidance takes precedence over AWMSG guidance.

In March 2010, Professor Philip Routledge, the chair of the All Wales Medicine Strategy Group, published his report on improving the availability of medicines for patients in Wales. This report has been accepted by the Health Minister and should help to reduce the inconsistencies that have been seen in accessing some new drugs across Wales.

### Northern Ireland

The Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland agreed in July 2006 to link with NICE. This means that they will look at any guidance issued by NICE and decide if it is relevant for Northern Ireland.

If NICE's guidance is not relevant, or if the DHSSPS decides that it is only partly relevant, they will advise on any changes that need to be made. This decision is made by the Drugs and Therapeutic Committee. Although the Drugs and Therapeutic Committee approves most NICE guidance, we were particularly concerned to hear the Committee process described as 'vague' and 'opaque'. It was also asserted that it could delay approval of medicines by up to a year.

## Conclusions and recommendations

The use of chemotherapy has increased significantly in recent years – one interviewee quoted an increase of 40% in the past three years. More patients are being offered chemotherapy, such as lung cancer patients, for whom it would not previously have been considered beneficial; many patients are also now having second and third line treatment.

There are several contentious issues related to chemotherapy provision. These include cost, with some drugs being just outside the designated NICE limit and patients (who may have become aware of the drug via the internet) having to be told it is not a treatment option on the NHS.

Other concerns centre on how the top-up payment scheme is working, but in practice few patients appear to be using this. Several interviewees also questioned the validity of the current NICE process and the quality of life calculation used.

- Where drugs have been referred to NICE for appraisal, they should be appraised quickly and as close to licensing as possible.
- The expertise of Cancer Network staff must be better used to improve the commissioning of chemotherapy treatments in the NHS.
- UK spending on new cancer therapies still lags behind the rest of Western Europe. Major cancer medicines are still being prescribed in the UK at under two-thirds of the European average, five years after licensing. Healthcare providers should encourage doctors to use these new drugs when treating cancer patients.
- There must be a continued commitment from local providers that all patients across the UK should have access to the appropriate treatments for their condition, regardless of where they live. Local providers should be reminded of their requirement to provide approved treatments.

## 10

## Information

*Traditional follow-up methods have been shown to be of little value, to say the least... so there's a lot of work saying – is this the best thing to do? We're looking at a phone follow-up after 6 months... then let the patient take control. If they've got a problem, phone in – Easy Access.*

CNS/Asst director of breast nurses, England

Providing patients with access to high quality information is a prerequisite for them to be able to participate in decision-making about their care and to reduce their fear of cancer. Information, alongside support to understand and act on that information, can empower patients to retain or regain control over their lives.

Individual patients will want to acquire information in different ways. For many, face-to-face communication with a health professional they trust is of paramount importance. Some patients will also want to supplement face-to-face communication with other types of information.

### Cancer Reform Strategy

The Cancer Reform Strategy introduced a single programme for advanced communication skills for senior healthcare professionals, and primary care trusts were expected to demonstrate this through peer review. It contained an expectation that health professionals, community-based clinicians and other healthcare staff who treat and support cancer patients would have to access good communication skills training at a range of levels.

The Cancer Reform Strategy also stated that ensuring patients receive written information which meets their needs at all phases of the care pathway was a high priority. Work in this area was to be taken forward in close partnership with Macmillan Cancer Support and Cancer Research UK. Key elements of the programme included the development of:

- 1 National information pathways by tumour type to provide high quality information products that healthcare professionals can offer to patients at key points in the cancer journey.
- 2 Information prescriptions to enable healthcare professionals to generate tailored or personalised written information at any point in the cancer pathway.
- 3 A support structure to ensure improvements in patient information delivery including the creation of patient information manager posts in each of the Networks along with patient information leads in each Trust at Network level.

### Better Cancer Care, An Action Plan

Better Cancer Care stated that a National Health Information and Support Service would be launched in 2009 to offer patients and carers consistent, high quality information in a variety of media.

### Designed to Tackle Cancer

Information for patients was not dealt with as a separate and distinct chapter within Designed to Tackle Cancer. However, a number of the site specific cancer standards include objectives to ensure that patients and their carers have the appropriate information throughout their cancer journey.



## Cancer Control Programme

The Cancer Control Programme encourages healthcare professionals and carers to be pro-active in building relationships with their patients and helping them to understand the nature of their illness and treatment. It committed to developing a strategy to ensure that there was a co-ordinated approach to the provision of high quality, accessible and accurate information. The programme set out an expectation that information should be offered to all patients and carers in a variety of formats and in the appropriate setting. The programme also included details about the phased implementation of a mandatory programme for health and social care professionals working with people affected by cancer to develop advanced communication skills.

## Implementation of the plans and strategies

Good progress has been made to improve the quality and availability of patient information. However, the pace of progress has varied and there is clearly more to do to ensure every patient has access to appropriate, high quality information and support.

### 1 – Role of Clinical Nurse Specialists

Research has shown that the development of tumour specific Clinical Nurse Specialist roles can contribute to improved health and well-being in cancer patients. A number of concerns arose during interviews about the role of Clinical Nurse Specialists including:

**a** In Scotland, experts stated that Clinical Nurse Specialists provided a good and valuable service. However, concern was expressed that funding for pump-primed posts would no longer be taken as it could not be maintained.

**b** In Northern Ireland, experts declared that there was a shortage of Clinical Nurse Specialists to deliver information. The experts strongly supported Standard 21 in the Service Framework for Cancer Prevention, Treatment and Care, which requires all patients to be assessed by a Clinical Nurse Specialist. In particular, experts urged the Department for Health, Social Services and Public Safety to set out in detail how it intended to implement this standard.

### 2 – Provision and equity of information

In Wales, we were concerned to hear that there was no coordinated plan to deliver information to cancer patients. Experts reported that delivery of patient information varied significantly across Wales.

In Northern Ireland, Scotland and Wales, experts were concerned about literacy and the difficulty of developing methods of communication for people who had problems with reading.

Research carried out as part of the literature review of patient experience also shows that some patients continue to be dissatisfied with the information they are given.<sup>77 78 79</sup>

National surveys have found that 'substantially more patients received written information at the time of their diagnosis about their cancer and treatment in 2004 than in 2000',<sup>80</sup> increasing from 45% to 61% of patients.

### Usefulness of written information

A national survey in 2004 found that printed information about a patient's condition was understood completely by 84% of those who received it and to some extent by the rest..

77 Mid Trent Cancer Network (2007) *Baseline Report Outlining Current Knowledge of How Patients, Carers and Health Professionals Find Out Where to Gather Information Materials and Their Experiences of Accessing and Receiving Information*. Available here:

[http://www.informationprescription.info/pilot\\_sites/documents/baselineinfo/Mid%20Trent.pdf](http://www.informationprescription.info/pilot_sites/documents/baselineinfo/Mid%20Trent.pdf) (accessed 2 July 2010).

78 Breast Cancer Care (2008) *England Health Check: Breast Cancer in England Survey 2008*. Available here:

<http://www.breastcancercare.org.uk/get-involved/campaigning/breast-cancer-in-england-survey-2008/> (accessed 2 July 2010).

79 Pan-Birmingham Cancer Network (2008) *Patient Survey Reports*.

Available at: <http://www.birminghamcancer.co.uk/viewdoc.ashx?id=1HgFxTWZzJlntpkpTv6Wg%3D%3D> (accessed 2 July 2010).

80 Comptroller and Auditor General (2005) *Tackling Cancer: Improving the Patient Journey*. London: National Audit Office.

Available at: [http://www.nao.org.uk/publications/0405/tackling\\_cancer.aspx](http://www.nao.org.uk/publications/0405/tackling_cancer.aspx) (accessed 2 July 2010).

### 3 – Information prescriptions and strategies

Experts in England welcomed the introduction of information prescriptions for cancer patients. The piloting of information prescriptions has been rolled out in two stages in June 2008 and February 2009 and an independent evaluation of the pilots is due to be published in summer 2010. The online information prescriptions service ([www.nhs.uk/ips](http://www.nhs.uk/ips)) launched in spring 2010, on NHS Choices, builds on the prototype from the pilots. This service together with an ambitious roll-out plan, due for publication in autumn 2010, will help to achieve the goal that, by end of 2012, all cancer patients will be offered information prescriptions.

Experts outlined concern about the time taken to introduce information prescriptions and felt it was essential that they were embedded to ensure all patients received timely information during their treatment.

In 2008, *Gaun Yersel*, the Self-Management Strategy for Long Term Conditions in Scotland,<sup>81</sup> identified the different stages at which people need support when living with a long term condition. These included:

- Improving quality and access to information available to patients about conditions, clinical services and the wider range of support that is available in local communities.
- Introducing personal health plans for people with long-term conditions.
- Supporting staff to further develop their communication skills and enable them to deliver care in a more empathetic and holistic way.

In conjunction with this, a patient-focused model has been developed<sup>82</sup> that identifies the kind of support that patients might require at each stage of their journey. An electronic Self-Management and Rehabilitation Managed Network<sup>83</sup> was launched in 2008 to enable users to access knowledge and evidence-based information.

### 4 – Delivery of information by health professionals

Studies of patient experience show that the delivery of information by health professionals is variable. Issues include problems with the number of patients who understand the explanation of what is wrong with them and what will happen next. For example, a study has shown that the percentage of patients who completely understood the explanation of what was wrong with them increased slightly from 84% in 2000 to 86% in 2004.<sup>84</sup>

## Conclusions and recommendations

Patients should be provided with accurate information about the treatment options available to them. This should be complemented with additional support for patients to understand and act upon the information they are given.

An essential part of a Clinical Nurse Specialist's role is to provide information, psychological care and practical advice to people with cancer and their families. Patients find Clinical Nurse Specialists an accessible and well informed source of support and information and view access to a nurse as an essential part of their care.

- **Tailored information for patients from hard to reach groups should be developed and appropriately targeted.**
- **All patients should have access to high quality information at all relevant points along the patient pathway to ensure that they can make fully informed choices about their care.**
- **Healthcare professionals also need to be provided with accurate and up-to-date information about the choices available to their patients, and how best to communicate with patients to ensure the choices they make are fully informed.**

81 Long Term Conditions Alliance and The Scottish Government (2008) *'Gaun Yersel', The Self-Management Strategy for Long Term Conditions in Scotland*. Edinburgh: The Scottish Government.

82 [www.scotland.gov.uk/bettercancer](http://www.scotland.gov.uk/bettercancer)

83 [www.enablinghealth.scot.nhs.com](http://www.enablinghealth.scot.nhs.com)

84 Comptroller and Auditor General (2005) *Tackling Cancer: Improving the Patient Journey* National Audit Office: London. Available at: [http://www.nao.org.uk/publications/0405/tackling\\_cancer.aspx](http://www.nao.org.uk/publications/0405/tackling_cancer.aspx) (Accessed 2 July 2010)

- Information on additional support from healthcare providers should be discussed before patients are discharged from hospital treatment.
- Healthcare professionals should, as part of their ongoing career development, receive training in communication skills, with a focus upon harder to reach communities.
- It is important to carry out patient experience surveys across all nations and at Cancer Network level to accurately assess patients' views of their treatment and care. The National Cancer Patients Experience survey in England and similar surveys in Scotland, Wales and Northern Ireland should be carried out on a biennial basis.



## Survivorship

*There's a bit of a selling job to be done on it [survivorship] – to make people see how it applies to them. There is scepticism out there – I've had it before: 'this is about breast cancer patients; it's not applicable to us'.*  
Network Deputy Director for Survivorship, England

Emerging survivorship initiatives offer important opportunities for the growing number of people who survive cancer. It is estimated that there are two million people living with or beyond cancer in the UK and this number is rising more than 3% each year. Patients who are cured of cancer may be left with physical or psychological effects from the diagnosis and treatment of their disease. Some patients may live for many years receiving active treatment as their disease relapses and remits. Survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs.

### Cancer Reform Strategy

The Cancer Reform Strategy stated that detailed consideration should be given to the services needed by survivors of cancer. It committed to a new National Cancer Survivorship Initiative to be taken forward by the National Cancer Director, Macmillan Cancer Support and other cancer charities. The Initiative was expected to consider a range of approaches to survivorship care and how these could be tailored to suit individual patients' needs.

### Better Cancer Care, An Action Plan

Better Cancer Care stated that there is a lack of current data on survivorship and commits to collecting this in order to fully understand the services that are needed to support those living with and beyond cancer. Under the direction of the Scottish Cancer Taskforce, Better Cancer Care committed to establishing a working group on survivorship in order to maintain national focus on this issue and identify areas for further research.

### Designed to Tackle Cancer

Designed to Tackle Cancer did not address survivorship.

### Cancer Control Programme

The Cancer Control Programme did not address survivorship.

### Implementation of the plans and strategies

#### I – The importance of support for survivors

*From the point of view of providers it'll always be bottom of priorities... it's not a 'must do', though that is changing slightly.*  
Commissioner, England

Interviewees believed that there was some recognition that this area was of growing significance, as an increasing number of people survived cancer and lived for longer with cancer.

However, although living with and beyond cancer was often felt to be an important area, which had not been given the focus it deserved in the past, some felt that only a few cancers were being considered in this context – for the rest it was barely relevant.

*We're turning our attention to this now; we've baselined all the supportive services, the next step will be to identify groups and see what arrangements should be put in place ...*

Network Director, England

When compared with diagnosis and treatment, living with and beyond cancer was a 'soft' area, and several respondents voiced a concern that it might inevitably be vulnerable to cuts.

## 2 – The future for survivorship

The best procedure for follow-up appointments is seen as a key issue for future work. The current system is recognised to be inadequate as more cancer patients survive for longer and oncologists' clinics are already full to overflowing.

A case was made by some to give patients a choice – to make a follow-up appointment if they feel they need or would like one, but not if they do not. Positively, this gives patients more control and choice – it could ensure they monitor their health better; and if something is amiss they may not be as tempted to 'leave it till the next follow-up'. However, not all patients would necessarily want this and the system would need to manage these differences.

## 3 – The Survivorship Initiative

In all four nations Macmillan involvement in this latter part of the cancer pathway was mentioned, with several references to the National Cancer Survivorship Initiative (NCSI) in England. The vision<sup>85</sup> for the NCSI was published in January 2010 and interviewees stated that various pilots were being undertaken with workshops for ex-cancer patients and a move to foster improved links between secondary care and GPs via 'Treatment Summary Records'.

A Network Director for Survivorship interviewed felt strongly that survivorship conversations should be threaded throughout an individual's cancer journey, not just 'pop up' at the end of treatment.

Experts in England reported that the National Cancer Survivorship Initiative has helped develop a greater understanding of self-management and post-treatment care and represents a shift in current cancer care to give cancer more of a chronic disease management profile.

## Recommendations

- Survivorship is an important and emerging policy area, which should be fully embedded in the patient care pathway.
- Wales and Northern Ireland should develop a survivorship initiative.

<sup>85</sup> Macmillan Cancer Care (2010) *National Cancer Survivorship Initiative*. Available at: <http://www.ncsi.org.uk/communicating-the-ncsi-vision/> (Accessed 2 July 2010)

## 12

## Palliative care

Palliative care has gained a higher profile in recent years and this is thanks, in part, to a stronger focus on the quality of the patient experience in current cancer plans. A number of non-cancer specific strategies have been developed to take forward work on palliative care. Their publication has been welcomed by the cancer community; for maximum effectiveness, these plans should be fully implemented. Many of those interviewed for this report voiced concern that, in a challenging economic climate, some of the gains made in palliative care may be lost. The workforce was invariably at pains to state that this would be a great shame.

### Cancer Reform Strategy

The Cancer Reform Strategy highlights the importance of end-of-life support. It states that a relationship must be established with the patient and their needs and preferences assessed at regular intervals. The Cancer Reform Strategy outlines very specific, detailed actions to be taken forward to improve supportive and palliative care services. However, there is a lack of funding attached to these actions, and very few are underpinned by a measurable deadline for achievement.

### Better Cancer Care, An Action Plan

Better Cancer Care is comprehensive in addressing the different aspects of palliative care. Initiatives are attached to funding and clear lines of responsibility are outlined. There is, however, no clear timetable for implementation of initiatives.

### Designed to Tackle Cancer

The Welsh Assembly Government published its policy on palliative care in 2003, entitled *A Strategic Direction for Palliative Care Services in Wales*,<sup>86</sup> which aimed to provide a more integrated service for patients between the statutory and voluntary sector.

Designed to Tackle Cancer committed the Cancer Services Co-ordinating Group to commission a national needs assessment for palliative care and put clear commissioning agreements in place with providers. Designed to Tackle Cancer also endorsed the use of the *All Wales Care Pathway for the Last Days of Life*.<sup>87</sup> The importance of choice in place of death and provision of appropriate support is highlighted as a key issue.

### Cancer Control Programme

The Cancer Control Programme refers to the NICE Guidance on *Improving Supportive and Palliative Care for Adults with Cancer*<sup>88</sup> and states that the Cancer Network, working through the Northern Ireland Cancer Network Supportive and Palliative Care Network, should develop an action plan for implementation of the recommendations.

The Cancer Control Programme recommends the enhancement of skills in the community sector to ensure that patients have the opportunity to remain at home if they choose to. Commissioners and service planners are tasked with drawing up local development plans by 2007 to ensure that as

86 Welsh Assembly Government (2003) *A Strategic Direction for Palliative Care Services in Wales*. Cardiff: Welsh Assembly Government.

87 Welsh Collaborative Care Pathway Project (2000) *Last Days of Life Care Pathway*. Cardiff: Welsh Collaborative Care Pathway. Available here: <http://wales.pallcare.info/index.php?p=sections&sid=11> (accessed 2 July 2010).

88 National Institute for Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. London: National Institute for Clinical Excellence.

soon as possible, but no later than 2010, there should be increased and improved service provision. Intensive coordinated home support to patients with complex needs who are at home should also be introduced.

### Implementation of the plans

A number of interviewees, some of whom worked or had worked in the area of palliative care, felt that insufficient attention had been paid to palliative care compared to other parts of the cancer pathway.

However, progress has been made in recent years. For example, a review of palliative care in Northern Ireland was undertaken in May 2000, and since then many positive steps have been taken to improve services. These include the creation of a network of GP facilitators in palliative care, the introduction of new resources such as the Cancer and Palliative Care Online Resource Network (CAPriCORN) and the ongoing training of community pharmacists in palliative care. Although real progress has been made, it is recognised that further work is necessary. In Wales, experts highlighted the publication of the Sugar Report<sup>89</sup> in 2008, which set out a number of recommendations for planning palliative care. Experts in Wales also mentioned a current review of primary care which was expected to have a significant impact on palliative care.

#### a) Incentivisation

Some interviewees talked about incentivising palliative care, which had been successfully implemented through the quality and outcomes framework (QOF). However, others pointed out the difficulty of developing performance indicators for palliative care.

*Without the palliative care Quality and Outcomes Framework we wouldn't have had half the improvements we've had in palliative care...*

Primary Care Lead, England

*Putting performance indicators on palliative care can be quite tricky as the processes aren't really there to start with. One is the whole piece around communication and co-ordination, and having a keyworker in position...*

Network employee, NI

#### b) The Gold Standards Framework

The Gold Standards Framework for palliative care was frequently referred to as an 'ideal'. However, there was concern that a financial charge was attached to the Gold Standards Framework which was proving to be a disincentive:

*It's a great shame that the GSF is now asking for money because it's putting practices off from taking it up... they've shot themselves in the foot. PCTs are coming up with their own versions*

Primary Care Lead, England

#### c) Capacity and resources

Experts in Wales highlighted that out of hospital care is complex and needs to be safe and appropriate. Further work is needed to enable patients to die at home if they wish. This includes scoping to decide how many community nurses are needed to deal with demand and to ensure that they have the correct skill mix.

In October 2008 *Living and Dying Well, A National Action Plan for Palliative and End of Life Care in Scotland*<sup>90</sup> was published. The strategy is generic rather than cancer specific. Significant work is needed before it becomes operational. Scotland has a good network of hospices but change is needed to replicate the same culture in hospitals. There should also be increased transparency about the intent of treatment. Interviewees felt there would be benefit from involving palliative care teams earlier in the patient pathway.

89 Sugar V (2008) *Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services* Cardiff

90 NHS Scotland (2008) *Living and Dying Well, A National Action Plan for Palliative and End of Life Care in Scotland* Edinburgh: The Scottish Government

To support the implementation of this plan, NHS Boards have been appointed executive level leads for palliative and end of life services, in partnership with Palliative Care Networks and Community Health Partnerships. Furthermore, a member of the Scottish Government Health Directorates Advisory Group on Palliative and End of Life Care will have a role to support the cancer plan. This will ensure that the plan is delivered in an integrated way.

In England, the End of Life Care Strategy has been developed. However, implementation to date has been mixed. There is a growing understanding of what needs to be done and there are some very good practice examples in operation.

Support for patients who wish to self-manage their cancer and die at home will reduce the burden on the NHS, and require fewer bed days in hospital, but progress needs to be made more quickly.

### Recommendations

- Palliative care strategies should be fully implemented for maximum effectiveness.
- Further work about how the intent of palliative care treatment is communicated to patients should be undertaken.
- Support for patients who wish to self-manage their cancer and die at home can be good for patients and will reduce the burden on the NHS and require fewer bed days in hospital. Work in this area should be accelerated.



## Appendices

- Research methodology
- Interview guide for in-depth interviews
- Discussion guide for primary care groups
- Cancer drugs appraised by NICE
- Glossary and list of terms

## Research methodology

This report assesses progress made in delivering the current UK cancer strategies.

For the purposes of this project, we undertook a qualitative comparative analysis rather than a detailed, initiative by initiative assessment of progress. Others have already produced a number of detailed progress reports.

Two update reports have been produced by the Department of Health to report on progress in implementing the Cancer Reform Strategy.<sup>91 92</sup> The Scottish government health department is expected to publish a progress report later this year. The Welsh Assembly Government has published statistics reporting progress towards meeting cancer standards<sup>93</sup> and the Northern Ireland Executive has recently consulted on the detail of their cancer strategy.<sup>94</sup> In addition, the National Audit Office (NAO) has undertaken several analyses of cancer policy in recent years.<sup>95 96 97</sup> These have focused on progress in England but have, at times, contrasted English progress with that in other UK nations. The NAO is due to publish another review of cancer services in late 2010.

To inform our analysis, we have reviewed available literature and spoken to many in the cancer community about the current state of cancer services across the UK.

To inform this report, we carried out the following research:

- 1 A desk based review of the current cancer strategies and relevant progress reports.
- 2 A patient experience literature review which reviewed available national patient surveys and information from local questionnaires which asked patients about their experiences of treatment.
- 3 Four expert meetings with cancer workforce and policy specialists. All meetings were held in March 2010. We held one meeting in each UK nation – in London, Edinburgh, Cardiff and Belfast. All meetings were independently facilitated and participants gave their views confidentially. We invited a wide range of cancer experts, spanning expertise across the patient pathway. We also invited experts from different parts of the cancer workforce – those working at national policy level, in specialist cancer centres, in universities, and those working at cancer network level.
- 4 Qualitative research with health professionals to understand how the cancer strategies have been received and are being delivered 'on the ground'.

We wanted to explore:

- Attitudes to the respective cancer strategy in each nation, and any differences by nation.
- What has happened at ground level since strategy publication.
- Perceptions of how successful implementation has been (successes, shortfalls, support needed) – focussing on detection and treatment.
- Barriers to implementation.
- Perceptions and workings of Cancer Networks.
- The extent to which relevant parties are in harmony over implementation.
- Support for anecdotal evidence that we had heard – for example, that the UK was making slow progress in working to meet inequalities commitments that were set out in the respective plans.

91 Department of Health (2008) *Cancer Reform Strategy: One Year on Report*. London: HMSO.

92 Department of Health (2009) *Cancer Reform Strategy: Achieving Local Implementation, Second Annual Report*. London: HMSO.

93 Cancer Services Co-ordinating Group (2009) *National Cancer Standards Compliance 2009*. Cardiff: CSCG. Available at: <http://www.wales.nhs.uk/sites3/docmetadata.cfm?orgid=322&id=157281> (accessed 5 July 2010).

94 Department of Health, Social Services and Public Health (2006) *Regional Cancer Framework: A Cancer Control Programme for Northern Ireland*. Belfast: DHSSPH.

95 Comptroller and Auditor General (2005) *Tackling Cancer: Improving the Patient Journey*. London: National Audit. Available at: [http://www.nao.org.uk/publications/0405/tackling\\_cancer.aspx](http://www.nao.org.uk/publications/0405/tackling_cancer.aspx) (accessed 2 July 2010).

96 Ibid.

97 Work in Progress: Progress in Delivering the Cancer Reform Strategy. Expected publication date: late 2010.

A series of one-to-one in-depth interviews lasting 45 to 70 minutes, on average an hour each, and two group discussions were held. The interviews were all face-to-face except for three telephone interviews. All qualitative research with health professionals was conducted by CM Insight, between December 2009 and March 2010.

The sample comprised a total of 66 respondents. The groups and all but three of the interviews were digitally recorded. All respondents apart from members of Cancer Research UK's *Primary Care Advisory Group*, see below, were incentivised, in recognition of the time respondents were giving. Some chose to donate their incentives back to their Cancer Network or Cancer Research UK.

Fifty-four in-depth interviews were carried out in seven Cancer Network (CN) areas, together with one two-hour mini-group of three respondents (in Merseyside and Cheshire), so this part of the sample comprised a total of 57 respondents.

The seven CN areas were selected to include a mix of four networks in England which covered both an urban and rural population. We also selected one Network each from Scotland, Wales and Northern Ireland. The Cancer Networks who participated in the research include:

#### England

- North West London CN (included one interview from North London CN)
- Merseyside and Cheshire CN
- Avon, Somerset and Wiltshire CN
- Anglia CN

#### Wales

- South East Wales CN

#### Scotland

- West of Scotland CN

#### Northern Ireland

- Northern Ireland CN

In each area approximately eight interviews were carried out. Four were carried out with those working in Cancer Networks either full or part-time and four were carried out with those working in secondary care multi-disciplinary teams (MDTs) – surgeons, oncologists, nurses and histopathologists.

We also held two 90-minute mini-group discussions with GPs: one with five GPs from central or suburban London, the other with four members of Cancer Research UK's *Primary Care Advisory Group*, bringing together GPs from London, southern England and Scotland. Members of Cancer Research UK's policy team observed in both groups. The interview and group discussion guides are in Appendix 1.

#### Cancer network and MDTs interviewees

	Number of multi-disciplinary team members interviewed	Number of Cancer Network members interviewed
North West London Cancer Network	4	4
Merseyside and Cheshire Cancer Network	4	4
Avon, Somerset and Wiltshire Cancer Network	4	4
Anglia Cancer Network	4	4
South East Wales Cancer Network	4	4
West of Scotland Cancer Network	4	4
Northern Ireland Cancer Network	4	4
Cancer Research UK	4	4

#### General practitioner interviewees

GPs from central and suburban London	5
GPs from Cancer Research UK's Primary Care Advisory Group	4

## Cancer strategies monitoring research interviews

**Interview guide for in-depth interviews***Introduction*

- Moderator's introduction to research: explaining anonymity, confidentiality, MRS Code of Conduct and tape recording, and that the research is being carried out on behalf of CRUK but that we as researchers are completely independent. Freedom to say exactly what they want – no restrictions of any kind.
- Respondents to introduce themselves: their current job role, where they work, how long they have been there; briefly, main rewards and main difficulties.

*Cancer services – context*

- How does respondent feel the UK is doing, compared with other countries?
- What are we doing well? What does respondent see as the big problem areas?
- How well do the different groups of health professionals connect/work together?
- What is the overall mood amongst the people you work with at this point in time?

*Cancer services over the past 2½ years:*

- What changes does respondent perceive there to have been
  - Nationally
  - Locally
  - For them in particular?
- What are the improvements? What, if anything, has got worse?
- What lies behind these changes? (policy – local/national; medical discoveries/research; other influences...?)
- What 'if only...'s does respondent have, in relation to cancer services?

*Awareness & understanding of relevant national strategy*

- **Cancer Reform Strategy/Better Cancer Care Strategy/Designed to Tackle Cancer/Northern Ireland Cancer Service Framework** (as relevant to respondent's nation): e.g.
- What is known of this; how familiar; since when has it been in operation  
(*NB some respondents will have read the Exec summary online*)?
- Objectives: how would respondent put its aims into words?
- What does it actually mean at ground level; to what degree and in what way would they have expected it to translate into action at this point?
- What are their general feelings towards the strategy; how much faith is there in it; how welcome was it; how involved do they feel; is there anything obviously missing or unrealistic, in their view?
- (*use the summary of the Exec summary, as appropriate*)

*Implementation of the strategy*

- **Cancer strategy in relation to respondent's work**, eg
- What actual differences and changes in their work have there been in the past 2½ years?
- Which of these can be associated with the strategy, and in what way?
- What positives and negatives can respondent point to?
- To what degree do they think patients have benefited as a direct result?
- Specifically, how effective do they feel the cancer strategy has been in relation to **detection**
- and **treatment**
- of cancer?
  - What examples could they give here?

### Strategy and cancer networks

- **Probe on strategy in relation to cancer networks** (for all respondents, but cancer network representatives in particular); e.g.
- What is the relationship here – in theory, in practice? What has been the networks' response to the strategy? Nationally (if aware)? Their own network?
- Could go through some of the points in the 'role cancer networks should play in delivering strategy', e.g. (taken from list)
  - Work with specialist groups to develop strategies for dealing with less common cancers
  - Raising public awareness of cancer risk factors
  - Improving access to palliative care, etc
- How successful do they feel their own cancer network has been regarding implementation; especially with regard to **detection** and **treatment**?
- What benefits and improvements have cancer patients experienced?
- In what areas is implementation falling short, or not happening?
- What should be the priorities for change (towards better/fuller implementation of strategy) – immediately, next year, within 2 years?

### Summary

- How would they sum up their own feelings as regards the strategy and its implementation?
- Any other relevant areas not covered, specific to respondent's area of expertise/remit?
- What else would they like to see happening at ground level (omissions, issues not being addressed)?
- What else should the government be doing?
- What else can CRUK do?

### Thank and close

Cancer strategies monitoring research

## Discussion guide for primary care groups

### Introduction (15 minutes)

- Moderator's introduction: confidentiality, MRS Code of Conduct, tape recording; research is being carried out on behalf of Cancer Research UK; freedom to say exactly what they want.
- Respondent introductions: where work, type of area, how long been a GP, any particular interests/groups or committees belonged to. Main rewards and main difficulties of job.

### Cancer services – context (15 minutes)

- How does respondent feel the UK is doing, compared with other countries?
- What are we doing well? What are the problem areas?
- Any feedback from patients with regard to their experiences.
- How involved do GPs get once they have referred a patient?
- Examples of positive and negative experiences.
- How well do the different groups of health professionals connect/work together?

### Cancer services over the past 2½ years (10 minutes)

- What changes have there been
  - Nationally
  - Locally
  - For them in particular?
- What are the improvements? What, if anything, has got worse?
- What lies behind these changes? (policy – local/national; medical discoveries/research; other influences?)
- What would be your 'wish list', in relation to cancer services?

### Awareness & understanding of relevant national strategy (20 minutes)

- Awareness of Cancer Reform Strategy
- What is known about it, if anything (aims & objectives?). Heard anything in press, or via NHS?
- What impact has it had?
- Any awareness of (participation in?) the Primary Care Audit? (part of the National Awareness and Early Diagnosis Initiative); any feelings around this?

Give each respondent 'summary of summary'. Allow 5 minutes to read through

- Spontaneous reactions
- What is familiar, having read the summary? (again, probe on Primary Care Audit)
- What impact has it had? How have patients benefited?
- Which parts are most directly relevant to you as GPs?
- Has anything changed (e.g. protocols) with regard to detection and referrals?
- What examples?
- Perceived successes/improvements in services.
- Shortfalls; barriers to change; what support is needed.
- To what extent is the pace of change quick enough?
- Does the strategy go far enough? What omissions?

### Strategy and cancer networks (15 minutes)

- Awareness of cancer networks.
- What is known about them. What do they do? How well respected are they?
- Do you have any contact with your network? If so, what, how, why?
- Impressions of how successful cancer networks are?
- How have patients benefited?
- In what areas is implementation of the CRS falling short, or not happening?
- What should be the priorities for change (towards better/fuller implementation of strategy) – immediately, next year, within 2 years?

*Summary (15 minutes)*

- How would you sum up your own feelings as regards the strategy and its implementation?
- Any other relevant areas not covered so far ?
- What else would you like to see happening at ground level (omissions, issues not being addressed)?
- What else should the government be doing?
- What else can CRUK do?
- Questions from CRUK observer

*Thank and close*

## Cancer drugs appraised by NICE

Drug	Indication	Approved	Notes
<b>Erythropoetin (alpha and beta) and darbepoetin</b> Hormone that stimulates red blood cell production	Cancer treatment induced anaemia	Yes	For treatment of symptomatic anaemia. Recommends research into effects of this treatment on health related-related QoL including fatigue.
<b>Temozolomide</b>	Recurrent malignant glioma/ brain cancer	Yes	2nd line after other chemotherapy has failed with left xxlifexxx expectancy of at least 12 weeks from beginning of treatment.
<b>Bevacizumab</b>	Metastatic breast cancer	No	Terminated appraisal as no evidence was submitted by the manufacturer or sponsor.
<b>Docetaxel</b>	Breast cancer	Yes	As adjuvant chemotherapy in early cancer and first line in advanced cancer.
<b>Paclitaxel</b>	Breast cancer – early	No	Lack of evidence of clinical and cost effectiveness compared with current standard practice in the NHS.
<b>Trastuzumab</b>	Breast cancer	Yes	Adjuvant treatment to women with HER2-positive early invasive breast cancer following surgery, chemotherapy, and radiotherapy. Treatment of metastatic cancer.
<b>Hormonal treatments (Anastrozole, Exemestane, Letrozole)</b>	Breast cancer	Yes	Early oestrogen-receptor-positive invasive Breast cancer in postmenopausal women <ul style="list-style-type: none"> <li>• Anastrozole for primary adjuvant therapy.</li> <li>• Exemestane for adjuvant therapy following 2–3 years of adjuvant tamoxifen therapy.</li> <li>• Letrozole for primary adjuvant therapy and extended adjuvant therapy following standard tamoxifen therapy.</li> </ul>
<b>Capecitabine</b>	Breast cancer	Yes	2nd and 3rd line in advanced cancer
<b>Vinorelbine</b>	Breast cancer	Yes	2nd and 3rd line in advanced cancer
<b>Gemcitabine</b>	Metastatic breast cancer	Yes	Treatment of metastatic breast cancer only where two other treatments could be used as alternatives.
<b>Topotecan</b>	Cervical cancer – Recurrent	Yes	Treatment of recurrent or metastatic cervical cancer only if they have not previously received Cisplatin.
<b>Capecitabine</b>	Colon cancer – adjuvant	Yes	For locally spread bowel cancer.
<b>Oxaliplatin</b>	Colon cancer – adjuvant	Yes	For Duke's C stage III cancer together with 5-fluorouracil and folinic acid.
<b>Irinotecan, Oxaliplatin</b>	Colorectal cancer advanced	Yes	<ul style="list-style-type: none"> <li>• Irinotecan and Oxaliplatin for advanced colorectal cancer</li> </ul>
<b>Raltitrexed</b>		No	<ul style="list-style-type: none"> <li>• Raltitrexed is not recommended as it did not improve overall survival or progression-free survival when compared to other treatments.</li> </ul>
<b>Cetuximab</b>	Colorectal cancer	Yes	1st-line treatment of metastatic colorectal cancer when spread is limited to the liver; is operable and patient is fit for surgery.
<b>Bevacizumab &amp; Cetuximab</b>	Colorectal	No	<ul style="list-style-type: none"> <li>• Bevacizumab as a 1st-line treatment for metastatic colorectal cancer would not be a cost-effective use of NHS resources.</li> <li>• Cetuximab, either as a 2nd-line or a subsequent-line treatment for metastatic colorectal cancer would not be a cost-effective use of NHS resources.</li> </ul>
<b>Cetuximab</b>	Colorectal cancer (metastatic)	Terminated	Terminated appraisal as no evidence was submitted by the manufacturer or sponsor.
<b>Capecitabine and Tegafur uracil</b>	Colorectal cancer	Yes	Should be among the first options for metastatic colorectal cancer.
<b>Laparoscopic surgery</b>	Colorectal cancer	Yes	As an alternative to open surgery if the patient is suitable and the surgeon is adequately trained.



## Cancer drugs appraised by NICE (continued)

Drug	Indication	Approved	Notes
Rituximab	Follicular lymphoma	Yes	Recommended as an option for the treatment of symptomatic follicular lymphoma that has spread in previously untreated patients.
Imatinib	Gastro-intestinal Stroma tumour (GIST)	Yes	1st-line management of people with unresectable and/or metastatic gastro-intestinal stromal tumours (GISTs).
Sunitinib	Gastro-intestinal Stroma tumour (GIST)	Yes	Treatment option for people with unresectable and/or metastatic malignant gastrointestinal stromal tumours if the drug cost of sunitinib (excluding any related costs) for the first treatment cycle will be met by the manufacturer and certain other drugs have not been tolerated.
Carmustine implants and Temozolomide	Glioma, newly diagnosed and high grade	Yes	<ul style="list-style-type: none"> <li>• Temozolomide is recommended in patients with otherwise good general health.</li> <li>• Carmustine implants are recommended as an option only for patients in whom 90% or more of the tumour has been resected.</li> </ul>
Carmustine	Recurrent glioma – adjunct	Terminated	Terminated appraisal as no evidence was submitted by the manufacturer or sponsor.
Cetuximab	Recurrent squamous cell carcinoma of the neck	No	Not believed to be cost-effective. Did not meet end of life criteria.
Cetuximab	Head and Neck cancer	Yes	In combination with radiotherapy recommended as a possible treatment for people with locally advanced squamous cell carcinoma of head and neck depending on severity.
Sorafenib	Hepatocellular cancer advanced and metastatic (1st-line)	No	Study compared with 'best supportive care'. Not believed to be cost effective despite clinical effectiveness.
Rituximab	Chronic Lymphocytic Leukaemia	Yes	Rituximab combined with other drugs is recommended as an option for the 1st-line treatment of chronic lymphocytic leukaemia.
Imatinib	Chronic Myeloid Leukaemia (CML)	Yes	Recommended for 1st-line treatment of CML of a specific type in the chronic phase and those presenting in acute deterioration of symptoms.
Fludarabine	Leukaemia (lymphocytic B cell chronic)	Yes	Recommended for 2nd-line treatment when patients have stopped using one of a number of chemotherapy combinations due to adverse effects.
Fludarabine	Leukaemia (lymphocytic) 1st-line	No	Not believed to be cost-effective.
Pemetrexed	Lung cancer – non small cell type	Yes	Recommended for 1st-line treatment of adenocarcinoma or large cell carcinoma.
Bevacizumab	Lung cancer – non small cell type	Terminated June 2008	Terminated appraisal as no evidence was submitted by the manufacturer or sponsor.
Topotecan	Lung cell – small cell type	Yes	Oral therapy only. For relapse when previous drug cannot be re-used and when patients cannot take specific combination of chemotherapy drugs.
Docetaxel, paclitaxel, gemcitabine and vinorelbine (known collectively as 3rd generation drugs)	Lung cancer – non small cell type (NSCLC)	Yes	For advances cancer.
Rituximab	Lymphoma (follicular non-Hodgkin's)	Yes	Recommended as an option for the induction of remission in people with relapsed advanced follicular non-Hodgkin's lymphoma. Also recommended as maintenance therapy.
Pemetrexed disodium	Mesothelioma	Yes	Recommended in advanced and inoperable cancer in patients with reasonable ability to carry out routine tasks.

## Cancer drugs appraised by NICE (continued)

Drug	Indication	Approved	Notes
<b>Bortezomib</b>	Mulitple myeloma	Yes	Recommended for treatment of relapse after one treatment and for those patients who have had a bone marrow transplant if possible.
<b>Lenalidomide</b>	Mutiple myeloma	Yes	For patients who have already had at least two other treatments.
<b>Rituximab</b>	Non-Hodgkin's lymphoma	Yes	Recommended as 1st-line in Stage 2,3,4 – not stage 1.
<b>Paclitaxel, pegylated liposomal doxorubicin hydrochloride (PLDH) and topotecan</b>	Ovarian Advanced – Relapsed only	Yes	Recommended as 2nd-line in combination with specific conditions for each individual drug
<b>Paclitaxel</b>	Ovarian cancer	Yes	Offered as alternatives for 1st-line chemotherapy (usually following surgery) in the treatment of ovarian cancer.
<b>Gemcitabine</b>	Pancreatic cancer	Yes	Recommended for people with advanced or metastatic cancer as 1st-line with reasonable general well-being. Gemcitabine should not be used as a 2nd-line treatment for people with pancreatic cancer, because there is insufficient evidence to support this practice.
<b>Docetaxel</b>	Prostate cancer (hormone-refractory)	Yes	Recommended for those patients well enough to care for himself with occasional assistance.
<b>Bevacizumab, sorafenib, sunitinib and temsirolimus</b>	Advanced and/or Metastatic renal cell carcinoma	No	Not believed to be cost-effective.
<b>Sunitinib</b>	Advanced and/or Metastatic renal cell carcinoma	Yes	First line if immunotherapy (for example, interferon alfa) would be suitable for them and they are mobile and can do light housework or office work.
<b>Trabectedin</b>	Soft tissue sarcoma- advanced	Yes	Recommended as an alternative if other drugs are not tolerated.

## Glossary and list of terms

### ADTC

Area Drug and Therapeutics Committees (Scotland)

### Better Cancer Care, An Action Plan

Plan which outlines the way forward for cancer services, which are required to support all those in Scotland who find themselves living with and beyond cancer.

### BME

Black and minority ethnic groups

### CAPriCORN

Cancer and Palliative Care Online Resource Network

### CCP

Cancer Control Programme (Northern Ireland) The Cancer Control Programme (2006) was developed by the Department of Health, Social Services and Public Safety and represents the first element of an overarching regional framework for cancer services that will set out clear standards for the quality of cancer care in Northern Ireland over the next ten years.

### Cancer screening programmes

Nationally coordinated in each of the four nations and constitute investigations aimed to identify patients either with or with a high risk of developing cancer.

### The Cancer Services Co-ordinating Group

All-Wales NHS organisation providing expert clinical advice to the Welsh Assembly Government regarding strategic development of cancer services in Wales. It also supports the development and work of the three Cancer Networks in Wales. <http://www.wales.nhs.uk/sites3/home.cfm?orgid=322>

### Cancer taskforce

The Scottish Cancer Taskforce oversees the actions outlined within Better Cancer Care, An Action Plan, which was published in October 2008.

### Carcinogenic

Property of a substance that is believed to be able to cause cancer; including tobacco smoke, ultraviolet radiation from the sun and asbestos.

### CEPAS

Chemotherapy Electronic Prescribing and Administration System

### Chemotherapy Planning Oncology Resource Tool

Designed to enable chemotherapy departments to use existing resources more effectively and for commissioners and providers to plan better for the future.

### CM Insight

Partnership carrying out qualitative research.

**CNS**

Clinical Nurse Specialist

A clinical nurse specialist (CNS) is an advanced practice nurse whose care focuses on a specific patient population.

**COSC**

Welsh Scientific Advisory Committee's Clinical Oncology Sub-Committee.

**C-Port**

C-Port is a web application which gives cancer professionals and healthcare managers the ability to model chemotherapy service delivery in a cost-free, risk free online environment.

**CRS**

Cancer Reform Strategy UK

Department of Health document published in 2007 following on from the NHS Cancer Plan in 2000.

**CSF**

Cancer Services Framework (Northern Ireland) Service Framework for Cancer Prevention, Treatment and Care. The framework prioritises the recommendations coming out of the Cancer Control Programme. It sets standards that span the whole patient pathway from prevention right through to survivorship.

**CT**

Computed tomography is a method of medical imaging used in the diagnosis and monitoring of some types of cancer.

**Cystectomy**

Surgical removal of all or part of the bladder.

**Cytology**

Study of cells used in cancer screening and diagnosis to identify cancerous or pre-cancerous cells.

**DHSSPS**

Department of Health, Social Services and Public Safety, Northern Ireland

**Digital mammography**

Technique used in breast screening.

**DTTC**

Designed to Tackle Cancer. Policy statement issued by the Welsh Assembly Government in 2006 outlining their commitment to fighting cancer.

**e-prescribing**

Allows medication and other prescribed therapies to be managed electronically at every stage, from prescribing to supply and administration.

**FAST questionnaire**

Brief screening tool used in assessing alcohol use/misuse in Scotland.

**Gold Standards Framework**

GSF is a systematic evidence-based approach to optimising the care for patients nearing the end of life delivered by generalist providers.

**Histopathologists**

Qualified doctors who specialise in the tissue diagnosis (taken by biopsy) of disease including cancer.

**HPV**

Human Papilloma virus is the primary cause of cervical cancer.

**IGRT**

Image Guided Radiotherapy

**IMRT**

Intensity Modulated Radiotherapy. Technique used in radiotherapy to deliver treatment to precise areas of cancerous cells and avoid healthy tissue.

**Incidence**

Incidence of new cases of a disease in a set time for a given population.

**JCCO**

Joint Collegiate Council for Clinical Oncology. It advises The Royal College of Physicians and The Royal College of Radiologists on matters relating to service needs, education, staffing and resources for treatment of cancer; and helps to produce specialist input and co-ordinated responses to all consultations and matters relating to cancer treatment, prevention and research.

**Jobbing GPs**

Non-partner GPs.

**Keep Well health check**

Free health check available to 45 to 64-year-olds at participating GP practices in Scotland which includes blood pressure and cholesterol check.

**Laparoscopic Surgery**

Also known as keyhole surgery

**Linac**

Linear Acceleration. Technology used to administer x-rays for diagnosis and treatment of cancer.

**Lymphoedema**

Swelling of areas of the body due to fluid accumulation which can be as a result of cancer or cancer treatment.

**MDT**

Multi-disciplinary team. Team comprising various staff members including doctors (specialising in pathology, radiology, chemotherapy), specialist nurses, dieticians, social workers, physiotherapists, who all have an input in the care of the patient.

**MRI**

Magnetic Resonance Imaging. Imaging technique used to look in detail at tissue and used in the diagnosis of cancer.

**NAEDI**

National Awareness and Early Detection Initiative

**NCAG**

National Chemotherapy Advisory Group (England)

**NCAT**

National Cancer Action Team (England)

**NCRI**

National Cancer Research Institute

**NHS Choices website**

Website resource detailing NHS services in England.

**NHS Life Check Programme**

Set of three online lifestyle assessment services developed by the Department of Health in England.

**NICaN**

Northern Ireland Cancer Network

**NHS QIS**

NHS Quality Improvement Scotland. Organisation helping NHS Scotland improve the quality of patient care by supporting the Quality Strategy.

**NICE**

National Institute for Health and Clinical Excellence

**NRAG**

National Radiotherapy Advisory Group (England)

**NRIG**

National Radiotherapy Implementation Group (England)

**NRPI**

National Research Prevention Initiative

**Pilot programme**

Small scale preliminary study to test feasibility of a larger scheme.

**Prevalence**

Number of cases of a disease in a population at a given time.

**Prostatectomies**

Surgical removal of all or part of the prostate gland used as a treatment for prostate cancer.

**QOF**

Quality and Outcomes Framework. A voluntary annual reward and incentive programme for all GP surgeries across the UK, detailing practice achievement results.

**RCAG**

Regional Cancer Advisory Group (Scotland)

**Regional Oncology and Haematology Drugs and Therapeutics Committee**

Established in 2004 to ensure that patients in Northern Ireland have equitable access to regionally-established and evidence-based funded treatments.

**SEA**

Significant Event Audit

**Sentinel Node Biopsy**

The sentinel node is the first lymph node to which cancer spreads. In this procedure, this lymph node is removed and tested for cancerous cells to assess spread.

**SMC**

Scottish Medicines Consortium

**SunSmart**

UK's national skin cancer prevention campaign. It is commissioned by the UK Health Departments and run by Cancer Research UK.

**Top-up payment scheme**

Scheme whereby patients opt to pay for non-NHS funded treatment.

**Two-week wait target**

Department of Health guidance stating that patients should wait no longer than two weeks between urgent referral by their GP for suspected cancer and seeing a cancer specialist.

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Cancer Research UK is a registered charity in England and Wales  
(1089464) and in Scotland (SC041666)