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Cancer, Health and the Health Service in Wales

A Final Report for ABPI Wales



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Contents

Acknowled	lgements	i
Foreword		ii
Executive S	Summary	iii
1	Introduction	1
2	The Impact of Cancer	2
2.1	Defining Cancer	2
2.2	Cancer Mortality	3
2.3	Patient Impact of Cancer	7
2.4	Historical Cancer Incidence	8
2.5	Cancer Prevalence	14
2.6	Cancer Survival	15
2.7	Risk Factors for Cancer	17
2.8	Treatment and Management of Cancer	19
3	The Future Economic Burden of Cancer in Wales	21
3.1	The Current Cost of Cancer	22
3.2	Future Cancer Incidence in Wales	29
3.3	Projected Costs of Cancer in Wales	30
4	Challenges to the Health System from Cancer	33
4.1	Responding to Cancer: Prevention, Screening, Treatment, Palliative Care and Cancer Research	33
4.2	How is Wales Responding?	34
5	Conclusions and Recommendations	50

Appendix A: List of Count	y Abbreviations	53
II	,	



List of Tables

Table 2.1	Cancer Mortality Rates in England and Wales Per 100,000 Population, 1999-2005	6
Table 2.2	Estimated Cancer Prevalence, UK, 2000	14
Table 2.3	Proportion of Elderly Population, UK, 2006 Estimates	18
Table 3.1	Average Number of Individuals Admitted to Hospital Per Year, Wales, 2000-2003	26
Table 3.2	Breakdown of the Direct Costs of Cancer, Selected Countries	27
Table 4.1	Percentage Reporting Sun Protection Knowledge and Behaviour by Age, 2005	38
Table 4.2	Number of Cancer Medicines in Clinical Development in the US FDA Approval Process, March 2007	42

List of Figures

Figure 2.	Per Cent of Total Deaths Caused by Cancer, EU-15,	
	2000 Estimate	4
Figure 2.	2 Cancer Mortality, EU-15, 2002	5
Figure 2.	3 Cancer Mortality, Countries of the UK, 2002-04	5
Figure 2.	Change in Health Related Quality of Life Over Time, With and Without Diagnosis of Cancer	7
Figure 2.	5 Cancer Incidence, EU-15, 2002	8
Figure 2.	5 Cancer Incidence, Countries of the UK, 2002-04	9
Figure 2.	7 Trend in Cancer Incidence, Wales, 1985-2005	10
Figure 2.	3 Cancer Incidence by Type of Cancer, UK, 2004	11
Figure 2.	Male Cancer Incidence, Wales, 1993-2002	12
Figure 2.	l 0 Female Cancer Incidence, Wales, 1993-2002	12
Figure 2.	1 Unemployment Rate, Wales, 2004	13

Figure 2	2.12	Median Survival Times in Years, All Cancer	
		(Excluding Non-Melanoma Skin Cancer), Wales, 1991-2000	15
Figure 2	2.13	Cancer Survival Rates, Selected European Countries	16
Figure 2	2.14	Cancer Survival Rates, Selected European Countries Including Wales	17
Figure 2	2.15	Cancer Incidence by Age Group, UK and Ireland, 1991-1999	18
Figure 3	3.1	Direct Costs of Cancer (£), Selected Countries, 2004	23
Figure 3	3.2	Direct Costs of Cancer Per Capita (£), Selected Countries, 2004	24
Figure 3	3.3	Spend on Cancer Medicines, Per Capita (£), Selected Countries, 2004	28
Figure 3	3.4	Spend on Top 20 Cancer Medicines, Per Capita (£), UK, Sept 2006	28
Figure 3	3.5	Projected Male and Female Cancer Incidence 2006 – 2024, Wales	30
Figure 3	3.6	NHS Wales Costs for Cancer and Prevention, 2003 – 2024, Wales, Current Values (£)	31
Figure 3	3.7	Scenarios of Expenditure on Cancer Medicines, UK, 2006-2012	32
Figure 4	4.1	Wales Cancer Network, 2006	36
Figure 4	4.2	Total Cancer Consultant Specialists, UK, 1997-2006	40
Figure 4	4.3	Euro Health Consumer Index Score for Speed of Deployment of Novel Cancer Drugs, 2006	43
Figure 4	4.4	Trastuzumab Uptake Across Europe, Selected Countries	44
Figure 4	4.5	Waiting Time Targets for 1st Treatment for Cancer	46
Figure 4	4.6	Comparison of Waiting Time Performance, England and Wales	47



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Foreword

Most of us are pleased when we read that our life expectancy is increasing. But we are also concerned that these years of added life may be blighted by ill health. This concern is both heightened and rational when we realise that the incidence of cancer increases with age.

The achievement of disease free added years of life for all could be described as the "holy grail" of medicine and as such is currently unattainable. However the transformation of the natural history of many forms of cancer from acutely lifethreatening to chronic conditions is already underway. The new and urgent challenge to the health system in Wales is to ensure the effective management of this new presentation of an old disease and the achievement of a good quality of life for those who may live for many years with the condition. A major element in meeting the challenge will be the allocation to the NHS in Wales of the necessary resources, both financial and other to enable it to do so.

In the mind of the public in Wales effective long term cancer care is associated with the availability of effective medication and there are signs that research and its application by the pharmaceutical industry will continue to provide drugs of increasing effectiveness. However such advances will only be fully realised if the organisation and management of health services, including the availability of trained and experienced staff, are optimum.

This commendably brief but comprehensive overview of the challenge of cancer to the health system in Wales is an important contribution to policy development in this field and to the implementation of appropriately resourced and managed services. Cancer has long been a priority in health policy development in Wales and major improvements in care have resulted. This report demonstrates that such priority must continue to be given to addressing the next phase of the fight to conquer the "big C".

Dame Deidre Hine

Wales Cancer Institute Partners Forum

Executive Summary

Wales, like many other countries, is likely to see increasing numbers of people with cancer in the future. This is, in part, because the population is getting older, but some lifestyle trends also appear to contribute, such as rising obesity levels. A simple projection model of incidence suggests that incidence for men could rise from 8,668 per 100,000 population in 2006 to 11,356 per 100,000 population by 2024. The corresponding figures for women are from 8,162 per 100,000 population in 2006 to 9,835 per 100,000 population by 2024.



Figure 1 Projected Male and Female Cancer Incidence 2006 – 2024, Wales

Source: NERA Calculation using data from Welsh Cancer Intelligence & Surveillance Unit, http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=27758

Wales is not alone in facing significant costs for preventing, screening, treating and managing cancer. With increasing innovations in treatment, including new medicines and technologies, cancer is rapidly transforming from a fatal disease towards a chronic condition. This is a success story for research, prevention, and treatment with the involvement of a range of stakeholders. However, even our simplistic extrapolations (which do not account for anything other than ageing) show that costs are going to rise (Figure 2) whilst associated research suggests that the cost implications are significant. This presents a challenge to ensure funding is available to meet the likely rise in demand for treatment in the future.



Figure 2 NHS Wales Costs for Cancer and Prevention, 2003 – 2024, Wales, Current Values (£)

Source: NERA calculation using Welsh Health Circular, Programme budgeting results 2003-04, 2 March 2005 http://www.wales.nhs.uk/documents/WHC_2005_021.pdf, Welsh Assembly Government, Population Estimate Revisions for 2002-2005, and Population Projection for Wales from the Government Actuary Department.

There is evidence however, that whilst Wales, and indeed the UK, are not alone in facing these trends, they are currently lagging behind other countries in terms of both preventing mortality (Figure 3) and in spending on cancer treatments, including medicines (Figure 4). It is encouraging that differences in survival are lessening over time across countries, but the UK and Wales remain laggards in comparison with other countries. ¹



Figure 3 Cancer Survival Rates, Selected European Countries Including Wales

Source: ABPI Investment in Cancer Treatment and Outcomes Personal Communication to NERA

Berrino, F et al (2007) Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995-99: results of the EUROCARE-4 study, http://oncology.thelancet.com Vol 8 September 2007



Figure 4 Spend on Cancer Medicines, Per Capita (£), Selected Countries, 2004

Together these raise a number of challenges to the health system. These include:

- How to develop and implement effective prevention and screening activities. Changing lifestyle behaviours could go a significant way to reducing the number of new cases of cancer in the future. Vaccination programmes could contribute to a reduction in cancer in the future. Wales appears to be behind its UK counterparts, particularly England, in implementing and expanding screening programmes.
- Ensuring sufficient expert staff to deliver care.
- Ensuring effective new medicines are available for patients. This is both in terms of;
 - providing access in a timely manner (requiring a balance between the time to review new products by agencies such as the National Institute for Health and Clinical Excellence (NICE) and when they are used in the NHS); and
 - implementing positive guidance across Wales.

Note: Data was converted from Euros (*e*), using £1= *e*0.695, http://www.xe.com as at 1 November 2007 Source: Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3

We found some gaps in the publicly available information on cancer in Wales when we completed our desk based review. These included:

- Lack of **forecasts of future incidence and prevalence of cancer in Wales**. Such forecasts would help to understand the future scale of needs and hence scale of funding needed to treat cancer.
- Lack of detailed data on **health care costs of cancer in Wales**. This kind of information could be used to inform future resourcing across the patient care pathway.
- Lack of data on the wider costs of cancer in Wales. These costs become relevant if policy makers wish to consider the full economic costs and benefits of preventing and managing cancer.
- Lack of **forecasts of future costs of cancer in Wales**. Forecasting is complex, but scenarios could be developed to help inform decisions on resourcing.

Some of this information may be available internally to the NHS (we understand that incidence forecasts are available for example) but these are not available to other stakeholders. It may therefore be difficult for researchers and others to comment on these forecasts and what it means for cancer in Wales in the future.

We recommend the need for further clarity about the role and responsibilities of the various agencies involved in providing guidance to the NHS in Wales.

We agree with recommendations from other researchers on cancer, that there needs to be further development of outcome measures to understand and monitor the impact of policy changes.

Critically, we recommend the need to **consider how policy makers will approach** the issue of high cost medicines, not only in terms of which products are available but also how to ensure equity of access and to involve patients in these decisions.²

² Rosen, R, Smith, A and Harrison, A (2006) Future Trends and Challenges for Cancer Services in England: A Review of Literature and Policy, Kings Fund

1 Introduction

Cancer is the second leading cause of mortality, behind circulatory diseases, in England and Wales.³ The trend in mortality is improving but the incidence (the number of new cases of cancer per year) is rising. There were 8,539 new cases of cancer in Wales in 2005.⁴ Cancer is also often a significant economic cost to individuals, the health care system and society as a whole.

This report is intended to inform and contribute to the debate on how to develop and improve cancer management in Wales. It is not a comprehensive review of the literature but rather a rapid review of the available information in the public domain (primarily derived from internet resources). It also seeks to draw out areas which need be further explored and researched to fully inform future policy decisions. In essence it asks what do we know about cancer in Wales and what more do we need to know to help inform policy? This review should be seen as an initial step at looking at these questions in the Welsh context.

This report provides a brief introduction to:

- The mechanism and pathology of cancer, including symptoms of cancer and it's impact on mortality, quality of life, trends in cancer incidence and survival in Wales, the UK and internationally, as well as selected risk factors for cancer, and the broad ways of treating cancer;
- The current costs and future burden of cancer in Wales;
- The challenges cancer imposes on the health system and how Wales is responding to managing cancer; and
- Areas for future research to better understand the impact of cancer on the population of Wales.

- ³ National Statistics Online, http://www.statistics.gov.uk/CCI/nugget.asp?ID=1337&Pos=2&ColRank=2&Rank=1000
- ⁴ Source: Wales Cancer Intelligence & Surveillance Unit, http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=27758

2. The Impact of Cancer

Key Points:

- Cancer has a significant impact on patients' quality of life and cancer is one of the leading causes of mortality.
- Cancer incidence is increasing, however survival rates are improving, indicating that cancer is transforming from a fatal disease to a chronic disease.
- There remains significant "avoidable" mortality from cancer in the UK.
- Cancer incidence is higher in Wales than in other parts of the UK, and Wales is seeing an increase in the number of new cases of cancer over time.
- Within Wales there are areas which face a greater incidence of cancer than others, this may be due in part to differences in levels of deprivation.
- Survival times are improving in Wales, however the UK as a whole is lagging behind the survival times seen in other countries.
- There are a range of risk factors for cancer. One of the most important risk factors is ageing, whilst others include diet and exercise. Improving levels of activity and improving diet could contribute to avoiding future cases of cancer. Other activities such as the use of a vaccine for HPV and improvements in screening should also reduce the future incidence of cancer.
- Medicines often play a vital role in improving survival. They are part of a whole host of activities which contribute to the management of cancer.
- Patient involvement has a greater focus in today's health systems, and there is research which suggests that cancer patients becoming more involved in their care and treatment choices leads to greater satisfaction levels and better quality of life.

2.1 Defining Cancer

Cancer is a disease of uncontrolled cell growth or the inability of cells to selfdestruct when they are old or damaged. Cancer cells that continue to divide form a tumour, which, if remains local, is benign. However cancer cells that spread to other parts of the body can disrupt the normal functions of vital organs. These tumours are malignant and life threatening.⁵ Cancer affects people of all ages, including children, but the elderly are especially vulnerable to developing the disease.⁶

⁵ National Cancer Institute, http://www.nci.nih.gov/cancertopics/understandingcancer/cancer

⁶ ABPI: Target Cancer, http://www.abpi.org.uk/publications/publication_details/targetCancer/default.asp

There are several types of cancer. Cancer can affect a variety of sites in the body ranging from the skin to specific organs, such as the lung. Cancer is often difficult to detect early because symptoms do not appear until the cancer has grown substantially or spread. The four phases of cancer are:⁷

- Phase 1: The tumour is very small, cannot be detected as a lump, and is contained in the original site.
- Phase 2: The tumour is still contained in the original site, but has grown so that it may be felt as a lump or detected on scans.
- Phase 3: The tumour has spread to the tissue immediately surrounding the original site.
- Phase 4: Also known as secondary cancer or metastatic disease, the tumour has spread to tissues and organs distant from the original site, often the liver, lungs and lymphatic system.

2.2 Cancer Mortality

Cancer is the leading cause of death worldwide, accounting for 7.6 million out of 58 million deaths in 2005 (13%).⁸ Among the European Union, cancer is the second leading cause of death behind circulatory disease. For the time period 2001-2003, cancer accounted for 25.3 per cent of all deaths in the Member States, and is the leading cause of death of those aged 45-64 (41%).⁹ The Office for National Statistics reports that 1 in 3 people in the UK will develop cancer sometime in their life, and 1 in 4 will die from cancer.¹⁰

Figure 2.21 shows the per cent of deaths caused by cancer in selected countries of the European Union. The UK is only just below the EU average with 24 per cent of deaths caused by cancer compared to the EU average of 25 per cent. Other countries do however have a lower proportion, with Portugal the lowest at 20 per cent

- 7 ABPI: Target Cancer, http://www.abpi.org.uk/publications/publication_details/targetCancer/default.asp
- 8 World Health Organization (2006) Cancer Fact Sheet, February 2006, http://www.who.int/mediacentre/factsheets/fs297/en/index.html
- ⁹ Eurostat (2006) Causes of death in the EU25, Significant differences among Member States, 96/2006 – 18 July 2006, http://epp.eurostat.ec.europa.eu/pls/portal/docs/PAGE/PGP_PRD_CAT_PREREL/PGE_CAT_PREREL_YE AR_2006/PGE_CAT_PREREL_YEAR_2006_MONTH_07/3-18072006-EN-AP.PDF

¹⁰ Office of National Statistics, http://www.statistics.gov.uk/cci/nugget.asp?id=915



Figure 2.1 Per Cent of Total Deaths Caused by Cancer, EU-15, 2000 Estimate¹¹

Figure 2.2 and Figure 2.3 illustrate cancer mortality for EU 15 countries and for countries of the UK. These show that the UK has one of the highest cancer mortality rates within the EU 15, and that Scotland has the highest mortality, followed by Wales for both males and females.

¹¹ See Appendix for list of country abbreviations



Figure 2.2 Cancer Mortality, EU-15, 200212





Note: Includes all cancers except non-melanoma skin cancer. Source: Office for National Statistics,

http://www.statistics.gov.uk/downloads/theme_health/UK_inc_mort_charts_tables2002_04.xls

¹² See Appendix for list of country abbreviations

Recent research has looked at avoidable mortality from cancer in England and Wales.¹³ Avoidable mortality is based on the concept that deaths from certain conditions should not occur in the presence of timely and effective health care. This research has found that the rate at which avoidable mortality from cancer has fallen every year from 1999 to 2005. This is illustrated in Table 2.1. (Note that the percentage change from 1999 to 2005 for malignant neoplasm of cervix uteri and body of the uterus (0-44 years) is positive overall, because the mortality rate for this cancer increased, although the magnitude of the percentage change is distorted by the small number of deaths.) For all the other cancers listed, a decrease was registered, though at a slower and slower rate over the years.

Condition (0-74 years)	1999	2000	2001	2002	2003	2004	2005	% Change 1999-2005
Malignant neoplasm of colon and rectum	12.92	12.36	11.91	11.63	11.43	11.27	11.09	-14.21
Malignant neoplasm of skin	0.21	0.23	0.19	0.19	0.20	0.21	0.18	-14.24
Malignant neoplasm of breast	13.00	12.67	12.40	12.08	11.63	11.34	11.24	-13.55
Malignant neoplasm of cervix uteri	1.40	1.45	1.34	1.23	1.17	1.17	1.11	-20.94
Malignant neoplasm of cervix uteri and body of the uterus (0-44 years)	0.04	0.05	0.04	0.05	0.03	0.05	0.05	28.28
Malignant neoplasm of testis	0.13	0.12	0.10	0.11	0.12	0.13	0.11	-15.06
Hodgkin's Disease	0.36	0.38	0.33	0.35	0.38	0.34	0.32	-10.13
Leukaemia (0-44yrs)	1.39	1.14	1.22	1.08	1.02	0.95	0.95	-31.49
Total Avoidable Mortality	29.45	28.40	27.52	26.73	25.98	25.47	25.04	-14.96
% Change year-on-year		-3.55	-3.09	-2.90	-2.79	-1.95	-1.69	

Table 2.1Cancer Mortality Rates in England and Wales Per100,000 Population, 1999-2005

Source: Gubb, J (2007) Just How Well Are We? CIVITAS

This research has therefore called into question the approach to preventing and treating cancer in the UK.

¹³ Gubb, J (2007) Just How Well Are We? CIVITAS

2.3 Patient Impact of Cancer

We have already highlighted the significant mortality from cancer. We discuss here the impact of cancer on morbidity. The impact of cancer on patients varies according to the type of cancer. For example, bone cancer can result in pain, swelling, tiredness, fever and weight loss and can impact upon daily activities.¹⁴ Cancer therefore often has a significant impact on patient quality of life. Surveys of those with cancer, compared with those without cancer, over time show a significant fall across a range of dimensions in health related quality of life as shown in Figure 2.4.

Research has shown that almost half of cancer patients surveyed in the UK (49 per cent) have experienced depression. Seventy five per cent have experienced anxiety. For some of those with cancer, it may be that the emotional impacts of cancer are the most difficult for them to cope with.¹⁵

Cancer will also impact not just on those diagnosed with cancer, but also their family, carers and friends.¹⁶ The impact of cancer on society is therefore much greater than the symptoms and loss of quality of life and mortality of patients diagnosed with cancer.



Change in Health Related Quality of Life Over Time, Figure 2.4

Note: Scores range form 0-100. Scores were taken in 1996 and 1998. Source: Boini, S, Briancon, S, Guillemin, F, Galan, P and Hercberg, S (2004) Impact of cancer occurrence on health-related quality of life: A longitudinal pre-post assessment.

Role-

Emotional

Social

Functioning

Vitality

General

Health

14 http://www.cancerhelp.org.uk/help/default.asp?page=4416

Macmillan Cancer (2006) Worried Sick: The Emotional Impact of Cancer, 15 http://www.macmillan.org.uk/About_Us/Newsroom/Impact_of_cancer.aspx

Role-Physical Bodily Pain Mental Health

16 Macmillan Cancer (2006) Worried Sick: The Emotional Impact of Cancer, http://www.macmillan.org.uk/About_Us/Newsroom/Impact_of_cancer.aspx

-2 -4 -6 -8 -10 -12 -14 -16 -18

Physical

Functioning

2.3 Historical Cancer Incidence

Incidence is the number of newly diagnosed cases during a specific time period (typically a year). Figure 2.5 and Figure 2.6 show cancer incidence for selected countries in the EU-15 and across the UK. The incidence rate of cancer per 100,000, population in the UK (273.6 per 100,000 in 2002) is broadly in the middle of the incidence rates seen in the EU-15. Wales has the UK highest incidence rate for men, and is second only to Scotland for female incidence of cancer.



Figure 2.5 Cancer Incidence, EU-15, 2002¹⁷

Source: OECD HEALTH DATA 2006, June 2006

¹⁷ See Appendix for list of country abbreviations.



Figure 2.6 Cancer Incidence, Countries of the UK, 2002-04

Cancer incidence is highest in Wales, yet male cancer mortality is second to Scotland (as seen in Figure 2.3). We have not researched what is driving this difference, it could be due to differences in treatment or a variety of other factors such as people presenting earlier or variation in risk factors across these countries. The past 20 years have observed an increasing trend in cancer incidence in Wales, with men developing cancer at a higher rate than women. The gap between male and female cancer incidence has grown overall as shown in Figure 2.7. We have not researched what is driving this trend and it could potentially be due to a variety of factors, perhaps linked to gender differentials in screening so that more cases are detected in women.



Figure 2.7 Trend in Cancer Incidence, Wales, 1985-2005

Source: Welsh Cancer Intelligence & Surveillance Unit, http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=27758

It is clear however that cancer incidence is increasing. Four types of cancer are responsible for over half of these new cases and they are breast cancer, lung cancer, large bowel cancer and prostate cancer (Figure 2.8).¹⁸

¹⁸ Cancer Research UK, http://info.cancerresearchuk.org/cancerstats/types/?a=5441



Figure 2.8 Cancer Incidence by Type of Cancer, UK, 2004

Note: N-H-L stands for Non-Hodgkin's Lymphoma and CNS stands for Central Nervous System. Source: Cancer Research UK, http://info.cancerresearchuk.org/images/excel/cs_inc_f1.1.xls

Incidence of cancer, as with most other medical conditions, differs between regions of Wales. For example from 1993-2002:

- Conwy had the highest incidence of cancer in females (515 per 100,000), and Newport had the lowest, (450 per 100,000);¹⁹
- Denbighshire had the highest incidence of cancer in males (565 per 100,000), and Ceredigion had the lowest (457).²⁰

Figure 2.9 and Figure 2.10 illustrate cancer incidence in Wales by Local Health Board (LHB) for males and females. The figures show incidence as a rate per 100,000 population so that LHBs can be compared irrespective of their absolute size of population. They highlight typically higher incidence associated with the legacy of heavy industry and the higher levels of relative socio-economic deprivation (see Figure 2.11 which illustrates the unemployment rate as a proxy for deprivation).





- ¹⁹ Welsh Assembly Government, Health in local areas; a compendium of maps, Chief Medical Officer's Report Series, Report 2, 2006
- 20 Welsh Assembly Government, Health in local areas; a compendium of maps, Chief Medical Officer's Report Series, Report 2, 2006



Figure 2.10 Female Cancer Incidence, Wales, 1993-2002

Note:

Welsh age-standardised incidence rate per 100,000 population (all malignancies except non melanoma skin cancer).

Source:

Welsh Assembly Government, Health in local areas: a compendium of maps, Chief Medical Officer's Report Series, Report 2, 2006

Figure 2.11 Unemployment Rate, Wales, 2004



2.5 Cancer Prevalence

Prevalence refers to the current number of people with a disease. The number of people currently with cancer is estimated to be over 1.2 million for the UK as a whole (we have not found a comparable estimate for Wales).²¹

Prevalence estimates in Table 2.2 show that the majority of cancer cases are accounted for by breast, bowel, lung and prostate cancer.

Type of Cancer	Number of People with Cancer
Breast	172,000
Large Bowel	77,000
Lung	32,000
Prostate	31,000
Melanoma	31,000
All Cancers	1,207,000

Table 2.2 Estimated Cancer Prevalence, UK, 2000

Cancer Research UK, http://info.cancerresearchuk.org/cancerstats/incidence/prevalence/

²¹ Cancer Research UK, http://info.cancerresearchuk.org/cancerstats/incidence/prevalence/

2.5 Cancer Survival

Survival rates from cancer have been improving over time in Wales, with a median survival time of 1.4 years following diagnosis in 1991-93 to 2.15 years in 1998-00 (Figure 2.12).





Source: Welsh Cancer Intelligence & Surveillance Unit, Relative Survival in Wales, 1991-2000 (followed up to 31/12/2005), http://www.wales.nhs.uk/sites3/Documents/242/S0709%5F070607.pdf

- ³⁶ http://www.yhpho.org.uk/PBS_diabetes.aspx
- ³⁷ National Public Health Service for Wales, personal communication to NERA, (12.6.06)

Whilst survival times in Wales are improving, both 1- year and 5- year survival rates for the UK are low compared to the rest of Europe (Figure 2.13).²² However, survival times in Wales remains below other parts of the UK (Figure 2.14). The reasons for this are likely to be varied (and reflect differences in the context of each country including risk factors for cancer and the respective performance of very different health care systems). Investigation of these differences could provide insights on how to improve survival rates in the UK including Wales. It is encouraging that differences in survival are lessening over time across countries, but the UK and Wales remain comparative laggards.²³



Figure 2.13 Cancer Survival Rates, Selected European Countries²⁴

Note: Includes all cancers except skin cancer.

Source: Wilking, N and Jonsson, B (2005) A pan-European comparison regarding patient access to cancer drugs, Karolinska Institute in collaboration with Stockholm School of Economics

- 22 Wilking, N and Jonsson, B (2005) A pan-European comparison regarding patient access to cancer drugs, Karolinska Institutet in collaboration with Stockholm School of Economics
- ²³ Berrino, F et al (2007) Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995-99: results of the EUROCARE-4 study, http://oncology.thelancet.com Vol 8 September 2007
- ²⁴ See Appendix for list of country abbreviations.



Figure 2.14 Cancer Survival Rates, Selected European Countries Including Wales

Source: ABPI Investment in Cancer Treatment and Outcomes Personal Communication to NERA

2.7 Risk Factors for Cancer

Research is ongoing to understand the causes of cancer. Given the range of cancers there are a complex set of risk factors and interactions. It's also important to note that some risk factors are modifiable and others, such as genetic endowment, are not.

Risk factors include:

• Age. There is a strong link between ageing and increasing incidence of cancer. Figure 2.15 illustrates cancer incidence by age group for the UK and Ireland. There is a sharp increase in incidence beginning at age 55, especially for men. Seventy-four per cent of cancer cases registered in 2004 were in patients aged 60 and above.²⁵

²⁵ Office of National Statistics, http://www.statistics.gov.uk/cci/nugget.asp?id=915



Figure 2.15 Cancer Incidence by Age Group, UK and Ireland, 1991-1999

Note: Includes all cancers except non-melanoma skin cancer. Northern Ireland 1993-99 and Ireland 1994-99 Source: Approximated from Office for National Statistics (2005) Cancer Atlas of the United Kingdom and Ireland 1991-2000

There are differences across the UK in terms of age demographics, Wales has the highest proportion of those aged over 65 within the UK (Table 2.3).

Table 2.3	Proportion	of Elderly	Population,	UK,	2006	Estimates
	1		1 /			

Country	Persons Aged 65+	Total Population (thousands)	Proportion Aged 65+ (thousands)
Wales	525	2,966	17.7%
England	8,086	50,763	15.9%
Scotland	838	5,117	16.4%
Northern Ireland	239	1,742	13.7%
United Kingdom	9,688	60,587	16.0%

Source: Office for National Statistics, Mid-2006 Population Estimates, released 22 August 2007

Wales is estimated to have an additional 5,000 cases of cancer in 2024 due specifically to its older population.²⁶

- **Smoking**. It has been estimated that 30 per cent of all cancer deaths in Wales are attributed to smoking (including 80% of all deaths caused by lung cancer).²⁷ This compares to an estimated 29 per cent of all cancer related deaths in the UK being attributed to smoking.²⁸
- **Diet**. It has been estimated that improving diet has the potential to lower cancer incidence and mortality by between 30 and 40 per cent.²⁹
- Alcohol. Alcohol is thought to be responsible for 3 per cent of all cancer cases.³⁰
- ▶ **Physical activity**. There is evidence that suggests physical activity reduces the risk of breast and colon cancer.³¹

2.7 Treatment and Management of Cancer

Given the range of cancers there are a variety of treatments for cancer. There are some main forms of treatment for cancer which include: $^{\rm 32}$

- **Surgery**. Currently one of the main treatments for cancer as it is focused on just treating the specific part of the body which has the cancer. If the cancer has spread however, surgery may not be able to effect a cure.
- ▶ **Radiotherapy**. Radiotherapy uses high energy rays to kill cancer cells. Like chemotherapy, it is used in conjunction with surgery or by itself to shrink the tumour, reduce the risk of the cancer returning and control symptoms in palliative care. Radiotherapy is administered externally, for example through X rays or internally through injections, drinks or implanted wires or pellets.
- Drug therapy including chemotherapy and biological therapy. Chemotherapy involves the use of anti-cancer medicines that can be used as a stand alone treatment or in conjunction with surgery or radiotherapy. It is used to eradicate the tumour, shrink the tumour, reduce the risk of the cancer returning and control symptoms in palliative care. Biological therapies are treatments made from natural body substances that either treat a cancer or
- 26 Cancer Research UK, Ageing Welsh face increasing cancer burden, 16 June 2004, http://info.cancerresearchuk.org/news/pressreleases/2004/june/38871
- 27 Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- 28 http://info.cancerresearchuk.org/cancerstats/causes/lifestyle/tobacco/
- ²⁹ Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- ³¹ Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- 32 http://www.cancerhelp.org.uk/help/default.asp?page=91

control the side effects caused by other cancer treatments. They stimulate the body to respond naturally to cancer. They are sometimes called biological response modifiers (BRM) or biologic agents (biologics) and include monoclonal antibodies (MAB).

- Bone marrow and stem cell transplants. Donated bone marrow or stem cells are used to replace cells killed by high dose chemotherapy or total body radiotherapy.
- Gene therapy. Gene therapy, also called molecular therapy, blocks expression of abnormal genes in cancer cells, repairs or replaces abnormal genes in cancer cells, encourage modifications of genes in cancer cells so that cells will die or become sensitive to treatment or uses viruses to carry treatment-activating enzymes into cancer cells.

Medicines are vital to the treatment and management of cancer.³³ After diagnosis, the appropriate use of a medicine may avoid the risks associated with surgery and rid the body of cancer cells, or greatly increase the likelihood of a successful surgery by shrinking the cancer first, and minimising the operable area. Medicines can also reduce the risk of a relapse. Innovation in cancer medicines have contributed to making cancer a less fatal disease and transforming it into a chronic disease.³⁴ When a cancer is too far developed to be treated curatively, medicines can also be used to control symptoms of the disease during palliative care.

There has also been recent focus on how patients can be informed about their cancer diagnosis and treatment and the information that they need to help make choices. Surveys have suggested that for some patients there is still a need for better information to contribute to patient empowerment.³⁵ Cancer patients who become more involved in the process of care, such as choosing therapy, and good patient-physician communication have been shown to have higher satisfaction ratings and thereby illustrating a better quality of life.³⁶ There is however a need to consider carefully what information is available to patients and how far they wish to be involved in decision making.³⁷

- ³⁴ Bosanquet, N and Sikora, K (2004) The economics of cancer care in the UK, The Lancet Oncology Vol 5, September 2004
- 35 ABPI, CancerBACUP, and Ask About Medicines (2005) The Cancer Information Maze
- ³⁶ Mandelblatt, J Figueiredo, M, and Cullen, J (2003) Outcomes and quality of life following breast cancer treatment in older women: When, why, how much, and what do women want? Health and Quality of Life Outcomes, 2003, 1 http://www.hqlo.com/content/1/1/45
- 37 http://info.cancerresearchuk.org/news/archive/pressreleases/2006/august/229677

³³ See Lichtenberg, F R (2004) The Expanding Pharmaceutical Arsenal in the War on Cancer, http://ideas.repec.org/p/nbr/nberwo/10328.html for discussion of improvements in life expectancy from medicines in the US. We are not aware of comparable work for Europe or for the UK and it constituent parts.

3. The Future Economic Burden of Cancer in Wales

Key Points:

- The cost of cancer is not well understood but estimates that do exist suggest the direct costs (essentially the costs of prevention and treatment) are significant. Spending on medicines is a very small element of health care expenditure on cancer.
- The UK spends less than other countries on medicines, and bringing the UK in line with other countries would require significant additional resources.
- Tackling other factors, such as deprivation, could reduce the direct costs of cancer as it costs more to treat those in more deprived areas compared to those who live in less deprived areas.
- The indirect costs of cancer, such as the cost to the economy, are not well understood but are likely to be significant and far higher than only direct health care costs.
- The incidence of cancer is likely to continue to rise. Based on ageing alone it could increase the incidence rate in Wales for men from 8,668 per 100,000 in 2006 to 11,356 per 100,000 in 2024. The increase for the incidence rate in Wales for women could be from 8,162 per 100,000 to 9,835 per 100,000 for the same time period.
- The future costs of cancer in Wales are also expected to increase. Based on ageing alone and using 2003 values, spending by the NHS Wales could rise from £226 million in 2003/4 to £248 million in 2024. This is likely to be a significant underestimate given the potential for costs to increase in response to greater needs, and the availability of new treatments including new higher cost medicines. However some medicines may have the potential to reduce other costs especially if they are able to avoid more costly hospital care.
- The projected rise in costs raises questions as to how the NHS should meet these costs and how policy makers and others will decide on the appropriateness of therapy rationing. This may be particularly true in the case of the availability of medicines.

3.1 The Current Cost of Cancer

The costs of cancer include:

- The cost to patients in terms of morbidity (the impact on quality of life) and associated costs from attending hospital appointments (lost income due to taking time off work, transportation and parking).
- The costs to non professional carers of those with cancer. Carers may also need to take time off work in order to care for family and friends with cancer.
- The costs to the health system for a range of activities from prevention (such as screening for cancer and public health messages), managing cancer (including the cost of medicines, machines and staff to treat cancer patients) and palliative care.
- The costs to social services arising from a range of care delivered from outside the health system e.g. nursing home costs.
- The costs to the economy arising from lower productivity and loss of productivity due to premature death.

The costs to the health system tend to be termed the direct costs of cancer, whilst the costs to patients, carers, and the wider economy tend to be termed the indirect costs of cancer.

The total costs of cancer are difficult to estimate because of a relative lack of data and because of the range of costs that are borne by different groups in society. It is also difficult to estimate the health care costs specific to cancer because it can be difficult to separate out expenditure across disease areas, and the costs of cancer to the health care system change over time as screening, diagnosis and treatments change and new treatments and devices become available.

Jonsson and Wilking (2007) note that "there are few studies that measure and compare both direct and indirect costs of cancer" and that "it is not always easy to separate health care costs into various diseases and the cost of cancer is also changing over time, which may explain why various studies in some cases have reported different estimates."

Recent research suggests that the direct costs of cancer (essentially the costs of the health care system including prevention activity) are substantial (Figure 3.1).

The indirect costs of cancer are also likely to be large. Research on the cost of skin cancer in England, suggests that the cost to the NHS represented only 37 per cent of the total cost of skin cancer (accounting for £71 million of the total cost of £190 million in 2002).³⁸ Other research suggests that indirect costs could account for around 70 to 85 per cent of the total costs of cancer.³⁹

³⁸ Morris, S Cox B and Bosanquet, N (2005) Cost of Skin Cancer in England, Tanaka Business School Discussion Papers: TBS/DP05/39

³⁹ Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3



Figure 3.1 Direct Costs of Cancer (£), Selected Countries, 200440

Whilst the UK spends in absolute terms more than a number of countries such as Spain and Portugal, in terms of spending per capita, the UK lags behind several other countries, including Sweden, France and Italy (Figure 3.2).

Note: Data was converted from Euros (€), using £1= €0.695, http://www.xe.com as at 1 November 2007. Source: Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3

⁴⁰ See Appendix for list of country abbreviations



Figure 3.2 Direct Costs of Cancer Per Capita (£), Selected Countries, 200441

These estimates suggest that:

- The direct health care cost of all cancers for the UK in 2004 was €5,634 (£3,921) million.
- This is equivalent to €94 (£65) per person in the UK.⁴²
- Cancer accounts for 5 per cent of total health care expenditure in the UK including private health care expenditure.⁴³

These estimates exclude costs due to inability to work, lost production due to short-term absence from work, and permanent disability and death before age 65.

- ⁴¹ See Appendix for list of country abbreviations.
- 42 Jonsson, B and Wiilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3
- ⁴³ Jonsson, B and Wiilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3

Note: Data was converted from Euros (€), using £1= €0.695, http://www.xe.com as at 1 November 2007. Source: Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3

Data on expenditure by the NHS in Wales suggests that:

- The NHS in Wales spent £226 million on cancer in 2003/4.
- This equates to £76.92 per capita.
- Cancer accounted for 6 per cent of total NHS expenditure in Wales in 2003/4, the fifth largest area of expenditure.
- An additional £89 million was spent on healthy individuals in 2003/4, which includes prevention and promoting healthy living programmes.⁴⁴
- Including prevention activities the NHS in Wales spent £107.22 per person.

It's clear therefore that cancer is a significant cost to the NHS. The Welsh Assembly Government has committed to an additional £4.5 million in funding from 2007/8.⁴⁵ This is equivalent to just over 1 per cent more funding than present levels (including prevention activities).

Use of the health care system is also a good guide to the burden of cancer. Table 3.1 illustrates the average number of people admitted to hospital per year in Wales

⁴⁴ Welsh Health Circular, Programme budgeting results 2003-04, 2 March 2005, http://www.wales.nhs.uk/documents/WHC_2005_021.pdf

⁴⁵ http://www.wales.nhs.uk/documents/cancer-services270307.pdf

Type of Cancer	Males	Females
All Malignant Neoplasms	11,466	11,034
Bladder	1,630	564
Brain & CNS	230	183
Cervix	n/a	246
Colon	1,532	1,113
Female Breast	n/a	3,101
Head & Neck	441	208
Kidney	299	175
Leukaemia	560	363
Malignant Melanoma	118	134
NHL	487	439
Oesophagus	440	246
Ovary	n/a	647
Pancreas	231	237
Prostate	2,242	n/a
Rectum	705	411
Stomach	462	241
Trachea, Bronchus & Lung	1,521	972
Uterus	n/a	391

Table 3.1Average Number of Individuals Admitted to Hospital Per Year,
Wales, 2000-2003

Note: "n/a" denotes not applicable. CNS stands for central nervous system, and NHL stands for Non-Hodgkin's Lymphoma.

Source: Welsh Assembly Government (2006) Designed to Tackle Cancer: A Welsh Assembly Government Policy Statement, December 2006

The cost of medicines within overall cancer expenditure is relatively small. Table 3.2 illustrates for selected countries the breakdown of direct health care expenditure on cancer based on a literature review by Jonsson and Wilking (2007). This data illustrates the relative lack of data on the costs of cancer, as much of it is now relatively dated. Jonsson and Wilking produce their own estimates of the costs of cancer, and their work suggests that for the UK, medicines account for 5 per cent of the direct costs of cancer.⁴⁶

⁴⁶ Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3

	Inpatient Care	Ambulatory Care	Medicines
Germany (2002)	67.0% + 9% other	16.0%	8.0%
Sweden (2002)	75.0% (hospital)	15.0% (including home care)	10.0%
France (1998)	83.0%	7.0% + 6% transport costs	4.0%
The Netherlands (1994)	60.0% + 11% non-hospital institutional care	18.0%	11.0%
Canada (1998)	75.0%	17.0% (physician care + additional direct cost)	9.0%
United States (1990)	65.0%	31.0%	4.0%
Australia (1993/1994)	71.0% (including nursing home)	26.0%	3.0%
Spain (1998)	77.0%	7.0%	16.0%

Table 3.2	Breakdown of the Direct Costs of Cancer, Selected Countries

Source: Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3. Note that Jonsson and Wilking (2007) do not present comparable figures for the UK

The UK is therefore spending relatively less than other countries on cancer medicines per capita (Figure 3.3). Similar conclusions are reached when considering the relative usage of the top 20 cancer medicines (Figure 3.4).



Figure 3.3 Spend on Cancer Medicines, Per Capita (£), Selected Countries, 2004⁴⁷

Note: Data was converted from Euros (€), using £1= €0.695, http://www.xe.com as at 1 November 2007. Source: Jonsson, B and Wilking, N (2007) A global comparison regarding patient access to cancer drugs, Annals of Oncology, Volume 18, 2007 Supplement 3



Figure 3.4 Spend on Top 20 Cancer Medicines, Per Capita (£), UK, Sept 2006

⁴⁷ See Appendix for list of country abbreviations

The spending on treatment, and in particular new therapies and innovative treatments has been effective in contributing to the declining mortality rate from cancer and improved survival rates.⁴⁸ However, the relatively low UK expenditure on the Top 20 cancer medicines as shown in Figure 3.3 and Figure 3.4 needs considerable analysis and explanation – which disappointingly is beyond the current scope of this report. It may be worth noting that of the above list of medicines, only Velcade has been appraised by the All Wales Medicines Strategy Group, with positive guidance issued in August 2005.⁴⁹

3.2 Future Cancer Incidence in Wales

We have not found estimates of the future incidence of cancer in Wales. We have taken a simple approach of applying the observed increase in incidence rates from data from the Welsh Cancer Intelligence and Surveillance Unit applied to age based population estimates from the Government Actuary Department in order to provide an indicative estimate of the likely scale of future cancer incidence in Wales.

This suggests that there will be 11,356 new male cases per 100,000 population in 2024 compared to 8,668 per 100,000 in 2006. For female incidence we estimate that there will be 9,835 new female cases per 100,000 population in 2024 compared to 8,162 per 100,000 in 2006. Our estimates are shown in Figure 3.5.

⁴⁸ Bosanquet, N and Sikora, K (2004) Scenarios for Change in Cancer Treatment 2004-2010: Impacts on Insurance, The Geneva Papers on Risk and Insurance Vol. 29 No. 4 (October 2004) 728-737

⁴⁹ www.wales.nhs.uk/sites3/Documents/371/ACF21D.pdf



Figure 3.5 Projected Male and Female Cancer Incidence 2006 - 2024, Wales

Source: NERA Calculation using data from Welsh Cancer Intelligence & Surveillance Unit, http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=27758

Given the predicted trends in risk factors (for example, an increase in the proportion of the population in England and Wales who will be classed as obese from 23.6 per cent of men and 23.8 per cent of women to approximately 33 per cent of men and 28 per cent of women by 2010⁵⁰) these simple age based estimates probably underestimate the scale of new cancer cases in the future. Reversing such trends could of course do much to reduce future cases. For example, experts have suggested that 1 in 10 breast cancer cases in the UK could be prevented by 2024 if changes such as exercising more, keeping a healthy bodyweight and reducing the use of Hormone Replacement Therapy are made.⁵¹ A vaccine for HPV should also have an impact on future incidence.

3.3 Projected Costs of Cancer in Wales

We have not found estimates of the current total cost of cancer in Wales, nor estimates of the likely future costs, nor how they break down into different components of health costs (such as surgery, screening, and other areas of activity).

As set out earlier, there are estimates of NHS spend in Wales on cancer. Using the £76.92 per capita based on NHS Wales expenditure, and £107.22 per capita if prevention activities are included, linked to future population estimates by the Government Actuary Department allows us to provide an indicative estimate of the likely scale of future costs to Wales.

- ⁵⁰ Government Office for Science (2007) Foresight Report: Tackling Obesities: Future Choices Project Report
- 51 National Cancer Research Institute, http://www.ncri.org.uk/ncriconference/info/releases/pr1.pdf

Our estimates suggest that the costs to NHS Wales will rise from £226 million (in 2003 values) to £248 million by 2024 (in 2003 values). Given that this is in 2003 values, based on ageing alone, and without any consideration of increased costings or patient needs, these are recognised as significant underestimates. It remains clear that more resources will be required in the future.





Research commissioned by the ABPI has looked at future funding for cancer medicines in the UK. Their research highlights the current low level of spending in the UK compared to other countries. If the UK was to increase spending to bring it in line with comparable EU countries a further £403 million a year (at 2006 rates) would be needed.⁵²

Other more complex scenarios have suggested that even higher levels of spending will be required to bring the UK up to international levels (Figure 3.7).

⁵² ABPI Future Oncology Funding Provided to NERA through Personal Communication



Figure 3.7 Scenarios of Expenditure on Cancer Medicines, UK, 2006-2012

Source: ABPI Future Oncology Funding Personal Communication to NERA

Our estimates of future direct costs of cancer are simple and crude but suggest that the costs will increase significantly into the future. This increase in costs poses a challenge for policy makers in deciding how to fund future health care costs, how to allocate resources across different activities to bring about the greatest improvements in health outcomes, and which treatments should be covered by the health system. This challenge is particularly pertinent to the area of medicines, where there is already an assessment of which products should be routinely funded by the NHS. Healthcare Technology Appraisal agencies such as the National Institute of Health and Clinical Excellence (NICE) and the All Wales Medicines Strategy Group (AWMSG) provide guidance to the NHS in Wales on the use of selected new medicines. We return to this in more detail later in this report

4. Challenges to the Health System from Cancer

Key Points:

- Cancer poses challenges to the health system, throughout the disease pathway.
- Wales has set out ambitious targets to tackle cancer.
- Cancer care is commissioned and delivered by a variety of providers. Commentators suggest co-ordination could be improved and that more could be done to ensure implementation of strategic plans developed by the Cancer Networks.
- NHS Wales is lagging behind England in implementing and expanding screening services.
- Delivery of care requires expert staff. The workload for some cancer experts is high in Wales and commentators have suggested more needs to be done to retain specialists.
- There is relatively slow uptake of medicines in the UK, and in Wales there are a variety of agencies which provide guidance on the use of new medicines. This however does not necessarily lead to implementation of guidance and access to high cost medicines remains a key issue.
- NHS Wales is lagging behind in terms of waiting time targets compared to England.

4.1 Responding to Cancer: Prevention, Screening, Treatment, Palliative Care and Cancer Research

Cancer poses a number of challenges to the health system. The main issues include:

• Optimising **prevention strategies**. There is evidence that changing lifestyle could have a significant impact on mortality. This requires the health system to engage with individuals about their lifestyle and with other stakeholders (such as employers) to encourage healthy behaviour. For policy makers there is the challenge of ensuring sufficient resources are allocated to preventative activity, as the benefits are likely to occur in the long term and the benefits split across a variety of stakeholders. There are a range of policy options from education campaigns through to more direct intervention such as providing subsidised gym places. Vaccination against human papilloma virus (HPV) is another part of prevention. The relative costs and benefits of differing policies are generally unknown.

- Optimising screening strategies. Similarly to prevention, there is evidence that screening offers the opportunity to proactively manage the risk of cancer and change behaviour or undertake preventative treatment. This requires the health system to engage with individuals to encourage attendance for screenings. For policy makers there is the ongoing challenge of funding these activities despite the relatively long time period before benefits are achieved. Screening is also complicated by the need to consider the potential side effects (such as false positives where an individual may be wrongly told that they have cancer) and decisions as to which groups to target.
- Optimising **treatment strategies** including the use of surgery, radiotherapy and the use of medicines. There are a range of treatment options available for cancer. Best treatment plans vary by type, site and stage of cancer, and are specific to the individual patient, recognising the importance of individual preference and response rates. This is especially true of the new generation medicines that have been developed to target specific attributes of cancers.
- Optimising **palliative care**. Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and emotional support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Alongside prevention, screening, treatment and palliative care that is available now, is research to improve these activities in the future.

4.2 How is Wales Responding?

This section discusses some examples of how Wales is responding to the challenges of cancer. It is not exhaustive but highlights some relevant examples and plans for the future.

Wales is already doing much to respond to the challenge of cancer, and has set out its broad approach to tackle cancer in Wales in the December 2006 report *Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement.* This report is focused on achieving two main goals which have been previously set for Wales:

- To reduce the Cancer European Age Standardised Mortality Rate for those under age 75 by 20 per cent by 2012 (excludes non-melanoma skin cancer); and
- To improve cancer mortality in all groups, with more rapid improvement for the most deprived groups.

Additional goals include:

- To reduce the incidence of cancer in Wales through primary prevention. In particular, to have comparable cancer incidence rates with the lowest European quartile by 2015.
- To improve survival rates by detecting cancer as early as possible through appropriate public education, information and screening. In particular, to have comparable one year and five year survival rates with the top European quartile by 2015.
- To provide diagnosis, treatment and palliative care services for people with cancer that match or surpass the best in Europe in terms of access. In particular, to achieve and sustain comparable one year and five-year survival rates with the top European quartile by 2015.
- To provide diagnosis, treatment, and rehabilitation and palliative care services for people with cancer that match or surpass the best in Europe in terms of quality. In particular, to achieve and sustain comparable one year and five-year survival rates with the top European quartile by 2015.

We are also aware that much is happening 'on the ground' in Wales (and of course in other parts of the UK) which is not picked up in our rapid review of publicly available sources of data. There are also other initiatives, such as Health Challenge Wales, which will impact on future incidence of cancer. This particular initiative encourages all stakeholders to consider health and in particular preventing ill health, to allow the health service to treat unavoidable disease.³³

The Welsh Assembly Government has also committed to an additional £4.5 million in funding from 2007/8.34 $\,$

- ³³ Health Challenge Wales, http://new.wales.gov.uk/subsite/healthchallenge/background/?lang=en
- ³⁴ http://www.wales.nhs.uk/documents/cancer-services270307.pdf

Wales has established 3 cancer networks, covering North Wales, Mid and West Wales and South East Wales, as illustrated in Figure 4.1.³⁵ Cancer centres in Manchester and Liverpool also provide services to patients living in North Wales.

Figure 4.1 Wales Cancer Network, 2006

The cancer networks are linked together under the Cancer Services Co-ordinating Group (CSCG), which advises the Welsh Assembly Government, providers and commissioners of services.⁵⁷ The networks are responsible for co-ordinating the planning, organisation and delivery of cancer and palliative care services for residents of Wales within their borders.⁵⁸ They have set out, for example, the radiotherapy equipment needs and workforce implications for Wales⁵⁹ and assessed the needs for palliative care.⁶⁰ LHBs and local providers deliver care (such as the cancer centres in Swansea, Cardiff and Bodelwyddan).

- Office for National Statistics (2005) Cancer Atlas of the UK and Ireland, Appendix I, Country profiles, http://www.statistics.gov.uk/downloads/theme_health/caUKI91_00/Appendix_I.pdf
- ³⁶ Office for National Statistics (2005) Cancer Atlas of the UK and Ireland, Appendix I, Country profiles, http://www.statistics.gov.uk/downloads/theme_health/caUKI91_00/Appendix_I.pdf
- ⁵⁷ Office for National Statistics (2005) Cancer Atlas of the UK and Ireland, Appendix I, Country profiles, http://www.statistics.gov.uk/downloads/theme_health/caUKI91_00/Appendix_I.pdf
- 58 South East Wales Cancer Network, http://www.wales.nhs.uk/sites3/home.cfm?orgid=362
- ⁵⁹ Cancer Services Co-ordinating Group (May 2006) Radiotherapy Equipment Needs and Workforce Implications 2006-2016
- 60 Tebbit, P (2005) Population Based Palliative Care Needs Assessment: An All Wales Summary of Assessments for North Wales, South East Wales, and South West Wales Cancer Networks

Wales has also introduced All Wales Cancer Expert Advisory Groups and set out minimum standards and clinical management guidelines⁶¹ Local Multidisciplinary Teams (MDTs) have been established which bring together the range of health care professionals involved in delivery cancer care. There is also a new programme of clinical audit. The Cancer Information System Cymru (CaNISC) has been set up to support clinical audit with the aim of providing reliable information to identify areas where improvement is needed.⁶² Specialist services are also commissioned across Cancer Networks by Health Commission Wales.⁶³ For example, Health Commission Wales carried out a review of brachytherapy treatment for prostate cancer and now commissions this service for patients in Wales.⁶⁴

These measures are welcomed by stakeholders in Wales, although some have suggested that more needs to be done to ensure co-ordination and appropriate planning.⁶⁵ This could reduce the health care costs since it may help to avoid sending patients outside of Wales. There have also been calls for the Cancer Networks to have authority over LHBs to ensure the implementation of their strategic plans.⁶⁶

4.2.1 Prevention

Wales has undertaken a variety of preventative activities, including health promotion activities and educating local communities.⁶⁷ Wales has also implemented other policies which may impact on future incidence of cancer. For example, a smoking ban was implemented in April 2007.⁶⁸ In addition, by March 2008, smokers will have access to an NHS smoking cessation service.⁶⁹ These types of activities should impact on future incidence of cancer.

- ⁶¹ Cancer Research UK Cymru's Response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services (Undated)
- ⁶² Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- 63 Cancer Research UK Cymru's Response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services (Undated)
- ⁶⁴ http://wales.gov.uk/about/cabinet/cabinetstatements/cabinetstates2007/1264102/?lang=en
- 65 Cancer Research UK Cymru's Response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services (Undated)
- ⁶⁶ Cancer Research UK Cymru's Response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services (Undated)
- ⁶⁷ Big Lottery Fund, http://www.biglotteryfund.org.uk/prog_cancer_care_wales.htm
- 68 Smoking Ban Wales, http://www.smokingbanwales.co.uk/english/
- ⁶⁹ Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006

Other campaigns have also been used to try to influence lifestyle behaviours which should in the future reduce cancer incidence. For example, in the summer of 2003, SunSmart, a national campaign in Wales to educate the public about skin cancer prevention, was launched. Comparison of behaviour reported in surveys suggests that there was some improvement in lifestyle behaviour after SunSmart. Four per cent more people reported actively protecting themselves from skin cancer.⁷⁰

There is however an ongoing challenge in ensuring behaviour changes. Research on the SunSmart campaign demonstrates that people are aware of how to reduce the likelihood of getting skin cancer, but many do not actively undertake these preventative measures (Table 4.1).⁷¹

Behaviour	Should Use This Sun Protection			Uses This Sun Protection				
by Age Group	16-34	35-54	55+	All	16-34	35-54	55+	All
Stay in Shade	45	57	64	56	23	36	44	35
Cover Up	34	40	39	37	20	21	27	21
Use 15+ factor sunscreen	66	64	50	60	50	49	34	44

Table 4.1Percentage Reporting Sun Protection Knowledge and
Behaviour by Age, 2005

Note: Results from 2003 survey are not included because of minimal difference to 2005 results.

Source: Gordon, C Blakey, G and Roberts, C (2006) Sun Protection and Skin Cancer: Public Knowledge, Attitudes and Behaviours, Welsh Assembly Government, Technical Report, June 2006 No.4

Wales will also be making vaccination against the HPV available from September 2008 which should reduce the incidence of cervical cancer.⁷² The vaccine will be offered to girls aged 12 and 13, alongside a two-year catch-up vaccination campaign starting in Autumn 2009 for all girls up to the age of 18. Details on how this will be implemented by LHBs are being finalised.

- ⁷⁰ Gordon, C Blakey, G and Roberts, C (2006) Sun Protection and Skin Cancer: Public Knowledge, Attitudes and Behaviours, Welsh Assembly Government, Technical Report, June 2006 No 4
- 71 Gordon, C Blakey, G and Roberts, C (2006) Sun Protection and Skin Cancer: Public Knowledge, Attitudes and Behaviours, Welsh Assembly Government, Technical Report, June 2006 No 4
- National Public Health Service for Wales, Press Release (31st Oct 2007) HPV Vaccination to be Offered In Wales From Next Year http://www.wales.nhs.uk/sites3/news.cfm?orgid=719&contentid=7861

4.2.2 Screening

Wales has two cancer screening programmes:

- Breast Cancer Screening. The Cancer Genetics Service for Wales tests women where there is a significant family history of breast cancer, and Breast Test Wales offers tests to women under 50 who have been identified by The Cancer Genetics Service for Wales to have an increased risk of breast cancer.⁷³ The programme achieved a 74.3 per cent take up rate in 2003.⁷⁴
- Cervical Cancer Screening. Wales achieved a 79.1 per cent take up rate of women aged 25-64 in 2003 presenting for cervical cancer screening.⁷⁵

There are concerns however about the future of these screening programmes due to shortages in staff.⁷⁶

A new bowel cancer screening programme is also being implemented. Routine screening for men and women between the ages of 50 and 74 is planned to be offered by the end of 2008/09. Alongside the screening is a programme to ensure the quality of endoscopy services, known as the Global Rating System.⁷⁷

The Department of Health which determines screening programmes for England is continuing to improve cancer screening services, but it remains to be seen if reforms in England will transfer to Wales. For example, the Department of Health has committed to expanding the current age range for women eligible for breast cancer screening from '50 to 70' to '47 to 73'.⁷⁸ Previous expansions in the age range of screened women, alongside taking two-view mammography instead of single-view in England, have led to significant increases in the number of cancers diagnosed (a 62%increase).⁷⁹ Improvements are also planned in England for speeding up cervical screening results, aiming for reports to be ready within 14 days. Currently, over half of patients screened wait 6 or more weeks for results.⁸⁰

- ⁷³ Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, December 2006
- ⁷⁴ Cancer Research UK Cymru's Response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services (Undated)
- ⁷⁵ Cancer Research UK Cymru (date unknown) Cancer Research UK Cymru's response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services
- ⁷⁶ Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, Designed for Life, December 2006
- 77 Health Minister Announces Bowel Cancer Screening Programme (5th February 2007), http://www.wales.nhs.uk/documents/bowelcancer060207.pdf
- ⁷⁸ M2 PressWIRE (2007) Cancer screening to be expanded and waiting times to be further reduced, 24 September 2007
- 79 Richards, M (2007) Cancer Ten Years On: Improvements across the whole care pathway
- 80 M2 PressWIRE (2007) Cancer screening to be expanded and waiting times to be further reduced, 24 September 2007

Research suggests that around a third of cancers could be cured if detected early and treated adequately.⁸² This makes screening an important part of the overall management strategy for cancer. Wales may be at a disadvantage because there is evidence that cancers are being detected and diagnosed later, potentially contributing to lower survival rates.⁸²

4.2.3 Treatment Including Medicines

4.2.3.1 Staff

Treatment cannot be delivered without a range of health care professionals. In the UK as a whole there has been an increase in the availability of trained cancer health care professionals. For example, there were approximately 49 per cent more specialist cancer consultants in 2006 than in 1997 across the whole of the UK (Figure 4.2).⁸³ This increase may not however be sufficient for growing needs. There may also be a need to expand training so that GPs in primary care can improve identification of those at risk for cancer. Over time this should improve survival rates as patients are identified earlier and can begin treatment sooner.⁸⁴

Figure 4.2 Total Cancer Consultant Specialists, UK, 1997-2006

Source: Approximated from Richards, M (2007) Cancer Ten Years On: Improvement across the whole care pathway

- 81 World Health Organization (2006) Cancer Fact Sheet, February 2006, http://www.who.int/mediacentre/factsheets/fs297/en/index.html
- ⁸² Welsh Assembly Government (2006) Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement, December 2006
- ⁸³ Richards, M (2007) Cancer Ten Years On: Improvements across the whole care pathway
- ⁸⁴ NHS (2000) The NHS Cancer Plan, A plan for investment, A plan for reform, September 2000

One expert we spoke to in Wales highlighted the current high workload for oncologists in Wales. For example, in some locations oncologists are taking on 500 new cases a year, this is far more than the guidelines for 230 new cases a year.⁸⁵

Appropriate training is only one element of ensuring that appropriate staff are available to deliver care. Retention of staff is another major issue. This is linked to the availability of equipment for research as this is an important element of choice of job location for specialists. Commentators have highlighted the need for increasing the number of linear accelerators and accessible CT/PET scanners, not only to meet rising health care needs, but also to help attract more clinicians to Wales as well as retain those currently employed in Wales.⁸⁶

The Assembly Government has recently announced a capital investment of £16.5 million to establish the Wales Research & Diagnostic PET Centre. Based in Cardiff it will be the first of its type in Wales and will provide the focus for research and teaching in PET for a network of higher education institutions as well as delivering a local clinical service for NHS Wales patients, particularly those in the South of Wales.⁸⁷

4.2.3.2 Medicines

Medicines are just one part of a range of activities to treat and manage cancer as discussed earlier in Section 2.8. This report does not provide comprehensive details but it does not intend to suggest that other elements of care are not vital in managing cancer and these are also key to optimising the prevention and treatment of cancer. This includes diagnostics, use of CT, MRI, PET scanning, endoscopy, pathology services and surgery. It's also relevant to note that some tests, such as for HER₂, enable more targeted use of medicines.

There are a complex range of medicines to treat cancer. These include:

- **Cytotoxic medicines** These are medicines that inhibit cell reproduction. These medicines include:
 - Alkylating agents These medicines stop cells from dividing by bonding to DNA and inhibiting replication.
 - Antimetabolites These medicines block the cell from producing the compounds that form DNA which also inhibits replication.
 - Agents that interfere with DNA unwinding These medicines block enzymes that are necessary for DNA to begin replication.
 - Anti-tumour antibiotics These medicines recognize and destroy cancer cells.

⁸⁵ John Wagstaff, Personal Communication to NERA

⁸⁶ Cancer Research UK Cymru (date unknown) Cancer Research UK Cymru's response to the National Assembly for Wales Health and Social Services Committee Review of Cancer Services

⁸⁷ http://www.cf.ac.uk/news/mediacentre/mediareleases/jan07/launch-imaging-centre.html

• Hormone-based medicines - For tumours that depend on hormones for growth, there are medicines which are specifically created to block the hormone production in the body

Research and development of new cancer medicines is ongoing, with over 200 new cancer medicines currently in clinical development in the US FDA approved process (Table 4.2).

Cancer Target	Pre- Registration	Stage I	Stage II	Stage III	Clinical	Total
Colorectal	1	33	55	12	1	102
Breast	3	34	70	22	2	131
Lung	1	11	13	2	1	28
Prostate	4	41	82	9	2	138
Bladder	0	10	6	4	1	21
General Cancer	1	168	44	5	4	222

Table 4.2Number of Cancer Medicines in Clinical Development in the
US FDA Approval Process, March 2007

Source: PhRMA, http://newmeds.phrma.org,accessed March 19, 2007

In the UK there is relatively slow uptake of new medicines for cancer. The 2006 Euro Health Consumer Index assesses health systems from the perspective of consumers and specifically looks at the speed of deployment of novel cancer drugs. This is a survey based approach and is not linked to health system targets. The UK scores poorly on this dimension in comparison to other countries (Figure 4.3).

Figure 4.3 Euro Health Consumer Index Score for Speed of Deployment of Novel Cancer Drugs, 2006

Note: Score of 3= less than 120 days between registration and inclusion in subsidy system, score of 2= less than 300 days, and score of 1= more than 300 days. Source: Euro Health Consumer Index 2006

Research has highlighted some examples where the UK falls significantly behind other European countries. Figure 4.4 shows trastuzumab sales per 100,000 population for a selection of countries. Four years after the introduction of trastuzumab, large patient populations were still not being given access to this treatment.⁸⁸

Figure 4.4 Trastuzumab Uptake Across Europe, Selected Countries

It has been suggested that access may be reduced in countries which have formalised health technology assessment.⁸⁹ It is also recognised that it can be difficult to assess medicines cost effectiveness at launch. This is especially true of cancer medicines licensed on the basis of results in 'late stage' and 'last resort' therapy. In the UK the National Institute for Health and Clinical Excellence (NICE) considers the cost effectiveness of technologies and provides guidance to the NHS (including the NHS in Wales) on which technologies are clinically and cost effective. NICE has appraised 92 cancer medicines.⁹⁰ On average, NICE appraisals take 15-18 months and it has been suggested there is an average delay of 12 months in comparison with the appraisal process as employed by the SMC.⁹¹ Including the time it takes for topic selection and scheduling into a programme, guidance may not be issued to the NHS for

⁸⁸ Karolinska Institutet in collaboration with Stockholm School of Economics, p. 40

⁸⁹ Wilking, N and Jonsson, B (2005) A pan-European comparison regarding patient access to cancer medicines, Karolinska Institutet in collaboration with Stockholm School of Economics, p. 70

⁹⁰ NICE, http://guidance.nice.org.uk/topic/cancer

⁹¹ J. Dear, C. O'Dowd, A. Timoney, K.R. Paterson, A. Walker, D.J. Webb, (2007) Scottish Medicines Consortium: an Overview of Rapid New Drug Assessment in Scotland, Scottish Medical Journal Vol. 52, Issue 3, Aug 2007

months or sometimes years after a new medicine is launched into the market.⁹² There is therefore an obvious tension between the time it takes for NICE to undertake their appraisal, and ensuring the NHS is optimally using medicines which are cost effective. Even with a positive recommendation from NICE there may still be marked differences in the implementation of its guidance and therefore access to medicines within the UK. Evidence suggests that this is improving, although considerable variations remain.⁹³

In Wales guidance on new cancer medicines and cancer medicines with significant new indications is developed by the All Wales Medicine Strategy Group (AWMSG). Following ratification by the Minister for Health and Social Services the funding of this guidance is considered mandatory and interim to any subsequent NICE appraisal. Even with NICE and the AWMSG guidance, there are still reports of post code variation in access to medicines which highlights the need for further investment in suitable guidance implementation and monitoring tools. The narrow gap between the time a product receives its marketing authorisation and the time when guidance is available to the NHS in Wales has led to the establishment of a new organisation, the All Wales New Cancer Drugs Group. This Group has been set up to provide horizon scanning information, informal (non-mandatory) guidance on the use of unlicensed medicines, new indications and, in exceptional circumstances, licensed medicines that have not been through the AWMSG/NICE process.

This will include:

- Being single point of expert advice to AWMSG New Medicines Group
- Influencing prioritisation of appraisals by AWMSG
- Providing interim assessment in special circumstances
- Ensuring unified clinical approach across Wales.94

It is therefore clear that the NHS in Wales receives a variety of guidance on the use of new cancer medicines, however evidence is awaited as to the cost effectiveness of such guidance and its effect on prescribing trends in Wales.

4.2.3.3 Waiting Times

Given the importance of early diagnosis and treatment to health outcomes, waiting times have become a key focus of policy makers. In Wales (and England) there are set waiting time targets for access to cancer care.⁹⁵ These are summarised in Figure 4.5.

- ⁹¹ NICE and access to medicines, 14th June 2006, Association of the British Pharmaceutical Industry, http://www.abpi.org.uk/publications/briefings/red_nice06.pdf
- 92 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/ digitalasset/dh_4139065.pdf
- 93 Presentation by All Wales New Cancer Drugs Group to Cancer Network (October, 2007)
- ⁹⁴ NHS (2000) The NHS Cancer Plan, A plan for investment, A plan for reform, September 2000

Figure 4.5 Waiting Time Targets for 1st Treatment for Cancer

Goo Day larger Aren Gri kelenarin ratient Diagnosed with career

In Figure 4.5 • refers to a maximum one month waiting time from diagnosis to treatment. Once a patient is diagnosed with cancer, the patient must begin treatment within one month. • refers to a maximum two month waiting time from urgent GP referral to treatment. If a GP suspects a patient has cancer and refers the patient to a specialist with an urgent request, and the patient is then diagnosed with cancer, treatment must begin within two months of the GP referral, regardless of how and when diagnosis occurred.

The aim was to meet these targets (and hence achieve 100%) in Wales by the 31st December 2006.^{96,97} For the quarter ending 30th June 2007, 91 per cent of patients received their first treatment within 2 months of being referred after urgent GP referral, and 97 per cent of patients received treatment within 1 month of diagnosis without urgent GP referral. This compares to 99 per cent for England in June 2006 for both pathways to treatment.^{98,99} Thus Wales is lagging behind England in meeting these waiting time targets. England also achieved higher performance much earlier than Wales (Figure 4.6).

Source: Adapted from NHS (2000) The NHS Cancer Plan, A plan for investment, A plan for reform

⁹⁶ NHS (2000) The NHS Cancer Plan, A plan for investment, A plan for reform, September 2000

⁹⁷ Welsh Assembly Government (2007) NHS Wales Cancer Waiting Times: Quarter Ending 30 June 2007, Experimental Statistics

⁹⁸ Welsh Assembly Government (2007) NHS Wales Cancer Waiting Times: Quarter Ending 30 June 2007, Experimental Statistics

⁹⁹ Rosen, R, Smith, A and Harrison, A (2006) Future Trends and Challenges for Cancer Services in England, A Review of Literature and Policy, King's Fund

Figure 4.6 Comparison of Waiting Time Performance, England and Wales

There is also significant variation within Wales in cancer waiting times. For example the 4 NHS Trusts within the South East Wales Cancer Network vary from a low of 70 per cent achievement of the waiting time target for urgent GP referral, to a high of 94 per cent during the period May to June 2007.¹⁰⁰

Waiting Times, http://www.performance.doh.gov.uk/cancerwaits/

4.2.4 Palliative Care

A Strategy for Palliative Care Services in Wales was published by the Welsh Assembly Government in February 2003.¹⁰¹ This document outlines certain key principles which govern the approach to commissioning, delivery and evaluation of palliative care services. These include:

- Every person with life-limiting conditions irrespective of age should be able to receive palliative care, appropriate for their assessed clinical, cultural, social and psychological needs
- Every health care professional should incorporate basic palliative care in their approach to clinical practice, knowing when to call in specialist palliative care colleagues to improve the quality of life of patients.

¹⁰⁰ South East Wales Cancer Network, http://wales.nhs.uk/sites3/page.cfm?orgid=362&pid=27510

¹⁰¹ Welsh Assembly Government (2003) Strategic Direction for Palliative Care Services in Wales, http://www.wales.nhs.uk/documents/pall-care-final-e.pdf

- Healthcare commissioning bodies should ensure that there is a clear strategy for the delivery of palliative care services to their defined population, that the resources (both facilities and trained staff) are available to meet the plan and that providers of care meet agreed standards of delivery both in volume and quality terms.
- Health commissioners should ensure that NHS and voluntary sector providers work together in developing the palliative care strategy and delivery of services.
- Every commissioner and provider of palliative care should ensure that patients and families are consulted on the quality and nature of the services.
- The three cancer networks in Wales must ensure that specialist palliative care services are incorporated into all aspects of service provision and are equitably available to the population served by the network.
- The cancer services networks should promote and facilitate research, education and training in palliative care as well as in oncology.

A recent review however has confirmed that palliative services remain patchy across Wales. As a consequence, the Minister for Health and Social Services, Edwina Hart A.M., recently announced extra funding of £2 million for hospices in Wales and wants LHB's to establish palliative and end-of-life planning groups to assess the local service need and to identify which statutory or voluntary organisations are best placed to provide that care.¹⁰² Central to this work is the Wales Palliative Care Planning Group which is charged with defining what is meant by 'core' palliative care service and how the NHS can measure quality of care.

^{102 £2}m Funding for Hospices Allocated, (24th October 2007) http://www.wales.nhs.uk/documents/W070816-Hlt.pdf

¹⁰³ Wales Cancer Institute, www.walescancerinstitute.co.uk

¹⁰⁴ Wales Cancer Trials Network, www.wctn.org.uk

4.2.5 Cancer Research

Wales has developed an integrated approach to cancer research through the Wales Cancer Institute which brings together a range of like minded organisations.¹⁰³ The institute provides a regular interface and dialogue between all interested stakeholders including the Welsh Assembly Government, ABPI Cymru Wales, charities, clinicians and researchers from both laboratory and clinical backgrounds.

For example, the Wales Cancer Trials Network (WCTN) was set up in 1998 as a jointly funded collaboration between Cancer Research UK and the Welsh Assembly Government to benefit patients by providing support to cancer teams in Wales to take part in cancer research to improve treatments for cancer.¹⁰⁴

WCTN supports prospective trials of cancer treatments and other well-designed studies sponsored by government research councils, academic research groups, pharmaceutical industry and cancer charities. The benefits of clinical research is well recognised by WCTN and it aims to make research a more routine and an acceptable part of high quality NHS care.

Since the WCTN was established, more than double the number of patients in Wales are now entering into cancer trials annually. Further investment, support and networking is expected to improve the speed, quality and integration of cancer research and ultimately deliver benefits to patients more quickly.¹⁰⁵

Wales also has the Wales Cancer Bank (WCB), the first national tumour collection facility that collects tissue and blood samples from cancer patients in Wales, funded by the Welsh Assembly Government.¹⁰⁶ The bank is designed to provide high quality biomaterials for translational research and is licensed by the Human Tissue Authority. Over 800 patients were recruited and consented from the six hospitals involved in the pilot phase and WCB is now planning to consent patients from all hospitals in Wales, providing a population wide collection. Researchers may apply to the bank for biomaterials in various formats for use in cancer related research projects.

- 105 http://www.wctn.org.uk/home/what_is_wctn.htm
- ¹⁰⁶ Wales Cancer Bank, www.walescancerbank.com

5. Conclusions and Recommendations

Our brief review of the publicly available information has highlighted a number of challenges for Wales in responding to cancer. These include:

- the rising incidence of cancer alongside falling mortality. Together this suggests that cancer is becoming a more chronic disease;
- the need to respond to rising incidence through prevention, screening, and optimising treatment (across the full range of activities to manage cancer);
- the inevitably higher costs to be borne by the health system;
- the need for a more efficient workforce;
- the need to catch up with England in terms of screening programmes and in achieving waiting time targets;
- as with the rest of the UK, the need to ensure comprehensive and timely access to medicines, especially those which are shown to be both clinically and cost effective.

There are a number of gaps that we found in completing our desk research of publicly available information. For example, we did not find:

- Forecasts of future incidence and prevalence of cancer in Wales. This has been done for other parts of the UK (for example Scotland has undertaken sophisticated analysis for future incidence of different types of cancer¹⁰⁷). Such forecasts help those involved to better understand the future scale of needs and hence scale of funding to treat cancer. Other researchers have also called for forecasts of the number of people with cancer to aid planning and allocation of resource across all types of health care.¹⁰⁸ The impact of changing risk factors needs to feed into these types of forecasts. Some of this information may well be available to the NHS on a local basis, but it is difficult for stakeholders to comment on these given that they are not in the public domain.
- Breakdown of health care costs of cancer in Wales. Whilst there is some data publicly available on the costs of cancer to the NHS in Wales, we did not find detailed breakdowns of where these costs lie within the health system. This type of data would be useful as a basis to understand how costs might evolve over time and the subsequent impact on resourcing different parts of the health system. More detailed breakdowns are available in other parts of the UK (most notably Scotland¹⁰⁹).

¹⁰⁷ Scottish Executive Health Department (2001). Cancer Scenarios: An aid to planning cancer services in Scotland in the next decade. Edinburgh: The Scottish Executive http://www.sehd.scot.nhs.uk/publications/csatp/csatp-00.htm

¹⁰⁸ Rosen, R, Smith, A and Harrison, A (2006) Future Trends and Challenges for Cancer Services in England: A Review of Literature and Policy, Kings Fund

¹⁰⁹ ISD Scotland Cancer Information Group (2003) The Cost of Cancer Care in Scotland 2002

- Wider costs of cancer in Wales. We did not find publicly available data on the likely significant other costs (for example costs to patients and carers from transport and lost earnings). These costs are very relevant if policy makers wish to consider the full economic costs and benefits of preventing and managing cancer.
- Forecasts of future costs of cancer in Wales. Forecasts would need to deal with the potential for new treatments to become available, changes in the setting of care (from secondary to primary care for example, or more home based care), and the potential for new medicines to bring about cost savings as well as contribute to higher medicine costs. These are issues recently highlighted by a Kings Fund review for English cancer care.¹¹⁰

More general recommendations for managing cancer in the future include the need to develop outcome measures to understand the impact of policy changes.

We note the variety of agencies already in place in Wales and suggest the need for further clarity about the powers of each and how they interact.

There appears to be an urgent need in Wales, also identified by the Kings Fund,¹¹¹ to consider how policy makers and others will approach the issue of higher cost therapies, including diagnostics, medicines and devices. This will need to be considered not only in terms of which products are routinely available but also how to ensure equity of availability and access for patients across Wales. The complex issues, include:

- How guidance is produced? Whilst outside the scope of this report there are a number of issues about how to determine cost effectiveness of cancer technologies and what society is willing to pay for benefits in terms of survival and quality of life.
- Who is involved in the production of guidance? We have noted a number of agencies concerned with which technologies should be available in Wales, however, it's not always clear as to how these agencies inter-relate. The involvement of patients and their preferences are also a crucially important aspect to consider.
- When guidance is published? There is a tension between when these decisions are reached and the delay in access that waiting for these decisions can bring.
- How well guidance is implemented and funded across Wales? A critical area which we understand is under review in Wales.

¹¹⁰ Rosen, R, Smith, A and Harrison, A (2006) Future Trends and Challenges for Cancer Services in England: A Review of Literature and Policy, Kings Fund

¹¹¹ Rosen, R, Smith, A and Harrison, A (2006) Future Trends and Challenges for Cancer Services in England: A Review of Literature and Policy, Kings Fund

• How patients are informed of guidance and funding decisions? This has been outside the scope of this report, however, if technologies are not to be available from the NHS, this becomes a more pressing issue to consider. An additional challenge will be to decide how and when patients' opinions and views on guidance are considered.

Appendix A. List of Country Abbreviations

AUS	Austria
BEL	Belgium
DEU	Germany
DNK	Denmark
ESP	Spain
FIN	Finland
FRA	France
GRC	Greece
IRL	Ireland
ITA	Italy
LUX	Luxembourg
NLD	Netherlands
PRT	Portugal
SVE	Sweden
UK	United Kingdom

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