

North West Public Health Observatory Merseyside & Cheshire Zone

Cancer and Inequalities in the North West of England

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February 2002



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February 2002

ISBN 1-874038 71 6

Acknowledgements

I would like to acknowledge all those who have given me their help, advice and support in the production of this Report. In particular, I would like to thank colleagues in the Department of Public Health, University of Liverpool, and the rest of the North Public West Health Observatory. I would also like to thank the Regional Cancer Modernisation Team and the North West Cancer Networks for their helpful comments on the Report. I am also grateful to the National Cancer Intelligence Centre at the Office for National Statistics for their help in acquiring the most up-to-date regional cancer data for use in this Report.

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Introduction

Cancer is a major public health concern. One in three people will develop cancer at some point in their lifetime. The disease has a great psychological impact on the patient, their family and friends and around one-quarter of the population will die from the disease. Currently, there are more than one million people in England and Wales who have been diagnosed with cancer. The government has therefore placed a high priority on tackling cancer. The national public health strategy, *Saving Lives: Our Healthier Nation*, set a target of reducing cancer deaths among people aged under 75 years by at least a fifth over the period up to 2010.¹ In addition, a National Cancer Director has been appointed to oversee the achievement of this target and implement the National Cancer Plan.²

The burden of ill health due to cancer, however, is not evenly spread. There are wide social and geographical inequalities, both within the North West Region and across the country as a whole. If the level of risk for the ten most common cancers were the same in deprived areas as in the most affluent, there would be around 20,000 fewer cases of cancer and 16,600 fewer deaths in the UK each year.³

This Report brings together a range of information to illustrate the social and geographic inequalities in cancer in the North West Region of England. It also identifies sources of information that are available for analysis. Local data are presented wherever they are available, and information on deaths is given most prominence as this is the most up to date. National statistics are included to complement the local information, and to provide a wide-ranging overview of cancer and inequalities.

1. Why focus on cancer and inequalities? The policy context

Independent Inquiry into Inequalities in Health (1998)

There is clear evidence to illustrate the scale and extent of health inequalities in Britain. The *Independent Inquiry into Inequalities in Health* (Acheson Report) described widespread variations in life expectancy and death rates between those at the top and the bottom of the social scale.⁴ Although the health of the population has shown a steady improvement during the 20th century, some sections of society have benefited more than others. People at the lower end of the social scale are still more likely to experience long-standing illness and to die prematurely from a range of causes, including lung cancer, coronary heart disease and stroke. Similar disparities in health are also evident between affluent and deprived areas around the country. Based on the evidence reviewed, the authors of the Acheson Report made a series of recommendations for the development of policies at all levels to reduce these unacceptable inequalities.

Saving Lives: Our Healthier Nation. The national public health strategy (1999)

The findings of the Acheson Report were one of the building blocks of the national strategy for public health, *Saving Lives, Our Healthier Nation* launched in 1999.¹ One of its two key aims was “to improve the health of the worst off in society and to narrow the health gap”. In February 2001, a series of national inequality targets were launched to support the monitoring of this objective.⁵ These focus on reducing variations in infant mortality and life expectancy between different social classes and geographic areas.

The NHS Plan (2000) and The National Cancer Plan (2000)

The two themes of this report, cancer and inequalities, are brought together in both the NHS Plan⁶ and the National Cancer Plan.² The NHS Plan outlines the government's strategy for the NHS to 2010. It has cancer as one of the priorities for action, and a specific section on improving health and reducing inequalities. The National Cancer Plan is a practical document, which sets out the targets and actions needed to improve cancer services and outcomes, and reduce existing inequalities.

Box 1. The National Cancer Plan – Aims and proposed targets

Aims

1. To save more lives
2. To ensure people with cancer get the right professional support and care as well as the best treatments
3. **To tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals**
4. To build for the future through investment in the cancer workforce, through strong research and through preparation for the genetics revolution, so that the NHS never falls behind in cancer care again.

Proposed Targets

New national and local targets to address the gap between socio-economic groups in smoking rates and the resulting risks of cancer and heart disease:

- we shall reduce smoking rates among manual groups from 32% in 1998 to 26% by 2010, so that we can narrow the health gap
- we shall set local targets making explicit what this means for the 20 health authorities with the highest smoking rates.

New goals and targets to reduce waiting times for diagnosis and treatment.

Source: The National Cancer Plan. A Plan for Investment, A Plan for Reform ²

Both documents acknowledge the importance to health of addressing disadvantage, from poverty and social exclusion, to educational achievement and discrimination. Inequalities in access to NHS Services between different social, ethnic or geographical groups are also recognised. To tackle these wider determinants of health and inequality, a partnership approach is being promoted at all levels: across government, between health and local authorities, and amongst the whole local health community.

2. Patterns of cancer in the North West

Measuring cancer in the population

Cancers are classified by the part of the body affected, known as the 'site', and by the type of growth. The burden of ill health and death caused by cancer in the population is generally described using information on new cases of disease, survival time after diagnosis, and deaths.

The terms used in this report are defined below. They may be used to explore the health experience of groups defined by age, sex or socio-economic characteristics.

Mortality: Deaths can be described in terms of numbers, or as a rate or ratio. A mortality rate provides information on how often deaths occur in a defined population. This population could be a social class group, or residents within a geographical area such as a Health Authority or electoral ward.

Crude death rates are of limited practical use because they do not allow comparisons to be made between different groups. Populations may differ in important characteristics, such as age structure, or sex balance. For example, the crude death rate in Southport will be higher than that in Warrington because a greater proportion of the Southport population is elderly. Standardisation is a statistical technique that is used to balance the effects of differences in age, sex, or other factors, when comparing different populations, or sub groups within one population.

Two different standardized measures are used in this report. The standardised mortality ratio (SMR) is a measure of how much more or less likely a person is to die in the group being studied, compared to someone of the same age and sex in England and Wales. The SMR of England and Wales is set at 100. SMRs above and below 100 represent higher and lower mortality for individuals in the study groups, compared to England and Wales. For example, an SMR of 120 is 20% higher mortality than England and Wales. SMRs are used to make *within* country comparisons.

The age-standardised mortality rate is a measure of how many people would die in a standard population (in this case a fictional European population) if they had the same mortality experience as the group being studied. The standardised mortality rate is expressed as a death rate per 100,000 population, and is useful for making comparisons *between* countries and over time.

Incidence: This is the number of new cases of cancer occurring during a given time period in a specified population. Incidence may be expressed as a rate per 100,000 population, or as a standardised ratio. These are interpreted in the same way as an SMR

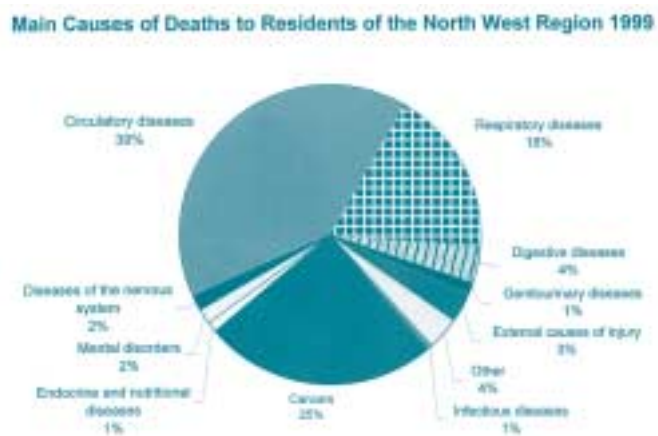
Survival: The survival rate is the proportion of persons in a specified group alive at the beginning of the time interval (e.g. 5 years), who survive to the end of the interval.

Prevalence: Point prevalence is the number of people in a given population, at a specified time who have been diagnosed with cancer.

Cancer deaths: How does the North West compare with the country as a whole?

Figure 1 shows the major causes of death in the North West in 1999. One quarter of the deaths (18,000) were attributed to cancer, making it the second commonest cause of death. The proportion of deaths from cancer (24-26%) is consistent across health authority districts in the North West, and comparable to that of England and Wales.⁷

Figure 1



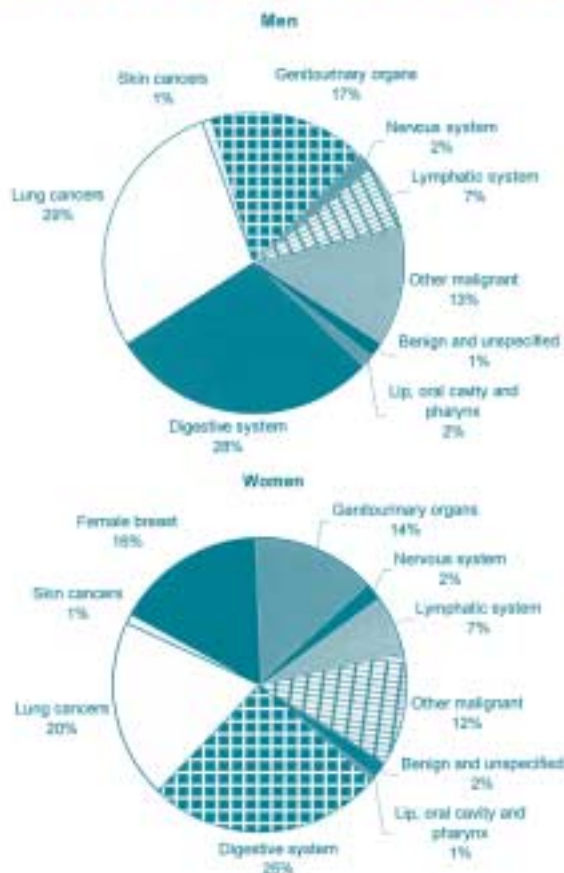
Source: Office for National Statistics. Mortality Statistics: Cause 1999. Series DH2 no. 26. (London: TSO 2000).

Figure 2 illustrates North West cancer deaths in 1999 by site and sex. Around half of the cancer deaths were attributed to the three most frequently occurring cancers. In men, these were lung (29% of cancer deaths), prostate (11%) and colorectal cancers (10%). In women, lung (20% of cancer deaths), breast (17%) and colorectal cancers (11%) occurred most often.⁷

Mortality from cancer is higher in the North West compared to England and Wales in all age groups except people under 35 years. In the period 1997-1999, the standardised mortality rate for all cancers in the North West was 261 per 100,000 for men, and 180 per 100,000 for women. In the same time period, the standardised mortality rate for England and Wales was 237 per 100,000 for men, and 164 per 100,000 for women.⁸

The incidence of cancer amongst residents of the North West Region is higher than in England and Wales as a whole. There were around 90,600 new cases of cancer diagnosed amongst residents of the North West Region between 1995 and 1997, excluding non melanoma skin cancers (an average of 30,200 a year). This figure represents incidence rates for cancer in the North West of 464 per 100,000 population for men, and 446 per 100,000 populations for women. For the period 1995-97, the incidence rates in England and Wales were slightly lower at 432 per 100,000 for men and 425 per 100,000 for women.⁹

Figure 2 Cancer Deaths to Men and Women in the North West Region 1999

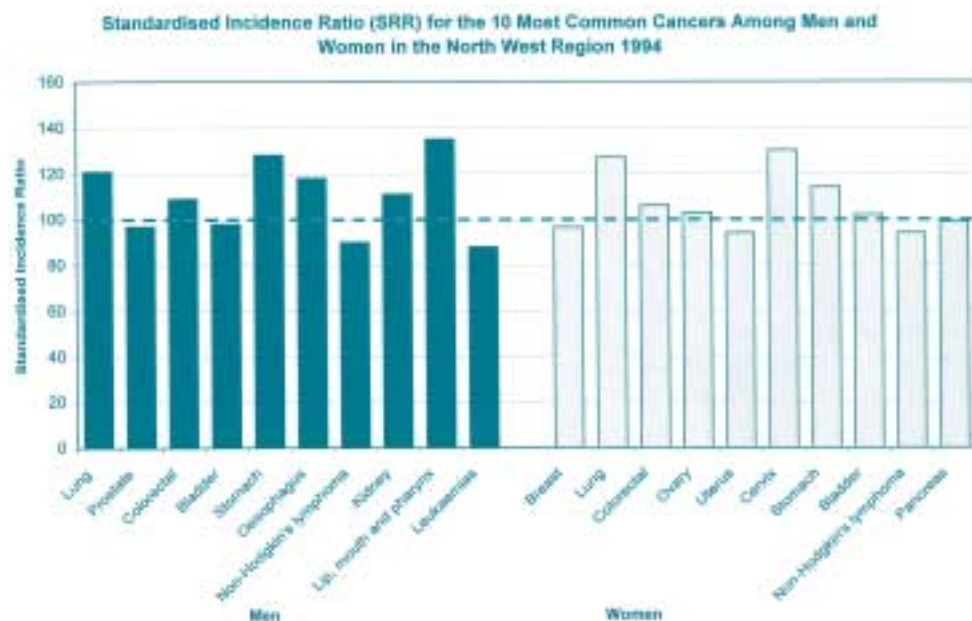


Source: Office for National Statistics. Mortality Statistics: Cause 1999. Series DH2 no. 26 (London: TSO, 2000)

Standardised incidence ratios for the 10 most commonly occurring cancers in the North West are shown in [Figure 3](#). Amongst men in the North West, incidence ratios for lung, colorectal, oesophageal, renal and laryngeal cancers were higher than those of England and Wales in 1994. For North West women, incidence ratios were higher for lung, cervical and stomach cancers. The North West has lower incidence ratios than England and Wales for lymphomas and leukaemias. However, these represent a small proportion of all cancers.¹⁰

Five-year survival for most of the common cancers is lower for patients in England and Wales compared with other European countries. The average five-year survival rate in England and Wales is at least 5% worse than it is in Europe for 10 out of the 38 most common cancers in men and for 17 out of the 39 most common cancers in women. The relative differences in cancer survival between England and Wales and the USA are even larger. Some of these variations will be due to differences in the definition and recording of the disease, and the methods commonly used for diagnosis.¹¹

Figure 3



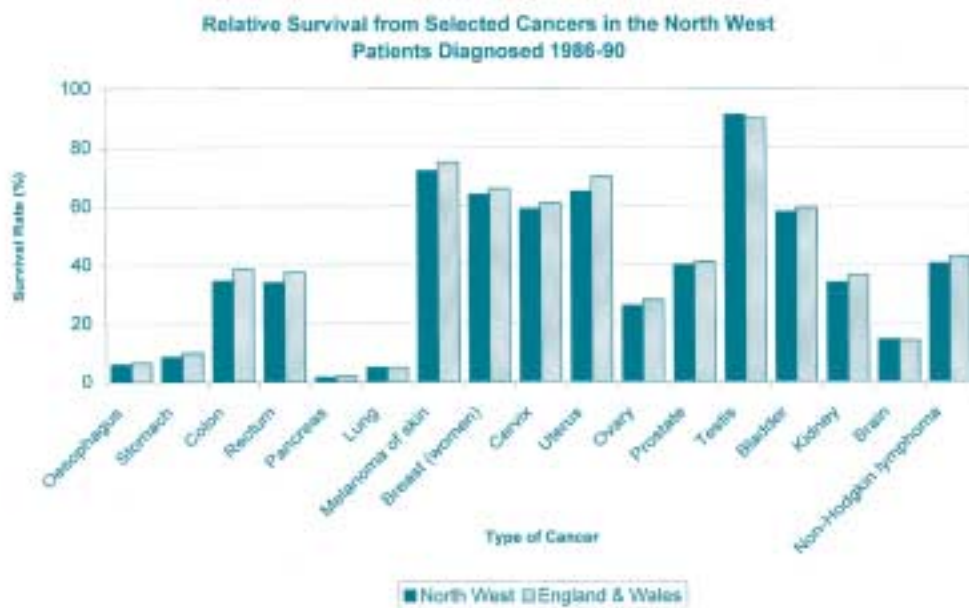
Source: Office for National Statistics. Cancer statistics registrations: 1994. Series MB1 no. 27. (London: TSO 2000)

[Figure 4](#) shows 5-year survival rates for 17 of the most common cancers in the North West Region (patients diagnosed in 1986-90) compared with England and Wales as a whole. Five-year survival from cancer in the North West is worse than in England and Wales as a whole.

As shown in Figure 4, survival rates for the most common cancers in the North West are consistently lower than those for England and Wales, with the greatest disparities in colorectal cancer (both sexes), malignant melanoma in men and cancer of the uterus.

Poor survival in the North West relative to the rest of the country is also seen in childhood cancer. In England and Wales, five-year survival after diagnosis of cancer in childhood has increased by at least 10% for each five-year interval between 1971-75 to 1986-1990.¹² Although the North West has seen survival from acute lymphatic leukaemia rise by 12% (95% Confidence Intervals 11-14) for boys and 7% (95% CI 6-8) for girls, overall cancer survival remains lower than that of England and Wales. However, cancer is rare in childhood, and the differences do not reach statistical significance.

Figure 4



Source: Cole et al. Cancer survival trends in England & Wales 1971 -95: deprivation and NHS Region (London:TSO 1999)

The pattern of cancer across society

Data for the North West Region describe a relatively high burden of cancer, and a poor outlook after diagnosis. Within this regional picture, variations in the experience of cancer may be seen between groups of different social or ethnic background, geographical location and level of deprivation. The manner in which cancer morbidity and mortality varies with social status or material circumstances can be studied in a number of different ways.

Social class based on occupation

The death certificate provides details of the occupation of the deceased, as well as the age and specific cause of death. Social class may be assessed from occupations, with people in professional occupations falling into class 1 and those in unskilled manual jobs into class V.

Table 1 compares the distribution of social classes in the North West Region with the rest of the country at the 1991 Census.

Social class may also be studied by using the ONS Longitudinal Study. This links the socio-economic information collected on a 1% sample of the population at the 10-yearly census to their subsequent cancer registrations, and if they die, to their individual death records.

Table 1 - Social class of men and women based on own occupation, North West compared with England & Wales

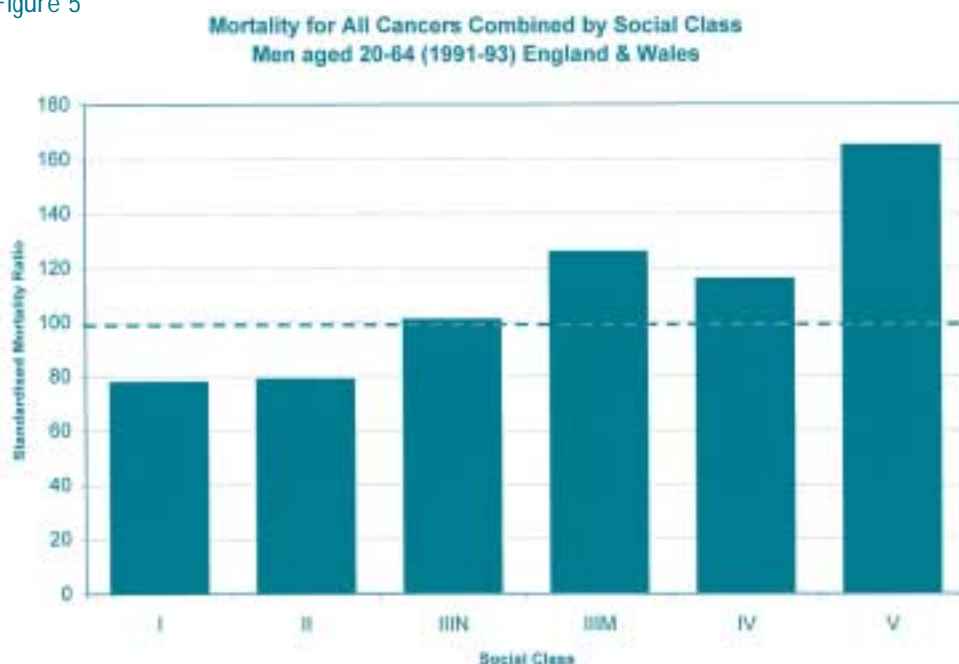
	Men (%)		Women (%)	
	North West Region	England & Wales	North West Region	England & Wales
I - Professional	5.9	6.5	1.4	1.8
II - Managerial and Technical	24.0	26.5	25.5	26.5
III(N) - Skilled (non-manual)	10.5	10.5	36.7	37.6
III(M) - Skilled (manual)	32.1	30.7	7.2	6.8
IV - Partly skilled	15.3	14.5	17.6	16.3
V - Unskilled	5.5	5.0	6.9	6.8
Inadequately described	1.9	2.3	1.3	1.2
Other economically active	4.9	3.9	3.4	2.9
Total economically active	72.0	73.7	49.8	50.5
Total retired	16.7	17.1	21.9	20.2

Source: 1991 Census Local Base Statistics ¹³.

Table 1 shows that, compared with England and Wales, the North West has a slightly lower percentage of men and women in non-manual social classes (I and II) but a higher proportion in manual classes (IIIM, IV and V).

There are clear variations in mortality by social class for all cancers. [Figure 5](#) illustrates this, using data from around the last census. Mortality for all cancers in unskilled manual workers (social class V) is more than double that of professionals (social class I). Unskilled manual workers have a 65% higher level of mortality from all cancers compared with the population as a whole. In contrast, professional men have a 22% lower rate of cancer deaths. Mortality of women aged 35-64 in social classes I and II is 24% lower than class IIIIM, while for classes IV and V it is 17% higher.¹⁴

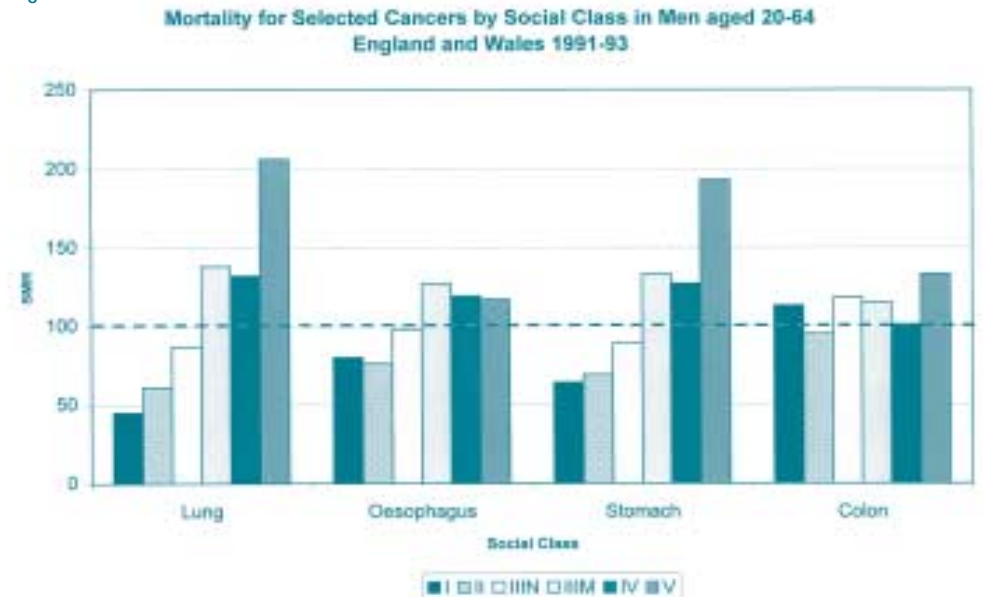
Figure 5



Source: Drever and Whitehead, 1997

Social inequalities are larger for some cancers than for others. [Figure 6](#) shows that mortality from lung cancer has the greatest social class gradient. Mortality in social class V is almost five times higher than that in social class I (SMR of 206 compared to 45). This social gradient is seen across all ages, but is steepest in the 45-49 age-group, where social class V had almost six times the mortality rate of social class I (European standardised mortality rate of 170 per 100,000 compared with 30 per 100,000). At age 50-59 there is a four-fold difference between social class V and social class I. At age 60-64, social class V has four and half times greater mortality than social class I.¹⁴

Figure 6



Source: Drever and Whitehead, 1997

Mortality for both stomach and oesophageal cancers is also higher in manual than non-manual social classes. In contrast, cancer of the colon shows no clear gradient. Analysis of other less common cancers shows that both rectal and pancreatic cancers tend to have higher levels of mortality among lower social classes.

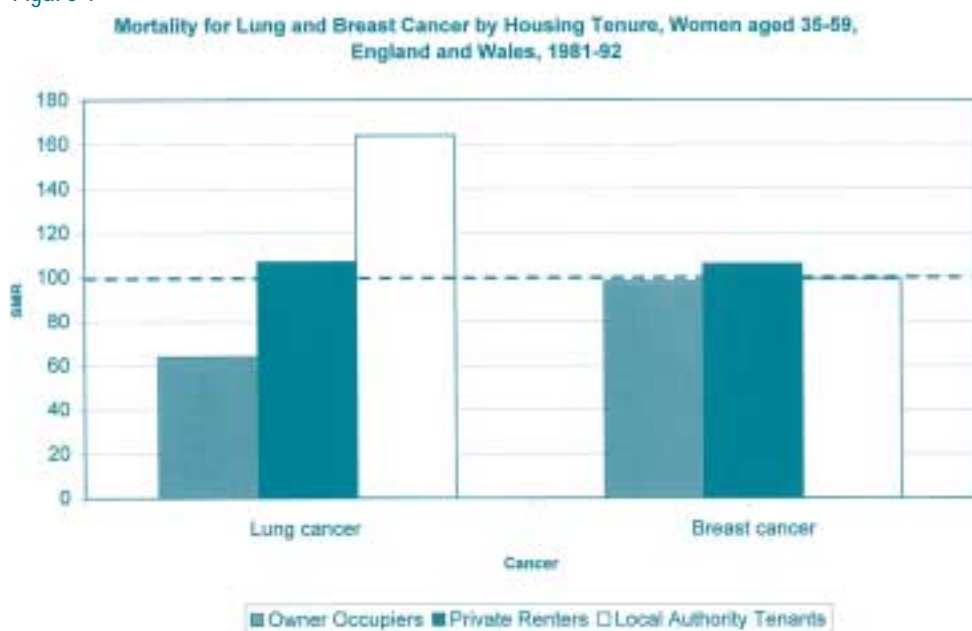
Amongst women, deaths from lung cancer in the 35-64 age group are more than double in manual compared to non-manual social classes. The social class gradient for lung cancer between manual and non-manual groups has increased progressively over the period 1976-1992. Death rates for women aged 35-64 in manual classes were nearly twice those in non-manual classes in 1976-81. By 1986-92 this difference had risen to over two and a half times. This widening of the social divide is part of a broader trend in which death rates among women in non-manual classes have fallen by 16% over the period between 1981-85 and 1986-92 whereas the death rates among manual groups have risen by 17% over the same period.¹⁴

In contrast, mortality from breast cancer (the third largest cause of death among women) is apparently unrelated to social class. In the 1970s, mortality from breast cancer was slightly higher among women in non-manual groups. Mortality rates have declined substantially among non-manual women, but hardly at all among manual women, so that the differential had disappeared by the 1990s.

Social status derived from housing tenure and access to cars

The health of people living in different social and economic circumstances may be compared using a variety of other social indicators. Two of the most widely used are housing tenure and access to cars.¹⁵ These are taken as indirect indicators of a person's household assets or long-term command over resources. Figures 7-8 show differences in mortality from lung and breast cancer in women aged 35-59 by housing tenure and car access

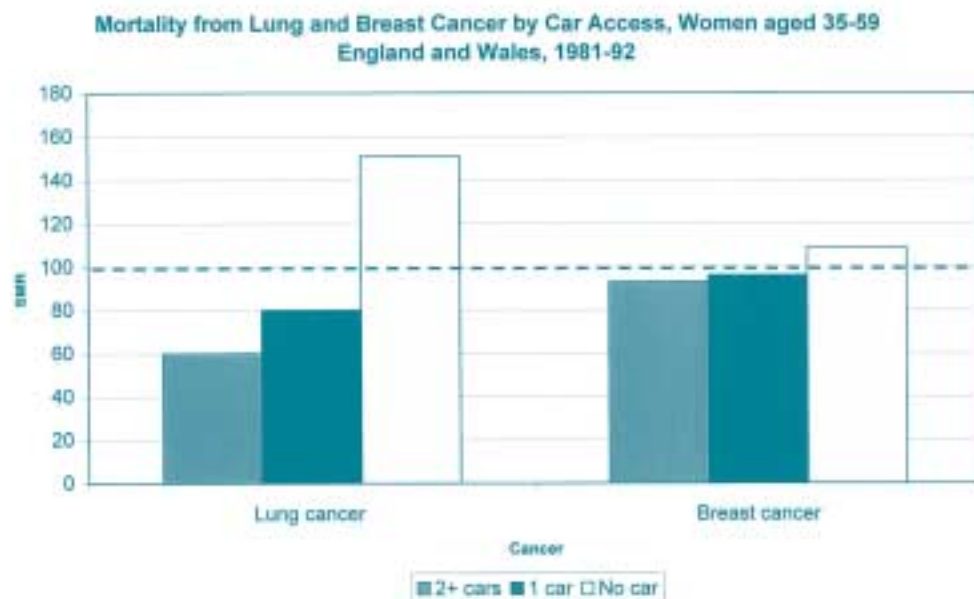
Figure 7



Source: Drever and Whitehead, 1997

The charts show that, for lung cancer, there is a clear gradient using both housing tenure and access to cars as a measure of social status, although the gap between the categories is slightly wider for housing tenure. Lung cancer mortality among women resident in council owned property is over two and a half times higher than that for women living in owner occupied property. In contrast, breast cancer shows no significant pattern using either of the two measures. There is a similar picture for women aged 60-74, although there is a narrowing of the gap between tenure and car access categories for lung cancer over time. However, given the diverse nature of the housing stock around the region, tenure may not always provide a good reflection of differences in the social composition of the population.

Figure 8



Source: Drever and Whitehead, 1997

Patterns of cancer by deprivation of area

Groups of people with certain socio-economic characteristics are often clustered in particular geographic areas, and this can give rise to inequalities in health between different parts of the country. The topographical, economic and political features of an area, such as the amount of green space and the level of crime, can also contribute to the level of health in an area. Levels of income and employment are also closely associated with life expectancy. For example, the most recent figures from the Office for National Statistics show that average life expectancy between local authorities varies by up to eight years.¹⁶

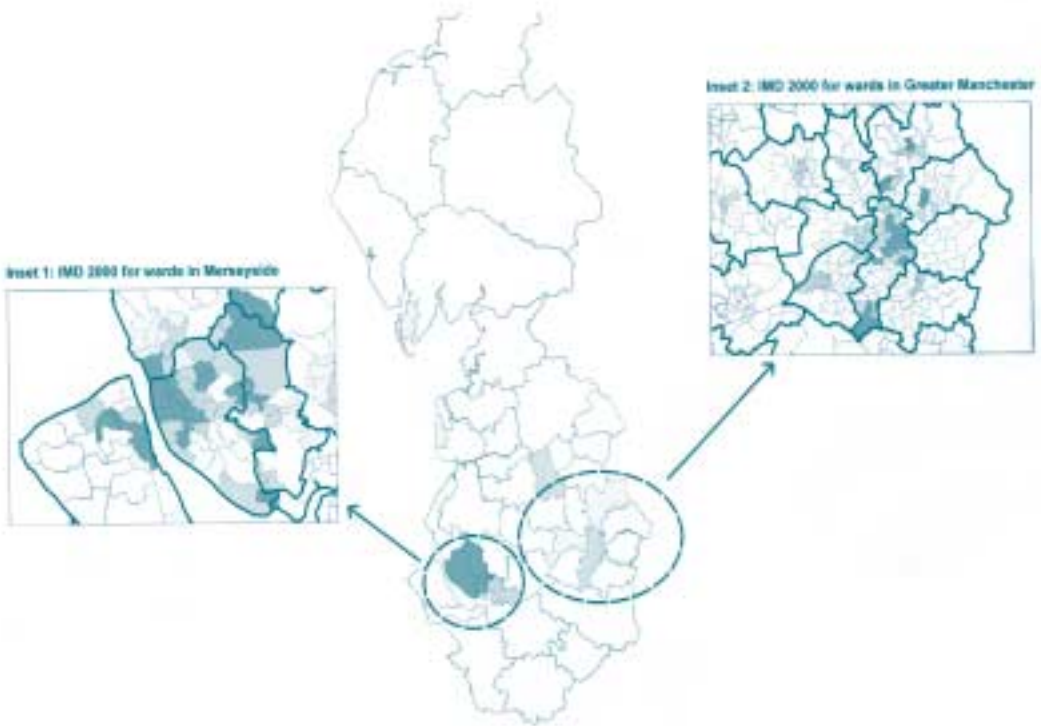
Large differences in cancer incidence and mortality are evident between areas classified by their level of deprivation. The level of deprivation in an area is often measured using a composite indicator that combines a number of different aspects of deprivation (e.g. poor housing, unemployment and low income) into a single figure. This Report uses two different indices to measure the level of deprivation in an area. At ward level, the Index of Multiple Deprivation 2000 is used.¹⁷ This draws on up-to-date data for wards as of 1998, taken from routine government statistics, and so does not rely on the 1991 Census. However, this index has not been calculated for individual health authorities. When looking at deprivation across health

authorities, the Townsend score, a 1991 Census based measure focused on material deprivation, is used.¹⁸

Map 1 shows deprivation scores for local authorities in the North West and electoral wards in Greater Manchester and Merseyside, based on the Index of Multiple Deprivation. The areas with the highest average ward deprivation scores are centred on the major urban areas of Manchester and Liverpool. These cities have some of the highest levels of deprivation in the country. However, within these areas, deprivation is not evenly spread. Generally deprived local authorities may contain a number of less deprived wards. Similarly, more affluent areas, such as South Cheshire, may contain several 'hot spots' of deprivation within their boundaries.

In 1997-99 (the latest available period), the standardised mortality rate for all cancers in the North West was 211 per 100,000, compared with a national rate of 193 per 100,000. The Health Authorities with the highest levels of deprivation have the highest cancer death rates for both men and women. Mortality in Manchester is 259 per 100,000 compared with 187 per 100,000 in South Cheshire. This gradient is similar in both men and women, although the pattern differs between health authorities. Amongst men, the highest death rate is in Manchester, for women it is in Liverpool.⁸

Index of Multiple Deprivation 2000 for local authority districts in the North West Region (showing ward level scores for Greater Manchester and Merseyside)



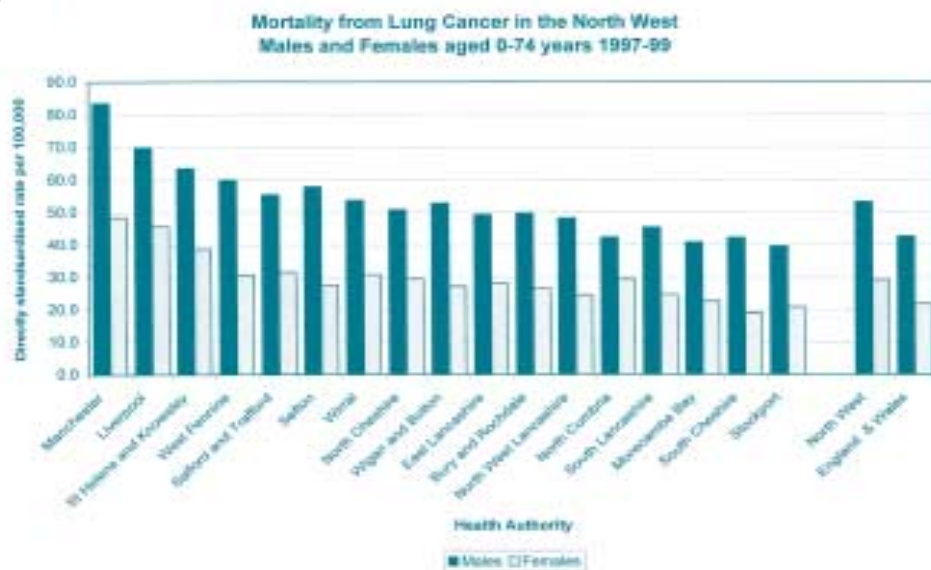
- Index of Multiple Deprivation 2000
Rank of Average of Ward Score
- In top 1% of local authorities in England
 - In top 5% of local authorities in England
 - In top 10% of local authorities in England
 - All other local authorities

Source: Department of Environment, Transport and Regions (August 2000)

Death rates from cancer have fallen over the last decade in all parts of the region, though inequalities between different areas have increased. Between 1989 and 1999, the gap between the health authorities with the highest and lowest death rates has increased from 24% to 32% - an increase of 8 percentage points. The mortality gap has increased far more for women than for men. In women, the gap has increased by 14% percentage points (from 21% to 35%) but in men it has remained the same across the whole period (29%). The greater disparities in female death rates are due to the fact that death rates from all cancers in the most deprived parts of the region, notably Manchester and Liverpool, have increased since 1989. In contrast, death rates in less deprived areas, such as South Cheshire and Stockport have continued to fall in line with the national trend.⁸

Overall, mortality is higher in areas of greatest deprivation, though the social gradient is stronger for some types of cancer than for others. Lung cancer, the most common cancer in the North West, has one of the strongest social gradients. **Figure 9** shows that mortality rates for lung cancer in the most deprived areas of the region are around twice those in the most affluent. The mortality rate for lung cancer in Manchester (65 per 100,000) is more than double that in South Cheshire (30 per 100,000).⁸

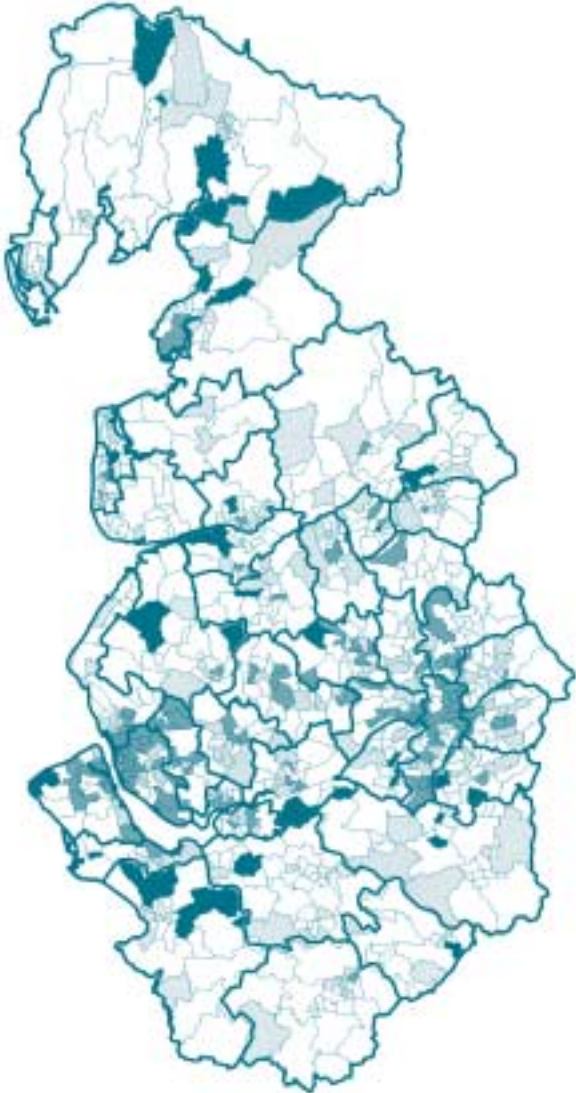
Figure 9



Source: Department of Health. Compendium of Clinical and Health Indicators 2000 (London: Department of Health 2000)

Maps 2 and 3 illustrate the clustering of higher standardized mortality ratios for cancer and lung cancer in the urban centers. This pattern of mortality closely mirrors the level of deprivation, highlighting the lower income areas of Manchester, Liverpool and parts of the Wirral. There are also areas of higher mortality in the former mill towns of central and east Lancashire, such as Blackburn and Burnley. The map also illustrates the existence of ‘hot spots’ of high mortality in the midst of areas, such as South Cheshire, which, on the whole, do not experience high levels of mortality.

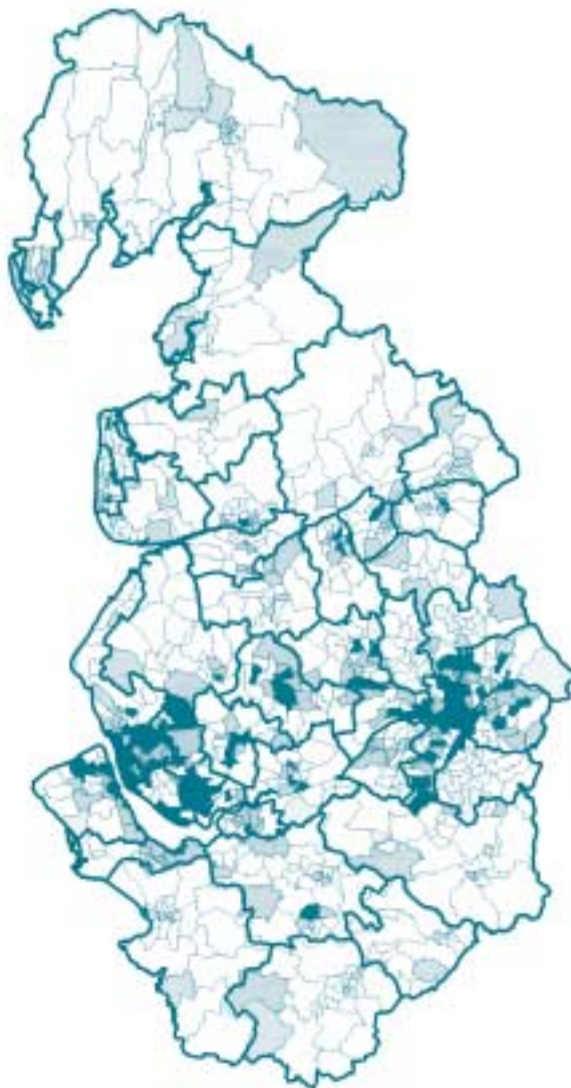
**Mortality from All Malignant Cancers by Electoral Ward
North West Region, 1997-99**



- SMR 1997-99
Population aged 0-74
- Rate in top third (statistically significant)
 - Rate in top third (not statistically significant)
 - Rate in Bottom third (statistically significant)
 - All other zone

Source: North West Small Area Database 2000 (NHS Executive North West, 2000)

**Mortality from Lung Cancers by Electoral Ward
North West Region, 1997-99**



- SMR 1997-99
Population aged 0-74
- Rate in top third (statistically significant)
 - Rate in top third (not statistically significant)
 - Rate in Bottom third (statistically significant)
 - All other zone

Source: North West Small Area Database 2000 (NHS Executive North West, 2000)

An alternative way of looking at the relationship between socio-economic factors and the level of cancer in a local area is to use a small area classification, such as Super Profiles. These combine a range of variables from different sources to define a number of distinct social areas, such as “Affluent Professionals” and “Lowest Income Households”. Super Profiles have been used extensively at regional level to look at the pattern of health inequalities in the North West.¹⁹ An analysis of mortality rates for all cancers by Super Profile types shows that areas with more affluent populations have levels of mortality similar to the expected national average, while areas with a more deprived population experience much higher levels of mortality from the disease.

Cancer incidence and deprivation by health authority area

In the period 1990-94, the incidence of cancers amongst residents of Health Authorities in Merseyside and Cheshire was higher than in England and Wales. The greatest differences were seen in the most deprived areas. Compared to England and Wales, men in Liverpool had a 37% higher incidence of cancer whereas the difference for men in South Cheshire was 4%. Similarly, women had a 32% higher incidence of cancer in Liverpool compared with a 7% higher incidence in South Cheshire.²⁰

Incidence rates for some of the most common cancers are higher in areas within Greater Manchester than in Lancashire.²¹ For example, the highest age standardised incidence rates for lung cancer (males and females diagnosed in 1993-96) were in Manchester and Salford & Trafford. In both these areas, the incidence rates were significantly higher than the rest of Greater Manchester and Lancashire. Significantly higher rates were also found in West Pennine (males) and Bury & Rochdale (females). For colon cancer there was a similar picture, with significantly higher incidence rates for males in Manchester, Wigan & Bolton and Salford & Trafford than elsewhere in Greater Manchester and Lancashire.

The pattern for other cancers is less clear. For a number of cancers (e.g. oesophagus, rectum, pancreas and bladder cancer) no health authority had a significantly higher incidence rate than the rest of Greater Manchester and Lancashire. These are cancers for which the number of occurrences is relatively small. Significantly higher rates of prostate cancer are found in North West Lancashire and South West Lancashire as well as in parts of Greater Manchester such as Stockport and Salford & Trafford.

Information provided by the Centre for Cancer Epidemiology also illustrates some of the trends in the incidence of cancer within Greater Manchester and Lancashire. It shows there have been rises in the incidence of breast and lung cancer in women, as well as in prostate cancer in men. Improvements in understanding and detection of the disease may account for some of this increase.

Cancer survival and deprivation

Cancer survival in England and Wales is generally lower in patients from deprived areas compared to residents of affluent areas. A recent report from the Office for National Statistics analysed cancer survival rates by sex and area deprivation category within each NHS region (cancers diagnosed 1986-1990). Patients living in deprived areas had a significantly lower survival rate than those living in more affluent areas for 20 common cancers.²²

Table 2 shows survival rates for residents of Health Authorities in the North West Region, diagnosed during 1992-1994 with the four major cancers. The Health Authorities are shown in order of their national ranking based on the Townsend Score, i.e. those nearer the top of the table are more deprived than the ones below.

Table 2 - 5-year relative survival (%) for patients diagnosed during 1992-1994.

Health Authority	Deprivation Ranking (1-99)	5-year relative survival rate (%)			
		Breast cancer	Prostate cancer	Lung cancer	Colon cancer
Manchester	5	72	39	5.2	39
Liverpool	6	67	56	6.5	43
St Helens & Knowsley	14	76	49	4.6	39
West Pennine	24	71	46	4.5	29
Salford and Trafford	29	72	56	4.5	39
Bury and Rochdale	33	69	56	4.7	42
Wigan and Bolton	37	75	48	5.0	35
East Lancashire	40	78	50	5.1	37
Sefton	42	75	61	6.4	37
North Cheshire	43	73	63	5.2	36
Wirral	44	73	50	6.9	39
North West Lancashire	49	75	61	4.2	39
North Cumbria	60	74	54	2.3	43
Morecambe Bay	77	75	56	3.6	45
Stockport	83	75	60	8.3	39
South Cheshire	93	73	56	4.9	41
South Lancashire	94	75	59	6.4	41
ENGLAND	-	75	55	5	42

Source: Office for National Statistics ²³

Table 2 shows that for some cancers there are wide variations in survival between patients in the most affluent and deprived areas of the region. Survival from lung cancer is low throughout the region, although there still are large variations between areas. In Stockport 8.3% of lung cancer patients diagnosed in 1992-1994 survived for 5-years or more (95% Confidence Interval 6.2-10.9) compared to 3.6% in Morecambe Bay (95% Confidence Interval 2.2-5.5). However, the picture is not consistent. Survival rates in Liverpool (6.5%) and Manchester (5.2%) are similar to or higher than the national average (5.2%) despite being highly deprived according to their Townsend Scores. This may reflect greater access to specialist health care.

For other cancers, there is a much clearer social gradient in survival. 5-year survival from prostate cancer in Manchester is 39% (95% Confidence Interval 32-46) compared with over 60% in North West Lancashire and Stockport. The 5-year survival rate for colon cancer in West Pennine (29%) is around a third lower than in Morecambe Bay (45%). There are many factors which might explain why survival is lower in more deprived groups. Existing health states, delays in seeking medical care, and the impact of poverty on recovery from treatment may all be influential.²⁴

3. The pattern of some key determinants of cancer in the North West

There are many factors associated with an increased risk of cancer. As well as tobacco and diet, genetic make up, living environment and working conditions may all be influential. Estimates made in the early 1980s and updated in 2001 of the proportion of cancer deaths attributable to different factors are shown in Table 3

Table 3 - Proportion of cancer deaths attributable to different factors

Factor or class of factors	% of all cancer deaths	
	Best estimate	Range of acceptable estimates
Tobacco	33	25-40
Alcohol	3	2-4
Diet	35	10-70
Food additives	<1	-5-2
Reproductive and sexual behaviour	7	1-13
Occupation	4	2-8
Pollution	2	<1-5
Industrial products	<1	<1-2
Medicines and medical procedures	1	0.5-3
Geophysical factors	3	2-4
Infection	15	1-?
Unknown factors	Unknown	Unknown

Source: Adapted from Doll and Peto 1981 and Peto 2001. ^{25 26}

The table highlights the number of risk conditions that have been identified as causes of cancer. For example, it is estimated that nearly one in three cancer deaths can be attributed to cigarette smoking and a further third may be due to diet.²⁵ The following section looks at some of the key lifestyle factors and highlights the links with social factors, such as poverty and unemployment.

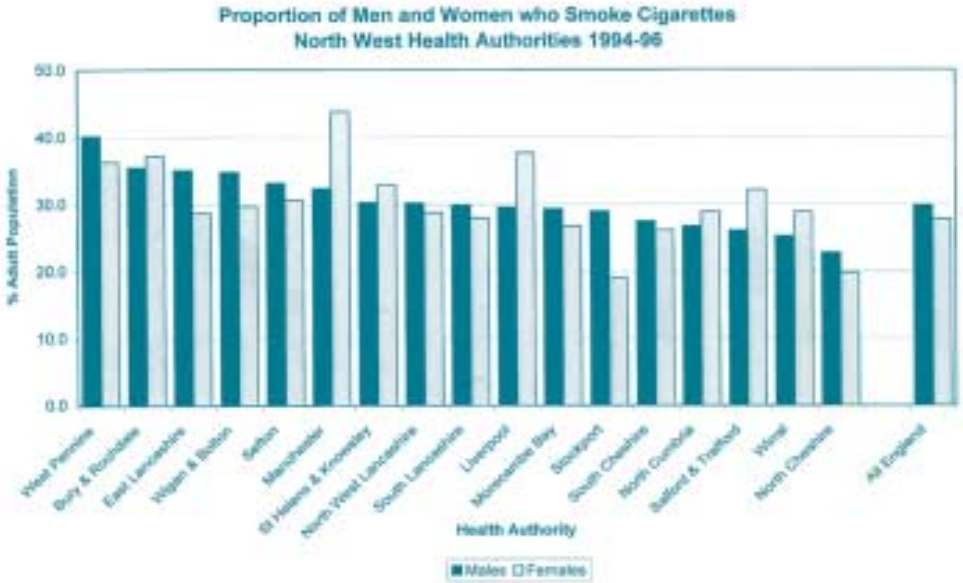
Smoking

The North West has one of the highest levels of smoking in the country. In 1998, 31% of adults (aged 16 and over) said they smoked cigarettes compared with 28% in England. Nationally, the prevalence of smoking is higher among those in manual socio-economic groups than among those in the non-manual groups. In 1998-99, over two-fifths of unskilled males and a third of unskilled females were smokers compared with 13% of males and 14% of females in professional social groups.²⁷ Smoking is implicated in the cause of a number of cancers, notably lung cancer, where more than 80% of cases are directly attributed to smoking.²⁸

The prevalence of smoking at Health Authority level may be estimated from the Health Survey for England (data from 1994-96).²⁹ Rates of smoking are higher in more deprived Health Authorities in Greater Manchester and Merseyside and lower in the less deprived rural or suburban areas of Cumbria, South Cheshire and South Lancashire. The proportion of adults who are current cigarette smokers ranges from 39% in Manchester to 21% in North Cheshire (Figure 10). The extent to which individuals are able to adopt or change a particular lifestyle is strongly influenced by their individual circumstances and by the social conditions of the area in which they live. The pattern of smoking shown in Figure 10 is therefore a close reflection of the pattern of deprivation within the region.

Areas with a higher prevalence of smoking (e.g. Manchester, West Pennine and East Lancashire) also have some of the highest rates of bronchitis, emphysema and lung cancer - those with the lowest smoking prevalence (e.g. Stockport, North Cheshire and South Cheshire) have some of the lowest rates. Occupation exposure to substances linked to the textile industry may be a factor in the higher level of respiratory diseases in parts of Greater Manchester and Lancashire.

Figure 10



Source: Department of Health. Geographic Variation in Health Indicators by Health Authority 1994-96 (London: Department of Health, 1999)

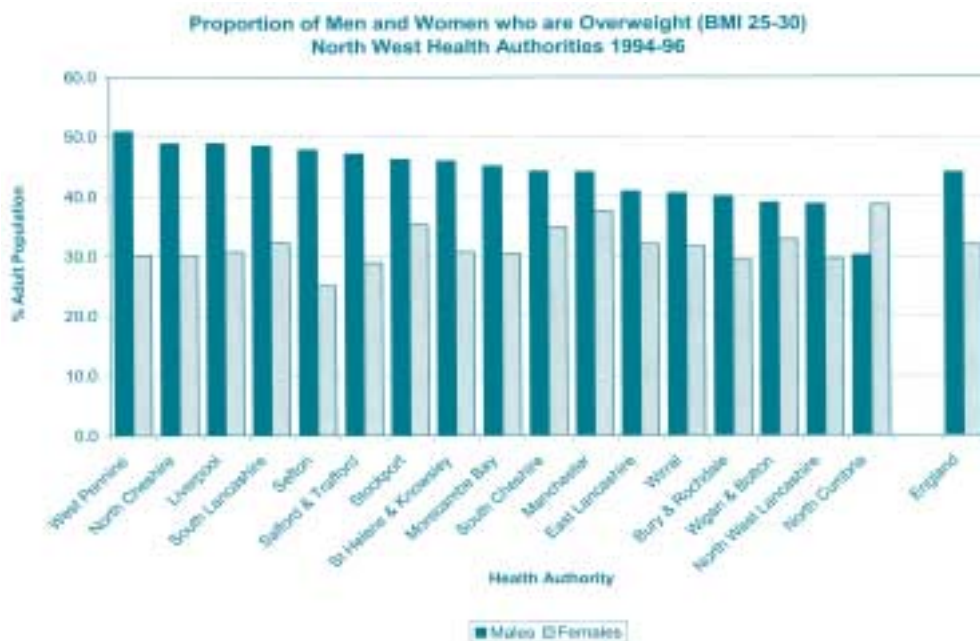
Diet and obesity

Diet is thought to be the second biggest risk factor for cancer. Although the link between cancer and diet is complex, low intakes of fruit and vegetable fibre and high fat consumption are associated with increased risk. There is also clear evidence that cancer occurs more commonly in people who are overweight.²⁶ Research from America (where obesity is more prevalent) suggests about 10% of all cancer deaths (7% in men and 12% in women) among non-smokers are caused by the individual being overweight.³⁰

In order to define overweight or obesity, a measurement is required which allows for differences in weight due to height. A widely accepted measure of weight for height, is the Body Mass Index (BMI), defined as weight (kg)/height (m²). Overweight is usually indicated by a BMI of greater than 25, obesity by a BMI of greater than 30. Data from the Health Survey for England 1998 showed that the proportion of adults in the North West who are overweight (45% of men and 33% of women) is similar to that of England as a whole (46% of men, 32% of women).³¹

In the more deprived Health Authorities of the region, a higher proportion of the population is overweight. This ranges from 41% in Stockport to 34% in North West Lancashire (Figure 11). However, it is important to note that these figures are based on a small sub-set of the overall survey data and they may not be robust.

Figure 11



Source: Geographic Variation in Health Indicators by Health Authority 1994-96 (London: DoH, 1999)

Occupational and environmental factors

Environmental and occupational factors are also associated with an increased risk of developing certain forms of cancer. It has been estimated that between 2% and 8% (3,000 - 12,000) cancer deaths per year in Great Britain may be due to occupational causes.³² Asbestos is one of the best identified occupational carcinogens, accounting for up to 5% of deaths attributed to lung cancer. Combined exposure to asbestos and tobacco smoke has been shown to increase the risk of lung cancer by 50-60 times that of non-exposed non-smokers.³³ Liver and bladder cancers have also been linked to various occupational agents and industrial processes.

4. Cancer services in the North West

Implementation of the NHS Cancer Plan in the North West

The NHS Cancer Plan introduced the concept of 'managed cancer networks' serving a population of 1-2 million people.² The networks are expected to bring together health service organisations, the voluntary sector and local authorities to plan cancer services for their population. In the North West, three cancer networks have been established covering the areas of Merseyside (including west Cheshire), Greater Manchester (including central and eastern Cheshire) and Lancashire and South Cumbria. These networks cover populations ranging from 1.5 to 3.2 million people and broadly relate to one of the three oncology centres in the region, located at Clatterbridge, Christie and Preston hospitals. Each of these networks has a Board and a number of multi-disciplinary teams and clinical sub-groups dealing with particular types of cancer, e.g. lung, breast and gynaecological cancers.

Cancer networks are responsible for developing strategic Service Delivery Plans covering all aspects of cancer services - prevention, screening, diagnosis, treatment, supportive care and specialist palliative care. They are expected to agree common protocols and service patterns to tackle variations and to make best use of resources. Workforce, education and training and cancer facilities strategies will also underpin the delivery plans.

Interventions

There are a number of key areas in which action can be taken to reduce the level of cancer in the population and improve the outcomes of cancer treatment. These fall into four categories:

- **Prevention** to reduce or eliminate some of the underlying determinants of the disease (e.g. smoking, industrial pollution).
- **Early diagnosis** to identify the cancer at an early stage and thereby increase the effectiveness of the resulting treatment (e.g. cervical and breast screening)
- **Treatment** to remove the cancer or prevent it spreading to other parts of the body (e.g. chemotherapy, radiotherapy)
- **Long term care** (e.g. palliative care) to control any distressing symptoms and improve the overall quality of life of cancer patients.

Prevention

Action to reduce the level of smoking is one of the most important preventative activities to minimise premature deaths and ill health from cancer. The NHS Plan, and the White Paper, *Smoking Kills*, set out a major expansion in smoking cessation activities.³⁴ Smoking cessation services were launched in the Health Action Zones in 1999/2000, and rolled out across the NHS in 2000/2001. In the North West, Health Action Zones are in operation in Bury and Rochdale, Manchester, Salford and Trafford and Merseyside. Recently released figures for April 2000 to March 2001 show that around 42% of people in the North West who set a quit date had successfully quit at the end of a four-week follow up period (based on self-report) compared with an average for England of 49%.³⁶

Although smoking is disproportionately high among people in more disadvantaged areas, men and women in lower social groups also have lower cessation rates. One measure of the extent to which people from lower social groups are embarking on smoking cessation schemes is the proportion of people setting a quit date who are eligible for free prescriptions. Entitlement to free prescriptions is given to people on Income Support and other benefits and is therefore linked to socio-economic status for those of working age (aged 18-59 years). In 2000/2001, 57% of clients in the North West who set a date to quit were eligible for free prescriptions compared with 56% in England. Within the region, this figure varies from 76% in Manchester to 28% in Wigan and Bolton.³⁶

Smoking cessation is only one of a range of measures that have been shown to be effective in reducing the level of smoking. Other interventions include enforcement of the legal restrictions on cigarettes sales, limiting smoking in public places, media campaigns to change public attitudes to tobacco, opportunistic advice from doctors and other health professionals, specialist counseling and nicotine replacement therapy.^{37 38 39} Fiscal policy, such as increasing the tax on cigarettes or tackling tobacco smuggling, can also be used to increase the financial costs to people who keep smoking.

Early detection

In the UK, screening programmes are in operation for female breast and cervical cancer. Data on the performance of these screening programmes include the following indicators.

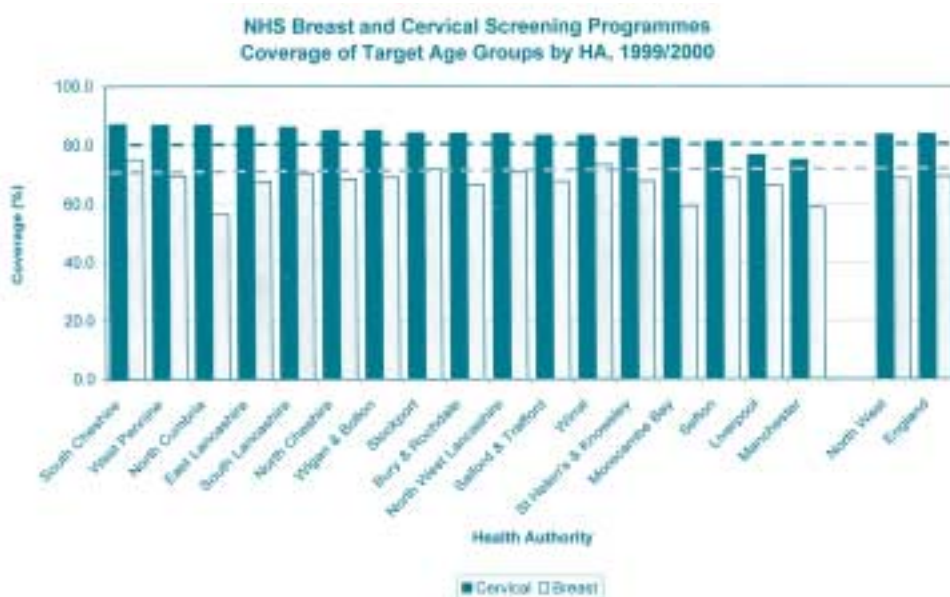
- Coverage - The % of eligible women resident in the population who are screened, and have a recorded result within a specified time period.

- Uptake - The % of eligible women invited for screening who attend, and have received a recorded result

The NHS Breast Screening Programme is targeted at women aged 50-64. It aims to screen and record a result for at least 70% of eligible women at least once every 3 years. The target age group for the Cervical Screening Programme is 20-64 but, because of the lower coverage in the 20-24 age-group, the coverage rate is expressed as a proportion of women aged 25-64. The national target is that 80% of eligible women aged 25-64 should be screened at least once every 5 years.

Coverage and uptake rates for both breast and cervical cancer screening in different parts of the North West show a clear social gradient. In 1999/2000, the coverage rate for the breast screening programme in the North West Region was similar to the national average (69%). However, more deprived areas tend to have lower coverage rates than more affluent areas. **Figure 12** shows that the coverage rate for breast screening in Manchester was 59% compared with 75% in South Cheshire. Similarly, the estimated uptake of invitation to screen among the target age group was nearly 10% lower in the Greater Manchester and Liverpool screening units (73%) compared with the Chester screening (82%).⁴⁰

Figure 12



Source: Department of Health Statistical Bulletins 2000/30 (Cervical Screening Programme, England 1999/2000) and 2001/10 (Breast Screening Programme, England 1999/2000).

The social gradient in the cervical screening programme is similar to that for breast screening. The regional coverage rate (84%) is similar to the national average, although at health authority level, lower coverage in more deprived areas is apparent. For example, coverage rates in Manchester (75%) are 12% lower than that in South Cheshire (87%).⁴¹

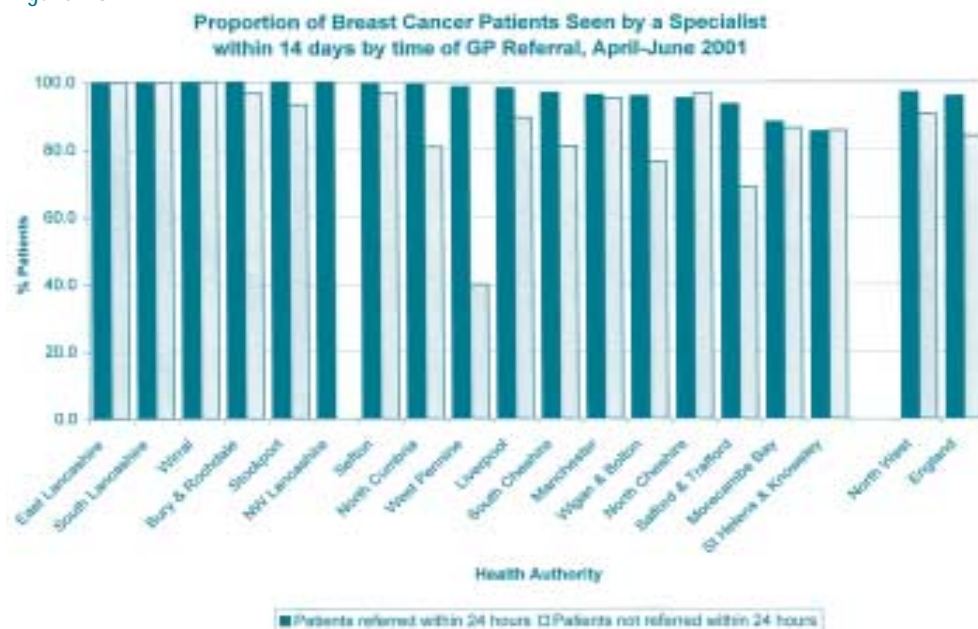
Diagnosis and treatment

There are three specialist (tertiary) oncology centres in the region, located at Clatterbridge Hospital on the Wirral, Christie Hospital in Manchester and Preston hospital. These hospitals treat less common types of cancer and provide services, such as radiotherapy, that are not available in smaller hospitals. The tertiary centres are supported by a network of cancer units in local hospitals, which are able to treat the more common forms of cancer. This model of care was recommended by the Calman-Hine Report in 1995.⁴²

The delivery of cancer services is also being guided by the recommendations set out in the NHS Cancer Plan, NICE guidelines and other documents.^{2 43 44} The aim is to reduce variations in the standard of cancer services across networks. Particular effort is being directed at waiting times. It is intended that patients should receive an urgent outpatient appointment within two weeks, and wait no longer than four weeks from diagnosis to treatment. A series of staged national milestones have been devised. The initial target will be to reduce maximum diagnosis to treatment waits to a month, with an average wait of two weeks. For breast cancer, the aim is to achieve the maximum two months wait by 2002; for all other cancers, the target year is 2005.⁴⁵

Figure 13 shows the proportion of breast cancer patients resident in Health Authorities within the North West who are seen by a specialist within two weeks of referral. These figures range from 100% to fewer than 90%. Patients who are referred within 24 hours of consulting a general practitioner are more likely to be seen by a specialist within 14 days. Ninety-seven per cent of urgent referrals made within 24 hours were seen by a specialist within 14 days, compared with 91% of referrals that were not made within 24 hours.

Figure 13



Source: Department of Health. Cancer waiting times - Monitoring the 'two week' target. Quarter 1 2001/02. (August 2001)

Specialist palliative care

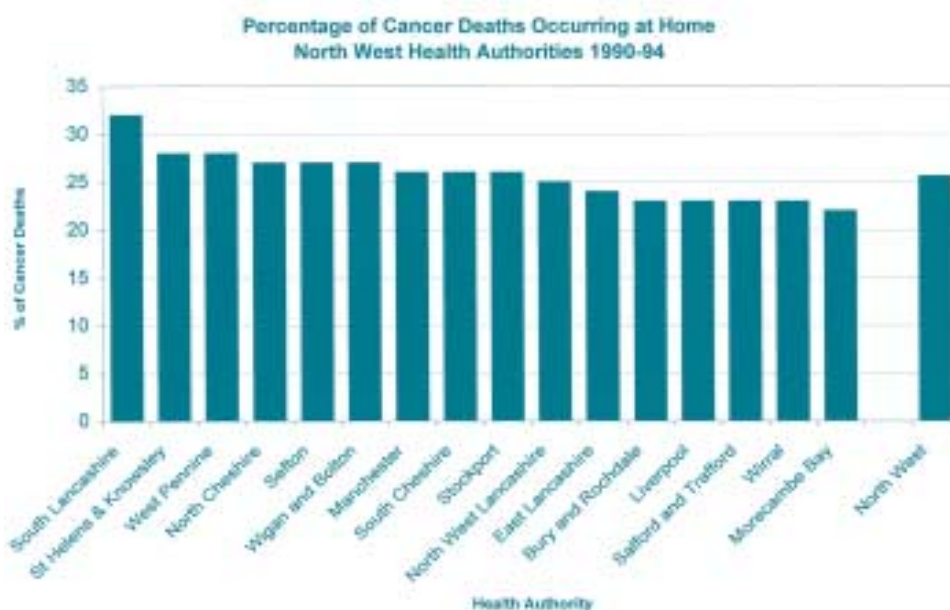
The World Health Organisation defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families".⁴⁶

The majority of people in contact with specialist palliative care services have cancer, although patients with other life-threatening illnesses, such as HIV/AIDS and Motor Neurone Disease may also be supported. The range of services provided by hospice or palliative care centres will typically include: in-patient, home and day care provided by specially trained nurses and doctors; support for carers; spiritual support; respite care and bereavement counselling.

In the North West, there are 25 inpatient units with 381 beds providing specialist palliative care for adults. This represents 58 beds per million population. In other regions of England, the number of inpatient beds ranges from 36 per million to 65 per million. However, the trend towards home care means that the number of beds may not reflect access to specialist palliative care.

Death at home is often used as a proxy for good care at the end of life. Figure 14 shows that there are clear differences between Health Authorities in the proportion of patients dying at home, ranging from 32% of patients in South Lancashire Health Authority to 22% in Morecambe Bay.⁴⁷ In the UK as a whole, patients are less likely to die at home if they live in a deprived area.^{48, 49} Whether this results from differing access to health and social care, variation in the quality of services, or local preferences is unclear.

Figure 14



Source: 1. Higginson. Which cancer patients die at home? Fact Sheet 31: North West (Hospice Information Service, 1999)

5. Sources of information about cancer

This section describes currently available sources of information about cancer and examines how different sources may be used to look at social variations in cancer. The information sources are divided into three types:

- Mortality and morbidity data;
- Information about the key determinants of cancer;
- Information about the diagnosis, treatment and care of cancer

Mortality and morbidity data

Information about mortality and morbidity is available as part of the national systems for registering deaths and reporting cases of cancer. These systems are part of a nationally standardised programme of data collection and, therefore, the information they produce is generally comprehensive and of good quality. However, because they measure different aspects of the condition, it is important to be aware of how the information is collected and what it can be used for.

Mortality data

Information about deaths from cancer is collected as part of the process for registering a birth or death. This process, known as Civil Registration, is governed by legislation (notably the Births and Deaths Registration Act 1953) and overseen by the General Registry Office (GRO) - now part of the Office for National Statistics (ONS). When a person dies, the Registrar of Births and Deaths in the district where the death occurred records information about the causes of the death, together with a set of personal information about the deceased. All this information is sent electronically to the General Registry Office, where it is then coded and compiled into a national database for further analysis. Extracts from this database are also made available for use by local health authorities (see next section).

The information collected through this process includes:

- Name and surname of the deceased;
- Date and place of birth and death;
- Usual address;
- Occupation; and
- Underlying and contributing causes of death.

Mortality statistics are one of the primary sources of information about social variations in cancer. The database includes the occupation of the deceased and can therefore be used to look at patterns of death by social class. In addition, because the postcode, and hence the area of residence, of the deceased is known, the data can be aggregated and linked to other sources of information about the social characteristics (including deprivation) of different geographical areas. The availability of historical data means that it is possible to show whether inequalities between different sections of society and parts of the country have widened or narrowed over time.

However, mortality data alone do not provide a comprehensive picture of the condition. This is because cancer is a long-standing disease and many people survive to die from other causes. As a result, people with cancer who die of a totally unrelated event may not be included in cancer mortality statistics. For example, someone with breast cancer who dies of a stroke would not be counted as a cancer death unless the cancer was the main contributing factor behind the death. Even where the cancer is mentioned on the death certificate, increases in survival time mean that the death may have occurred many years after the diagnosis was made. There may also be problems with using mortality data to look at social class based on occupation among particular groups (e.g. women, children and ethnic minorities).

Morbidity Data

Cancer registration is conducted by ten regional cancer registries. They collect data on cancers among people resident in their region. There are two Cancer Registries in the North West, covering Merseyside and Cheshire and Greater Manchester and Lancashire. The Merseyside and Cheshire Registry is based at the University of Liverpool. The Registry covering Greater Manchester and Lancashire is based at the University of Manchester and is linked to the Centre for Cancer Epidemiology.

The cancer registration database is made up of information from a number of different sources, including:

- Details of cancer patients supplied by local hospitals;
- Death certificates sent by the Office for National Statistics;
- Data from the national breast and cervical screening programmes recorded by local health authorities;
- Information requested from General Practitioners; and
- Information provided by private hospitals.

Since 1971, data have been collected on a continuous basis and stored in a national cancer registration database. The database currently holds around 6 million records of patients with cancers diagnosed in 1971 and onwards. It is continuously updated as the regional registries submit their data sets and as amendments are made as a result of the many quality checks built into the system.

The cancer registration database contains a range of data items covering aspects such as:

- Date and source of registration;
- Treatment of the registered cancer;
- Hospital admissions related to the cancer;
- The presence of any recurrent or secondary tumours;
- Other illnesses suffered during the course of the disease;
- Date and cause of death.

Registration data provide information on the incidence of cancer, and combined with mortality data, they may be used to calculate survival rates. Registration also incorporates information about the personal characteristics and area of residence of individual patients, which means that social and geographical variations in cancer may be explored.²²

Tardy and incomplete information is an inevitable part of cancer registration. The impact of deficiencies in the data will vary between cancers at different sites, and from registry to registry. Under-reporting is thought to be a particular problem for non-invasive skin cancers, for example. Delays may also arise from the fact that Cancer Registries are population based. If a patient is treated in a region where they do not reside, the information will pass through the Cancer Registry where the hospital is located and from there to the appropriate Registry. Such variations may make it difficult to produce timely comparative data. For this reason, nationally published statistics refer to events that occurred several years in the past (e.g. UK statistics published in 2001 use data for cancers registered in 1995-97).

Key determinants of cancer

Behavioural factors

Registration data contains little information on the health-related behaviour of individuals. Such data are usually collected by specific surveys looking at a cross-section of the population.

Nationally, these surveys include the General Household Survey (GHS) and the Health Survey for England (HSE). The use of population surveys to look at social and geographical variations in health-related behaviour can be illustrated by looking at the issue of smoking.

Nationally, statistics on the prevalence of smoking in different sections of the population are collected from a number of sources:

- Information about smoking in children is gathered through a survey of secondary school children, which has been carried out by the Office for National Statistics (ONS) on behalf of the Department of Health every two years since 1982. The most recent of these was a survey of drug use, smoking and drinking among young teenagers in 1999.⁵⁰
- Data about smoking in adults are collected through a number of major national surveys of the population such as the General Household Survey (GHS) and the Health Survey for England (HSE). Both of these are carried out at regular intervals and thus provide a set of trend data about smoking trends in England.^{51 31}
- Evidence about smoking-related behaviour and attitudes is collected using a series of questions included in the Office for National Statistics (ONS) Omnibus surveys. These data were collected for the fourth time in 1999.
- Information about smoking among pregnant women is available from the Infant Feeding Survey, carried out by the Office for National Statistics on behalf of the Department of Health Departments every five years since 1975.⁵²

Some of these surveys collect information about the social characteristics of the respondent, and may be used to illustrate social variations in the prevalence of smoking or other behaviours. Most of the national surveys mentioned also allow the data to be broken down geographically in order to show variations between different parts of the country. However, the volume of data collected is usually only large enough to allow the information to be analysed at regional level.

It is much more difficult to find information describing the variations in smoking and other types of behaviour between Health Authority and other small geographical areas, such as electoral wards. However, the Department of Health has combined 3-years worth of data from the Health Survey for England (HSE) to produce a data set which can be split down to Health Authority level. Data from this source was used earlier in this Report.²⁹

At a local level, some Health Authorities have carried out local population surveys to look at the health needs and pattern of health-related behaviour in their area. These surveys have sought to collect information on a number of aspects of health and lifestyle. A recent review of health surveys in the region found that the most common areas for investigation were risk-related behaviours (e.g. diet, exercise, smoking and drinking); mental well being; self perceptions of health; long standing illnesses; social isolation (e.g. social contact, community involvement, communication links etc.) and use of health services. In some areas, the surveys have been repeated several times in order to look at changes over time.

Examples of health and lifestyle surveys carried out in the North West are shown in the box below:

Box 2 Health and Lifestyle surveys in the North West

- North Western Region 'Baseline' Health Needs Survey 1992 (All Health Authorities in Greater Manchester and Lancashire)
- Morecambe Bay Health Needs Survey (1995)
- East Lancashire Health Needs Survey (1996)
- North West Lancashire Health Needs Survey (1997)
- South Lancashire Health Needs Survey (1997)
- West Pennine Health Needs Survey (1997)
- Wigan and Bolton Health Needs Survey (2001)
- Wirral Health and Lifestyle Survey (2001)
- North Cheshire Health and Community Survey (2001)
- St Helens & Knowsley Health and Community Survey (2001)

These surveys have been produced sporadically and under different conditions. It can therefore be difficult to combine the results in order to create a complete and consistent set of information for the region as a whole.

Environmental and occupational factors

The Department of Environment, Transport and the Regions' Air Pollution Monitoring Network is a network of over 1,500 sites across the UK that collect information about air quality. The sites are located in both urban and rural locations across and measure a wide range of pollutants, including Ozone, Nitrogen Oxides, Carbon Monoxide, Sulphur Dioxide, Particles (PM10), and Hydrocarbons. Much of this information is available through the UK National Air Quality Information Archive.

There is no single comprehensive source of information for occupational and work-related disease statistics. The statistical picture must be pieced together from different sources. Moreover, it can be difficult to assess the proportion of cancer deaths that have a direct occupational link because of the complex causes of the disease, many of which may not be occupational in origin. Some cancers take a long time to grow and it can be difficult to establish a connection between the onset of the disease and the initial exposure to an occupational cause.

The Health and Safety Commission collates information about occupational exposure to cancer inducing factors, such as asbestos and industrial agents in their annual Health and Safety Statistics report.³² This includes estimates of the number of occupational related cancers gathered from several sources. Most of these cancers are prescribed diseases and qualify for compensation under the Industrial Injuries Scheme (IIS) administered by the Benefits Agency for the Department of Social Security (DSS). Diseases are only prescribed if an occupational cause is well established and if it has a genuine occupational origin. Figures for prescribed diseases are published on an annual basis.

Some cancers are also reportable under the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations (RIDDOR). These Regulations require employers to report all cases of a defined list of diseases (based on the DSS list of prescribed diseases) among their employees where they receive a doctor's written diagnosis and where the affected employees job involves activities specifically associated with the disease. However, evidence suggests that there is significant under-reporting under RIDDOR, particularly for diseases with long induction period, such as occupational cancers. Death certificates are also useful for monitoring fatal cases of diseases caused by asbestos and certain other occupational lung diseases, including lung cancer.

There are also a number of non-regulatory schemes for the reporting of occupational diseases by specialist doctors. Lung and other respiratory cancers are covered by the Surveillance of Work-related and Occupational Respiratory Disease scheme (SWORD). This is based on systematic, voluntary and confidential reporting of all new cases seen by consultant chest physicians.⁵³ This scheme is part of the Occupational Disease Intelligence Network (ODIN), run from the University of Manchester. The ODIN scheme is based on a monthly sample of a doctor's workload and any data taken from it should therefore be regarded as a minimal estimate of the true incidence of work related disease. Moreover, in many industries, employees may not have access to an occupational doctor and the data cannot, therefore, be used to make comparisons between different industries or occupations.

The Health and Safety Executive has carried out two surveys of self-reported work-related illness (in 1990 and 1995) based on a sample of households from the Labour Force Survey. They aimed to get a view of work-related illness based on the perceptions of individuals. Participants were asked whether they had suffered from any illness caused or made worse by their work and, if appropriate, re-interviewed about the nature of their illness. The 1995 Survey also sought confirmation and additional details from the doctors of people who reported a work-related illness.⁵⁴ Information from this survey is based on the opinions of individuals and, although this is of interest, it cannot be taken as an indicator of the 'true' extent of work-related illness.

Diagnosis, treatment and care of cancer

Cervical screening

There has been a national screening programme for cervical cancer since 1988. All eligible women aged between 20 and 64 are invited to attend for a cervical smear test at least once every five years.⁵⁵ The primary source of information about the national cervical screening programmes is the KC53 form, which is completed by all Health Authorities in England and submitted annually to the Department of Health. The data collected on this return are taken from the local call and recall system. This system is linked to the local patient register, which contains details of all people resident in the area. The system holds the screening record of all women who eligible to be included within the cervical screening programme, including:

- Eligibility status
- Date of last smear test
- Result of smear test
- Whether the women has been recalled following the smear result

Additional information about cervical smears examined by pathology laboratories is collected on the KC61 form. This includes details of:

- Source of smear (GP, community clinic or NHS hospital)
- The number of smears examined
- The number of inadequate specimens received
- The result of the examination.

A national summary of the information collected on the KC53 and KC61 form is produced as a Statistical Bulletin by the Department of Health.⁵⁶ This Bulletin contains a series of tables

describing the performance of the cervical screening programme. Most of this information is provided at a national level but there are some tables that present the information for individual health authorities and pathology laboratories. This can be used to look at variations in coverage and uptake by different geographical areas and levels of deprivation. The information on the KC53 and KC61 Returns is aggregated, and does not allow examination of differences in the social characteristics of women covered by the cervical screening programme. Individual health authorities may analyse data from their own call and recall systems but such analyses are not carried out consistently at a national level.

The quality of the information in both the KC53 and KC61 is highly dependent on the data provided. The KC61 is particularly vulnerable to incomplete reporting by the 163 laboratories involved in analysing cervical smear tests.

Breast screening

The national breast-screening programme invites all women aged between 50 and 64 for a mammogram at three yearly intervals.⁵⁷ Data are collected by breast screening units and health authorities, and submitted to the Department of Health as KC62 and KC63 returns. Together, these may be used to measure:

- The coverage of the screening programme among women aged 50-64
- The time elapsing between each screening
- The uptake of invitations for screening
- The outcome of the screening
- Any cancers detected by the screening

This information may also be used to look at geographical variations in coverage and uptake and to relate this to levels of deprivation.

Hospital Treatment

The Admitted Patient Care Commissioning Data Set (CDS) contains a complete record of all patients admitted to NHS hospitals, including patients receiving private treatment in these hospitals. It is based on data submitted to health authorities by NHS Hospital Trusts via the NHS-wide Clearing Service (NWCS).

The Admitted Patient Care Data Set contains a number of items of information, including:

- the patient's personal details (e.g. sex, date of birth, marital status, ethnic group etc.)
- the patient's stay in hospital (e.g. date and method of admission and discharge)
- the responsible Consultant or Midwife
- the diagnoses made
- the clinical activities carried out
- the patient's GP
- whether the patient is referred to another hospital or clinic.

Other Commissioning Data Sets deal with different aspects of hospital care, including Outpatient clinics and Accident and Emergency (A&E) Departments. Some types of CDS are optional (e.g. A&E) and the exchange of this information is dependent on the outcome of local negotiations. The possibility of developing a national data set to record information specifically related to cancer is currently being investigated as part of the NHS Cancer Information Strategy. This work is described in more detail in the next section of this Report.

Specialist palliative care

Information about specialist community nursing, including palliative care, is submitted annually to the Department of Health on the KC59 Return ("Patient Care in the Community - Specialist Community Care Nursing").⁵⁸ It contains information on the number of initial contacts (i.e. new episodes of care) made in a year by different staff groups, including Macmillan nurses, hospice nurses, Marie Curie nurses, oncology and other terminal/cancer care nurses. Results are available for Regional Offices and NHS Trusts. The Department of Health produces an Annual Summary based on information contained in the return. However, this contains no information on the sorts of activities carried out by these nurses, and cannot be used to judge the appropriateness or effectiveness of their interventions.

The Hospice Information Service undertakes an annual data collection exercise with all the hospital and palliative care services in the UK and Ireland, including inpatient, home care, day care and hospital based services. At the beginning of each year a Directory is published which lists all the individual services, showing what kind of service each provides.

In addition, an annual survey is undertaken to collect more specific information on:

- the numbers of admissions
- deaths and discharges
- day care places
- the numbers of patients seen by home care teams.

These surveys used standard definitions developed in conjunction with the National Council for Hospice and Specialist Palliative Care. This means that the data are comparable across areas and time periods. A selection of information extracted from the surveys is available from the Hospice Information Service web site.

6. Developments in cancer information

The previous section describes currently available sources of information about cancer and outlines some of the advantages and disadvantages of each source. This section describes some of the initiatives that are underway to improve existing cancer information sources or develop new ones.

The NHS Cancer Information Strategy

The national NHS Cancer Information Strategy aims to ensure that accurate, comprehensive and understandable information about cancer is accessible to a range of different users.⁵⁹ It is designed to underpin the provision of evidence-based guidance for individual cancers and tumour groups, and to support audit looking at the quality of cancer service provision.

The focus of Strategy is on four different types of information:

- Generic information about cancer
- Information about cancer services
- Information about individual cancer patients
- Information about groups and populations of cancer patients.

The strategy contains seven main recommendations, which are broken down into around ninety detailed action points. The three priority areas for early action are:

- The development of mandatory national standards for the recording and communication of clinical data about the diagnosis, treatment and care of cancer patients.
- Improving the timely communication of clinical information between health professionals in all settings and care sectors (including acute cancer care, hospice and palliative care services, and other care providers such as nursing homes).
- The production of national standards for the content, presentation and delivery of appropriate information for cancer patients and their carers.

A National Cancer Dataset is currently under development. It includes a set of data items that will be recorded for all diagnosed tumours together with a number of site-specific additional data items for specific tumour sites, currently head and neck, breast, colorectal and lung cancers. This is currently being piloted to test the suitability and flexibility of the content of the dataset and to assess how well it can be collected in a working environment.⁶⁰ It is envisaged that the implementation of the dataset will be taken forward through local *Information for Health* work programmes.

Strategic Reviews of Business Information Needs (RoBIN)

These Reviews were commissioned by the NHS Executive Board in March 2000 to ensure that the Executive has the information it needs to support the development of National Service Frameworks (NSFs) and to implement other longer-term strategies, such as Information for Health. Cancer was defined as one of the three initial subject areas for review, the others being Performance Management and Race Equality.

The Reviews seek to:

- Establish who needs what information, for what purpose, and when;
- Identify gaps in the current provision of information and make prioritised recommendations for meeting requirements;
- Produce a 'map' of the Department's organisational interests and the links between them for their respective information areas.

The review of cancer information will specifically address the linkages between morbidity, mortality, treatment, workforce and financial information. As with the other reviews, the work will explicitly cover a variety of different types of information, from routine statistics to ad-hoc surveys or sampling exercises, and include secondary analysis and research based sources. In doing this, it will help to show up cross-health care/public health information issues and pick up on data sources from outside the Department of Health.

Cancer Registry Standards

In 1999 the Department of Health commissioned a review of Cancer Registries in England (the "Gillis Report"). In response, the Department of Health produced an Action Programme for Cancer Registration.⁶¹ One of the key recommendations of the Action Programme was a revision of the existing National Core Contract for Cancer Registries. The aim of this was to allow the Cancer Registries to contribute to the wider cancer agenda by establishing a more consistent and standardised approach to key roles and responsibilities for the relevant stakeholder groups, including regional Government Offices, cancer registries, cancer networks, NHS Trusts, ONS and Primary Care Trusts.

Following on from this, a draft set of Cancer Registry Standards for England has been produced.⁶² This contains national standards and performance indicators for Cancer Registries in England, covering areas such as:

- The completeness of the data captured for the Cancer Registry Core Dataset.
- The quality of the data received from suppliers.
- The use of nationally agreed data items.
- The speed with which the registration of cases are completed.
- The implementation of national policy on Patient Confidentiality.

The standards are intended to enable both the commissioners and providers of Cancer Registry services to assess the quality of the service provided and plan their development in a standardised and consistent way.

7. Where to find further information about cancer

This section outlines where to find some of sources of cancer data described earlier in this Report. Cancer data are available in a number of different forms. These include:

- Raw data
- Paper based sources (including published summaries, research reports and 'ad-hoc' publications)
- Web-based resources

The types of data listed above together form a sort of 'information hierarchy'. At the bottom of this hierarchy are individual records of people diagnosed with, or dying from, cancer. This raw data can be aggregated into larger geographical areas or population groups and then published in a summarised form. At each stage of the hierarchy, the data occurs in a more aggregated form.

However, not all of these sources are available to all audiences. For example, individual records of deaths from cancer are available to Health Authorities and authorised researchers but will not usually be available to the general public. Conversely, published summaries of data, such as those released annually by National Statistics, are generally available to anyone. Many sources are now available on the World Wide Web (WWW).

Raw data

Access to the raw data on which most cancer statistics are based is usually restricted. Health Authorities can purchase individual records of deaths in their area from the Office for National Statistics (ONS) in an electronic format. The Public Health Mortality File (PHMF) contains a complete record of all the data items collected by the local registrar at the time of death (including name and address) and is available from ONS on a weekly or monthly basis. Alternatively, an annual extract, containing an abbreviated version of the data set, is available. This includes any amendments to the data set made after the death was registered and is thus a more final version of the data. This makes it more suitable for analysis, e.g. comparing death rates from different types of cancer for different geographical levels and population groups.

The raw data used as the basis of registration statistics are held by the local cancer registries and submitted to ONS at regular intervals. Extracts from this local data are compiled nationally and used to create the national Cancer Registration Database. Individual cancer registries may also

hold additional information that has been collected in response to local requirements (e.g. for research purposes) but is not submitted to ONS for incorporation into the national data set.

Both the mortality and cancer registration data sets contain identifiable information that are used to identify, directly or indirectly, an individual person. Access to this information is strictly controlled under the terms of the Data Protection Act and other legislation. However, Health Authorities or Cancer Registries may be able to carry out specific analysis of the original data in order to produce aggregate, non-identifiable information, for further analysis.

Paper-based sources

Published summaries

Summary information about mortality in England and Wales is published by ONS in a series of Annual Reference Volumes (ARV), journals and ad-hoc publications. Cancer data may be found in the DH2 (Mortality Statistics: Cause) and DH3 (Mortality Statistics: Childhood, infant and perinatal deaths) volumes. In addition, a Decennial Supplement is produced by ONS every 10 years. This reviews the mortality data for the previous decade and analyses the influence of socio-economic factors on different causes of death.¹³

Summary tables of selected causes of deaths for different social groups and geographic areas are also released as part of the journals Population Trends and Health Statistics Quarterly. These are both available via the ONS web site (see next section for address). Many public libraries and NHS organisations will also own copies of the paper versions of the relevant Annual Reference Volumes and Statistical Bulletins.

Information from the regional cancer registries are collated and released annually by ONS, three to four years after the date the cancer was diagnosed. The data are published in annual volumes, monitors, and on CD-ROM. Information is available down to Health Authority level, though local cancer registries are able to produce information for more specific geographical areas using postcodes.

National data on breast and cervical screening are published annually by the Department of Health in a Statistical Bulletin. These are based on data extracted from the KC53 and KC61 forms sent in by individual health authorities or screening units. The information is presented

for England as a whole, or broken down by region, health authority of residence and individual pathology laboratory. The text of this bulletin, together with the supporting data tables, is available on the Department of Health website.

Research Reports

The Office for National Statistics has recently issued two publications on cancer that combine a large amount of data from different sources. The first, "Cancer Trends in England and Wales 1950-1999", looks at trends in the incidence, prevalence and mortality for common cancers by sex, age, and area of residence. A series of appendices contain statistics about cancer in England and Wales.¹⁰

The second, "Cancer survival trends in England and Wales, 1971-1995: deprivation and NHS Region" presents survival trends since 1971 for almost 60 different cancers in adults and children in England and Wales according to deprivation of area of residence. The data are based on an analysis of 2.9 million cancer patients diagnosed during 1971-90 and followed up to the end of 1995. A CD-ROM is also available (separately from the book) that contains the data sets used in the analyses, plus supporting information, such as dictionaries of the major cancer sites.²²

The North West Public Health Observatory has produced a report summarising patterns of alcohol, tobacco and drug use in the region. This reviews the evidence regarding the problems associated with the use of these substances and provides a North West perspective to issues related to policy and treatment.⁶³ The Report is available on the North West Public Health Observatory web site.

'Ad-hoc' local reports

Both of the cancer registries in the region have produced reports describing the patterns of cancer in their area.^{20 21} Publications from the Merseyside and Cheshire Registry include 5-year incidence reports, bulletins on particular cancer sites and a number of research papers. A full list of these reports is contained in the box below.

Box 3 Recent publications from local agencies analysing cancer data

- Trends in Cancer Incidence and Survival in Greater Manchester and Lancaster (Centre for Cancer Epidemiology, University of Manchester, 1998)
- Cancer Incidence in Merseyside and Cheshire 1990-1995 (Merseyside and Cheshire Cancer Registry, University of Liverpool, 1998)
- Breast Cancer Bulletin: Stimulating the debate (Merseyside and Cheshire Cancer Registry, University of Liverpool, 1994)
- Skin Cancer Bulletin: Establishing the baseline (Merseyside and Cheshire Cancer Registry, University of Liverpool, 1994)
- Cervical cancer in the North Western Region (Centre for Cancer Epidemiology, University of Manchester, 1994)
- Skin cancer in the North West (Centre for Cancer Epidemiology, University of Manchester, 1994)
- Breast cancer in the North Western Region (Centre for Cancer Epidemiology, University of Manchester, 1993)
- Lung Cancer Bulletin: A framework for action (Mersey Regional Cancer Registry, University of Liverpool, 1993)

Web-based resources

The Policy context

As part of the electronic government initiative, all major policy documents are now available on-line. The national NHS Plan and other related documents are accessible on the Web site <http://www.doh.gov.uk/nhsplan/index.htm>. The Saving Lives: Our Healthier Nation site at <http://www.ohn.gov.uk/> provides a gateway to information and policy documents relating to improving health and tackling health inequalities.

The cancer index site at <http://www.doh.gov.uk/cancer/index.htm> contains links to different strands of cancer policy, including the Calman-Hine Report, the NHS Cancer Plan, the Cancer Plan Policy Forum and the Cancer Commissioning Pilots. For easier reference, the various links are divided into those relating to 'action', 'good practice' 'information' and 'other

documents'. A full version of the NHS Cancer Plan, together with other supporting material, can be accessed at: <http://www.doh.gov.uk/cancer/cancerplan.htm>

General cancer information

NHS Direct Online (<http://www.nhsdirect.nhs.uk/>) provides a national gateway to information about a range of medical conditions and treatment, including those for cancer. It also includes a set of audio clips on a wide range of health topics.

The UK Cancer Index (<http://www.CancerIndex.org/>) contains an annotated directory of over 4,000 Internet links sorted by cancer type, medical specialty, country and other topics and provides a useful 'one stop' guide to cancer resources on the Web. It also includes an introduction to the medical terminology used in connection with the disease. CancerBACUP (<http://www.cancerbacup.org.uk/>) contains over 2000 pages of up-to-date cancer information for use by both patients and professionals.

Statistical data and reports

Full versions of ONS publications can be viewed online or downloaded for future reference at <http://www.statistics.gov.uk>. The ONS web site also contains a link to StatBase, an on-line searchable database of Government statistics. This can be accessed via the ONS web site at <http://www.statistics.gov.uk/statbase/mainmenu.asp>. The site also provides a detailed description of other statistical products and services, together with contact points for further information. Copies of ONS publications can also be purchased from local Stationary Office bookshops or on-line at <http://www.theso.co.uk/>.

The Department of Health publishes a range of statistical data, some of which is held on the Statistics and Surveys section of the Department of Health web site at <http://www.doh.gov.uk/public/stats1.htm>. The site includes the data used to measure *Our Healthier Nation* targets, the NHS High Level Performance Indicators and information about the national breast and cervical screening programmes.

The web site of the National Cancer Services Analysis team has been set up to disseminate key documents, data sets and clinical databases to health care professionals, patients, carers and members of the public. It also provides access to the Cancer Network Toolkits, a suite of programs designed to collect and analyse a variety of data on cancer services. This web site can be found at <http://www.canceruk.net/cancernw/cancernw.htm>.

Data drawn from the annual survey of hospices and palliative care services undertaken by the Hospice Information Service are available at <http://www.hospiceinformation.co.uk/facts>. A copy of the minimum data set collected by these surveys is also available on this site.

The Epidemiology and Medical Statistics Unit (EMSU) of the Health and Safety Executive carries out a wide range of tasks, including the collation, analysis and publication of data from a range of statistical sources. It also carries out epidemiological studies into particular risks; and advises on the interpretation and use of epidemiological evidence. Further information about EMSU can be obtained through the Health and Safety Executive's web site at <http://www.hse.gov.uk>.

Other data specifically relating to the North West are available through the North West Public Health Observatory at <http://www.nwpho.org.uk>. This site allows users to download data for different geographic areas in the North West and to search for other national, regional and local data sets.

Cancer Registration

Information about cancer registration in the UK and abroad is also available on the Internet. The UK Association of Cancer Registries (UKACR) has a web site at <http://www.thames-cancer-reg.org.uk/ukacr/ukacr.htm>. Further details of cancer registration outside the UK can be found via the European Network of Cancer Registries at <http://www.dep.iarc.fr/encr.htm> or the International Association of Cancer Registries at <http://www.dep.iarc.fr/iacr.htm>. This last site also provides access to information about the International Agency for Research on Cancer and contains the facility to download data about global and European cancer rates.

Developments in cancer information

Further details of the NHS Cancer Information Strategy and its related projects can be accessed via the NHS Information Authority (NHSIA) at <http://www.nhsia.nhs.uk/cancer/>. This site also contains background information about the national NHS Information Strategy, Information for Health and a copy of the document itself.

Information about the ongoing Strategic Reviews of Business Information Needs (ROBIN) around cancer, performance management and race equality can be found on via the Department of Health web site at <http://www.doh.gov.uk/robin/>.

The draft Cancer Registry Standards for England (Version 2.1) can be accessed via the Department of Health cancer site at <http://www.doh.gov.uk/cancer/index.htm>.

Charities and research organisations

Charities and research organisations provide a useful source of information about cancer and the services available to patients and their families. Among the largest of these are the Cancer Research Campaign (<http://www.crc.org.uk/>), the Imperial Cancer Research Fund (<http://www.imperialcancer.co.uk/>) and Macmillan Cancer Relief (<http://www.macmillan.org.uk/>).

Action on Smoking Health (ASH) is a London-based charity that campaigns to reduce the unnecessary addiction, disease and premature death caused by smoking. It also provides information on all aspects of tobacco. Their web site may be found at <http://www.ash.org.uk/>.

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The North West Public Health Observatory aims to improve health in the North West by enhancing access to public health information and intelligence. The Merseyside and Cheshire Zone aims to help local users to make better use of health related information by increasing awareness of local information sources and facilities the flow of knowledge between users and producers of public health information. In doing so, it seeks to promote the use of this knowledge to inform policy and practice in local areas.



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