

Evidence to March 2010 on  
cancer inequalities in England

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# Evidence to March 2010 on cancer inequalities in England



**National Cancer Action Team**

## Note on previous publication

This report was originally published in March 2010 as an annex to the National Cancer Equalities Initiative (NCEI) report '*Reducing cancer inequality: evidence, progress and making it happen*'. It is republished here as a summary of the National Cancer Intelligence Network's work on cancer inequalities, supplemented where appropriate with references to other published work and the NCEI's visioning events.

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## Introduction

*Reducing cancer inequality: evidence, progress and making it happen* makes clear the critical importance of accurate information on the extent, nature and causes of cancer inequalities if action to promote greater cancer equality is to be effective. A significant part of the first phase of the NCEI has been to gather evidence and stimulate discussion amongst experts, creating a more comprehensive evidence base to inform concerted action to promote equality.

This annex brings together information from the visioning events which were organised and facilitated by the NCEI, as well as the results of the National Cancer Intelligence Network's work during its first 18 months of operation. The annex:

- Summarises the evidence base on inequalities in cancer in England according to deprivation, age, gender, ethnicity, disability, sexual orientation and religion (although much more is known in some areas than others);
- Highlights the important messages which anyone considering commissioning or undertaking interventions to promote greater cancer equality should consider; and
- Signposts readers to sources of more detailed information.

The advances that have been made in collecting evidence on cancer inequalities is a tangible demonstration of the importance of partnership working. Many of the analyses conducted since the publication of the Cancer Reform Strategy are a direct result of the partnership forged between the NCIN and the NCEI. This approach will continue as the NCEI moves into its next phase. In order to inform local action, it will be important that information on cancer inequalities should be available on as local

a level as possible. Therefore this annex should be used in conjunction with the equalities portal ([www.ncin.org.uk/equalities/](http://www.ncin.org.uk/equalities/)) which will be an invaluable resource to inform local action, measure progress and compare performance on promoting cancer equality. The metrics contained in the portal will be updated over time and expanded as new data and analyses become available.

### Where does information on cancer inequalities come from?

Much of the information that is available on cancer inequalities in England (and the UK) comes from cancer registries. These record data on all individuals diagnosed with cancer, including date of birth (age), gender and postcode of residence. These data inform the publication of statistical reports on cancer incidence, mortality, survival and other measures. In addition to information on age and gender, postcode can be used as a good proxy for affluence/deprivation, especially in analyses involving very large numbers of patients, through the use of geographic measures such as the index of multiple deprivation. More recently, the National Cancer Intelligence Network has been able to link cancer registrations to Hospital Episode Statistics (HES), which provide data on hospital inpatient admissions. This, for the first time, has allowed national analyses of cancer incidence and survival by ethnicity.

In addition to the data that should be collected about every cancer patient in England, surveys of population samples can provide valuable insights. For example, the recently published Cancer Awareness Measure (CAM) provides a validated instrument for assessing the public's knowledge of cancer and has been used both locally and in two national surveys.

Data generated from the initial national surveys using the CAM are now available from the UK Data Archive ([www.data-archive.ac.uk](http://www.data-archive.ac.uk)) and are summarised in the equalities portal. Similarly, the National Cancer Patient Experience Survey Programme will provide information on the experiences reported by a large sample of cancer patients, building on previous similar exercises by the Department of Health and the National Audit Office.

Information gained through NHS data collection can be supplemented by smaller scale research studies. Many of these were presented at the visioning events and, where appropriate, their findings are summarised in this annex.

As set out in *Reducing cancer inequality: evidence, progress and making it happen*, the information which is available on inequalities varies according to equality group. As a consequence of differences in data capture and the differences in population numbers associated with different equality groups, there is much more information for some inequality areas than for others. In particular, there is much less information related to sexual orientation, disability and religion and belief than to ethnicity, age, gender and socioeconomic deprivation. It is also important to stress that some cancer information (for example 5 year survival data) may, of necessity, be several years old and this can affect the utility of some analyses.

### Information on equality groups

This annex contains information on each of the equality groups considered by the NCEI. Information has been summarised under the following groupings:

- Incidence and mortality;
- Survival and prevalence;
- Awareness and stage of diagnosis;
- Screening;
- Treatment;
- Patient experience; and
- End of life care.

### Developing the evidence base

The NCIN is prioritising further information on a number of areas of the cancer pathway. Work will particularly focus on:

- Treatment – to identify confidently equality issues in this area it is important to understand not just what treatment a patient received, but also how clinically appropriate the treatment was. This requires information on both how advanced the patients cancer is (the stage of disease) and any unrelated diseases that may affect treatment (co-morbidities). Unfortunately, for most types of cancer, data on stage at diagnosis and co-morbidities are not available at a national level. A high priority for NCIN is working with the NHS to improve collection of this vital information.
- End of life care – information on the services that patients from different equality groups receive near the end of their life remains limited. The NCIN is working with the newly created End of Life Care Intelligence Network, established as a result of the End of Life Care Strategy, to develop the evidence base in this area.

In addition, the impact of rurality on cancer has not been fully explored. As set out in *Reducing cancer inequality: evidence, progress and making it happen*, the NCIN is now collaborating with the Commission for Rural Communities to address this.

## Gender

### Key facts

- Adjusting for women's longer life expectancy, men are diagnosed with more cancers and have a higher mortality from cancer. As a result, there are more women than men living with or beyond a diagnosis of cancer. Men's one-year survival is generally similar to or slightly better than women's for individual cancer types. Despite this, the different mix of cancers in women means that their overall one-year survival is significantly better.
- The National Cancer Patient Survey of 2004 showed that, for those cancers which affect both sexes, men generally report more favourably on their care than women. However, this and an earlier survey showed poor patient experience for men with prostate cancer.
- Men have a lower awareness of the signs and symptoms of cancer and a lower uptake of screening. Although it has been assumed that men delay seeking help, there is no evidence that this is the case.
- More men than women die at home. This may be explained by men, on average, dying at a younger age than women and therefore being more likely to have a care giver, often a spouse.

**More information can be found in: *The Excess Burden of Cancer in Men in the UK*<sup>1</sup>**

### Cancer incidence and mortality

The total number of new cases of cancer diagnosed each year in this country is remarkably similar (147,000 in males; 146,000 in females). The number of cancer deaths in males (81,000 per annum) is somewhat higher than that for females (75,000 per annum).

However, these very similar headline figures mask some major differences in incidence and mortality once age is taken into account. Women live longer and could therefore be expected to have higher numbers of new cases and deaths. Once these figures are age standardised there is an excess incidence of 16% and an excess mortality of 38% in men, although this varies according to cancer type. A recent study undertaken by the NCIN in collaboration with the NCEI, Cancer Research UK, The Centre for Men's Health at Leeds Metropolitan University and the Men's Health Forum

has highlighted these differences, which are shown in Table 1 below<sup>1</sup>.

### Cancer survival and prevalence

Overall, one year relative survival for women is better than for men (69% vs 64% in 2000-2004). This is caused by high one year survival rates for breast cancer as well as differences in the relative incidence of different cancers in men and women (for example a greater proportion of lung cancers in men due to historical smoking patterns )<sup>2</sup>.

Survival rates among males have been improving more quickly than for females over the past two decades and therefore this gap is closing (as shown in Figure 1). For cancers which affect both sexes, however, there was little difference between one-year survival from men and women in the period 2000-2004. For several sites male survival was slightly better and for bladder cancer one year relative survival was 77.4% compared to 65.7% for females. For women, higher

**Table 1. Excess Incidence and Mortality in Men.**

	Excess in men	
	Incidence	Mortality
All cancers except non-melanoma skin cancer (ex. NMSC)	16%	38%
All cancers ex. NMSC and lung	10%	31%
All cancers ex. NMSC, breast and sex specific cancers	62%	69%
All cancers ex. NMSC, breast, lung and sex specific cancers	61%	71%
Oesophagus	148%	168%
Stomach	148%	132%
Colorectal	54%	56%
Liver	121%	99%
Pancreas	27%	27%
Lung	64%	65%
Melanoma	-8%	46%
Kidney and other urological	99%	107%
Bladder	230%	194%
Brain and central nervous system	53%	52%
Non-Hodgkin's Lymphoma	39%	57%
Myeloma	52%	39%
Leukaemia	72%	79%

This table shows the excess incidence and mortality for UK men in 2006 (incidence) and 2007 (mortality). Figures are for all ages and are based on the age standardised rate ratios presented in the NCIN report on 'The Excess Burden of Cancer in Men in the UK'<sup>1</sup>. NMSC is Non Melanoma Skin Cancer.

relative survival rates were only seen for malignant melanoma, where one-year survival for both sexes was over 95%<sup>2</sup>.

Overall, it is estimated that there were 1.6 million people alive with a cancer diagnosis in England at the end of 2008. Of these, around 60% were women. The most prevalent types of cancer are those with a relatively high incidence rate and a good prognosis. For example, the most prevalent cancer in males is prostate cancer and in females is breast cancer<sup>3</sup>.

### Awareness and stage of diagnosis

It is widely assumed that men seek advice on symptoms which could be related to cancer later than women. However, a systematic review of the research literature found little evidence to support this assumption<sup>4</sup>. There is evidence from use of the CAM that levels of awareness amongst women and men vary according to cancer and knowledge of the

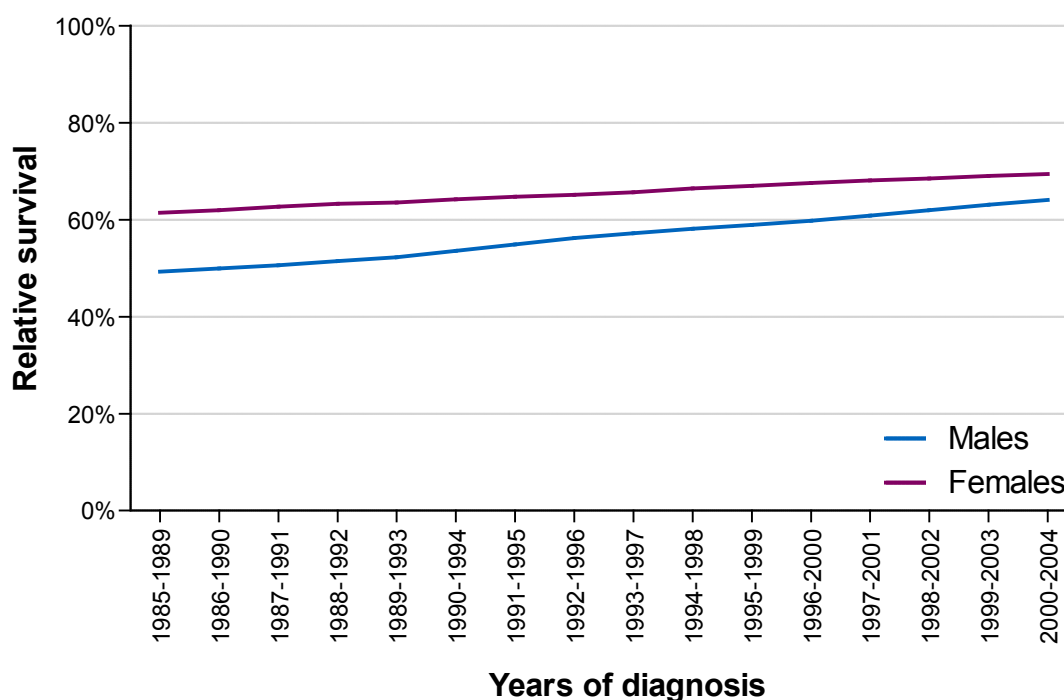
warning symptoms and signs of cancer is somewhat lower amongst men than women. Men also anticipate a longer delay in seeking help than women but this may not reflect their actual behaviour<sup>5</sup>.

Experts at the NCEI's gender visioning event highlighted that men and women access, and respond to, information about cancer signs and symptoms in very different ways and that this should be taken into account when planning interventions. It was also noted that some men find GP services to be inaccessible and that further work is needed to develop 'male friendly' primary care services<sup>6</sup>.

### Screening

Bowel cancer screening is the only national cancer screening programme which applies both to men and women. Uptake rates vary according to screening centre, but in both the pilot study<sup>78</sup> and the initial

**Figure 1. One year relative survival for all malignant neoplasms (ex. NMSC) for males and females by period of diagnosis.**



Reproduced from the NCIN report on 'One Year Cancer Survival'<sup>2</sup>. NMSC is Non Melanoma Skin Cancer.

rollout of the national programme have been somewhat lower in men than women<sup>9</sup>.

### Treatment

There is some evidence that men and women with comparable cancers receive different treatment, although the reasons for this are not clear<sup>10</sup>. During 2010, NCIN will produce a national report on the use of curative surgery for major cancer sites, including an analysis of differences in the rate of surgery between age groups and gender.

### Patient Experience

The national cancer patient survey<sup>11</sup> showed that, for those cancers which affect both sexes, men generally report more favourably on their care than women. However, both this and the later survey by the NAO showed poor patient experience for men with prostate cancer<sup>12</sup>. It is possible that this reflected the underdevelopment of specialist teams for prostate cancer at the time of the surveys, in comparison with those for breast, colorectal and lung cancer.

### End of Life Care

Including all causes, hospital is the most common place of death for both men and women. However, men are more likely than women to die at home, while the proportion of women who died in nursing homes was almost twice that of men (11% vs 6%)<sup>13</sup>. It is possible that this is due to men's lower life expectancy, which means they are more likely to have a care giver, often a spouse. This has implications for patients, carers and health and social care services.





## Socio-economic deprivation

### Key facts

- The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups. A large part of this is likely to be attributable to lifestyle factors, and especially the higher smoking rates in deprived groups. The excess mortality may also be linked to later presentation/diagnosis in more deprived groups.
- There is a clear survival gap between the most and least deprived. Survival rates are lower in Spearhead PCTs, although the rate of improvement is faster than for the population as a whole.
- Health literacy is likely to be a particular problem for some socioeconomically deprived patients.
- Awareness of the signs and symptoms of cancer is lower amongst socially deprived groups than the population as a whole and, for the cancers where there is a national screening programme, uptake of screening is also lower.
- There is some evidence to suggest that otherwise similar patients from different socioeconomic groups receive different treatment within the NHS, although this requires further investigation to understand how much of this is due to later stage of presentation and co-morbidities.
- People from more deprived social groups are less likely to die at home than those from more affluent groups.

***More information can be found in: Cancer Incidence by Deprivation<sup>14</sup> and Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001<sup>15</sup>***

### Cancer incidence and mortality

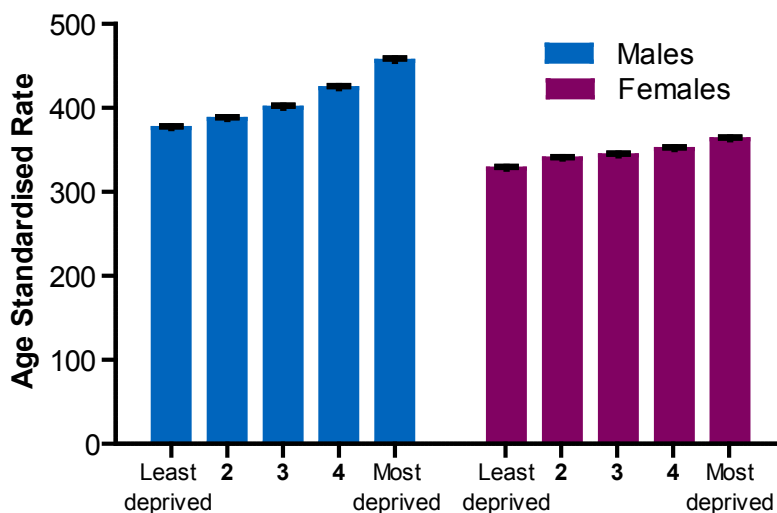
The use of socio-economic measures, such as the Index of Multiple Deprivation<sup>16</sup>, allows the analysis of cancer registration and other data where geographic residence of the patient is known. Overall, socioeconomic deprivation is associated with increased incidence of cancer. From 2000-2004 there would have been around 71,600 fewer cases of cancer if the incidence for all quintiles had been the same as the least deprived<sup>14</sup>.

Figure 2 displays age standardised incidence rates for males and females by deprivation quintile. This shows that there is a statistically significant increase in overall cancer incidence with deprivation. The analysis also shows that the increase in incidence by

deprivation quintile is significantly larger for males than the increase for females.

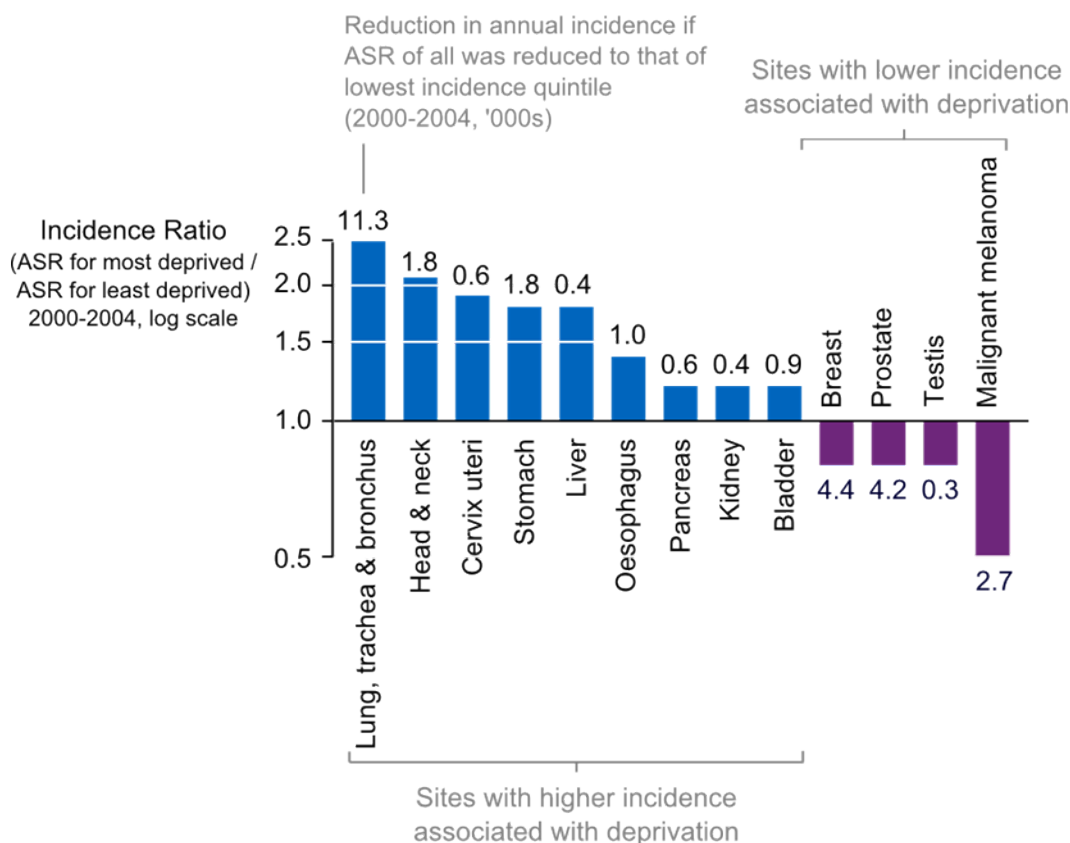
There is a close association between deprivation and cancer risk factors including smoking, alcohol consumption, obesity and infections (Helicobacter Pylori / Hepatitis B&C)<sup>17-20</sup>. Reproductive factors, UV exposure and uptake of PSA testing also vary with deprivation but, unlike the previous set of factors, tend to increase incidence among the more affluent (although patterns of UV exposure are shifting)<sup>18,21,22</sup>. Figure 3 shows incidence ratios for the most deprived compared with the least deprived for selected cancer sites. Figure 3 also shows the possible reduction in annual incidence if the age standardised rate for all groups was the same as the quintile with lowest incidence. The greatest opportunity remains

**Figure 2. Age standardised incidence for all malignant neoplasms (ex. NMSC) by deprivation quintile, England, 2000-4.**



Reproduced from the NCIN report on ‘Cancer Incidence by Deprivation’<sup>14</sup>. Error bars show 95% confidence intervals. NMSC is Non Melanoma Skin Cancer.

**Figure 3. Age standardised Incidence rate ratios (most deprived / least deprived) for selected sites, England, 2000-4.**



Based on ratios published in the NCIN report on ‘Cancer Incidence by Deprivation’<sup>14</sup>.

a reduction in the incidence of lung and other associated cancers through smoking cessation programmes.

### Cancer mortality

Mortality from all cancers between 1999 and 2003 was 70% higher among the most deprived men and 40% higher among the most deprived women when compared to the least deprived groups. The difference between men and women is at least partially explained by the tumour mix, with a greater proportion of men’s cancers being made up of lung cancers (which has a high level of mortality), while women have a large proportion of breast cancers with lower mortality<sup>23</sup>.

There is no relationship with deprivation for breast cancer and only a small negative association for prostate cancer, despite higher incidence for the most affluent. This suggests that the better survival

for the affluent offsets the higher incidence of these cancers.

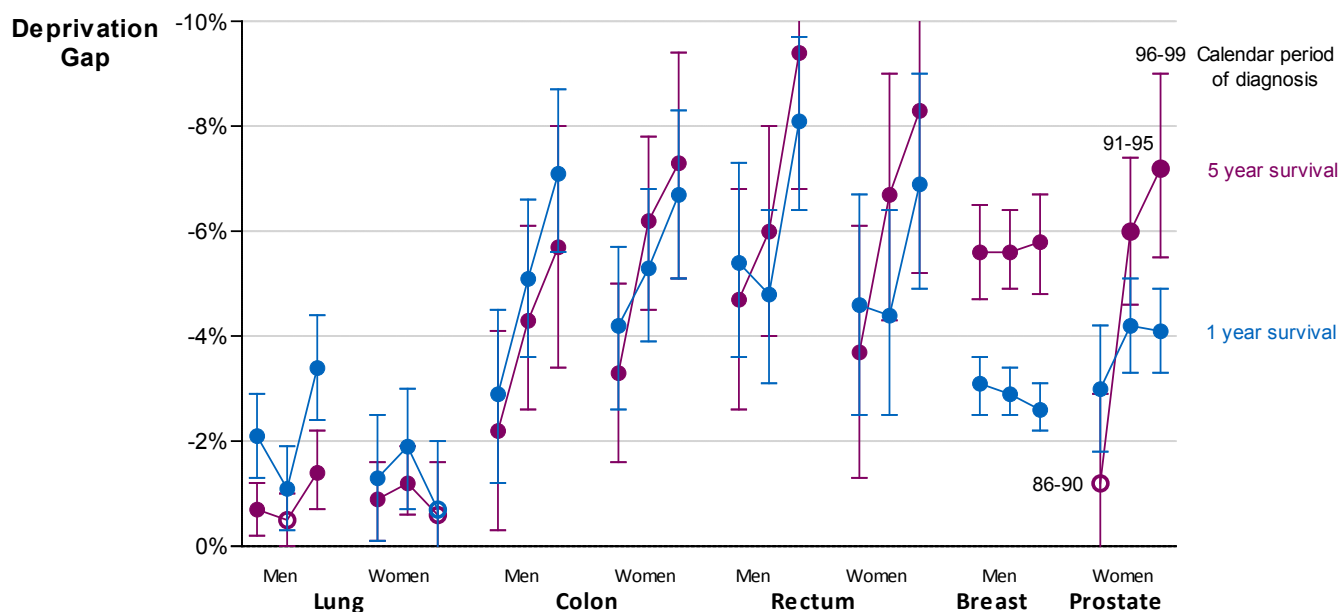
As described in Reducing cancer inequality: evidence, progress and making it happen, the mortality target for the Spearhead Group of PCTs has already been met. Data on mortality by PCT were published in the second annual report on the CRS<sup>24</sup> and are available from the Equalities Portal.

### Cancer survival and prevalence

The most recent comprehensive analysis of cancer survival in England comes from a supplement to the British Journal of Cancer published in December 2008<sup>15</sup>.

Figure 4 shows deprivation gaps in 1 and 5 year survival and changes in these over time for five selected sites. Survival is significantly worse for the more deprived groups at both 1 and 5 years for each of the most common cancers (except lung cancer in women). For cancers of the colon, rectum and

**Figure 4. Deprivation gap for 1yr and 5yr relative survival for three diagnosis periods (selected sites, England and Wales).**



The deprivation gap is the absolute difference in relative survival between the most deprived and most affluent groups, fitted by a regression model to take account of all deprivation groups. Negative values indicate lower survival for the most deprived. Error bars show 95% confidence intervals, open circles indicate that deprivation gaps are not statistically significant at the 5% level. Based on information in ‘Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001: population-based analyses and clinical commentaries’<sup>15</sup>.

**Table 2. Five year relative survival estimates (age standardised) up to 2005 for adult patients diagnosed during 2000-4, major cancers, Spearhead Primary Care Trusts and the rest of England.**

Cancer		Spearhead PCTs		Rest of England		Difference (% points)
		Number of patients	Five-year relative survival	Number of patients	Five-year relative survival	
Breast	Women	56, 178	80.5%	110,401	81.2%	-0.7
Colon	Men	14,794	47.7%	27,423	49.5%	-1.9
	Women	13,569	49.3%	26,903	50.2%	-0.9
Lung	Men	33,872	6.5%	48,935	6.7%	-0.1
	Women	23,377	8.2%	31,629	8.4%	-0.2
Prostate	Men	42,959	75.4%	87,182	75.4%	0.1

Reproduced under the terms of the Click-Use Licence from 'Trends in cancer survival in Spearhead Primary Care Trusts in England, 1998-2004'<sup>25</sup>.

prostate these gaps have clearly grown worse with time. Possible causes for these gaps include:

- Differential stage at diagnosis, related to uptake of screening and early diagnostic procedures
- Differential access to optimal treatments
- Co-morbidities that impact treatment

One-year cancer survival for breast, lung and colorectal cancer at PCT level was published in the second report on the Cancer Reform Strategy<sup>24</sup>. A separate analysis of survival rates in Spearhead PCTs (reproduced in Table 2) showed that one year survival was lower in spearhead PCT's compared to the rest of England for 11 of the 16 common cancer sites analysed<sup>25</sup>. The study did note, however, that improvements were being made at a slightly greater rate within spearhead PCT's than the rest of England.

### Awareness and stage of diagnosis

For some cancers patients from socioeconomically deprived groups tend to present later than others and thus have more advanced disease and a worse prognosis. A recent systematic review<sup>4</sup> has shown a significant relationship between lower socioeconomic status and delayed presentation for men with prostate cancer and for patients with symptoms of upper gastrointestinal cancers. Lower levels of education were associated with greater delay

for breast cancer and colorectal cancer. However, the pattern is not uniform across all cancers. Some sites showed no significant relationship between delay and socioeconomic status (colorectal cancer, gynaecological cancers, lung cancer) or educational attainment (urological cancers, gynaecological cancers, lung cancer).

Initial use of the CAM has shown that those from lower Socio Economic Status (SES) groups recall (i.e. identify without prompting) or recognise (i.e. identify from a list of possible symptoms) fewer cancer symptoms than those from higher SES groups<sup>5</sup>. Information on recall of cancer symptoms is presented in the Equalities Portal.

### Screening

Uptake of invitations to screening is lower in socially deprived groups for each of the three cancers for which screening is available (breast, cervix and bowel)<sup>26-28</sup>. Screening uptake by PCT was published in the second annual report on the CRS<sup>24</sup> and is available from the Equalities Portal.

### Treatment

There is some evidence to suggest that otherwise similar patients from different socioeconomic groups receive different treatment within the NHS. Women with breast cancer are less likely to receive

surgery (even when adjusted for stage of disease) and less likely to receive breast conserving surgery<sup>29</sup>. The less deprived are more likely to receive active treatment for lung cancer<sup>30</sup>. There is greater use of abdominoperineal excision (a procedure which may be less effective and result in lower quality of life for many patients) for those from deprived groups with colorectal cancer<sup>10</sup> and fewer patients from deprived areas receive radiotherapy<sup>29</sup>. The NCIN's report on curative surgical will include an analysis of differences in the rate of surgery by deprivation.

### **Patient Experience**

The 2004 survey of cancer patient experience published by the National Audit Office did publish findings according to socioeconomic group but did not find any significant difference in experience<sup>12</sup>.

### **End of Life Care**

The likelihood of dying in hospital from all causes increases with social deprivation (60% of the most deprived quintile vs 53% of the least deprived quintile). In contrast, the proportion of people dying at home or in an old people's home is lowest for the most deprived and the likelihood of dying in a hospice decreases with social deprivation (although not for over 85s)<sup>13</sup>.



## Age

### Key facts

#### *Older people*

- For the vast majority of cancers, incidence increases with age. Just over half of all cases of cancer diagnosed in 2003-5 in England occurred in people over 70 years and over a fifth in people over 80 years. Despite this, older people may not be aware of their increased risk and may have lower awareness of cancer symptoms than younger age groups.
- Significant reductions in cancer mortality have been achieved among the under 75s over the past decade. However, the improvement has been much less marked for the over 75s. Cancer survival decreases with age and there is evidence that older people's cancers are investigated and treated less intensively.

*More information can be found on Cancer Research UK's 'Cancer Stats' website<sup>31</sup>*

#### *Younger people*

- Cancers in children aged less than 15 years old are rare, with an age standardised incidence rate of 139 per million children each year in the period 1991-2000. For teenagers and young adults (aged 13 to 24), the overall incidence rate of cancer was 224 cases per million persons each year in the period 1999-2003.
- Overall five-year survival from childhood cancers was 76% for children diagnosed between 1996 and 2000 and has increased significantly over the last forty years. Despite this, cancer remains a significant cause of death among children, teenagers and young adults (but not infants aged less than 1), exceeded only by transport accidents.
- The low incidence of cancers in these age groups presents challenges to GPs in terms of identifying potential signs and symptoms of cancer and referring appropriately. There is some evidence that teenagers and young adults are not always referred to the appropriate specialist services<sup>32</sup>.

## Cancer and older people

### Cancer incidence and mortality

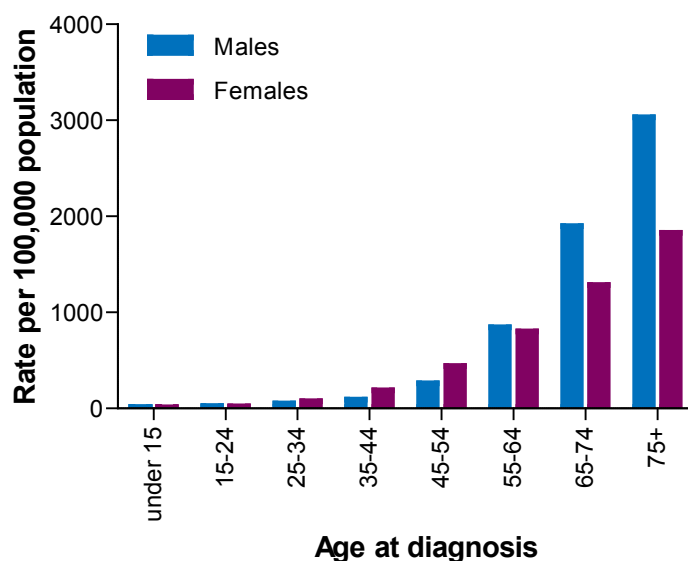
For the vast majority of cancers, incidence increases with age. Figure 5 shows incidence rates for all cancers (ex. NMSC) by broad age groups in the UK for 2006.

This trend is seen for each of the four most common cancers (breast, lung, colorectal and prostate),

with 44% of all cases of colorectal and lung cancer occurring in patients age over 75 (see Table 3).

Unsurprisingly, mortality rates also increase with age and are therefore highest amongst the over 85s (see Figure 6). In 2007, over 50% of all cancer deaths occurred in patients aged over 75. The number of people dying from cancer in the under 75s dropped by around 17% between 1998 and 2007. However, improvements in mortality have been less pronounced in people aged 75-84 years with the

**Figure 5. Incidence rates for all cancers (ex. NMSC) by age group, UK, 2006.**



Reproduced with permission from Cancer Research UK Cancer Stats website<sup>31</sup>. NMSC is Non Melanoma Skin Cancer.

age-truncated mortality rate falling by only 4% from 1998 to 2007. Amongst people over 85 years there has been a small decrease in mortality for males and a small increase for females (Analysis of data from Cancer Research UK Cancer Stats website<sup>31</sup>).

**Cancer survival and prevalence**

Consistent with the increasing incidence of cancer with age, the prevalence of cancer is higher in older age groups. On 31<sup>st</sup> December 2008, the prevalence of cancer for males aged over 65 was estimated to be 13,136 per 100,000 population, compared with 392 per 100,000 for males under 44 and 2,563 per 100,000 for those aged 44-65. For females the equivalent figures were estimated as 12,661 for the over 65s, 538 for under 44 year olds and 4,990 for 44-65 year olds<sup>3</sup>.

In general cancer survival decreases with age (see Figure 7). This may be due to co-morbidities or general frailty, differences in treatment (see below), to differences in the nature of the cancers diagnosed in younger people, or to differences in the stage at which the disease is diagnosed<sup>34-36</sup>.

**Awareness and stage of diagnosis**

Awareness of the symptoms and signs of cancer increases in people up to 64 years<sup>5</sup>. However, some older people may not be aware that they are at higher risk of developing cancer than younger people. This has, for example, been clearly demonstrated with regard to breast cancer<sup>37</sup>.

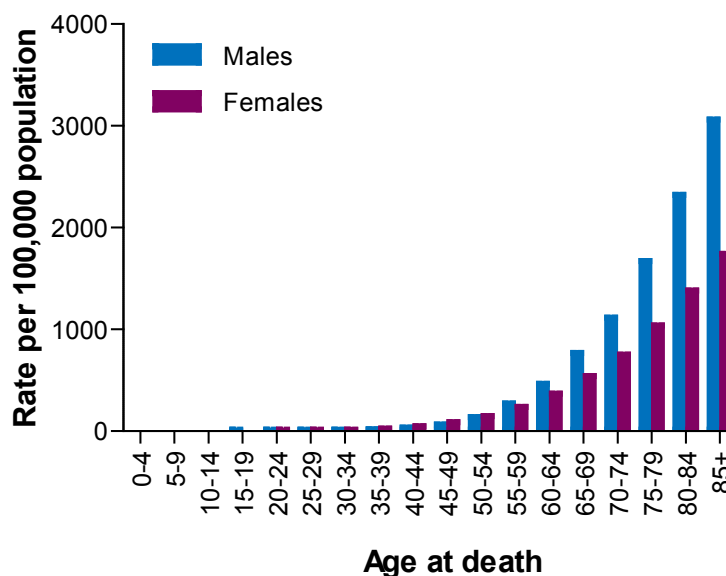
There is strong evidence that older women present later with breast cancer than younger women. Somewhat surprisingly, the research evidence for

**Table 3. Proportion of newly diagnosed cancers, by age group, England, 2007.**

	Total cases	Under 24	25-49	50-74	75+
All cancers ex. NMSC	245,327	1%	10%	53%	36%
Breast (female)	38,048	0%	19%	56%	24%
Prostate	30,201	0%	1%	62%	37%
Colorectal	30,727	0%	5%	51%	44%
Lung	31,571	0%	3%	53%	44%

Reproduced under the terms of the Click-Use Licence from Registrations of cancer diagnosed in 2007, England. Series MB1 No. 38<sup>33</sup>. (NMSC is non melanoma skin cancer).



**Figure 6. Deaths and mortality rates for all cancers (ex.NMSC) by age group, UK, 2007.**

Reproduced with permission from Cancer Research UK Cancer Stats website<sup>31</sup>. NMSC is Non Melanoma Skin Cancer.

other cancers related to late presentation at older ages is much more equivocal<sup>4</sup>. However, particularly poor one year survival rates in older populations suggest that later presentation may be an issue<sup>38</sup>.

### Screening

All screening programmes have an upper age limit at which people are routinely invited for screening. At present these are 65 years for cervical screening, 69 years for bowel cancer screening and 70 years for breast cancer. The age range for bowel cancer is set to be extended to 75 years and for breast cancer to 73 years as part of the Cancer Reform Strategy<sup>39</sup>. These age ranges are largely determined by the results of trials of the effectiveness of screening. Older women can undergo mammographic screening every 3 years at their own request<sup>37, 40</sup>.

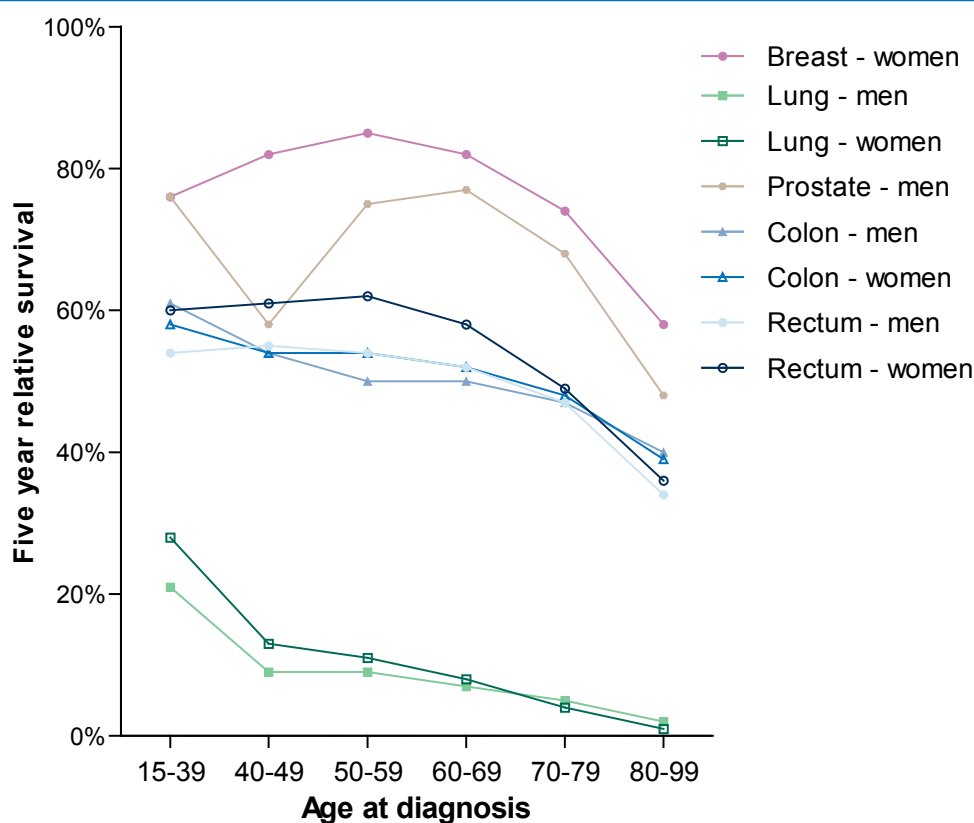
The review undertaken by Sir Ian Carruthers OBE and Jan Ormondroyd, Achieving age equality in health and social care, recommended that, *“a programme of research is commissioned that enables the Advisory Committee on Breast Screening to advise on the upper limit of the breast cancer screening programme, and regularly updates the evidence.”*<sup>41</sup>.

To take this recommendation forward, the Department of Health will use the opportunity for research provided by the planned extension of the breast screening programme to women aged 47-49 and 71-73. The extension is being randomised by screening batch so that half of eligible women will be invited at age 47-49 and half at age 71-73, creating natural control groups of those women not invited in those particular age ranges. The Advisory Committee on Breast Cancer Screening has also recommended that the cohort of women being invited at age 71-73 should be re-invited for a further two screening rounds at ages 74-76 and 76-79. This would give sufficient numbers in the screened cohort and the control cohort to make decisions based on the benefits and harms of screening in this age range.

### Treatment

In general, older people with cancer receive less intensive/radical treatment than younger people<sup>42</sup>. The issue is whether or not this is appropriate for their condition. Older people may be frailer than younger people and thus less able to withstand intensive treatment. They may also present with more advanced disease, for which radical treatments may not be appropriate. However, older people are

**Figure 7. Five-year relative survival, by site and age at diagnosis, England and Wales, 1996-1999 followed up to the end of 2001.**



Prepared based on data from Cancer Research UK Cancer Stats website<sup>31</sup>.

not uniformly frail and may enjoy good biological health and many years' life expectancy.

Detailed research studies have been undertaken on the treatment given to older women with breast cancer in the North West. These have shown that older women are investigated less intensively and are less likely to receive potentially curative surgery. Older age was shown to be the major factor determining treatment even when tumour characteristics had been accounted for<sup>43</sup>. A study on chemotherapy has also revealed that age is a major factor in influencing clinical judgement, irrespective of other factors such as co-morbidities and tumour size<sup>42</sup>. More information is urgently needed in this area, but existing evidence indicates that under-treatment of older people with cancer may be a substantial problem. The NCIN's report on curative surgical will look for any differences between age groups.

## Patient Experience

In the survey of cancer patient experiences conducted by the Department of Health in 1999/2000 older patients reported more favourably on the quality and adequacy of their care than younger patients<sup>11</sup>. Future surveys of patient experience commissioned as a result of the Cancer Reform Strategy will provide more up to date information on differences in patient experience with age.

Despite the commonly expressed view that older people are less likely to want cancer information, the evidence suggests that older people are almost as likely to want information about their cancer, its treatment and prognosis as any other age group<sup>42</sup>.

## End of Life Care

Looking at all causes, the proportion of people dying in their own homes decreases with age and there is a corresponding rise in the number of deaths in old people's homes. The proportion of people dying in

hospices decreases with age - almost a third of people who die in a hospice are under the age of 65, while only 2% of people age 85 or over died in a hospice<sup>13</sup>.



## Children and Teenagers and Young Adults

### Cancer incidence and mortality

Cancers in children aged less than 15 years old are rare, with an age standardised incidence rate of 139 per million children each year in the period 1991-2000. This is equivalent to a 1 in 493 risk of developing cancer before the age of 15. Incidence rates among children are highest in the first five years of life and boys have a higher rates incidence of cancer than girls throughout childhood<sup>44</sup>.

From 1966 to 2000, the incidence of childhood cancer increased by just less than 1% per year from 1966-2000, equivalent to a total increase of 38% over this period. This change is likely to be due in part to better and earlier diagnosis of childhood cancers but, it is also likely to include some real increase in the risk of childhood cancer, although what factors are responsible for this risk remain unclear<sup>45</sup>.

For teenagers and young adults (aged 13 to 24), the overall incidence rate of cancer was 224 cases per million persons each year in the period 1999-2003. Incidence increases with age and, as with children, has increased over time. From 1979 to 2003, incidence increased by just over 1% in both the 13-14 and 15-19 age groups and by 1.9% per year for the 20-24 age group. Some of this change (for example increases in the incidence of melanoma and cervical carcinoma) may be due to behavioural changes and potentiality avoidable<sup>46</sup>.

The most frequent types of cancer in children and teenagers and young adults differ from those seen in older age groups. For children, leukaemias, central nervous system tumours, lymphomas and

neuroblastoma are the most common types of cancer, although this varies between ages and sexes<sup>44</sup>.

The age-standardised mortality rate from childhood cancer was around 31 deaths per million children in 2000-2004, less than half the mortality rate in 1965-9. In teenagers and young adults aged 13-29 the mortality rate was 65.6 per million persons each year – extremely rare when compared to the mortality rates experienced by adults. Despite this, cancer remains a significant cause of death among children, teenagers and young adults (but not infants aged less than 1), exceeded only by transport accidents. Deaths from cancer caused 21% of total deaths for 1-14 year olds in 2000-2004 and 12% of deaths for 13-29 year olds in 2002-2005<sup>47/48</sup>.

### Cancer survival and prevalence

Overall five-year survival from childhood cancers was 76% for children diagnosed between 1996 and 2000, a marked increase from 28% in 1966-70. Much of this improvement is due to a series of successful clinical trials focused on the treatment of children<sup>49</sup>. Overall five-year survival for teenagers and young adults has increased from 63% in 1979-84 to 74% in 1996-2001<sup>50</sup>. For children diagnosed in 2004, one-year survival was 90% while for teenagers and young adults it was 91.5%<sup>2</sup>.

These high survival rates mean that there are increasing numbers of survivors of cancers (both children and adults) who were diagnosed as children or teenagers and young adults. These groups may have worse perceived physical health<sup>51</sup> and may suffer from long term effects of their treatment<sup>52</sup>.

Overall survival from cancer is good for these age groups and huge improvements have been seen in survival for childhood cancers. Despite this, due to a background of generally low mortality, cancer is still a major cause of death. These high levels of survival also create a requirement to address the long term needs of increasing numbers of cancer survivors.

### **Awareness and stage of diagnosis**

Cancer in children and young people is relatively rare; it has been estimated that a GP will on average see one child under the age of 15 years with a cancer every 20 years. Added to the variety of possible cancer symptoms in children, teenagers and young adults, many of which may be non-specific and common, this poses a significant diagnostic challenge<sup>53</sup>.

### **Screening**

There are no screening programmes for cancer in younger people.

### **Treatment**

Children or teenagers and young adults who develop cancer have different needs and it is important that care for them is provided in an age appropriate setting. Approximately 90% of children with cancer are treated in one of 22 specialist treatment centres around the British Isles<sup>54</sup>. However, there is some evidence that teenagers and young adults are not being referred to appropriate specialist centres for treatment<sup>32</sup>.

The centralisation of children's cancer services and close links with the United Kingdom Children's Cancer Study Group (UKCCSG) mean that the majority of children have the opportunity to participate in clinical trials<sup>54</sup>. Accrual into trials for teenagers and young adults is less impressive at about half the rate seen in children, possibly because they are treated by adult services where a lower priority is given to clinical research on rarer tumours<sup>55</sup>.

### **Patient Experience**

There is no national collection of information on patient experience for children or teenagers and young adults. However, the fact that teenagers and young adults are or not being referred to specialist centres suggests that their particular needs may not be being met<sup>32</sup>.

### **End of Life Care**

Most children with cancer receive palliative care and end of life care in the community, usually within the home. There is no central and systematic data collection on this making it difficult to get a clear and complete picture.

## Ethnicity

### Key facts

- There are variations in cancer incidence between ethnic groups, which are likely to be the result of a mixture of lifestyle and genetic factors. White men and women have a higher incidence of many cancers than those from other ethnic groups.
- Women from Black and Minority Ethnic (BME) groups are more likely to present with more advanced breast cancers and have poorer survival than White women.
- Awareness of cancer is generally lower in BME groups than amongst White men and women and screening uptake is generally lower in minority ethnic groups than in the population as a whole. Although there may be some cultural factors involved in this, it is also likely to be related to deprivation.
- There is a need for access to culturally relevant information about cancer and its signs and symptoms; existing cancer information rarely reflects multi-ethnicity in terms of images and language.

***More information can be found in the report on Cancer Incidence and Survival by Major Ethnic Group prepared by NCIN and Cancer Research UK<sup>56</sup>***

### Cancer incidence and mortality

Linkage of cancer registration data to HES by the NCIN has allowed the first national analysis of cancer incidence and survival by ethnicity for a multitude of sites. Although the recording of ethnicity is not complete, this does enable the most accurate estimates of incidence and survival to date. The first national report on cancer incidence and survival by major ethnic groups was prepared jointly by NCIN and Cancer Research UK in 2009.

In comparison with White ethnic groups, Black people have significantly higher rates of multiple myeloma and stomach cancer. Black men have higher rates of prostate cancer. Asian women have increased rates of cancers of the mouth. For many other cancers there are reduced rates amongst non-White ethnic groups<sup>56</sup>.

Differences in environmental factors as well as genetic factors are thought to play a role in the variations in cancer incidence between ethnic groups. Some

ethnic groups will have a genetic risk of particular cancers but in many cases environmental and lifestyle factors are likely to play a greater role. There is evidence that when people migrate from one country to another the pattern of cancers that they develop generally changes to that of the host country within a few generations<sup>57</sup>. It is hoped that improved ascertainment of ethnicity in cancer registry and related datasets will stimulate further work in this area.

National information on cancer mortality by ethnic group is not available within the UK. Studies of cancer mortality by country of birth have shown differences but there are limitations in using country of birth as a proxy for ethnicity<sup>58</sup>.

### Cancer survival and prevalence

Initial analyses of cancer survival by ethnic group have indicated that differences may exist, but due to data completeness, there is a high level of uncertainty in these results and therefore great care

needs to be taken when interpreting them<sup>6</sup>. Black and Asian women with breast cancer have poorer survival rates, which may be explained by later presentation<sup>59</sup>. As ethnicity data collection improves, analysis of survival by ethnic group will become more reliable.

### Awareness and stage of diagnosis

A recent survey using the CAM<sup>5</sup> has shown that awareness of cancer is generally lower in Black and Minority Ethnic (BME) groups than amongst White men and women. A further survey focusing on ethnic minority groups<sup>60</sup> both reinforced the low awareness and showed significant differences between minority groups.

A systematic review of the literature has found that non-White ethnic origin is associated with longer delays in presentation for urological and breast cancers but with shorter delays for stomach cancer<sup>4</sup>. Recent studies in England have shown that Indian, Pakistani, Black Caribbean and Black African women are significantly more likely to present with advanced (metastatic) breast cancer than White women<sup>59</sup>. However, this does not seem to be the case for prostate cancer, where stage at presentation is very similar for White, Indian, Pakistani and Black men<sup>61</sup>. Better collection of staging data in future will allow national analyses of stage at presentation.

### Screening uptake

Uptake for breast<sup>62</sup>, cervical<sup>63</sup> and colorectal<sup>64</sup> screening programmes is generally lower in minority ethnic groups than in the population as a whole.

### Treatment

There is no evidence that BME groups receive different treatment from their White counterparts for comparable cancers. However, this area has not yet been assessed in detail.

### Patient Experience

The numbers of patients from BME groups who responded to the National Cancer Patient Experience Survey and to the National Audit Office National Cancer Patient Survey of 2004 were relatively small. However, across several domains of patient experience, patients from these groups reported less favourably on their experience<sup>11,12</sup>.

In terms of patient information, access to culturally relevant information about cancer and its signs and symptoms has been recognised as an issue and there may be an unmet need from BME communities for cancer awareness outreach<sup>12</sup>. Existing cancer information may not always reflect multi-ethnicity in terms of images and language (e.g. that skin might appear red after radiotherapy).

The NCEI visioning event on ethnicity concluded that there is a need for more data bands for minority ethnic groups, to ensure that people's ethnicity is accurately collected. This is outside the remit of the NCEI, but we note that this has been recommended by the Equality and Human Rights Commission.

Community outreach was also identified as an important mechanism for engaging with people from black and minority ethnic groups. Voluntary sector 'buddying' schemes and community outreach were regarded as particularly important to connect with BME communities and for those communities to connect to services.

### End of Life Care

A study in South East England has shown that Black Caribbean and Black African women who die from breast cancer are less likely to die at home than White Women. Black African men are less likely than White men to die at home from prostate cancer<sup>65</sup>. Lower levels of awareness of hospice and palliative care and language differences amongst minority ethnic groups can limit their use of services<sup>66</sup>.



## Sexuality

### Key facts

- There is evidence for differences in health and other behaviours among lesbian, gay and bisexual people compared with the general population and these may lead to differences in cancer incidence.
- Perceptions of risk and healthcare seeking behaviour may also vary. For example, there is some evidence to suggest that lesbians may delay seeking help from a healthcare professional when compared with heterosexual women.
- Information on sexuality is not routinely collected by the NHS and therefore the evidence base for cancer inequalities and sexual orientation is under-developed and is often based on US studies or small UK surveys. Efforts are underway to address this in surveys of cancer awareness and patient experience.

### Cancer incidence and mortality

Differences between the health and other behaviours of lesbian, gay, bisexual and trans people and the general population may lead to differences in cancer incidence with sexuality. For example, lesbian, gay and bisexual people are more likely to smoke, increasing their risk of lung cancer<sup>67,68</sup>. It is also estimated that anal cancer is 31 times more common in gay men<sup>69</sup>. Lesbian women appear to have a small but significant increase in their risk of breast cancer, largely due to a lower chance of pregnancy or use of contraceptive pills<sup>70,71</sup>.

Both HIV infection and a diagnosis of AIDS are associated with an increased incidence of cancer<sup>72</sup> and, in the UK, gay and bisexual men are at the greatest risk of contracting HIV<sup>73</sup>.

Some lesbians and health professionals believe that lesbians are at a lower risk of cervical cancer due to a lower perceived risk of human papillomavirus (HPV) infection. However, reported rates of HPV infection among lesbians range from 3.3% - 30%, with a prevalence of 19% for lesbians with no reported history of heterosexual sex<sup>74</sup>.

The incidence of cancer among trans people is not well understood but expected higher rates of smoking would increase the risk of lung cancer. The long term impact of hormone treatments is not known but they may increase the risk of breast and ovarian cancer for trans men and the risk of prostate cancer for trans women.

### Cancer survival and prevalence

There is little information on whether mortality and survival rates differ according to sexuality, primarily due to the absence of routine recording of sexuality in the NHS.

### Awareness and stage of diagnosis

From January 2009 ONS has collected data on sexuality in all of its major continuous surveys and the Cancer Awareness Measure will also be used to assess differences in awareness by sexuality. This will enable the analysis of levels of awareness of cancer risks, signs and symptoms according to sexuality.

It is possible that negative experiences with healthcare professionals lead to delays in presentation by lesbian, gay and bisexual people. One US study

found that although lesbians were more likely, than heterosexual women, to find a lump themselves, the average timescale for a heterosexual woman to seek a doctor's advice was two weeks while for lesbians the timescale was 1.9 months<sup>75</sup>.

### Screening uptake

There is evidence for differences in levels of screening uptake, with lesbian and bisexual women up to 10 times less likely to have had a cervical smear test in the past three years than heterosexual women. Rates of never being screened range from 12% - 17% for lesbian and bisexual women who have never had sex with men<sup>74</sup>. This is up to double the rate of 40-74 year old women in the general population who report never having been screened<sup>63</sup>.

Research has suggested that trans people have adverse experiences in healthcare and they may be at risk of late diagnosis because they avoid regular physical examinations and routine screening tests<sup>76</sup>. Cervical screening is recommended for trans men.

### Treatment

There is no evidence to suggest differences in cancer treatment based on sexuality and this has not been addressed by cancer patient surveys.

### Patient Experience

There is very limited recent evidence on differences in cancer patients' experience with sexuality. However, in cancer services and in healthcare environments more generally, there is a routine assumption of heterosexuality (widely known as heterosexism). Heterosexism in services means that there are few positive representations of lesbian, gay, bisexual and trans people as patients. GPs may not always feel equipped to deal with their needs and are sometimes embarrassed to provide care for lesbian and gay patients<sup>77</sup>. One UK study of 5909 lesbian and bisexual women found that they were less likely to have come out to a healthcare professional (49%

had not so disclosed) than in other public settings, such as the workplace, where in comparison 27% of lesbian and bisexual women had not disclosed<sup>78</sup>. These assumptions may have an impact on their access to social support: lesbians are less likely to report participation in a cancer support group than heterosexual women<sup>79</sup>.

Participants at the NCEI visioning event on sexuality considered that healthcare professionals appear to believe that LGBT people do not have different needs to those of heterosexual people. However, the message from the LGBT community is that these groups would like to receive information which is relevant to their sexuality.

As set out in Reducing cancer inequality: evidence, progress and making it happen, the National Cancer Patient Experience Survey Programme will collect data on patients' sexuality, which will allow analysis of any differences in experience.

### End of Life Care

There is no evidence to suggest that access to end of life care differs based on sexuality but little work has been done in this area in relation to cancer. The General Medical Council has recently consulted with lesbian, gay and bisexual communities with a view to including their concerns in the End of Life Care strategy. Some qualitative research in this area is currently underway.

## Disability

### Key facts

- Disability encompasses a wide range of issues from mental health to learning disability and sensory impairment as well as physical disability. There is no national information on variations in cancer incidence, treatment and outcomes for people with a disability.
- There is some evidence for increased incidence of cancer associated with some mental illnesses (although those with schizophrenia may have a lower incidence of respiratory cancers). This is associated with increased cancer mortality.
- People with learning disabilities appear to have a similar age standardised incidence to the general population although patterns of incidence may be different.
- Screening uptake for those with learning disabilities and mental health needs seems to be lower than the general population. People with physical disabilities may also experience barriers to screening.
- Those with learning difficulties may struggle to express changes to their health, potentially complicating and delaying diagnosis.

### Cancer incidence and mortality

There is some evidence for a different pattern of cancer incidence amongst patients with mental health needs. Patients with schizophrenia have up to a three-fold increased risk of colorectal cancer; a 52% increased risk of breast cancer; and a 47% reduced risk of respiratory cancer. There is also evidence of higher cancer mortality in this group, which may be due to late presentation and delayed diagnosis<sup>80</sup>. Patients with bipolar disorder have an increased incidence of respiratory cancer, but this can be explained by smoking and other risk factors<sup>81</sup>.

Age standardised incidence rates for cancer in those with learning disabilities seem to be similar to the general population, although there is some evidence for different patterns of incidence for particular cancer types<sup>82,83</sup>. People with Down syndrome have a higher incidence of leukaemias and other cancers<sup>84,85</sup>.

### Cancer survival and prevalence

There is no national information on cancer survival for those with disabilities. However, it is possible that survival rates will be lower in patients with mental health problems and learning disabilities because of late presentation and delayed diagnosis.

### Awareness and stage of diagnosis

People with learning disabilities may have difficulty in communicating changes in their health to carers and to doctors<sup>86</sup>. This has the potential to delay diagnoses and thereby lead to poorer outcomes in these groups.

### Screening uptake

There is currently no central collection of information about differences in screening uptake for people with learning or physical disabilities or mental health problems. An audit of women in contact with the NHS Learning Disability Service in one Lancashire PCT found that uptake of breast screening was

comparable with the national average but that uptake of cervical screening was much lower<sup>87</sup>. Other surveys have found similar patterns of low cervical screening uptake but higher levels of breast screening<sup>88,89</sup>. There is also some evidence from the USA of barriers to screening attendance for those with physical disabilities<sup>90</sup>.

A study of patients at psychiatric units in London suggested that, although psychiatric patients overall were as likely to attend for breast screening as the general population, those with a history of multiple hospital detentions or a diagnosis of psychosis were significantly less likely to attend<sup>91</sup>.

### Treatment

It may be harder for people with learning disabilities to make informed choices about their care. There may also be ethical issues around decision making and consent to treatment for patients with learning disabilities or mental health problems<sup>89</sup>.

### Patient Experience

There have been no detailed studies of the patient experience reported by cancer patients with disabilities. People with learning disabilities often have communication issues and therefore they need to have explanations in a different way to other patients, which may affect their experience of care.

### End of Life Care

Challenges have been identified around planning for end of life care and learning disabilities. People with learning disabilities are less likely to receive a full range of hospice and palliative care services<sup>92</sup>. Problems are most notable in communications around the issues and are potentially problematic if a patient wishes to die at home. It may be more difficult for patients with disabilities to be cared for at home as self care may be more difficult. In ensuring high quality end of life care for people with disabilities, it will be particularly important to consider the needs of carers.

## Religion

### Key facts

- There is very little information on differences in cancer incidence, treatment or outcomes by religion and none at a national level. Many issues faced by religious groups are closely linked to ethnicity and culture.
- Religious practices (for example fasting during Ramadan) can impact upon cancer treatment.

There is very little information on differences in cancer incidence, treatment or outcomes by religion and none at a national level.

Some equality issues which are explicitly related to religion may be identified. Patients may find it difficult to access health services during religious festivals. One example cited to the NCEI was the impact that Ramadan can have on attendances at cancer clinics. It will be important that NHS services work with

local communities to address these issues. Similarly, practices such as fasting may impact upon cancer treatment and interfere with medication regimes<sup>93</sup>.

However, many of the issues faced by different religious groups are closely related to ethnicity and culture. Therefore action on many of the issues identified in the section on ethnicity above will also have a positive impact on tackling inequalities according to religion.

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## NCIN Publications

One Year Cancer Survival Trends, England, 1985-2004

One Year Cancer Survival by Cancer Network, England, 2000-2004

Cancer Incidence and Mortality by Cancer Network, UK, 2005

Cancer Incidence by Deprivation, England, 1995-2004

Cancer Incidence and Survival by Major Ethnic Group, England, 2002-2006

One, Five and Ten Year Cancer Prevalence by Cancer Network, UK, 2006 (updated May 2010)

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