Equality and Inclusion Team Ref: 1410

IMPROVING OUTCOMES: A STRATEGY FOR CANCER

Assessment of the Impact on Equalities (AIE)

Published alongside *Improving Outcomes: A Strategy for Cancer*

January 2011

Department of Health

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Other documents

Improving Outcomes: A Strategy for Cancer
Impact Assessment of *Improving Outcomes: A Strategy for Cancer*

Note

Parts of *Improving Outcomes: A Strategy for Cancer* refer to health issues, like smoking, where lead policy responsibility resides outside of cancer. These policy areas are developed with cancer in mind but are published separately. For assessments on the impact of equalities on these areas consult the relevant publications from the Department of Health.

1. Inequalities and *Improving Outcomes: A Strategy for Cancer*

Statement of duties

1.1 The Department of Health (DH) recognises that Equality Impact Assessment is an essential part of identifying and assessing relevant evidence on policies and helps it to meet its duties in relation to equality legislation and regulations. The Department's guidance currently requires assessments to consider the following characteristics: age, disability, ethnicity (race), gender (sex), gender identity, religion or belief and sexual orientation as well as socio-economic disadvantage and human rights. The Department uses assessments to identify opportunities to promote equality of opportunity as well as identify and address potential negative impact.

1.2 The Equality Act 2010 mandates an integrated Equality Duty, which is expected to commence in April 2011, on all public bodies and those discharging a public function to consider how they can:

- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Act;
- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- Foster good relations between persons who share a relevant protected characteristic and those who do not share it.

1.3 The Department is in the process of updating its approach to equality impact assessments to reflect the requirements of the Equality Duty.

1.4 One of the key aims of *Improving Outcomes: A Strategy for Cancer* is to reduce inequalities in cancer services and outcomes. Indeed an entire chapter of this strategy is devoted to reducing cancer inequalities.

1.5 The purpose of assessing the policies in *Improving Outcomes: A Strategy for Cancer* for the differing impact they have on different groups is that where any differences are found these can be mitigated and in rare cases justified on the grounds of the greater good. In addition by conducting an AIE potential policies are improved in relation to inequalities before they become Government policy.

1.6 This AIE has been developed concurrently with *Improving Outcomes: A Strategy for Cance*r. The high level advisory board of patients, clinicians, charities and other cancer experts that advised ministers on the strategy considered inequalities as an important part of their remit. In addition, the Large numbers of organisations and individuals have been involved in the development of this strategy have inputted into this strategy with equalities as an important part of their remit.

1.7 Many organisations have devoted a great deal of constructive thought to how cancer policy should develop in the context of the NHS reforms, including the following with many commenting on equalities issues specifically:

Action on Bladder Cancer, Afiya Trust, Beating Bowel Cancer, Brain Tumour Research Campaign, Breakthrough Breast Cancer, Breast Cancer Campaign, Breast Cancer Care, Bowel Cancer UK, Cancer 52, Cancer Campaigning Group, Cancer Research UK, Clic Sargent, GistSupport UK, Independent Cancer Patients, International Brain Tumour Alliance, Leukaemia Care, Leukaemia & Lymphoma Research, Lymphoma Association, Macmillan Cancer Support, Melanoma Taskforce, Myeloma UK, Oesophagael Patients Association, Ovarian Cancer Action, Pancreatic Cancer UK, Rarer Cancers Foundation, Roy Castle Foundation, Samantha Dickson Brain Tumour Trust, Target Ovarian Cancer,Teenage Cancer Trust, The British Lung Foundation, The Prostate Cancer Charity, United Kingdom Lung Cancer Coalition, World Cancer Research Fund

1.8 Over 200 different stakeholders from a wide range of backgrounds and specialities have been involved in advising on *Improving Outcomes: A Strategy for Cancer*. In consulting on the development of the strategy, all stakeholders were asked the question "As we develop the work to improve outcomes, how can we make sure that we continue to try and tackle inequalities in cancer care?" 35 stakeholder specifically responded to this question, and a high level summary of this feedback is as follows:

- Better data – to better understand inequalities and develop key performance indicators to measure improvements (better data on rarer cancers highlighted)
- Social deprivation – more use of social marketing techniques to better target people with prevention and symptom awareness messages
- Treatment of older people – more needs to be done to understand this issue and better equip the professionals on decision making in this area
- Accessible information and choice – roll-out of information prescriptions and targeted information for different groups
- General support for the work of the National Cancer Equality Initiative (NCEI - see below) and the priorities it has identified

1.9 Within the work of the National Cancer Programme the NCEI (NCEI) has been driving for improvements in inequalities for cancer patients and their work has been integral to the new strategy and significantly informs this AIE.

1.10 The EqIA of the original CRS was very well received and used as a model of how EqIAs should be undertaken in DH. This AIE of the review of the Cancer Reform Strategy, published as *Improving Outcomes: A Strategy for Cancer*, does not aim to reassess those policies assessed as part of the original CRS. Nor does it attempt to equality assess the new architecture of the NHS – this is set out in the AIEs on those particular policies set out in the *White Paper Equity and Excellence: Liberating the NHS* (eg Outcomes Framework, GP Consortia) and the Public Health White Paper.

1.11 What this AIE does attempt to do is provide a baseline for the evidence and assess how the new specific policies outlined in the *Improving Outcomes: A Strategy for Cancer* affect the promotion of equality and the elimination of discrimination in each of the equality groups.

2. The purpose of ***Improving Outcomes: A Strategy for Cancer***

Background

2.1 Significant progress has been made on cancer services and outcomes since the publication of the Calman-Hine report in 1995, with the NHS Cancer Plan (2000) and the Cancer Reform Strategy (CRS - 2007) contributing to this progress. Cancer mortality has fallen, survival rates are improving for many cancers and patients' experience of their care has improved.

2.2 Despite the considerable progress, survival rates in England for many cancers are currently lower than in many comparable countries. The Coalition Government wants to tackle this, and to focus on improvement in quality and outcomes for cancer patients.

Aims of *Improving Outcomes: A Strategy for Cancer*

2.3 This Strategy sets out the actions that need to be taken to deliver on the Coalition Government's commitment to improve cancer outcomes and reduce inequalities.

2.4 The Cancer Plan (2000) and the Cancer Reform Strategy (2007) set out a range of actions to improve cancer services – and significant progress has been made. But it is generally recognised that more needs to be done, and that the Cancer Reform Strategy should be reviewed. This Strategy sets out plans for moving forward.

2.5 We are developing new systems and structures which will deliver improved outcomes. But these will take time to be implemented and we need to make sure that no time is lost in improving outcomes for cancer – in terms of prevention, treatment and longer term care. So this Strategy looks at what can be done now, in the transitional period, as well as looking ahead to how the new systems and structures will work.

2.6 The strategy concentrates on the key issues in the White Paper, *Equity and excellence: Liberating the NHS*:: putting patients and the public first ("No decision about me, without me"); improving quality and healthcare outcomes; autonomy, accountability and democratic legitimacy; and cutting bureaucracy and increasing efficiency. The strategy also has a focus on the key challenges on cancer:

- rising incidence
- achieving better survival rates (primarily through earlier diagnosis)
- lowering mortality rates, especially in older people
- rising prevalence (3% per year)
- suboptimal care for survivors
- inequalities, both in terms of experience of care and in outcomes
- slow diffusion of new technologies
- managing the costs of cancer

2.7 The strategy looks at service developments for cancer up to 2015, along with areas for savings and levers for improvement in the new NHS.

3. Cancer inequalities baseline assessment

3.1 The Cancer Reform Strategy (CRS - December 2007) made clear that every person affected by cancer should receive world class services at each stage of their cancer journey. Yet we know that inequalities between different groups of people persist.

National Cancer Equality Initiative

3.2 The vision outlined in the original CRS was to achieve high quality, personal treatment and care for everyone affected by cancer by tackling inequalities and promoting equality across cancer services in England. To achieve this, the National Cancer Equality Initiative (NCEI) was established in 2008. The NCEI Advisory Group provided strategic direction and expertise and has a diverse membership: charities, academia, clinicians and patients. The NCEI has undertaken a range of activities:

- mapping existing work to tackle inequalities
- publishing guiding principles to spread best practice
- facilitating expert visioning events on different equality areas
- stimulating research and analyses
- bringing together evidence to encourage and monitor further action

3.3 The work of the NCEI culminated in the publication of the award winning[1] major report Re*ducing cancer inequality: evidence, progress and making it happen* in March 2010, and the NCEI Advisory Group was changed to become an Implementation Advisory Group to drive forward the actions in the report.

3.4 As this report was developed, the National Cancer Intelligence Network (NCIN) produced an accompanying Annex which set out all the known evidence on cancer and equalities. For the purpose of this AIE the evidence set out in this Annex has been reworked to reflect the chapters in the new *Improving Outcomes: A Strategy for Cancer*, and this appears at Annex A.

3.5 As the report was only published in March 2010, there is little new evidence to include in this baseline assessment, apart from the 2010 Cancer Patient Experience Survey and the Routes to Diagnosis work (see below). However, to reflect this evidence and the importance the cancer community places on advancing equality and reducing inequalities in cancer services, *Improving Outcomes: A Strategy for Cancer* has a specific chapter devoted to this issue: Chapter 7 – Reducing Cancer Inequalities (included here as Annex B). This chapter sets out the actions already underway following the NCEI report, and commits to new actions where new evidence has emerged (eg the results of the 2010 Cancer Patient Experience Survey). In summary, the actions are:

- The National Cancer Equality Initiative will continue to support commissioners in tackling inequality

[1] Leading Change in Equality and Diversity, Civil Service Diversity and Equality Awards 2010

- Key cancer data will be disaggregated and published by demographic group
- Information will be supplied to cancer commissioners and providers to help them reduce inequality
- New tools to help clinicians in assessing the most appropriate treatment for older patients and groundbreaking research into clinical attitudes will be undertaken
- A new human rights-based approach to support commissioners, providers and regulators in delivering personalised cancer care will be developed
- Tackling inequality will continue to be embedded as a core function of every part of cancer services

2010 National Cancer Patient Experience Survey

3.6 The 2010 National Cancer Patient Experience was the biggest survey of its kind on cancer services in England. 158 NHS Trusts providing cancer services identified cancer patients for the survey, and 67,713 chose to respond (67%). To support different groups, the survey provider ran a national freephone helpline for patients, and supported completion of the survey through textphone and language translation facilities.

3.7 The results of the survey provide invaluable insights into equality issues, as patients were asked to provide details on their age, gender, and ethnicity. Patients were also asked about any disabilities they had: deafness/severe hearing impairment; blindness/partially sighted; long standing physical condition; learning disability; mental health conditions; and long standing illness. For the first time, we also asked patients about their sexual orientation, and 87% of patients were willing to give us this information (5% preferred not to answer and 8% did not answer the question at all). The breakdown of patients by equality group is shown in the following tables[2]:

Table 1 - Gender

Gender of respondents	Number of respondents	Percentage
Male	31,694	47%
Female	36,019	53%

Table 2 – Age

Age of respondent	Number of respondents	Percentage
16-25	442	1%
26-35	1,100	2%
36-50	7,313	11%
51-65	22,957	34%
65-75	21,141	31%
76+	14,760	22%

[2] National Cancer Patients Experience Survey Programme: 2010 National Survey Report (December 2010)

Table 3 – Ethnicity

Ethnicity of respondent	Number of respondents	Percentage
White (British, Irish or other white)	61,757	96%
Asian or Asian British	1,007	1.6%
Black or Black British	879	1.4%
Mixed background	260	0.4%
Other	215	0.3%

Table 4 – Sexual orientation

Sexual orientation of respondent	Number of respondents	Percentage
Heterosexual	58,674	99%
Bisexual	130	0.2%
Gay or lesbian	362	0.6%
Other sexuality	308	0.5%

Table 5 – Long term conditions

Respondents with a long term condition	Number of respondents	Percentage
Deafness or severe hearing impairment	6,626	10%
Blindness or partially sighted	1,684	2%
A long standing physical condition	9,168	14%
A learning disability	301	0.4%
A mental health condition	1,184	2%
A long standing illness	8,695	13%

3.8 Full results of the survey are now available at [website], but headline equality results are:

- White cancer patients report a more positive experience than other ethnic groups – particular differences were noted on questions around receiving understandable answers, being given enough care after discharge, and staff working well together
- Younger people are the least positive about their experience, particularly around understanding completely what was wrong with them
- Men are largely more positive about their care than women, particularly around staff and staff working together
- People with a disability or long term condition reported a less positive experience than other patients across a wide range of issues measured in the survey. This was particularly marked for patients with a mental health condition or a learning disability

- Non-heterosexual patients reported less positive experience, especially in relation to communication and (broadly) being treated with respect and dignity
- Despite what might be expected, there is no statistically significant link between deprivation and patient experience, taking all quintiles of deprivation together
- People with rarer forms of cancer in general reported a poorer experience of their treatment and care than people with more common forms cancer

3.9 *Improving Outcomes: A Strategy for Cancer* suggests that commissioners will wish to encourage providers to take note of these differences and to consider positive action to address the distinct needs of people from different groups. In particular, those wishing to incentivise improvements in patient experience through CQUIN schemes, may wish to identify particular groups where improvement is required.

3.10 The 2010 survey data will also be made widely available to researchers and policy makers to encourage a wide range of analysis on equality issues.

Routes to diagnosis

3.11 To help promote early diagnosis of cancer and improve survival rates, we need to better understand the different routes taken by patients in their cancer diagnoses, to examine what effect this has on overall outcomes. For all patients diagnosed in 2007, the National Cancer Intelligence Network (NCIN) used existing routinely available data sources to work backwards through their cancer journey to examine the sequence of events that took them to their diagnosis. These route included inpatients, outpatients, screening and emergency presentation. The study found that 23% of newly diagnosed patients came through as emergency presentations[3]. For almost all cancer types, one-year survival rates were much lower for patients presenting as emergencies than for those presenting via other routes.

3.12 The NCIN also examined how the routes to diagnosis vary by different tumour types and by age, sex and deprivation to highlight differences in relative one-year survival rates. The proportion of emergency presentations varied widely between tumour types (eg melanoma 3%, brain and central nervous system 58%) and by age. Patients aged under 25 and patients over 75 were the most likely to present as emergencies. A socio-economic gradient was also observed, with more affluent patients being less likely to present as emergencies.

3.13 The authors of the report acknowledge that it would have been desirable to examine the effect of ethnicity on the routes to diagnosis. However, there was significant underreporting of ethnicity data in the "Routes to Diagnosis" dataset, as shown in the table.

[3] Routes to Diagnosis: NCIN data Briefing, September 2010

Table 6 – Comparison of ethnicity recording in the NCIN ethnicity report against the 'Routes to Diagnosis' dataset

Ethnicity data profile	**NCIN Ethnicity report**	**Routes to Diagnosis**
	People (%)	**People (%)**
White	435,168 (73%)	140,369 (40%)
Asian	6,685 (1%)	1,603 (0%)
Black	6,540 (1%)	1,619 (0%)
Chinese	651 (0%)	264 (0%)
Mixed	1,058 (0%)	378 (0%)
Other	3,194 (1%)	148,515 (42%)
Unknown	145,299 (24%)	58,018 (17%)
Total	**598,595 (100%)**	**350,766 (100%)**

4. Assessment of *Improving Outcomes: A Strategy for Cancer* impact on inequality

4.1 *Improving Outcomes: A Strategy for Cancer* makes a number of recommendations to improve cancer services in England. These are described below and are followed by an assessment of any potential inequalities they may cause and how these will be mitigated or can be justified.

Radiotherapy

4.2 During the implementation of the CRS capacity and capability have both increased, training infrastructure has improved and the Radiotherapy Data Set (RDS) has been mandated. Emerging evidence from the RDS and the analysis conducted as part of the National Audit Offices' review of the CRS implementation, highlights wide variations in the delivery of radiotherapy by individual units and to populations. This suggests that there are both efficiencies to be gained from better use of the existing installed equipment and opportunities for improved treatment for patients in some areas.

4.3 In the light of this new evidence, *Improving Outcomes: A Strategy for Cancer* outlines plans to use additional funding secured through the SR 2010 to make maximum use of existing radiotherapy capacity by, for example, ensuring that centres are fully staffed or that essential maintenance work is undertaken out of hours. The funding also supports an additional 12 machines over the SR period. This will ensure that capacity is in the right place and enable an additional 600k fractions to be delivered per annum by the end of the SR period.

4.4 The National Radiotherapy Advisory Group reported in 2007 that an increased uptake of new technologies was required to ensure best outcomes for patients. One of the technologies it recommended was Proton Beam Therapy (PBT). Because of its very precise nature, PBT can avoid damage to critical tissues near the tumour. The strongest clinical case for PBT relates to children and young people with brain tumours.

4.5 While facilities are developed in England to treat 1500 patients per annum, patients are referred overseas for treatment. A "high priority" list of cancers has been identified and recognised that there is limited capacity to treat patients overseas and that travelling for treatment will not always be appropriate. A clinical reference panel advises on individual cases. To date, the numbers of patients for the "high priority" list of cancers being treated overseas has not reached the estimated 400 patients per year though the number of cases referred to the panel is increasing. *Improving Outcomes: A Strategy for Cancer* anticipates that this number will be reached in the next SR and the planned funding allows for this number.

Inequality assessment

4.6 The above improvements in radiotherapy capacity and maximisation of radiotherapy usage will benefit all groups in society. This will be monitored to ensure it increases appropriately in all parts of the country. The expansion

of the number of patients being able to seek treatment abroad will also benefit all groups in society, but predominantly children who are more likely to suffer from the cancers where PBT makes a difference.

4.7 Particular concerns have been expressed over the under-treatment of older people, and as their radiotherapy capacity improves commissioners and providers will wish to be aware of this issue and in the future take note of the findings of the jointly funded Department of Health and Macmillan Cancer Support two year pilot programme to improve intervention rates for people over 70 who have a cancer diagnosis. The project aims to identify, test and evaluate a simpler way to comprehensively assess an older person for cancer treatment, provide practical support and information to aid patient/ practitioner decision-making and train professionals involved in this pathway to promote age equality and address age discrimination. Age UK are also involved in this initiative. Pilot sites will be confirmed in December 2010, with sites going live for a 12 month period and a national evaluation produced ready to inform commissioning decisions for Autumn 2012.

Cancer Screening

Flexible Sigmoidoscopy (FS)

4.8 Flexible sigmoidoscopy (FS) is an alternative and complementary bowel screening methodology to Faecal Occult Blood (FOB) testing. A randomised controlled trial funded by Cancer Research UK, the Medical Research Council and NHS R&D took place in 14 UK centres between 1994 and 2010 to evaluate screening for bowel cancer using FS. It concluded that FS is a safe and practical test and, when offered only once between ages 55 and 64 years, confers a substantial and long lasting benefit. Based on trial figures, experts estimate the programme would prevent around 3,000 cancers every year.

4.9 *Improving Outcomes: A Strategy for Cancer* commits the Government to invest £60 million over the next four years to incorporate FS into the current bowel screening programme. Pilots will begin during 2011-12 with the aim of achieving 30% coverage by the end of 2013-14 and 60% by the end of 2014-15. It is envisaged that full roll out will be achieved in 2016.

Inequality assessment

4.10 A demonstration project on FS screening in North West London has shown that uptake of FS screening delivered as a population-based programme was over 50% among the eligible population in a socio-economically and ethically diverse area of London[4]. Acceptance of the FOBt programme in London is around 40%, and in the two PCTs involved in the FS project FOBt uptake is 39% and 48%.

4.11 Despite FS requiring bowel preparation, a visit to the hospital, and a more invasive test than FOBt screening, uptake rates for the two tests are

[4] Robb et al Flexible sigmoidoscopy screening for colorectal cancer: uptake in a population-based pilot programme *J Med Screen* 2010: **17**: 75-78

surprisingly similar[5]. This suggests that barriers to CRC screening are likely to lie not in the specifics of the test but in the public's lack of awareness of the high incidence of colorectal cancer or the potential value of screening[6].

4.12 Most commonly cited perceived barriers to screening are limited awareness of bowel cancer, anxiety regarding the invasiveness of the test or the bowel preparation and fear of a cancer diagnosis[7]. A recommendation from this paper is that ethnically tailored health promotion materials and involvement of general practitioners would be a way of overcoming these barriers.

4.13 The independent Bowel Screening Advisory Committee (BSAC) have advised that FS should be offered to men and women from age 55 as this is the age where evidence of effectiveness begins. BSAC have also advised that the FS pilots should look at different strategies for re-inviting non-attenders, such as timing of reminder letters, and that non-attenders should be eligible for screening up until the point they join the FOBt part of the programme at age 60.

Human Papilloma Virus (HPV) Triage

4.14 HPV testing as triage (sorting) for women with mild or borderline cervical screening test results has been piloted and shown to be effective. Women with mild or borderline results are tested for HPV and if negative are returned to the routine screening programme. Women who are HPV positive are referred to colposcopy. HPV testing can also be used to test whether women who have had cervical abnormalities treated have been cured and this has shown to be effective.

4.15 *Improving Outcomes: A Strategy for Cancer* sets out how the Government will roll out HPV testing across England as triage for women with mild or borderline cervical screening test results and as a test of cure for treated women. This will deliver a more targeted service for women, reducing the need for significant numbers of repeat tests, with all the anxiety and costs that involves. For a modest investment of £17.5 million across 2011-12 and 2012-13 to embed the new service, major savings of up to £16million per year will be made. This will give women a more personalised and timely service and save the NHS time and money.

Inequality assessment

4.16 The new policy will benefit all women with mild or borderline cervical screening test results, ensuring a more personalised screening and assessment pathway. However, we know there is a lower acceptance of cervical screening within BME groups than the average and this is independent of socioeconomic status. The table below demonstrates the correlation between lower than

[5] Wardle and Atkin, Colorectal cancer prevention through screening: population acceptance of flexible sigmoidoscopy *J Med Screen* 2010; **17**: 55-57

[6] Robb et al, Demographic and psychosocial factors associated with perceived risk for colorectal cancer. *Cancer Epidemiol Biomarkers Prev* 2004; **13**:366-72

[7] Austin et al.2009, J Med Screen. 16(4):174-9

average screening coverage (screening test result within the previous five years) and high numbers of ethnic minorities.

Table 7 Cervical Screening Coverage and Racial Minorities[8]

Area	Screening Coverage by Area (2005/06)	Racial Minorities as percent of Population by Area (2001 Census)
Nottinghamshire County	86.5%	3%
Derbyshire County	85.1%	4%
Northumberland	85.0%	2%
English Average	79.2%	13%
Manchester	74%	40%
Wandsworth	72.3%	35%
Camden	71%	47%
Kensington & Chelsea	72.2%	50%
Lambeth	71.7%	50%
Westminster	71.2%	52%
Brent Teaching	71.6%	71%
Tower Hamlets	70.2%	47%
Southwark	70.6%	48%
City & Hackney	70.6%	55%
Hammersmith & Fulham	67.4%	42%
* Figures are indicative only as geographical areas may vary slightly in some cases.		

4.17 That is why *Improving Outcomes: A Strategy for Cancer* says that to maximise the benefits from the screening programmes, we need to encourage the greatest number possible from all groups and communities (particularly those under-represented and excluded) to make an informed choice to participate. We are therefore working with the Cabinet Office Behavioural Insight Unit to consider options for promoting uptake.

4.18 Within the NHS Cervical Screening Programme, women aged 25 to 49 are invited every three years and women aged 50 to 64 every five years. In a recent National Cancer Intelligence Network report on ethnicity and cancer incidence, Asian females had a significantly higher risk of cervical cancer, but only for those aged 65 and over (ratio between 1.1 and 2.7). In contrast, those aged below 65 years, or those of all ages had significantly lower risks with ratios between 0.3 and 0.8 for Asians relative to the White ethnic group[9]. Although women aged over 65 are not routinely invited for screening, they are eligible if they have never been screened or if their last three screens were not negative. The Advisory Committee on Cervical Screening keep the eligible age for invitations constantly under review.

[8] Figures from: Information Centre: *Cervical Screening Programme, England, 2005-06*, London, The Information Centre and National Statistics, 2006 and figures from: National Statistics: *National Census 2001*, London, Office for National Statistics, 2002

[9] Cancer Incidence and Survival By Major Ethnic Group, England, 2002 – 2006 (National Cancer Intelligence Network, June 2009)

Earlier Diagnosis

4.19 Cancer survival rates in England have been steadily improving, though further improvements could be made. It is now generally agreed that the most important reasons for lower survival rates in England compared with other European countries are low public awareness of the signs and symptoms of cancer, delays in people presenting to their doctors, and patients having more advanced disease at diagnosis.

4.20 We know that generally the earlier a cancer is diagnosed the greater the chance that it can be treated successfully. Based on analyses of 5 year survival rates in Europe, we estimate that up to 10,000 lives could be saved each year in England by bringing survival up to the best countries in Europe.

4.21 As part of the CRS, the National Awareness and Early Diagnosis Initiative was established in 2008. The aim of the initiative is to improve the public's awareness of the signs and symptoms of cancer, encourage those with symptoms to seek help earlier than they currently do and support primary care in diagnosing cancer earlier – leading to earlier stage at diagnosis and improved outcomes for patients.

4.22 Four areas are associated with earlier diagnosis:

- More diagnostic tests for cancer. We plan to improve access to tests from primary care, minimising the extra burden on secondary care clinicians
- Work to change behaviour around early presentation – campaigns and local interventions to raise symptom awareness and encourage earlier presentation.
- Support to GPs to diagnose cancer earlier, including support on when to commission and how to interpret diagnostic tests.

<u>Better GP access to diagnostics</u>

4.23 By improving GPs access to diagnostic tests, the aim is to help improve the chances of a patient being diagnosed earlier and therefore receive treatment earlier.

4.24 Latest diagnostic waiting times data (June 2010) shows that patients can expect to wait an average of around 2 weeks for one of the 15 key diagnostic tests. However, at present, some GPs do not have direct access to the full range of diagnostic tests.

4.25 GPs would not necessarily require access to all diagnostic tests. The focus of this work is on a number of selected tests which the Cancer Diagnostics Advisory Board (a panel of experts to support the development of work on diagnostic access) identified as priority areas for improving earlier diagnosis:

- Chest x ray: to support diagnosis of lung cancer
- Non-obstetric ultrasound: to support diagnosis of ovarian cancer
- Flexi sigmoidoscopy/colonoscopy: to support diagnosis of colorectal cancer
- MRI brain: to support diagnosis of brain cancer.

4.26 Given the large assumed increases in GP referrals, it will take time for the NHS to gear up and be in a position to deliver the extra activity. A phased implementation is assumed, as shown in table 7:

Table 8 - Assumed phasing of delivery of extra tests

Test	2011/12	2012/13	2013/14	2014/15
Chest X-ray	10%	25%	40%	100%
NOU	10%	25%	40%	100%
Flexi-Sig	10%	20%	30%	40%
Colonoscopy	10%	25%	40%	100%
MRI Brain	10%	25%	40%	100%

4.27 For four out of the five tests, it is assumed that the full increase in activity can be delivered by 2014/15. For flexi-sig, advice from clinical leads suggests it could take longer than this to get up to the required levels. A slower implementation is therefore assumed for this test.

Inequality assessment

4.28 To access the proposed tests, patients would first have to attend at their GP Practice. Regarding access to GPs, *Attitudes of Ethnic Minority Communities to Patient Choice*[10] found that there is evidence indicating that younger Caribbean and African men and older Black African women are generally least engaged with the NHS and a number do not feel well served by their GPs or by the health service in general. As a result, they may be less likely to seek out information about healthcare or to be aware of their right to choice unless GPs provided information about patient choice.

4.29 Evidence also suggests that older Bangladeshi and Pakistani patients and younger recent immigrants from these communities can lack English skills and some have low literacy levels. Whilst usage of the NHS may be high, they are dependant on the quality of communication to them via their GP or family members.

4.30 Responses from the 2008-09 GP Patient Survey continues to highlight that Black and Minority Ethnic (BME) groups tend to be less satisfied with all aspects of services. Across the five key access indicators, the gap in average satisfaction between BME groups and the population as a whole has increased for 48 hour access, advanced booking and seeing a specific GP but reduced for telephone access and satisfaction with opening hours. Similar patterns can be seen in other areas of the survey, with Bangladeshi, Pakistani and Indian groups indicating less positive responses than other groups.

4.31 The extract results below illustrate the largest % difference for a particular ethnic group and the national average.

[10] Report for DH by COI, November 2008

Table 9

% of People saying they were able to book an appointment fairly quickly	
Bangladeshi	**-16%**
Pakistani	**-13%**
Indian	**-8%**

Table 10

% of People saying they could book an appointment 2+ days ahead	
Bangladeshi	**-18%**
Pakistani	**-14%**
Indian	**-9%**

Supporting GPs to diagnose cancer earlier

4.32 We have work under way to support GPs to achieve earlier diagnosis, piloting risk assessment tools for GPs, improving the information available to GPs to assess their performance, and funding GP leaders to support other GPs in diagnosing cancer earlier. In addition, GPs will need support during the roll out of the diagnostic access, and we will look at different ways to provide this, through development and provision of tools, guidance and potentially training (e.g. on-line learning modules). Evidence for this approach comes from Dr Willie Hamilton's work on helping GPs with a risk assessment tool for those presenting symptoms in primary care. Further evidence is being collected – eg through the International Cancer Benchmarking Project – and will also be collected as the earlier diagnosis work progresses. We recognise that some of the evidence base for interventions is not strong, but we need to test different approaches in order to have scope to save the 10,000 lives currently lost per year.

*Inequality assessmen*t

4.33 In addition to different groups access to GP services discussed above, across cancer sites the lack of symptom awareness is the main factor in patients presenting late at primary care. A study by Macleod et al[11] showed there is strong evidence of an association between older age and patient delay for breast cancer; between lower socio-economic status and delay for gastro-intestinal and urological cancers and between lower education level and delay for breast and colorectal cancers. For practitioner delay, 'misdiagnosis' occurring either through treating patients symptomatically or relating symptoms to other health problems was an important theme across cancer sites. The study concludes that having sought hep for potential cancer symptoms, it is important that practitioners recognise these symptoms, and examine, investigate and refer appropriately. The NAEDI work will support this, and benefit all groups in society who are registered with a GP to aid early diagnosis of cancer and improve outcomes.

[11] Macleod et al, Risk Factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers, *British Journal of Cancer* (2009) **101**, S92-S101

Public behaviour change around early diagnosis

4.34 A shift in public behaviour is needed for people to present earlier to primary care with symptoms that might be cancer. This enables earlier diagnosis, leading to improved outcomes.

4.35 Cabinet Office have agreed to a range of work both local and on a national scale in 2010/11 to achieve greater awareness of cancer symptoms and reduce barriers to presentation. While we have considerable information already about what works at local level in terms of raising awareness and encouraging presentation, we hope from this work to find out more, and also to find out how far national campaigns can add benefit. Our plan would be to continue with campaigns and local initiatives on this issue, building on this year's successes.

4.36 Evidence for this approach comes from a range of different local campaigns, eg the Doncaster 'Cough Campaign' which encouraged residents to visit their GP and ask for a chest x-ray if particular symptoms persisted and the importance of early diagnosis, or the healthy communities collaborative, which used volunteers to encourage people to visit their doctors with symptoms from a range of cancers.

Inequality assessment

4.37 Since the publication of the original CRS and he establishment of the National Awareness and Early Diagnosis Initiative (NAEDI), the British Journal of Cancer published a supplement on the evidence supporting the initiative in 2009[12]. Many of the studies reported in the supplement, and outlined below, concentrated on issues advancing equality and reducing inequalities.

4.38 A systematic review[13] has shown that interventions delivered to individuals may increase cancer awareness. Interventions delivered to communities may promote cancer awareness and early presentation, although the evidence is limited.

4.39 In a study by Robb et al[14], awareness of cancer warning signs was low when open-ended (recall) questions were used and higher with closed (recognition) questions. On either measure awareness was lower in those who were male, younger, and from lower socio-economic status (SES) or ethnic groups. The most common barriers to help seeking were difficulty making an appointment, worry about wasting the doctor's time and worry about what would be found. Emotional barriers were more prominent in lower SES groups and practical barriers (eg too busy) more prominent in higher SES groups. Anticipated

[12] British Journal of Cancer, Diagnosing Cancer Earlier: Evidence for a National Awareness and Early Diagnosis Initiative, Volume 101, Supplement 2, 3 December 2009

[13] Austoker et al, Interventions to promote cancer awareness and early presentation: systematic review, *British Journal of Cancer* (2009) **101**, S31-39

[14] Robb et al, Public awareness of cancer in Britain: a population-based survey of adults, Development of a measurement tool to assess public awareness of cancer, *British Journal of Cancer* (2009) **101**, S18-S23

delay was lower in ethnic minority and lower SES groups. The report concluded that a combination of public education about symptoms and empowerment to seek medical advice, as well as support at primary care level, could enhance early presentation and improve cancer outcomes.

4.40 The Improvement Foundation's programme on helping volunteers in disadvantaged communities (19 Spearhead PCTs) to lead work on raising awareness and promotion of earlier presentation of cancer symptoms in partnership with primary care and other professionals is delivering early positive results[15].

4.41 An intervention to equip older women with the knowledge, skills, confidence and motivation to detect breast cancer symptoms and seek help promptly increases breast cancer awareness at 1 year[16]. Future research will evaluate whether the intervention, using a 10-minute interaction with a radiographer at the last invited breast screening appointment plus a booklet, promotes early presentation and reduces breast cancer mortality.

4.42 Evidence has shown that the Cancer Awareness Measure (CAM)[17] is a reliable and valid measure of cancer awareness and can be used to provide a comprehensive assessment of cancer awareness. The CAM has now been administered in a large scale, population-based, British sample with a substantial ethnic boost. The CAM can also be used by researchers to develop informed interventions and to assess the impact of interventions designed to target gaps in public awareness of cancer either in whole populations or specific sub-groups. There is a need for culturally sensitive, community-based interventions to raise awareness and encourage early presentation[18].

4.43 All of this evidence was taken into account when selecting the pilot sites for the local NAEDI work. In 2010/11 we are funding 59 projects across 109 PCTs (£9 million) to raise public awareness of the early signs and symptoms of bowel, breast and lung cancer and to change public behaviour to promote early presentation to primary care.

4.44 Examples the methodology being used includes social marketing campaigns to promote the early signs and symptoms of one or all three tumour sites; the creation of local partnerships between the public, healthcare professionals and voluntary organisations to raise awareness and make more information available to the public – especially those at risk; and looking at adapting existing services to increase engagement with hard to reach groups.

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[15] Lyon et al, Improving the early presentation of cancer symptoms in disadvantaged communities: putting local people in control, *British Journal of Cancer* (2009) **101**, S49-S54

[16] Linsell et al, A randomised controlled trial of an intervention to promote early presentation of breast cancer in older women: effect on breast cancer awareness, *Journal of Cancer* (2009) **101**, S40-S48

[17] Stubbings et al, Development of a measurement tool to assess public awareness of cancer, *British Journal of Cancer* (2009) **101**, S13-S17

[18] Waller et al, Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England, *British Journal of Cancer* (2009) **101**, S24-S30

4.45 The majority of projects are focussing on men and women over 50 years of age in the most deprived wards of the country, with 27 running public facing activities on breast cancer, 50 on lung cancer and 41 on bowel cancer. 11 of the projects are specifically targeting BME groups, 3 projects have a focus on rural populations and 2 are focused on travelling communities. Two specific examples are outlined in the boxes below.

Box 1 - Greater Manchester collaborative

The Greater Manchester collaborative consists of 11 PCTs and they are building on the work that they have conducted in recent years using the award winning 'Don't be a Cancer Chancer' campaign. They are running two strands to their activity – extending the reach of 'Don't be a Cancer Chancer' in the lower socio economic, white population in Greater Manchester. The second strand will focus on the South Asian communities. It was apparent from previous work that the existing campaign did not resonate with this audience in the same way. A more tailored creative is now in development which will focus on personal stories and use photography to profile people which the target audience will be able to relate to. The Greater Manchester team will be producing an advert which will run on South Asian TV from April / May 2011 as well as other marketing collateral which will be used in the community

Box 2 - North East Lincolnshire

North East Lincolnshire are building on the foundation of previous work and developing a successful model of community led initiatives to encourage earlier presentation of lung cancer. A team of up to 15 volunteers will work to develop partnerships between communities and services through joint action and interventions within the community.

This project is focussed on men and women over 40 living in deprived areas across North East Lincolnshire. The overall aim of the project is to reduce mortality by encouraging an increase in the number of individuals who participate in screening, and an increase in the number of 2 week wait referrals.

4.46 These local NAEDI projects, couple with increasing activity on the early diagnosis of cancer outlined in the Outcome Strategy for Cancer, will greatly add to the evidence base on how we can encourage different groups to be aware of the symptoms of cancer and present earlier when they occur, thus advancing equality and reducing inequalities in cancer outcomes.

Molecular Diagnostics

4.47 Traditionally cancer therapies have been given in a "one size fits all" approach, and patients who did not respond would then be offered alternative therapies one by one until a positive effect was observed. However, our understanding of the human genome, and the way that medicines act inside the body, has grown considerably in the last decade. These advances mean that we

now have the opportunity to target treatments, getting the right therapy to the right patient at the right time. This is called stratified medicine.

4.48 Identifying patients that are more likely to benefit or to experience an adverse reaction in response to a given therapy, and thereby better match patients with therapies, could have a major effect on both clinical practice and the development of new drugs and diagnostics. This was identified as a priority in the 2009 report of the House of Lords on Genomic Medicine. The Department has already begun work with its partners to identify how this technology might translate into benefits for the NHS via the new Human Genomics Strategy Group.

4.49 At present these tests are done "to order" using specific tests (or sometimes commercialised kits) which look for the relevant mutation associated with each drug. This will increasingly not be cost-effective and new technologies will allow multiple tests to be done on a tumour (or even ultimately to sequence the full cancer genome). Cost-effective uptake of cancer stratified medicine in NHS molecular pathology laboratories will increasingly have to rely on high throughput testing and analysis. Our view is that a piecemeal approach to rolling out such technologies will mean that inefficiencies will remain in the pathology system as high throughput testing technologies may be under-utilised.

4.50 In addition, cutting edge research is now showing that a range of mutations, such as those controlling cell growth, are present in the majority of tumours and could indicate the effectiveness of therapies developed for the same mutation in a different cancer. It will therefore be critical, going forward, to assess each tumour for this range of mutations, and be able to correlate this with treatment outcomes. Within 5-10 years, this combination of service delivery and research should be routine practice.

4.51 For most drug treatments on the "one size fits all" approach, only around 25% of patients with a particular indication are likely to benefit. Targeting treatment appropriately through genomic testing will therefore provide benefits in four key ways:

- the NHS may save on drug costs (and associated administration) for the 75% of patients who will not benefit from the "one size fits all" treatment
- patients will be directed more quickly to a treatment pathway that is more likely to work for them, thereby saving lives and costs associated with treatment of more advanced disease
- patients will be spared the side effects of treatments that do not work
- the NHS will be spared the costs of managing the side effects of treatments that do not work.

4.52 Cancer Research UK has already started planning for stratified medicine, working with the DH, the Medical Research Council, TSB, industry partners, clinicians and researchers.

Inequality assessment

4.53 The development of molecular diagnostics will benefit all groups in society. However, the NHS needs to be aware of the concerns over the under-treatment of older people (as outlined above under radiotherapy) as this important work develops.

5. Conclusion

5.1 This AIE has assessed the new policies in *Improving Outcomes: A Strategy for Cancer* for any potential to increase inequalities between different groups in society and the potential for them to advance equality. Where identified, evidence based measures have been set out so the NHS can consider how to best resolve potential inequalities. In a few cases a potential inequality has been justified on the grounds of being for the greater good, such as the flexible sigmoidoscopy screening programme and a reliance on GPs on early diagnosis, but we have also set out evidence based approaches of how such exacerbation of inequalities can be reduced.

5.2 Equality issues have been embedded through *Improving Outcomes: A Strategy for Cancer* and the National Cancer Equality Initiative will continue to monitor progress. Ultimately it will be for the NHS Commissioning Board, GP Consortia and Public Health England to ensure that, as we strive to improve outcomes, we do so for all groups in society by advancing equality and tackling inequalities where they exist.

Annex A

Reducing cancer inequality: evidence, progress and making it happen: A report by the National Cancer Equality Initiative, Annex 1 – A reworking of the evidence to date on the cancer inequalities in England provided by the National Cancer Intelligence Network (NCIN – March 2010)

1. The challenge of cancer

Background

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.

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 ad 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.

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.

Ethnicity: 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.

Incidence, survival, mortality and outcomes

Gender: 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[1].

	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 + other urological	99%	107%
Bladder	230%	194%
Brain + central nervous system	53%	52%
Non-Hodgkin's Lymphoma	39%	57%
Myeloma	52%	39%
Leukaemia	72%	79%

Table 1. Excess Incidence and Mortality in Men. 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'[1]. NMSC is Non Melanoma Skin Cancer.

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)[2].

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 relative survival rates were only seen for malignant melanoma, where one-year survival for both sexes was over 95%[2].

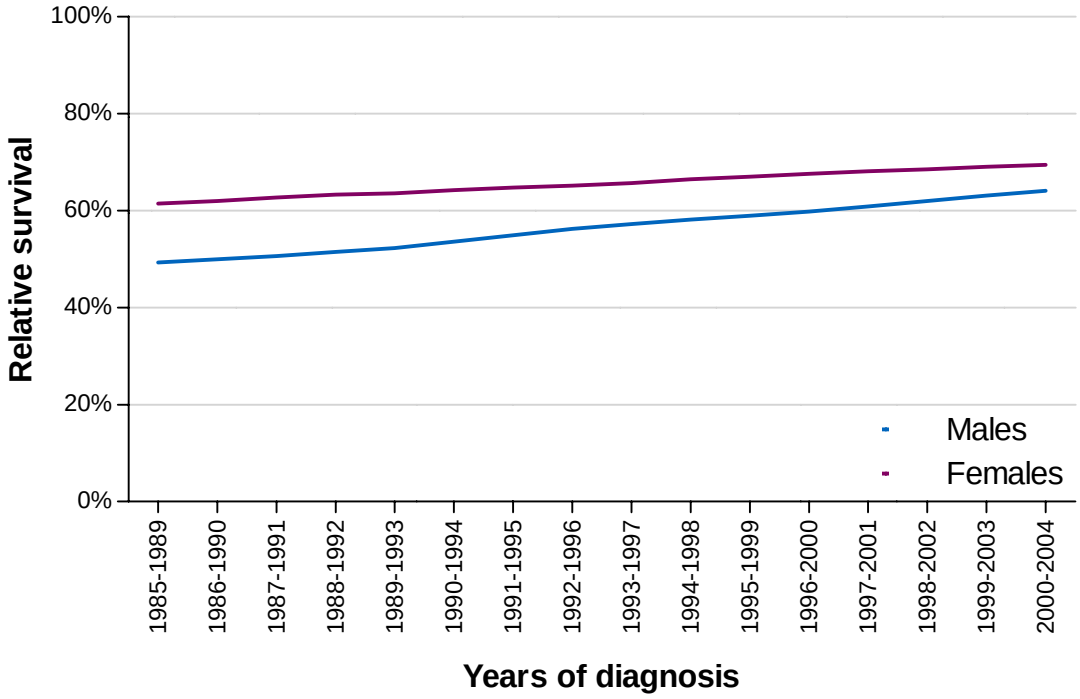

Figure 1. One year relative survival for all malignant neoplasms (ex. non-melanoma skin cancer) for males and females by period of diagnosis. Reproduced from the NCIN report on 'One Year Cancer Survival'[2].

Deprivation: The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups.

The use of socio-economic measures, such as the Index of Multiple Deprivation[16], 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[14].

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.

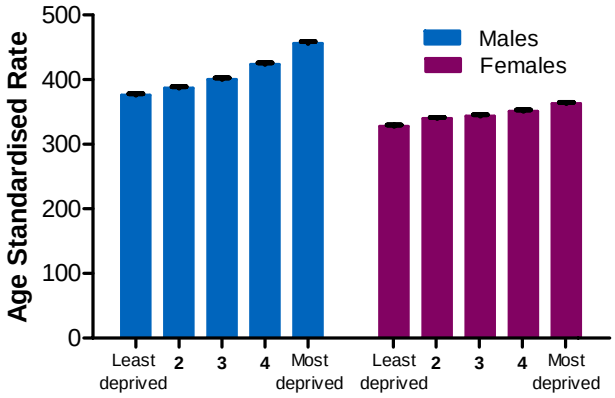

Figure 2. Age standardised incidence for all malignant neoplasms (ex. non-melanoma skin cancer) by deprivation quintile, England, 2000-4. Reproduced from the NCIN report on 'Cancer Incidence by Deprivation'[14]. Error bars show 95% confidence intervals.

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[23].

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[24] and are available from the Equalities Portal.

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

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 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

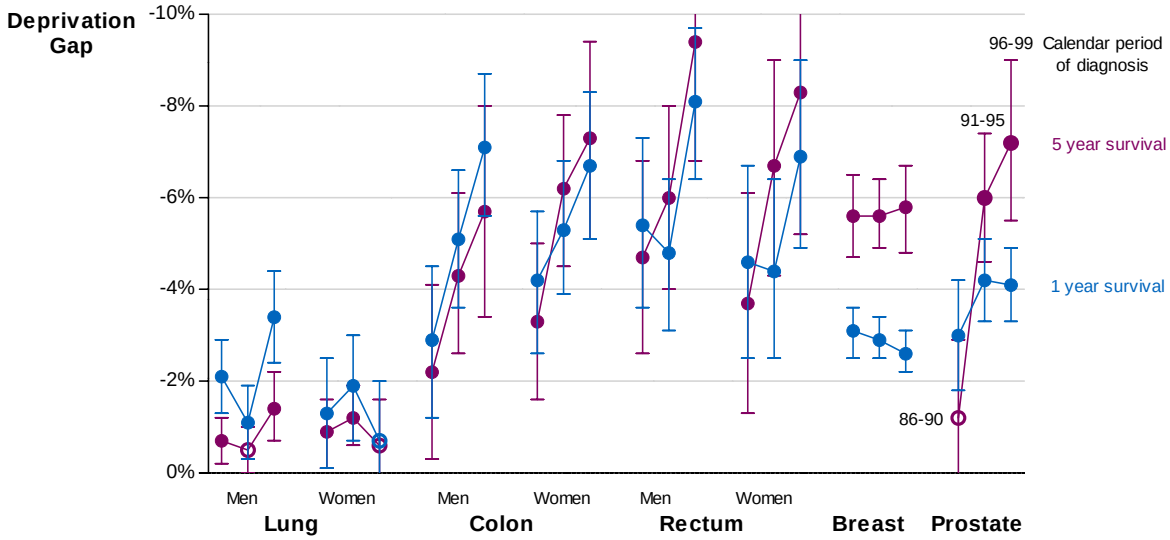

Figure 4. Deprivation gap for 1yr & 5yr relative survival for three diagnosis periods (selected sites, England and Wales). The deprivation gap is the absolute difference in relative survival between the most deprived and most affluent groups, fitted by a regression model to take account of all deprivation 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'[15].

One-year cancer survival for breast, lung and colorectal cancer at PCT level was published in the second report on the Cancer Reform Strategy[24]. 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[25]. The study did note, however, that improvements were being made at a slightly greater rate within spearhead PCT's than the rest of England.

		Spearhead PCTs		**Rest of England**		
Cancer		***Number of patients***	***Five-year relative survival***	***Number of patients***	***Five-year relative survival***	**Difference (% points)**
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

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

Age: 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.

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.

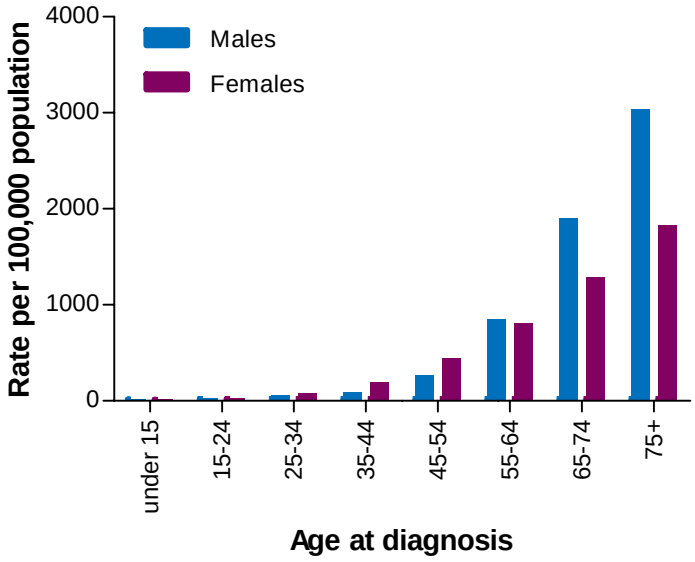

Figure 5. Incidence rates for all cancers (ex. non melanoma skin cancer) by age group, UK, 2006**.** Reproduced with permission from Cancer Research UK Cancer Stats website[31].

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).

	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%

Table 3. Proportion of newly diagnosed cancers, by age group, England, 2007. Reproduced under the terms of the Click-Use Licence from Registrations of cancer diagnosed in 2007, England. Series MB1 No. 38[33]. (NMSC is non melanoma skin cancer).

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 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[31]).

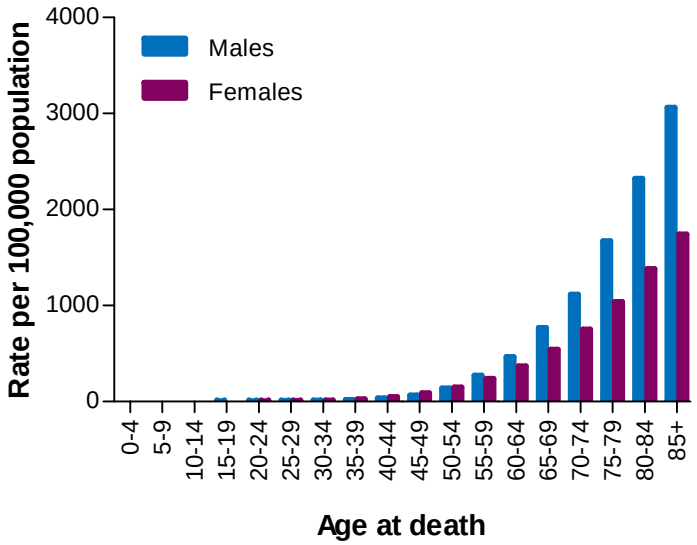

Figure 6. Deaths and mortality rates for all cancers (ex. non melanoma skin cancer) by age group, UK, 2007. Reproduced with permission from Cancer Research UK Cancer Stats website[31].

Consistent with the increasing incidence of cancer with age, the prevalence of cancer is higher in older age groups. On 31st 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[3].

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[34-36].

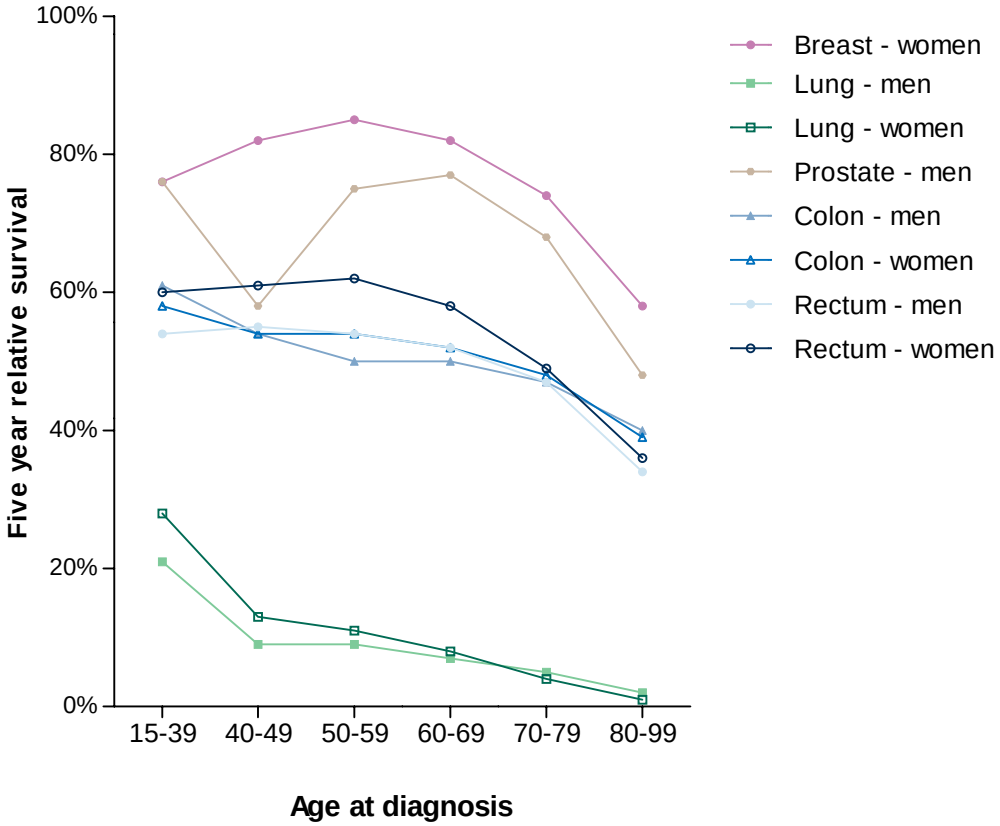

Figure 7. Five-year relative survival, by site and age at diagnosis, England and Wales, 1996-1999 followed up to the end of 2001. Prepared based on data from Cancer Research UK Cancer Stats website[31].

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[44].

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[45].

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[46].

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[44].

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[47, 48].

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[49]. Overall five-year survival for teenagers and young adults has increased from 63% in 1979-84 to 74% in 1996-2001[50]. For children diagnosed in 2004, one-year survival was 90% while for teenagers and young adults it was 91.5%[2].

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[51] and may suffer from long term effects of their treatment[52].

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.

Ethnicity: 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.

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[56].

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[57]. 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[58].

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[56]. Black and Asian women with breast cancer have poorer survival rates, which may be explained by later presentation[59]. As ethnicity data collection improves, analysis of survival by ethnic group will become more reliable.

Mental health: 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.

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[82, 83]. People with Down syndrome have a higher incidence of leukaemias and other cancers[84, 85].

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.

Sexual orientation: 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.

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.

3. A public health service for cancer: prevention, screening and awareness

Improving 1-year survival and other public health outcomes e.g stage at diagnosis

Gender: 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.

Risk factors and primary prevention

Deprivation: The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups. This is likely to be attributable to lifestyle factors, and especially the higher smoking rates in deprived groups.

There is a close association between deprivation and cancer risk factors including smoking, alcohol consumption, obesity and infections (*Helicobacter Pylori* / Hepatitis B&C)[17-20]. 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)[18, 21,

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

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[57]. It is hoped that improved ascertainment of ethnicity in cancer registry and related datasets will stimulate further work in this area.

Ethnicity: 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.

Sexual orientation: 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[67, 68], increasing their risk of lung cancer. It is also estimated that anal cancer is 31 times more common in gay men[69]. 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[70, 71].

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

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[74].

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.

Mental health: Patients with bipolar disorder have an increased incidence of respiratory cancer, but this can be explained by smoking and other risk factors[81].

Screening

Gender: 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[7, 8] and the initial rollout of the national programme have been somewhat lower in men than women[9].

Deprivation: 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)[26-28]. Screening uptake by PCT was published in the second annual report on the CRS[24] and is available from the Equalities Portal.

Age: 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[39]. 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[37, 40].

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."*[41].

'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.

Ethnicity: Uptake for breast[62], cervical[63] and colorectal[8, 64] screening programmes 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.

Sexual orientation: 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[74]. This is up to double the rate of 40-74 year old women in the general population who report never having been screened[63].

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[76]. Cervical screening is recommended for trans men.

Mental health: 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.

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[87]. Others surveys have found similar patterns of low cervical screening uptake but higher levels of breast screening[88, 89]. There is also some evidence from the USA of barriers to screening attendance for those with physical disabilities[90].

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[91].

Awareness and early presentation

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) and are summarised in the equalities portal.

Gender: Men have a lower awareness of the signs and symptoms of cancer and a lower uptake of screening. 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[4]. 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[5].

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[6].

Deprivation: Awareness of the signs and symptoms of cancer is lower amongst socially deprived groups than the population as a whole. Excess mortality in these groups may also be linked to later presentation/diagnosis in more deprived groups.

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[4] 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[5]. Information on recall of cancer symptoms is presented in the Equalities Portal.

Age: 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.

Awareness of the symptoms and signs of cancer increases in people up to 64 years[5]. 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[37].

There is strong evidence that older women present later with breast cancer than younger women. Somewhat surprisingly, the research evidence for other cancers related to late presentation at older ages is much more equivocal[4]. However, particularly poor one year survival rates in older populations suggest that later presentation may be an issue[38].

Ethnicity: 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.

A recent survey using the CAM[5] 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[60] both reinforced the low awareness and showed significant differences between minority groups.
Although there may be some cultural factors involved in this, it is also likely to be related to deprivation.

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[4]. 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[59]. 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[61]. Better collection of staging data in future will allow national analyses of stage at presentation.

Sexual orientation: 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.

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[75].

Mental health: There is evidence of higher cancer mortality in patients with mental health needs, which may be due to late presentation and delayed diagnosis[80].

4. Diagnosing cancer earlier

GP support for early diagnosis and referral and access to diagnostic tests

Age: The low incidence of cancers in younger 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[32].

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[53].

Mental health: People with learning disabilities may have difficulty in communicating changes in their health to carers and to doctors[86]. This has the potential to delay diagnoses and thereby lead to poorer outcomes in these groups.

5. High quality treatment

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.

Treatment: surgery, radiotherapy, drugs

Gender: There is some evidence that men and women with comparable cancers receive different treatment, although the reasons for this are not clear[10]. 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.

Age: 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.

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.

In general, older people with cancer receive less intensive/radical treatment than younger people[42]. 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 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[43]. 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[42]. 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.

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[54]. However, there is some evidence that teenagers and young adults are not being referred to appropriate specialist centres for treatment[32].

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[54]. 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[55].

Deprivation: 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. 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[29]. The less deprived are more likely to receive active treatment for lung cancer[30]. 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[10] and fewer patients from deprived areas receive radiotherapy[29]. The NCIN's report on curative surgical will include an analysis of differences in the rate of surgery by deprivation.

Ethnicity: 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.

Sexual orientation

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

Religion: Religious practices (for example fasting during Ramadan) can impact upon cancer treatment.

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[93].

6. Living with and beyond cancer

Information and choice
Deprivation: Health literacy is likely to be a particular problem for some socioeconomically deprived patients.

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[42].

Ethnicity: 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[12]. Existing cancer information may not always reflect multi-ethnicity in terms of images and language (e.g. that skin might appear red after radiotherapy).

Sexual orientation: 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.

Mental health: 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[89].

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.

Survivorship and rehabilitation
Gender: 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.

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[3].

Engagement
Ethnicity: 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.

Patient experience survey
Men: The national cancer patient survey[11] 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[12]. 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.

Deprivation: 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[12].

Age: 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[11]. 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.

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[32].

Ethnicity: 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[11, 12].

Sexual orientation: 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[77]. 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[78]. 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[79].

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

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

Gender: 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%)[13]. 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.

Deprivation: The likelihood of dying in hospital 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)[13].

Age: 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[13].

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: 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[65]. Lower levels of awareness of hospice and palliative care and language differences amongst minority ethnic groups can limit their use of services[66].

Sexual orientation: 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.

Mental health: 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[92]. 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.

Annex B

7. Improving outcomes for cancer patients: reducing inequalities

Introduction

7.1 Tackling health inequalities in England is essential to improving outcomes and achieving cancer survival rates which match the best performing countries in the world. *Equity and Excellence: Liberating the NHS* makes clear the Government's ambition to reduce health inequalities and improve the health of those with the poorest outcomes.

7.2 Incidence and mortality rates from cancer are higher in disadvantaged groups and areas, leading to worse outcomes and lowering our overall performance. Therefore the greatest scope to make rapid improvements is by focussing activity on *disadvantaged* groups and areas.

7.3 As with many health conditions, there is a range of inequalities in the outcomes and experience of cancer patients. These can occur at every stage of the patient pathway, including in awareness, incidence, access to treatment and care, patient experience, survival and mortality. They can also affect a range of groups in society, including socio-economically disadvantaged groups and areas, black and minority ethnic groups, older or younger people, men or women, people with disabilities, people from particular religions or with particular beliefs and the lesbian, gay, bisexual and transgender (LGBT) community.

National Cancer Equality Initiative (NCEI)

7.4 Since its establishment in 2008, the NCEI has undertaken a range of activities, including the publication of the major report *Reducing cancer inequality: evidence, progress and making it happen* in March 2010[i]. This set out a series of national and local actions to reduce inequalities in cancer care around: data collection, analysis and publication; targeted interventions; training, development and research; evaluation and monitoring and embedding equality, all of which are highly relevant to cancer services in the new environment.

7.5 The work of the NCEI was recognised at the 2010 Civil Service Diversity and Equality Awards, where the NCEI won the award for Leading Change in Diversity and Equality.

7.6 Advancing equality and reducing inequalities are clearly important to the cancer community. In preparing this strategy, over 35 submissions were received to the mailbox which directly related to equality issues. There was broad support for the work of the NCEI, with comments relating to four themes:

- better data are required to improve the understanding of inequalities and develop key performance indicators to measure improvement;
- social deprivation requires more use of social marketing techniques and behavioural economics to better target people with prevention and symptom awareness messages;

- under-treatment of older people is unacceptable and more needs to be done to understand this issue and better equip the professionals on decision making in this area; and
- accessible information and informed choice requires the roll out of information prescriptions and targeted information for different groups.

7.7 In order to deliver the actions set out in *Reducing cancer inequality: evidence, progress and making it happen* and to ensure that equality issues are taken into account as we focus on improving outcomes, the NCEI advisory group has been transformed into an implementation group to assess and advise on local and national implementation.

7.8 The NCEI will continue to gather evidence on the nature, extent and causes of cancer inequalities; advise other parts of the National Cancer Programme on action; and identify and spread good practice.

Developing the evidence base on inequalities

7.9 The NCEI report set out several equality research priorities which are being discussed with the NCIN and the National Cancer Research Institute (NCRI). In addition, the NIHR National Cancer Research Network is exploring inequalities in access to clinical trials and whether steps are need to improve access in any patient group.

7.10 To explore the relationship between schizophrenia and bowel cancer, where research has shown that schizophrenics have a 40% increased chance of developing bowel cancer, NHS Cancer Screening Programmes has commissioned researchers in Oxford and London to undertake a detailed study. The study began in February 2010 and is expected to report in early 2012.

7.11 The results of the national cancer patient experience survey also provide invaluable insights into equality issues, as patients were asked to provide details on their age, gender, and ethnicity. Patients were also asked about any disabilities they had: deafness/severe hearing impairment; blindness/partially sighted; long standing physical condition; learning disability; mental health conditions; and long standing illness. For the first time, we also asked patients about their sexual orientation, and 87% of patients were willing to give us this information (5% preferred not to answer and 8% did not answer the question at all). Full results of the survey are now available at [website], but headline equality results are in Box 2:

Box 2 - results of the Cancer Patient Experience Survey 2010

White cancer patients report a more positive experience than other ethnic groups – particular differences were noted on questions around receiving understandable answers, being given enough care after discharge, and staff working well together

Younger people are the least positive about their experience, particularly around understanding completely what was wrong with them

Older people are less likely to have access to a Clinical Nurse Specialist

Men are largely more positive about their care than women, particularly around staff

and staff working together

People with a disability or long term condition reported a less positive experience than other patients across a wide range of issues measured in the survey. This was particularly marked for patients with a mental health condition or a learning disability

Non-heterosexual patients reported less positive experience, especially in relation to communication and (broadly) being treated with respect and dignity

Despite what might be expected, there is no statistically significant link between deprivation and patient experience, taking all quintiles of deprivation together

People with rarer forms of cancer in general reported a poorer experience of their treatment and care than people with more common forms cancer

7.12 Commissioners will wish to encourage providers to take note of these differences and to consider positive action to address the distinct needs of people from different groups. In particular, those wishing to drive improvements in patient experience through contracts may wish to identify particular groups where improvement is required. The survey data will also be made widely available to researchers and policy makers to encourage a wide range of analysis on equality issues.

Targeted interventions

7.13 As a result of the work of the NCEI, a number of targeted interventions are being developed to address equality issues which have been identified.

7.14 There is now evidence that older people are not always receiving the same standard of treatment as younger patients. Sometimes healthcare professionals make assumptions about an older person's preferences about treatment and a decision that an older person will not be able to cope with treatment is often made without fully assessing their overall physical health. Work is ongoing to support clinicians by making sure they have accurate information about an older person's ability to benefit from cancer treatment rather than making assumptions on the basis of age, including:

- the DH and Macmillan Cancer Support are jointly funding a two year pilot programme to improve intervention rates for people over 70 who have a cancer diagnosis. The project aims to identify, test and evaluate a simpler way to comprehensively assess an older person for cancer treatment, provide practical support and information to aid patient/ practitioner decision-making and train professionals involved in this pathway to promote age equality and address age discrimination. Trail-blazer health and well-being boards may well have a role to play also. Pilot sites have recently been confirmed, with sites going live for a 12 month period; and
- the Pharmaceutical Oncology Initiative, in partnership with DH, is commissioning research to explore the extent to which age is a factor in treatment decisions for a range of cancers, as well as the extent to which clinical attitudes vary across different cancer types and in different countries. The results will be available in the first half of 2011.

7.15 There are links between race and cancer that are complex and which vary between different populations. It also recognised that patient experience surveys have shown that BME groups, in general, report a worse experience of treatment and care. The National Cancer Action Team (NCAT) has been working with BME charities and Cancer Networks to provide a national voice to BME cancer patients and to understand better why they report a poorer experience.

7.16 Given that fewer men take up bowel screening than women, the Department of Health commissioned the Men's Health Forum to look at why this might be and to recommend actions that will encourage more men to actively consider taking up the offer of screening. A conference will be held in January 2011 to discuss the results and generate advice and ideas for the final report, which will be disseminated via local public health services and screening centres.

Applying a human rights approach to delivering personalised cancer care

7.17 As well as targeting interventions to address specific equality issues, tackling inequalities will require that every patient is offered personalised care, which addresses their particular needs rather than the perceived needs of their demographic group. For example, a patient may be a black older male, who comes from a disadvantaged community. Ensuring he receives appropriate care and that his needs are met in the way that he wishes them to be met will require a personalised approach.

7.18 Applying a human rights-based approach lends itself well to supporting cancer services in commissioning and delivering personalised care. The Department of Health is therefore supporting Macmillan Cancer Support in undertaking a project to apply a human rights approach to the delivery of cancer treatment and care. The purpose of the project is to assist services in moving away from using process measures to assess progress on equality issues, towards measuring the outcomes that really matter to patients. The outputs from this project will be available in 2011 and we will work with Macmillan Cancer Support to ensure that they are applied to promoting equality in cancer services.

Embedding equality

7.19 Equality issues should not be an add-on, but rather should be embedded by all aspects of cancer services in implementing this strategy. At a national level, the NCEI is working closely with other national initiatives such as NAEDI and the NCSI to ensure that equality issues are addressed at each stage of the patient pathway.

7.20 At a commissioner level, information will be provided to consortia on the equality and inequality characteristics of their cancer populations, as well as how their performance compares with other areas. The equality metrics, available through the Equality Portal, will provide commissioners, stakeholders and the public with readily accessible and comparable information on equality issues. Commissioners will wish to use this information to work with providers to tackle embedded inequalities in cancer care at every stage of the pathway.

7.21 At a provider level, Multi-Disciplinary Teams (MDTs) are being encouraged to embed equalities into clinical practice. We will develop and distribute patient

characteristics profiles to MDTs. In future, MDT Health Equity Audits will form part of National Cancer Peer Review Programme.

[i] http://www.cancerinfo.nhs.uk/healthcare-professional/ncei/reports