

# Reducing cancer inequality: evidence, progress and making it happen

A report by the National Cancer Equality Initiative



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# Foreword

The Cancer Reform Strategy 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: in incidence, access to services and treatment, patient experience and outcomes.

Our vision is to achieve high quality, personal treatment and care for everyone affected by cancer by tackling inequalities and promoting equality across cancer services in England.

Every professional involved in the delivery of treatment, care and support has the opportunity to play an important role in promoting equality throughout the patient pathway: from working to reduce or manage people's risk factors for developing cancer, to promoting earlier diagnosis, ensuring people are offered the right treatment at the right time, and feel that they are treated with dignity and respect.

This report sets out the progress that has been made so far, but also makes clear the scale of the challenge that remains for our vision to be achieved. In its development, the National Cancer Equality Initiative has brought together experts in different equality issues as well as new sources of data to create an unprecedented picture of the extent and nature of cancer inequalities in England. This evidence base will be

invaluable in informing both national and local activity that can make cancer equality a reality.

Although this is challenging, the opportunities are great. The analysis presented in this report shows that, although cancer services have improved for everyone, the progress made in achieving better cancer outcomes has been uneven. Addressing this will make a significant contribution to achieving world class cancer services and outcomes, the key aim of the Cancer Reform Strategy.

This report sets out a comprehensive range of activity to achieve our vision. From national action to improve data collection, pilot new approaches and stimulate greater research, through to opportunities for multi disciplinary teams to embed equality audits and a person-centred approach in their everyday work, we all have a role to play in making it happen.



**Professor Sir Mike Richards**  
**National Cancer Director/Co-chair NCEI**



**Joanne Rule**  
**Co-chair, NCEI**

# Executive summary

**1** The NHS Constitution makes clear that a core duty of the NHS is to promote equality and the Cancer Reform Strategy made promoting equality a priority for NHS cancer services.

**2** 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 deprived groups, 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.

**3** This document summarises the progress made by the National Cancer Equality Initiative (NCEI) to date, and sets out the next steps for tackling inequalities in cancer, as well as promoting greater equality. It identifies a range of activity to be taken forward nationally and activity to be considered locally.

## Evidence on inequalities

**4** Much of the information that is available on cancer inequalities in England (and the UK) comes from cancer registries. In recent years there have been significant improvements in the quality of information on inequalities that is collected by the cancer registries.

**5** In addition, other relevant information comes from a wide range of different sources including lifestyle and awareness surveys, data collected on the national cancer screening programmes, Hospital Episodes Statistics (HES), large scale surveys of patients' experiences of care and research studies.

**6** The launch of the National Cancer Intelligence Network (NCIN) has provided a major opportunity to bring together these sources of information to enable new insights into cancer inequalities and the NCEI has worked closely with the NCIN to capitalise on this opportunity.

7 There is now a range of evidence about the nature and extent of inequalities which occur in cancer, including:

- > Cancer incidence and mortality are generally higher in deprived groups compared with affluent groups, older compared with younger people and men compared with women. Conversely, breast cancer has higher incidence in more affluent groups, but mortality is actually higher in less affluent women. The picture for ethnic minority groups varies according to cancer type and ethnic group. In general, incidence is lower amongst ethnic minority groups, although there are some important exceptions (incidence of prostate cancer is greater amongst Black African and Black African-Caribbean men, liver cancer in South Asians, and mouth cancer in Bangladeshis);
- > Levels of public awareness of cancer signs and symptoms are generally low, but even lower in some groups, such as deprived communities, some BME groups and men. This may contribute to lower uptake of screening and later presentation when symptoms arise;
- > Lifestyle factors (such as smoking, obesity, alcohol consumption and physical inactivity) almost certainly account for most of the variance in cancer incidence between the most and least deprived;

> Poorer experience of care is reported by black and minority ethnic groups, men with prostate cancer, and people living in London;

- > Part of the variance in mortality rates can be attributed to delayed diagnosis amongst deprived groups, older people (at least for breast cancer) and certain BME groups (at least for breast cancer). The contribution of delayed diagnosis to poorer survival rates and higher mortality amongst men than women is still uncertain; and
- > Improvements in mortality have been slower in older people than in younger people. Older people with cancer receive less intensive treatment than younger people. In many cases this may be clinically appropriate. However, there is increasing evidence that under-treatment of older people may occur.

8 A detailed summary of the evidence base on different equality areas produced jointly by the NCIN and NCEI is at Annex 1. This brings together data on the nature and extent of inequalities, as well as feedback from experts.

9 There are, however, a number of gaps in the evidence base which need addressing. It remains the case that there is more information available for some inequality

areas than for others. In particular, there is less information available on religion and belief, disability and sexual orientation than on ethnicity, age, gender and socio-economic deprivation. This is in part due to the difficulties in recording information through routine NHS data collection on these service areas.

## NCEI activity to date

10 In order to help tackle these inequalities and promote greater equality, the NCEI was established in 2008. The NCEI has undertaken a range of activities, including:

- > Mapping existing work to promote equality or tackle inequalities;
- > Publishing guiding principles for effective equality working;
- > Facilitating a series of expert visioning events to assess the existing evidence on different equality areas, as well as what could be done to tackle inequalities;
- > Stimulating further research and analyses to strengthen the evidence base on inequalities; and
- > Bringing together the evidence so as to encourage its use in informing further action to promote cancer equality and tackle inequalities.

11 The NCEI has also worked closely with other parts of the national cancer programme to ensure that action to tackle inequality and promote greater equality is embedded into all aspects of cancer service delivery.

## Further action to promote cancer equality

12 This document sets out a comprehensive range of activity for consideration at every level of cancer services to tackle the inequalities which persist in cancer incidence, services and outcomes, to effectively promote greater equality.

13 Proposals to collect more data on equality issues should be considered to inform activity to tackle inequalities and to measure progress. To support further improvement on cancer equality, a series of equality metrics have been developed to enable the measurement of progress on issues where there is a proven link with inequality. It is intended that these metrics will be developmental and will be added to over time, as improved data and evidence become available. The equality metrics have been published alongside this document on a dedicated cancer equality portal ([www.ncin.org.uk/equalities/](http://www.ncin.org.uk/equalities/)) and will also be accessible through the Cancer Commissioning Toolkit. They will be incorporated in future versions of the Cancer Commissioning Guidance.



14 At a national level a range of actions will be taken to further tackle inequalities. The Cancer Patient Experience Survey Programme will provide sufficient data to get a comprehensive view of whether, and to what extent, experience varies by age, gender, deprivation and ethnicity. It will also seek information on patients' sexual orientation and disability. The Department of Health will also provide advice and support to Macmillan Cancer Support's Human Rights Project, including acting as a pilot site.

15 NCIN will continue to collect and analyse data which will further develop the evidence base on equality issues, contributing to the equality metrics mentioned above. In addition, in 2010 a new data linkage will be established to enable the NCIN to analyse existing cancer data sets according to the rurality of a patient's home address, shedding light on the extent to which rurality affects cancer incidence, patient experience and outcomes. The NCIN will also continue to work with cancer services to support improved recording of ethnicity.

16 In order to support clinicians in fully assessing older patients' suitability for different forms of treatment, the Department of Health will work in partnership with Macmillan Cancer Support to pilot a range of approaches to formally assessing frailty in older people

when considering treatment options. This will help clinicians to make sure that they have accurate information about an older person's ability to benefit from cancer treatment rather than making assumptions on the basis of age. Tailored packages of support for older people receiving active treatment will also be tested. In order to more fully explore clinical attitudes and culture in relation to the treatment of older people, the Department of Health and the National Cancer Action Team (NCAT) will work with the Pharmaceutical Oncology Initiative and others to commission research into the issue.

17 The National Awareness and Early Diagnosis Initiative (NAEDI) is already targeting groups with a lower socio-economic status and will be asked to support targeted initiatives aimed at raising awareness amongst older women and Black and Minority Ethnic groups, where later presentation is known to be a problem. In addition, results will shortly be available from a survey using the Cancer Awareness Measure to test whether there are differences in awareness levels according to sexual orientation.

18 The National Cancer Survivorship Initiative (NCSI) will support the development of holistic needs assessment and care planning for every cancer patient.



Care plans are being tested to take account of patients' individual needs related to their age, gender, ethnicity, educational attainment, disability or any other equality aspect affecting their treatment and care.

**19** The National Cancer Research Institute (NCRI) will work closely with NCIN to help fill gaps in the evidence base relating to the extent and causes of inequalities in cancer incidence and mortality. NCRI will also consider explicitly, and where appropriate address, inequalities in all the research initiatives that it takes forward. This is already happening in the National Prevention Research Initiative (NPRI) and NAEDI and is under consideration in the NSCI). The National Cancer Research Network (NCRN) will be asked to explore inequalities in access to clinical trials and whether steps are needed to improve access in any patient group(s), though it is recognised that here may need to be improvements in information flow before this is possible.

**20** The National Cancer Peer Review Programme will review the cancer peer review measures to ensure that they reflect the importance of multi-disciplinary teams (MDTs) assessing equality issues within their patient caseloads and taking appropriate action to address them.

**21** NHS Cancer Screening Programmes will continue to promote and fund equality projects as appropriate, such as the recent work on lesbians and cervical screening. NHS Cancer Screening Programmes are also working closely with the Men's Health Forum on the emerging findings of their bowel cancer screening in men project.

**22** Using the equality metrics, good cancer networks will work with local commissioners and providers to assess the nature of cancer equality issues in their area and to target action to address them. In planning interventions to promote awareness and early diagnosis, good cancer networks will consider whether there are any groups in local populations where delayed presentation and diagnosis may be a particular issue. Networks will also wish to work to support early MDT adopters for patient-level equality audits.

**23** Good practice will be for PCTs and PCT commissioners to consider working with their Cancer Networks and providers to understand and act upon any collection of data relating to equality issues and consider the importance of this data in relation to markers of quality. Future versions of the Cancer Commissioning Guidance will reflect this. Good practice will be for PCTs and PCT commissioners to review local levels of screening coverage and uptake to consider whether further action is required to improve coverage and uptake amongst some equality groups.

24 Multi disciplinary teams (MDTs) can also have an important role to play in improving cancer equality. In future, it will be good practice for MDTs to consider undertaking annual patient-level equality audits, reflect upon their practice and document the findings. Appropriate measures to assess progress are being developed for the National Cancer Peer Review Programme, and will be subject to Review of Central Returns (ROCR) processes, as appropriate. NCAT will work with cancer networks in 2010 to identify volunteers for early adopter sites for patient-level equality audits.

25 The aim of the NCEI is to facilitate the embedding of equality and inequality work into cancer services by taking actions nationally and encouraging actions locally. Moving forward, the NCEI will stage a national equality conference on 22 March 2010 to stimulate thinking on the local action to promote equality and to facilitate the sharing of good practice. The NCEI will also continue to work to gather evidence on the nature, extent and causes of cancer inequalities; advise other parts of the National Cancer Programme on the action required to address cancer inequalities; identify, champion and spread good practice in promoting cancer equality; assess national

information and local information where available; and provide advice to the Cancer Reform Strategy Advisory Board and the Cancer Programme Board on the progress made in tackling cancer inequalities as well as on any further steps which should be taken to promote greater equality.

# 1. Introduction

**1.1** The *Cancer Reform Strategy* aims to ensure that every person affected by cancer should receive world class services at every stage of their cancer journey. Translating this vision into reality requires concerted action to promote equality. This document sets out the progress that has been made since the publication of the *Cancer Reform Strategy* in furthering our understanding of the inequalities that exist in cancer and delivering change, as well as the action that now needs to be taken to promote equality. This is critical in both improving outcomes and patient experience.

**1.2** The *NHS Constitution* makes clear that a core duty of the NHS is to promote equality:

*“The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.”*

**1.3** *Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England post-2010*, published in February 2010, identifies that health inequalities are a matter of fairness and social justice, and that health inequalities arise from social inequalities. Cancer is a key theme in the review because of the strong evidence that cancer as a condition is strongly related to health inequalities.

**1.4** *NHS 2010–2015: from good to great: preventative, people-centred, productive* makes clear that tackling inequalities and promoting equality should remain a core priority of the NHS.

**1.5** 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 and can affect a range of groups in society, including socio-economically deprived groups, 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.

1.6 Good progress has been made in improving overall outcomes for cancer. Initiatives to improve timely access to cancer services, ensure that all patients are considered by multidisciplinary teams and expand access to innovative treatments have all helped reduce inequalities in cancer. However, cancer outcomes and the experience reported by patients of their treatment and care continue to vary inequitably for different groups in society. More needs to be done to tackle all forms of inequality in cancer.

## The National Cancer Equality Initiative (NCEI)

1.7 A key aim of the Cancer Reform Strategy is to reduce inequalities in public awareness of the signs and symptoms of cancer, in patient experience, in access to services and in service quality – thereby reducing inequalities in cancer outcomes.

1.8 To achieve these objectives, it is important to understand more about the nature, extent and causes of inequality in cancer, as well as the interventions which are most effective in achieving greater equality. This is why the *Cancer Reform Strategy* announced the creation of the National Cancer Equality Initiative (NCEI) to ensure that tackling inequalities remained central to the NHS' efforts to develop world class cancer services.

1.9 The NCEI aims to:

- > Bring together experts in the field to identify problems and areas of good practice, facilitating the spread of what works;
- > Work across the wider national cancer programme to ensure inequalities are both identified and addressed within individual initiatives and fully integrated within work programmes to support improvement;
- > Identify areas, in collaboration with the National Cancer Intelligence Network (NCIN), through the National Cancer Dataset Initiative where data collection can be improved within the NHS and ensuring that data are analysed and published to support service providers to make improvements; and
- > Uncover gaps in research and work with stakeholders and academic institutions to improve knowledge and evidence around cancer inequalities.

1.10 The NCEI is co-chaired by Professor Sir Mike Richards and Joanne Rule, and is supported by the National Cancer Action Team (NCAT) and the Department of Health. The initiative reports to the Department of Health's Cancer Programme Board. The NCEI has an advisory group which is diverse and includes representatives from third sector

organisations, DH, academic institutions, clinicians, allied health professionals and patients. The full membership of the NCEI advisory group is included in Appendix 1.

## NCEI work to date

**1.11** Since its establishment in 2008, the NCEI has undertaken a range of activities which are summarised in Chapter 3. As a result, the NCEI is now in a position to set out the next steps for promoting cancer equality. This document:

- > Provides a progress report on the activity undertaken to promote cancer equality since the publication of the *Cancer Reform Strategy* in December 2007;
- > Summarises existing and new evidence;
- > Signposts stakeholders to the resources which can be used to inform the development of interventions;
- > Sets out the further actions which can be taken to tackle cancer inequalities across the patient pathway; and
- > Establishes a series of metrics which can be used to measure progress in reducing cancer inequalities at a national and local level.

**1.12** The NCEI engaged with the All Party Parliamentary Group on Cancer (APPG) during its recent inquiry into inequalities in cancer, including providing a written briefing and both co-chairs giving oral evidence. Many of the issues raised in the APPG's report are addressed in this document. Action to improve the services available to people with rarer cancers is being taken forward by other aspects of the National Cancer Programme, as the issue falls outside the remit of the NCEI.

**1.13 NCIN will conduct an analysis on rarer cancers during 2010 examining:**

- > **Changes in survival and mortality in rarer cancers over the last decade; and**
- > **Whether there are geographical variations in the incidence of rarer cancers.**

**1.14 NCIN will work closely with NCEI on this analysis to ensure that inequalities identified in these cancers are considered as part of NCEI's wider work.**

**1.15** It is hoped that the activity generated by the NCEI will have a positive impact on rarer cancers.

## Next steps for the NCEI

1.16 The first phase of the NCEI has focused on gathering evidence, stimulating discussion on cancer inequalities and ensuring that promoting equality is at the heart of every initiative of the National Cancer Programme. The next phase will focus on encouraging local ownership of the importance of promoting cancer equality, as well as the need for comprehensive action at all levels. NCEI will provide national support and leadership to promote this.

1.17 This report is intended to assist every individual and organisation with a commitment to reducing cancer inequalities, including:

- > Cancer networks;
- > Primary Care Trusts;
- > Service providers and clinicians
- > Strategic Health Authorities;
- > Charities;
- > Researchers; and
- > Policymakers.

1.18 This document sets out a range of activity over the period 2010 to 2012, although further activity to encourage greater equality in cancer will be required after this period.

1.19 The NCEI intends to embed equalities and inequalities work into mainstream cancer delivery, at both a local and a national level.

1.20 **Moving forward, the NCEI will:**

- > **Continue to work to gather evidence on the nature, extent and causes of cancer inequalities, both on a population-wide and individual patient level;**
- > **Advise other parts of the National Cancer Programme on the action required to address cancer inequalities;**
- > **Identify, champion and spread good practice in promoting cancer equality;**
- > **Assess local and national implementation; and**
- > **Provide advice to the Cancer Reform Strategy Advisory Board on the progress made in tackling cancer inequalities as well as on any further steps which should be taken to promote greater equality.**

## 2. Progress in addressing cancer inequalities

**2.1** Reducing cancer inequalities is a key priority of the *Cancer Reform Strategy*. Every chapter of the Strategy is relevant to reducing different aspects of inequality. Action to address inequalities cannot be seen in isolation, but rather as an integral part of the wider national cancer programme. For example:

- > Efforts to encourage healthier lifestyles will particularly benefit groups in society where the prevalence of cancer risk factors such as smoking, obesity, alcohol consumption and physical inactivity are notably high, and where a particular focus on socio-economic disadvantage is required;
- > Measures to raise awareness of cancer signs and symptoms and ensure faster referral and diagnosis for people where cancer is suspected will help those who may otherwise be less informed about cancer signs and symptoms, and where a particular focus on those most likely to experience inequality is required;
- > Reducing cancer waits will enable faster treatment for all patients;
- > Expanding radiotherapy capacity will ensure equal access to a treatment needed by more than half of all patients with cancer;

- > Enhancing the quality and timeliness of information available to cancer patients will ensure that all patients are given the appropriate information, advice and support throughout their cancer journey, and where a focus on providing information to groups who are least likely to access it themselves or for whom English is not their first language or have low educational attainment or other needs is required; and
- > Developing the financial, psychological and clinical support available to people living with or beyond cancer will improve the experience reported by patients from all groups in society, and where a focus on individual needs arising from culture, ethnicity, income, language, age and faith will be needed.

**2.2** A key task of the NCEI is therefore to work with all parts of the National Cancer Programme to support action to promote cancer equality.

### Equality legislation and how it applies to cancer

**2.3** Equality of outcomes and personalised services will only be delivered by working with communities, recognising difference and tailoring provision rather than adopting a 'one size fits all' approach. In recognition of this, the Department of Health has published



a *Single Equality Scheme* which is intended to support those who commission and provide services in proactively ensuring that people's individual needs are met, and their dignity and human rights respected at every stage of the care journey.

**2.4** Reducing inequalities in the provision of cancer services and the experience of cancer patients is the right thing to do, but is something legislation encourages us to tackle. Public authorities, including the Department of Health and the NHS, are bound by statutory equality duties set out in a range of legislation. This is streamlined and strengthened by the Equality Bill currently being considered by Parliament.

**2.5** The Government strongly believes that ageism has no place in a civilised society. That is why the Equality Bill bans age discrimination in services and public functions, including in social care and healthcare. Subject to the Bill completing its parliamentary processes, these provisions will come into force in 2012. The Bill also creates a new equality duty on public bodies and others carrying out public functions. The duty applies to age, as well as to seven other protected characteristics. The new duty will come into force from April 2011.

## Reducing geographical inequalities in cancer outcomes

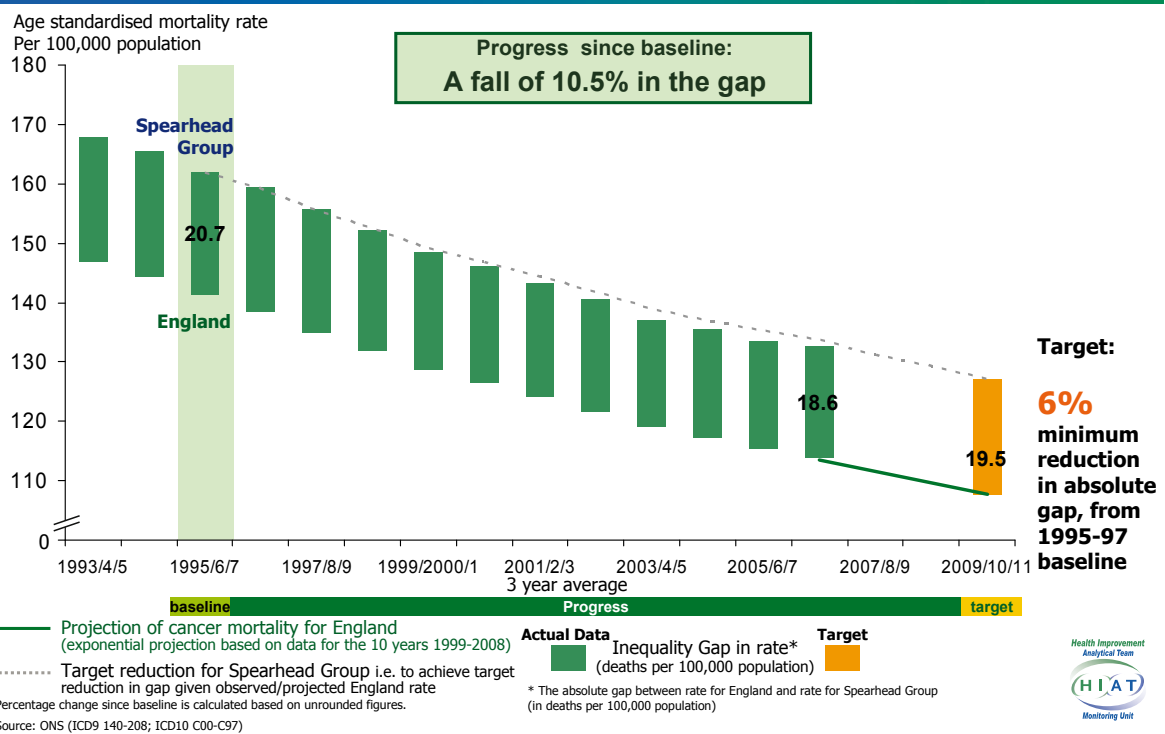
**2.6** To date, the major focus of NHS activity has been on addressing the inequalities in cancer outcomes between different areas, based on poor health and deprivation. In recognition of the importance of reducing cancer inequalities, the Department of Health's Public Service Agreement (PSA) for cancer mortality (ages under 75) includes commitments to reduce the absolute gap in mortality rates between England and the areas with the worst health and deprivation (Spearhead PCTs) by at least 6% by 2010, compared to a baseline from 1995-97, as well as to deliver an overall reduction in mortality of at least 20%. Reducing cancer mortality in the Spearhead area at all ages is a key component of the national inequalities target to narrow the life expectancy gap between Spearhead areas and England. High cancer mortality under 75 years was one of the five factors used to select Spearhead areas.

**2.7** Progress on the PSA has been encouraging, as demonstrated in Box 1. Three-year average mortality rates for cancer (ages under 75) in England have fallen for each period since 1995-97 (the baseline) and are now 18.2% below this rate. If this trend continues, the target will be met. Progress

## Box 1

## Cancer mortality in people under age 75 – Inequality gap

England 1993-2008 and target for the year '2010'



on reducing the gap between England and the Spearhead Group of PCTs has also been significant. The gap has reduced by 10.5% since the baseline, compared to the targeted reduction of at least 6% by 2009-11.

**2.8** The cancer mortality target and NCEI work link closely to action on reducing gaps in life expectancy, as cancer is one of the three major causes of lower life expectancy in Spearhead areas, accounting for some 17% of the gap. Action on cancer complements inequalities work on other major diseases,

particularly cardiovascular disease, diabetes and coronary obstructive pulmonary disorder. To achieve the target to narrow the gap in life expectancy, more needs to be done on cancer in Spearhead areas than is implied in the target. Cancer deaths for men and women in their 60s, 70s and 80s are contributing to a widening in the life expectancy gap between Spearheads and the whole population, meaning that there has been a relative increase in deaths at these ages compared to the 1995-97 baseline.

## Box 2 – Reducing inequalities in the Baker's Dozen

The Health Inequalities National Support Team (HINST) and NCAT have been working in collaboration with the thirteen Spearhead PCTs that will have the most impact on achieving the 2010 health inequalities – “the baker's dozen” – to reduce mortality due to cancer.

On 19 November 2009 the Baker's Dozen Cancer Learning Network was launched with the aim to share intelligence to accelerate reduction in excess mortality due to cancer in the most deprived areas by:

- > Reviewing effective practice coming from the NAEDI initiative that can be taken up by Spearhead partnerships;
- > Defining the preferred approach to networking the cancer leads in the thirteen Spearheads; and
- > Publishing a guide for Spearheads, “*How to reduce inequalities in health due to cancer*” as a means of sharing effective practice within the Learning Network.

It is recognised that the Baker's Dozen is only the beginning for this work and in time learnings from this project will be rolled out to include all Spearhead PCTs.

**2.9** A support programme has been provided for Spearhead PCTs and Local Authorities lead by the Health Inequalities National Support Team (HINST) for health inequalities; this includes specific work on cancer. More information about targeted action to reduce inequalities in mortality is included in Box 2.

## Work of the other national cancer initiatives

**2.10** The NCEI works closely with the other national initiatives which were created as a result of the *Cancer Reform Strategy* and which have themselves led important programmes of work to promote equality and increase the evidence base about what causes inequality and what interventions are effective.

### Box 3 – National Awareness and Early Diagnosis Initiative (NAEDI) work on equality

NAEDI co-ordinates and provides support to activities that promote the earlier diagnosis of cancer. There is strong evidence to suggest that late diagnosis is a major factor in poor survival rates. Variations in the stage of presentation are believed to be a major explanation of inequalities in outcome.

Work undertaken by NAEDI, using the Cancer Awareness Measure (CAM), has identified that awareness of cancer signs and symptoms is generally lower amongst BME and lower socio-economic groups. This work also highlighted lower levels of awareness in men.

Two nationally-organised awareness programmes aimed at equality groups have also been initiated:

- > The Healthy Communities Collaborative involved 19 sites in disadvantaged areas across the country. Each site undertook targeted interventions developed by a local team of health professionals and volunteers focussing on lung, bowel and breast cancer. The projects targeted different groups at greater risk of late presentation for cancer: men, older people, BME groups and people with learning disabilities. Interventions were delivered in a variety of community settings to reach target audiences, including bingo halls, post offices, mosques, amusement arcades and betting shops. The interventions engaged people through a range of activities emphasising the importance of fun and humour, these have involved snakes & ladders, quizzes, mannequins with breasts and bowels, and hand massages. The interim results are promising, with increases in the numbers of cancers with no spread at diagnosis.
- > *Ahead of the Game* is a pilot initiative run by the Football Foundation in partnership with the the Department of Health and Men's Health Forum. It aims to use the appeal of football to raise awareness and increase the knowledge of the signs, symptoms and risk factors of bowel, prostate and lung cancer among men over 55. Five football clubs are running community-based projects as part of *Ahead of the Game*. The projects are encouraging men to 'Organise your defence' by arming themselves with information which could help reduce their risk of developing cancer and help them spot signs of cancers early.

#### **Box 4 – National Cancer Intelligence Network (NCIN) work on equality**

The NCIN manages the collection, analysis and publication of comparative national information on diagnosis, treatment and outcomes for types of cancers and types of patient. The data collected and analysed by the NCIN has been at the core of the NCEI's efforts to develop a better understanding of the nature, extent and causes of inequalities in cancer.

The NCIN has already published a number of reports relevant to inequalities, including those on ethnicity, gender, age and deprivation. Annex 1 brings together the evidence on cancer inequalities.

#### **Box 5 – National Cancer Survivorship Initiative (NCSI) work on equality**

The NCSI is developing and piloting a range of approaches to improving the care and support available for all people living with cancer. As inequalities occur throughout the care pathway, it is important to ensure that the support offered to cancer patients addresses their personal needs in a manner which is appropriate for their culture.

A number of initiatives have been launched with the intention of promoting greater equality in the survivorship phase of the care pathway, including:

- > Piloting a framework for assessment and care planning, enabling a patient's needs to be assessed in a holistic manner, taking account of physical, social and psychological issues;
- > Developing personalised care plans which assess and document the tailored support that patients should receive;
- > Improving access to personalised and appropriate information, ensuring that written information is provided in a relevant and accessible format for all patients.

Continued

**Box 5 – Continued**

It is important to note that the support which matters most to patients will vary according to their background, circumstances and preferences. The Department of Health has been supporting stakeholders in developing tailored support for different groups, including:

- > Supporting the Men's Health Forum in adding more information on survivorship issues to the Haynes' *Men and Cancer* manual;
- > Providing a grant to the charity My New Hair to extend its nurse-led hairdresser training into the area of hair re-growth, following cancer treatment. The grant will also enable the charity to provide information for health professionals and cancer patients about hair loss and hair re-growth. The training and information manual will also cover the particular needs of BME groups and the training programme will be targeted at hair professionals who provide services to BME groups.

The NCSI recently published its *Vision*, which can be read here: [www.ncsi.org.uk](http://www.ncsi.org.uk)

### Links to wider work on tackling health inequalities and promoting equalities

**2.11** The work on inequalities in cancer is part of a broader cross government programme of work to tackle health inequalities led by the Department of Health. This focuses on both the wider social determinants of health and shorter term action around the national health inequalities targets to narrow the gap in life expectancy across geographical areas and the gap in infant mortality across social groups.

**2.12** A post-2010 cross government health inequalities strategy is being developed, linked to an independent review of health inequalities chaired by Professor Sir Michael Marmot, published in February 2010.

**2.13** Efforts to reduce cancer inequalities will also be supported by wider efforts to promote equality in the NHS. For example, the Pacesetters Programme is a partnership between local communities who experience health inequalities, the NHS and the Department of Health.

2.14 Cancer was included as a specific focus in Wave 2 of the Programme, launched in 2008, resulting in the development of 14 projects on different aspects of cancer and equality. Development areas identified include breast screening in the over 70s, breast screening in BME women, cervical screening for lesbians, testicular cancer awareness in young men, screening for trans-men and trans-women, and palliative care for cancer patients from different faith groups.

2.15 The aim of the Programme is to support the NHS in developing innovative approaches to reducing local health inequalities for patients and local communities and to produce working environments that are fair and free of discrimination. As a result of the Programme, it is expected that:

- > NHS organisations will become better equipped to deal with equality issues, enabling them to mainstream equality into the core business of the NHS;
- > Communities will experience less ill health and higher life expectancy than at present; and
- > The NHS will be better able to attract, develop and retain the best talent across all professional groups from all communities.

2.16 Early feedback is encouraging, with improved data collection being reported as well as greater community engagement and NHS participation in cancer equality initiatives. Wave 2 of the Pacesetters Programme will be subject to a national and local evaluation and quality assurance, incorporating quantitative as well as qualitative outcome measures.



## 3. NCEI work to date

**3.1** Part of the challenge in tackling cancer inequalities has been the lack of available evidence about what the nature, extent and causes of cancer inequalities are, as well as what interventions are effective in addressing them and promoting equality. In developing this vision, a range of NCEI-specific activities have therefore been undertaken, including:

- > Mapping existing activity to tackle inequalities and collating examples of good practice;
- > Developing a series of good practice principles to inform future interventions; and
- > Bringing together experts on different areas of inequality and equality as part of 'visioning events' which reviewed the evidence base and assessed what action should be taken to reduce inequality.

### Mapping existing activity

**3.2** On behalf of the NCEI, the National Cancer Action Team undertook an informal survey of Cancer Networks, voluntary sector and patient groups to develop a more informed picture of the extent, focus and effectiveness of existing equality activity.

A mapping exercise was undertaken between November 2008 to February 2009. Examples were reviewed by members of the NCEI who evaluated them on target area, impact on target and impact on reduction in target equality area.

**3.3** Overall, more projects were mapped which aim to tackle inequalities relating to ethnicity, age and socio-economic deprivation than for inequalities relating to disability or sexual orientation. A number of projects were aimed at women or men, but did not necessarily address health issues specifically relating to gender. Most projects also appear to relate to the earlier stages of the patient pathway, such as awareness, screening and patient information. This may be the optimum mix of projects, but this is as yet unknown.

**3.4** It is clear that a good deal of activity has taken place, often through partnerships between the NHS, voluntary sector and academia. However, many projects have been small in scale and it has been difficult to evaluate the impact of activity, making it challenging to encourage its widespread adoption.

## Box 6 – Principles for good equality and inequalities working

1. You have an evidence base
2. Work is targeted and specific
3. There is community engagement
4. There is service improvement and innovation
5. Interventions are tested and refined
6. You are able to measure effectiveness
7. You have champions and work in partnership with others
8. You evaluate your work
9. Sustainability is built-in
10. Learning is shared

### Good practice principles

3.5 The mapping exercise has informed the development of a set of principles for good equality working, which were published in September 2009. These are intended to support NHS or voluntary sector organisations considering developing a cancer inequalities project.

3.6 The good practice principles can be found at: [http://www.cancerinfo.nhs.uk/images/stories/ncei\\_docs/final\\_principles\\_guidance\\_doc.pdf](http://www.cancerinfo.nhs.uk/images/stories/ncei_docs/final_principles_guidance_doc.pdf)

### Visioning events

3.7 In order to focus efforts on the areas which can make the biggest difference, optimise the impact that interventions will have and embed equalities and inequalities work in every aspect of the national cancer programme, the NCEI facilitated a series of visioning events for each equality area:

- > Older age;
- > Gender;
- > Ethnicity;
- > Disability;
- > Children and younger people;
- > Sexuality;
- > Socio-economic deprivation; and
- > Rurality.

For religion, a written engagement exercise was undertaken to seek the views of faith-based groups, to explore whether or not there were issues other than those relating to end of life ones, about which an earlier consultative event had been held in the development of the End of Life Care Strategy.

**3.8** The objective of the visioning events was to assess:

- > Current knowledge;
- > Gaps in the evidence base;
- > The challenges which exist in tackling inequalities;
- > Interventions which have been successful;
- > Priorities for data collection and research; and
- > Immediate and longer term priorities for action.

**3.9** The events have involved many of the leading experts in each area, including patient groups, clinicians, researchers and charities. The wide range of stakeholder organisations who took part in the events is listed at Appendix 3. These events have played an integral role in informing the evidence summarised in Chapter 4, as well as the vision and actions described in Chapter 5. These have also stimulated further thinking

and action amongst key equality stakeholders, including the extension of existing projects and the development of new research projects.

**3.10** In addition, a workshop on the impact of rurality on cancer was held in February 2010, jointly hosted by the NCEI, NCAT, Macmillan Cancer Support and the Commission for Rural Communities. The purpose of the workshop was to inform further NCEI work to address inequality issues relating to cancer in rural areas and to assess how data sources on cancer and rurality could best be brought together to support further research into the issue.

## 4. The evidence base on cancer inequalities

4.1 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. The last can be used as a good proxy for affluence/deprivation, especially in analyses involving very large numbers of patients.

4.2 In recent years there have been significant improvements in the quality of information on inequalities that is available to the cancer registries. A national linkage between cancer registration data and Hospital Episode Statistics (HES) has been commissioned by the NCIN. Currently 88% of inpatients whose records have been linked to cancer registration data have at least one record of their ethnicity in HES and reporting is improving year on year. This has enabled useful analyses of cancer incidence and survival for different ethnic groups to be undertaken by the NCIN. However, we are concerned to raise these rates significantly and as soon as possible.

4.3 Other relevant information has come from a wide range of different sources. These include:

- > Lifestyle surveys;
- > Surveys of public awareness of cancer;

- > Data published annually by ONS/the NHS Information Centre on the cancer screening programmes;
- > Hospital Episodes Statistics (HES);
- > Large scale surveys of patients' experiences of care undertaken by the Department of Health in 2000 and the National Audit Office in 2004; and
- > Research studies, although these tend to have focused more on inequalities in breast cancer than on other cancers.

4.4 The launch of the NCIN has provided a major opportunity to bring together these sources of information to enable new insights into cancer inequalities. The NCEI has worked closely with the NCIN to capitalise on this opportunity.

### Evidence on inequalities in cancer

4.5 Key evidence on the nature, extent and causes of inequalities includes:

- > Cancer incidence and mortality are generally higher in deprived compared with affluent groups, older compared with younger people and men compared with women. Conversely, breast cancer has higher incidence in more affluent groups. The picture for ethnic minority groups varies according to cancer type and ethnic group;

- > Lifestyle factors (such as smoking, obesity, alcohol consumption and physical inactivity) almost certainly account for most of the variance in cancer incidence between the most and least deprived;
- > Part of the variance in mortality rates can be attributed to delayed diagnosis amongst deprived groups, older people (at least for breast cancer) and certain BME groups (at least for breast cancer). The contribution of delayed diagnosis to poorer survival rates and higher mortality amongst men than women is still uncertain;
- > Awareness of cancer is lower amongst some BME groups. Men have a lower awareness than women. This may contribute to lower uptake of screening and later presentation when symptoms arise; and
- > Older people with cancer receive less intensive treatment than younger people. In many cases this may be clinically appropriate. However, there is increasing evidence that under-treatment of older people may occur.

**4.6** There is a close relationship between the issues faced by different equality groups. For example, socioeconomic deprivation often explains other apparent equality differences, particularly in relation to

ethnicity. Similarly, for religion, although data is not collected, some of the issues encountered by different groups are closely related to issues of ethnicity.

**4.7** A summary of the evidence that has been gathered to date about the extent, nature and causes of inequality is included in Annex 1. Jointly produced by the NCIN and the NCEI, the annex is intended to provide a reference point for anyone interested in promoting greater equality in cancer. It demonstrates some of the early benefits of the collaboration between the NCEI and the NCIN.

### Gaps in the evidence base

**4.8** It remains the case that there is more information available for some inequality areas than for others. In particular, there is less information available on religion and belief, disability and sexual orientation than on ethnicity, age, gender and socioeconomic deprivation. This is in part due to the difficulties in recording information through routine NHS data collection about these factors. This lack of data collection and information for all equality groups is a significant concern for the NCEI.

**4.9** There are three key issues which need to be explored if cancer inequalities are to be effectively tackled and a good evidence base for promoting equality established. It will be important to know:

- i. Whether there are differences to the general population?
- ii. If so, why do these differences exist and do they matter?
- iii. What interventions are effective in addressing these differences?

4.10 The extent of the evidence on these three areas varies according to equality group, as demonstrated in Box 7.

4.11 Researchers who contributed to the NCEI's vision events reported a perception that there have been difficulties in securing funding to conduct extensive equalities research and that this, combined with difficulties in routine data collection, has hindered the development of the evidence base.

### Box 7 – Summary of evidence base on inequalities and cancer

	Whether there are differences with the general population?	Why do these differences exist?	What interventions are effective in addressing these differences?
Deprivation	+++	++	+
Age	+++	++	+
Gender	+++	++	+
Ethnicity	++	+	+
Disability	+	+	o
Sexual orientation	++	+	o
Religion	+	+	o

**Key:**

- o Little or no evidence
- + Some evidence, with many gaps
- ++ Developing evidence, with some gaps
- +++ Comprehensive evidence, with few gaps

## 5. The next steps in promoting equality in cancer

**5.1** Every cancer patient and every carer should have equal access to high quality services, a high quality experience of their treatment and care, and an equally good chance of experiencing world class outcomes.

**5.2** Many of the inequalities that exist have deep-rooted causes and tackling them will not be easy. Addressing them will require a clear commitment across the patient pathway, at every level of NHS cancer services. It will also require strong partnerships with charities, community groups and other public services.

**5.3** Inequalities in cancer will not have been eliminated by 2012. We hope that by 2012 the importance of promoting equality is recognised across all cancer services, and local equality issues are identified and acted upon. Furthermore, there will be a better understanding of what causes inequalities and how they can best be addressed, underpinned by greater research activity in the this area.

**5.4** In addition to further progress in reducing the absolute gap in mortality rates between England and the Spearhead Group of PCTs, it is expected that this will have translated into improved outcomes from cancer for all groups in society, as well as a better experience of treatment and care.

**5.5** This chapter sets out the actions that can be taken to promote greater equality across the cancer patient pathway.

**5.6** Achieving the ambition set out in this document will require consideration of the proposed activity to reduce inequalities and promote equality nationally and locally. This can include:

- > Local services understanding the issues in their own areas, and considering a systematic approach to the delivery of interventions to address inequalities, proportionate to the size of the problem;
- > Consideration of the assessment of the circumstances of individual patients by collecting and reflecting on information, and then addressing the needs affecting particular patients;
- > National support to highlight and spread good practice, as well as identify equality trends; and
- > Consideration of establishing a baseline from measurement of progress to enable local areas of persistent inequality to be prioritised and interventions adjusted in the light of experience gained.



**5.7** The NHS faces a challenging financial climate and further action to promote equality will take place in this context. However, financial pressures cannot be used as justification for delaying action in this area, as this is crucial to improving both patient experience and outcomes. The economic context does, however, reinforce the importance of targeting action on the areas which will make a difference in terms of survival or experience.

**5.8** As set out in chapter 4, many of the underlying causes of inequalities in cancer are similar in nature:

- > Greater risk factors, either because of lifestyle or genetic predisposition;
- > Later diagnosis, because of lower levels of awareness and therefore presentation, problems within primary care in identifying potential signs and symptoms, or lower uptake of screening opportunities;
- > Lower levels of active treatment, either because of patient preference or the assumptions made by clinicians about patient preference; and
- > Poorer experience of treatment and care, either because of different needs and preferences not being recognised/met, or patients not feeling they have been treated with dignity and respect.

**5.9** Therefore action to improve prevention, promote earlier diagnosis, as well as to ensure that all patients are offered appropriate active treatment and have a positive experience of their care (all of which are cornerstones of the Cancer Reform Strategy) could make significant contributions towards securing greater cancer equality.

**5.10** Much work on these important areas is being taken forward by other areas of the National Cancer Programme and this document does not attempt to summarise this. Rather, it focuses on the actions which will be taken specifically to promote equality in the following areas:

- > Collecting better information on cancer inequalities;
- > Establishing equality metrics against which progress can be measured;
- > Stimulating research;
- > Preventing cancer;
- > Diagnosing cancer earlier;
- > Ensuring better treatment;
- > Supporting people living with and beyond cancer;
- > Developing the cancer workforce to promote equality;

- > Providing national support to the NHS in championing equality in cancer; and
- > Tracking and reporting on progress.

**5.11** Further information on the progress made in implementing other elements of the Cancer Reform Strategy can be read in its second annual progress report, available at: [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_109597.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109597.pdf)

## Collecting better information on cancer inequalities

**5.12** A lesson from the first stage of the NCEI is that high quality data on inequalities are of critical importance to informing action to promote greater cancer equality. The NCIN, working in close partnership with the NCEI, has led the way in collecting, analysing and publishing unprecedented information on the nature of cancer inequalities in England. However, there are still significant gaps in our understanding of the nature and extent of cancer inequalities and it will be important that further work is undertaken to fill them. This can be taken forward in part through the review of the National Cancer Dataset (subject to NHS Information Standards Board approval) in collaboration with NCIN.

### **5.13 Moving forward, the use of three main forms of data will be encouraged:**

- > **Population-wide analyses, using data collected on all cancer patients to make available analyses at a PCT, cancer network or national level as appropriate;**
- > **Sampled data, using data collected through surveys to gain an insight into trends in public awareness and patient experience; and**
- > **Consideration of patient-level assessments, enabling services to collect information on patients, reflect on what it tells them and apply it to improve provision, so addressing service-level inequalities.**

**As far as possible these data will be collected so that they can be broken down by equality groups.**

**5.14** As mentioned in chapter 4, it remains the case that there is more information available for some inequality areas than for others. Wherever possible, work will be undertaken to fill information gaps. To date, it has not been possible to fully assess the impact that rurality (alongside other equality issues which affect rural areas, such as deprivation or age) has on cancer.

This is despite the fact that approximately one-fifth (9.7 million) of the population of England live in areas which are designated as rural. **In 2010 a new linkage in data will be established to enable the NCIN to analyse existing cancer data sets according to the rurality of a patient's home address.**

**5.15** Building on preliminary work already undertaken by the Commission for Rural Communities, this should facilitate analyses on the impact of rurality on incidence, mortality and one year survival; access to services; as well as issues such as hospital bed utilisation.

**5.16** There are difficulties in recording information through routine NHS data collection on religion and belief, disability and sexual orientation. However, a number of approaches are being tested to overcome this. **The Cancer Awareness Measure has now been used to test whether there are differences in awareness levels according to sexuality and the results will be available shortly.**

**5.17** The Cancer Patient Experience Survey will take place in spring 2010, and around 60,000 patients will be invited to take part in the survey. **It will provide data sufficient to get a comprehensive view of whether, and to what extent, experience**

**varies by age, gender, deprivation and ethnicity. It will also seek information on patients' sexual orientation and disability.**

A dedicated helpline service will be available to assist people whose first language is not English, or who have a learning disability to complete the survey questionnaire. As well as publishing a national report in autumn 2010, every Trust taking part in the survey will receive a bespoke report on the experience of their patients broken down by cancer type grouping. This will allow Trusts to benchmark themselves not only nationally, but also within their own Trust.

**5.18** The Cancer Patient Experience Survey will not include children aged under 16 due to data protection regulations and the methodology of the survey – different questions would have to be used to those we will use for adults and for children of different ages. **As part of the ongoing work of the Cancer Patient Experience Survey Programme, other surveys will be considered in addition to the main national survey, and the CRS Patient Experience Advisory Group will consider other methodologies in getting feedback from children on their cancer patient experience.**

**5.19** Good progress has been made in improving the coding and recording of ethnicity within the Hospital Episode Statistics (HES). Currently 88% of inpatients

whose records have been linked to cancer registration data have at least one record of their ethnicity in HES. It will be important that this progress is sustained. Good practice will be for commissioners and provider MDTs working together to ensure that ethnicity is coded and recorded accurately. **The NCIN will continue to work with cancer services to support improved recording.**

**5.20** A significant step forward has been the collection and publication of one year survival rates. This information can be used as a proxy for late diagnosis and was published for the first time in the second annual report on the Cancer Reform Strategy. This will be important to equality issues as information suggests that some equality groups are more likely to delay presenting with the signs and symptoms of cancer.

**5.21** In addition to the population-wide analyses of trends, the NCEI believes that the use of patient-level data will be an important mechanism for local improvement. A good MDT should already know:

- > How many new patients it sees;
- > The ethnicity, age, gender and postcode of all patients; and
- > The primary treatment given to each patient.

**5.22** It is also desirable for the MDT to have an accurate record of the stage of presentation for each patient. Such data should, of course, also be sent to the relevant cancer registry and submitted to appropriate national clinical audits.

**5.23** It is recognised that, at an MDT level, not all data will be of sufficient sample size to be statistically relevant. However, the NCEI believes that the use of these data to inform clinical practice should be given a high priority. By ensuring that these data are collected, reflecting on them and acting to address any findings, it should be possible to improve cancer equalities at the service level as well as at a population level.

**5.24** **Good practice will be for MDTs to undertake patient-level equality audits, reflecting annually on their practice and document the findings. Appropriate measures to assess progress on this will be included in the National Cancer Peer Review Programme, subject to ROCR approval where appropriate. The National Cancer Action Team will work with cancer networks in 2010 to identify volunteers for early adopter sites for patient-level equality audits. It is recognised that where equality data are not routinely collected by the NHS, consideration will need to be given to develop and implement appropriate**

**processes. Good practice will see MDTS considering the use of Health Equity Audits to compare service provision with need as a starting point for informing any action to tackle inequalities.**

5.25 National analyses will of course be informed by locally collected data (as they are now) and will also be an invaluable mechanism for validating or benchmarking local findings. The information which should be available at different service levels is summarised in box 8.

## **Establishing equality metrics against which progress can be measured**

5.26 To date, the only equality measure which has been routinely measured and published has been progress in reducing the absolute gap in mortality rates between England and the Spearhead Group of PCTs. This alone is not enough to enable effective measurement of the progress made in promoting cancer equality, nor is it sufficient to enable commissioners and providers to take action to tackle persistent inequalities or to assess whether interventions are proving value for money in a challenging funding environment.

5.27 Experience from improving cancer services suggests that metrics can play an important role in improving performance, enabling patients to make choices, commissioners to benchmark quality and providers to compare and improve their practice.

**5.28 To support further improvement on reducing cancer inequalities, a series of equality metrics have been suggested by the NCEI Advisory Group. The metrics are drawn from existing sources and do not require expensive and time consuming new data collections.** The metrics can be used to:

- > Measure aspects of cancer services which are known to be relevant to equalities;
- > Enable the NHS at a local and national level to track progress and consider adjustments to services to promote greater equality and narrow inequalities gaps; and
- > Build on the work undertaken by the NCIN.

5.29 As relatively good quality information exists on age, ethnicity, gender and socio-economic status, these areas will be the focus for the majority of equality metrics. For metrics where data are generated

through population-based surveys (e.g. the Cancer Awareness Measure or the Cancer Patient Experience Survey Programme), it may be possible to expand the range of equality groups to include sexual orientation, religion and disability.

**5.30** Tools such as Health Equity Audit, the Health Inequalities Intervention Toolkit and materials from the Health Inequalities National Support Team, when used alongside the equality metrics, will also help local services with making population level improvements in health inequalities.

**5.31** The table overleaf sets out the equality metrics which can be collected, the timing of when the data is published, and the population level at which data will be available.

**5.32** **It is intended that these metrics will be developmental and will be added to over time, as improved data and evidence become available.**

**5.33** **Information on the metrics, as well as data on performance, will be available through a new equality portal, bringing together key sources of information on cancer equality. The portal, which is being launched alongside this document, is available at: [www.ncin.org.uk/equalities/](http://www.ncin.org.uk/equalities/)**

## Stimulating research

**5.34** The visioning events, summarised in Chapter 4, identified a series of important gaps in the evidence base, both in terms of the nature, causes and extent of inequalities, but also in terms of what works in addressing them.

**5.35** Researchers who participated in the visioning events also reported difficulties in securing funding to undertake research on equality issues. The visioning events have in themselves stimulated new partnerships and research collaborations. However, it is clear that further action will be required to stimulate research into equality issues.

**5.36** Based on the feedback from the visioning events, as well as separate contributions from the research community, the NCEI has identified a series of priority research issues which require further investigation. Currently religion is not being covered because no issues other than those being taken forward by the End of Life Strategy were identified. The key issues for investigation on each equality area is set out in Box 9.

## Box 8

Area	Metric	Description	Equality groups addressed	Lowest population level at which data will be published*	Publication date
<b>Cancer outcomes</b>	Incidence	Number of cases of cancer diagnosed	Gender Ethnicity Socio-economic deprivation	Cancer network	Immediate (updated as further data becomes available)
	One-year survival	Percentage of patients who survive one-year after diagnosis	Older age Gender Socio-economic deprivation Spearhead vs non-spearhead PCTs	PCT	Immediate
	Mortality	Numbers dying of cancer	Older age (over 75's) Gender Spearhead vs non-spearhead PCTs	PCT	Immediate
<b>Awareness &amp; early diagnosis</b>	Symptom awareness	Symptom awareness amongst equality groups vs the general population	Older age Gender Ethnicity Socio-economic deprivation	National	Immediate
	Stage at presentation	Stage of disease at presentation	TBC	National	TBC
	Screening uptake	Proportion of eligible population undergoing screening	Spearhead vs non-spearhead PCTs	PCT	Immediate



Area	Metric	Description	Equality groups addressed	Lowest population level at which data will be published*	Publication date
<b>Treatment</b>	Cancer waits	Number of referrals through the two-week wait pathway and compliance with cancer waiting time targets	Spearhead vs non-spearhead PCTs	PCT	Immediate
	Curative surgery	Proportion of patients given surgery with curative intent	Older Age Gender Socio-economic deprivation	Cancer network	2010
	Radiotherapy	Proportion of patients receiving radiotherapy	TBC	TBC	From 2011
	Chemotherapy	Proportion of patients receiving chemotherapy	TBC	TBC	From 2012
	Patients reported being treated with dignity and respect	Proportion of patients reporting being treated with dignity and respect	Older age Gender Ethnicity Socio-economic deprivation Spearhead vs non-spearhead PCTs Sexuality Disability	Provider organisation	2010 (via patient experience survey)
<b>Other</b>	Prevalence	Number of patients alive up to 1-yr, 5-yr, 10-yr and at any time after diagnosis	Gender Age	Cancer network	Immediate
	Ethnicity coding	Proportion of cancer patients with ethnicity coding in HES	Ethnicity Gender	PCT	Immediate

\* NB information on each equality group listed may not be available at this level due to issues of patient confidentiality and sample size.

### Box 9 – Key research issues

Equality area	Key research issue
Deprivation	<ul style="list-style-type: none"> <li>&gt; To what extent does knowledge, attitude and beliefs contribute to late presentation and poorer outcomes in deprived populations?</li> <li>&gt; What action is effective in improving timing of presentation for disadvantaged groups?</li> </ul>
Age	<ul style="list-style-type: none"> <li>&gt; Why is the reduction in mortality in older people slower than for younger people and slower than in other countries?</li> <li>&gt; To what extent does poor patient health and patient choice contribute to poorer outcomes?</li> <li>&gt; How effective would pre-treatment health assessment be in reducing adverse outcomes and age inequalities?</li> </ul>
Gender	<ul style="list-style-type: none"> <li>&gt; What accounts for the differences in incidence and mortality between males and females and to what extent can these be accounted for by known risk factors, such as smoking, alcohol consumption and obesity?</li> <li>&gt; What are the most effective ways to communicate cancer risk, prevention and screening messages to men and women across the equalities spectrum?</li> </ul>
Ethnicity	<ul style="list-style-type: none"> <li>&gt; To what extent do knowledge, attitude and beliefs contribute to late presentation and poorer outcomes in different ethnic populations?</li> <li>&gt; What action is effective in raising awareness of cancer risk, cancer prevention and screening in BME communities?</li> </ul>
Disability	<ul style="list-style-type: none"> <li>&gt; What is the prevalence of cancer in people with mental health problems, learning and other disabilities? How far can these differences be explained in terms of known risk factors?</li> <li>&gt; How do people with learning disability and mental health problems access cancer services and what is the role of carers/families primary and secondary care?</li> <li>&gt; What is the experience of cancer care and support for those with learning disabilities and mental health problems?</li> </ul>
Sexual orientation	<ul style="list-style-type: none"> <li>&gt; What is the experience of cancer care and support for LGBT people? What is the prevalence of cancer in LGBT and how far can these differences be explained in terms of known risk factors?</li> </ul>

**5.37** Research that addresses some issues of inequality is already under way within the National Prevention Research Initiative (NPRI), included in the brief for the NAEDI research workstream and planned for the NCSI. Equality issues relevant to life-style factors, early diagnosis and survivorship will be taken forward as part of these programmes.

**5.38** The NCEI will now also engage in discussions with NCIN, and research funders, through the NCRI, to prioritise additional research in these areas. NCRN will be asked to explore inequalities in access to clinical trials and whether steps are needed to improve access in any patient group(s), though it is recognised that there may need to be improvements in information flow before this is possible.

## Preventing cancer

**5.39** Evidence suggests that some of the excess incidence of cancer reported for some equality groups can be explained by lifestyle factors. Therefore it will be important that prevention messages are targeted at groups most at risk. **Building on its work undertaken to date, the NCEI will provide advice to the Department of Health's prevention programme on the interventions which may work best with different groups in society.**

## Diagnosing cancer earlier

**5.40** As set out earlier in this document, later diagnosis is a key factor in poorer outcomes for many of the equality groups. Early findings from the Cancer Awareness Measure show that awareness of cancer symptoms was lower in men, younger people, those from a lower socio economic status group and ethnic minorities. There was lower recall of signs and symptoms within ethnic minority groups, and significant variation between ethnic groups.

**5.41** NAEDI's work to encourage earlier presentation and diagnosis will therefore be critical to tackling inequalities. Programmes such as *Ahead of the Game* and the Healthy Communities Collaborative are already raising awareness amongst equality groups (men and deprived communities respectively).

**5.42** A variety of local initiatives are also being funded with the intention of encouraging symptom awareness and earlier diagnosis amongst equality groups. Examples include:

- > Conducting baseline assessments on levels of awareness in different groups as well as the differences that can exist in GP referral patterns, depending on the population they serve;

- > Developing an anticipatory care calendar for people with learning disabilities or dementia in care homes;
- > Posters and awareness raising activities at gypsy and traveller sites;
- > Targeting women who have never attended breast cancer screening (known to be more likely to be from a disadvantaged group) and encouraging them to consider participating;
- > Fostering community action on cancer awareness in deprived areas; and
- > Community development awareness initiatives targeting BME groups.

**5.43 NAEDI will be asked to support targeted initiatives aimed at raising awareness amongst older women and Black and Minority Ethnic groups, where later presentation is known to be a problem.** When developing local awareness and early diagnosis initiatives, PCTs and cancer networks should also consider how interventions to promote early diagnosis could help address local equality issues.

**5.44** The national cancer screening programmes for breast, bowel and cervical cancer present important opportunities to diagnose these cancers at an early stage. Yet evidence suggests that people from some of the equality groups are less likely to accept

an invitation to participate in screening. A summary of the available evidence of inequalities in screening is available in the UK National Screening Committee report which is available at: <http://www.screening.nhs.uk/publications>

**5.45** Encouragingly, an initial reluctance to accept screening does not remain fixed. For example, over half of South Asians who refused breast screening in 1989 accepted a later invitation to mammography. This underlines the importance of health services encouraging participation in groups where uptake is low. **Good PCTs will wish to assess levels of participation in screening programmes and target interventions at groups with low participation rates as part of awareness and early diagnosis strategies.**

**5.46** In March 2006 NHS Cancer Screening Programmes published the good practice guidance '*Equal access to breast and cervical screening for disabled women*'. The guidance recommends good practice to ensure that, wherever possible, women with a disability:

- > Have access to information to enable them to make their own decisions about whether or not to accept an invitation to attend for breast or cervical screening
- > Know what to expect when they attend for screening so that it is a positive experience

- > Understand the possible consequences of screening and of not having screening and the need to be aware of changes in their own bodies.

**5.47** NHS Cancer Screening Programmes have funded a study to fully investigate the relationship between schizophrenia and breast and bowel cancer. The study is being carried out by researchers at the University of Oxford and University College London, and will be examining large scale databases, such as the Million Women Study database and primary care research databases. The study began in February 2010 and will run for two years.

**5.48** Further information is required on participation in screening by some equality groups, for example people with other mental health issues or physical disabilities.

**Going forward NCEI will work with information experts to investigate the possibility of obtaining screening data on the various equality strands.**

**5.49** Through a three-year Section 64 grant, the Department of Health are funding the Men's Health Forum to undertake a project on the uptake of bowel cancer screening in men. The research on which the programme is based, and the pilot which informed decisions about roll-out, both showed that men were less likely to take up their invitations to complete a Faecal Occult

Blood (FOB) testing kit than women. NHS Cancer Screening Programmes are working closely with the Men's Health Forum on the emerging findings of the project, and a number of interventions will be tested to inform future activity within the programme.

**5.50** In September 2009 NHS Cancer Screening Programmes developed a leaflet on cervical screening for lesbian and bi-sexual women. This was produced to explain the reasons why it is still important for these women to attend cervical screening and so that they are aware of the risks.

**5.51** In addition to this, national leaflets have been produced on breast, cervical and bowel screening for people with a learning disability. These materials are available at [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)

## Ensuring better treatment

**5.52** Access to curative treatment is a key determinant of cancer outcomes. The Cancer Reform Strategy made clear that the only acceptable criteria for not giving a clinically appropriate and cost effective treatment should be poor patient health or a patient themselves making a choice not to receive further treatment. Yet despite this there is evidence that some groups are offered less intensive treatment. This is a particular problem for older people.

**5.53** Comorbidities or patient choice alone do not explain why older people receive less intensive treatment. It is likely that there are a range of contributory factors, including clinical attitudes, a misunderstanding of the toxicities and side effects of modern cancer treatments and problems in providing appropriate community support for older cancer patients. **In order to more fully explore clinical attitudes and culture in relation to the treatment of older people, the Department of Health and the National Cancer Action Team will work with the Pharmaceutical Oncology Initiative and others to commission research into the issue.**

**5.54** It is expected that the patient-level equality audits which MDTs will undertake will be an important mechanism for helping MDTs to consider whether the treatment, information and support needs of all their patients are being appropriately met. However, in relation to the treatment of older patients, the NCEI believes that further support for clinicians will also be required.

**5.55** Stakeholders have reported that some healthcare professionals make assumptions about an older person's wish to be treated, or not, and that sometimes they assume older

people are not able to cope with treatment, without fully assessing their overall physical health. It can be difficult for clinicians to make balanced assessments about older people's needs and this can result in services adopting variable treatment practices for older people.

**5.56** **In order to support clinicians in fully assessing older patients' suitability for different forms of treatment, the Department of Health, in partnership with Macmillan Cancer Support, will pilot a range of approaches to formally assessing frailty in older people when considering treatment options and offering appropriate care packages to support older people receiving treatment. This will help clinicians to make sure that they have accurate information about an older person's ability to benefit from cancer treatment rather than making assumptions on the basis of age.**

**5.57** Older people can play an important role in helping to design age appropriate cancer services, ensuring that appropriate support is provided to patients and their families and carers. There are good examples of NHS services working effectively with service users and these need to be spread.

### Box 10 – Screened Out?

In November 2009, a joint Breakthrough Breast Cancer/Leonard Cheshire Disability survey was sent to disabled women aged 50 and over across England to find out more about their experiences of accessing breast screening services. Some women highlighted that they had a positive experience of the service:

*“I found the service excellent. Initially I was given an appointment in a mobile unit but due to my disability (I use two walking sticks) they moved the appointment to the main hospital. The staff were very happy to help and gave me more time for my appointment so that I was not rushed”*

However, more women reported that they did not feel adequately supported or informed of the options available to women with mobility impairments. In particular, women were not informed that the breast examination could take place sitting down which made the process difficult for some and made some women decline their screening invitation. One woman stated:

*“The first time I attended it was obvious I had mobility and balance problems. It was only after the test, during which I was terrified of falling, that I was told I could have been examined sitting down”*

Better understanding of barriers or inequalities that are preventing disabled women from receiving appropriate breast screening services is needed. During 2010, Breakthrough Breast Cancer and Leonard Cheshire Disability will consult breast screening service providers, service users and relevant health care professionals to facilitate better understanding of the origins of, and possible solutions to, any existing shortcomings in service provision.

For further information contact: Lizzie Cook, Senior Local Engagement Officer, Breakthrough Breast Cancer [lizziec@breakthrough.org.uk](mailto:lizziec@breakthrough.org.uk)

[www.breakthrough.org.uk](http://www.breakthrough.org.uk)  
[www.lcdisability.org/](http://www.lcdisability.org/)



**5.58** As set out in Chapter 2, mortality in older people is widening the life expectancy gap between Spearheads and England. It will therefore be particularly important for Spearhead areas to increase their activity to reduce cancer deaths, paying particular attention to deaths over 60, including those at much older ages. The reason for this change is not known, but MDTs will wish to consider if age discrimination may be playing a part.

## Supporting people living with and beyond cancer

**5.59** The NCSI has identified a range of survivorship issues which will have an impact on equality, including the provision of financial advice and support to cancer patients, access to follow up, assistance in returning to employment and access to psychological support. The NCSI has published a vision document, setting out the next steps on these areas. The vision can be accessed at: [www.ncsi.org.uk](http://www.ncsi.org.uk)

**5.60** **The NCSI will support the development of holistic needs assessment and care planning for every cancer patient. Care plans will be developed which will take account of patients' individual needs related to their age, gender, ethnicity, educational attainment, disability or any other equality aspect affecting their treatment and care.**

**5.61** Every cancer patient will have needs which are particular to their own personal situation and it is important that these are assessed and addressed. There are a variety of projects underway which are intended to personalise the support given to cancer patients, including the National Cancer Patient Information Programme, which is developing personalised and tailored information prescriptions. **The NCEI will work with the National Cancer Patient Information Programme to help deliver information to all cancer patients which is tailored to their personal needs and circumstances.**

**5.62** The framework for assessment and care planning, which is currently being piloted, will be an important process for ensuring that the needs of all cancer patients are appropriately assessed and then action is taken to address them. This personalised assessment will identify the physical, social, and psychological needs of cancer survivors and plan how these are met, to improve equity of care for all cancer patients.

**5.63** In addition, the NCEI is working closely with Macmillan Cancer Support in developing a human rights project. The project aims to integrate a human rights standard into provider and commissioning plans for cancer networks, PCTs, and SHAs.

NCEI is working with Macmillan to identify seven pilot sites by 2012 to test and develop the human rights models of care to improve patient experience for socially excluded communities and to ensure robust key performance indicators are embedded in local and national commissioning frameworks to achieve equality compliance. Currently the approach is being piloted in three locations:

- > Bury PCT is developing a new end of life care pathway and seeking to integrate equality principles into staff training and performance assessment;
- > Merseyside and Cheshire Cancer Network is developing an anticipatory care calendar for people with learning difficulties who are affected by cancer; and
- > South East London Cancer Network is developing a new common needs assessment for cancer patients which should ensure that the equality needs of all patients are identified.

**5.64** Early results show that there is a convergence between what patients want and what staff would like to be able to do but behavioural change throughout the system is required in order to realise this potential. It also demonstrated that there is an appetite amongst healthcare staff for

a human rights based approach to tackling health inequalities. The project will now be extended to two additional pilot sites which will develop the concept further during 2010 and 2011.

**5.65** **The NCEI will continue to support Macmillan Cancer Support in developing the human rights project. Following piloting, and if evaluation proves it to be successful, the project will be rolled out across the NHS. The practical application of human rights will be particularly important in ensuring a person-centred approach to cancer treatment and care, including for those with whom communication may be difficult, such as people with severe learning disabilities or mental ill-health.**

**5.66** There are successful projects undertaken as partnerships between cancer networks and learning disability teams. Cancer networks are encouraged to replicate these partnerships in order to offer greater equity of access to screening, treatment and care of people with learning disabilities across the country. For example, Merseyside and Cheshire Cancer Network has developed an anticipatory care calendar for people with learning disabilities to help social care staff identify changes in client's health. This helps in the decision making process about

when and where a patient needs to access the healthcare system and prevents crisis management as signs and symptoms of a healthcare need are identified early. This is now being piloted in patients with dementia. The principle of effective collaboration between different clinical teams is one which could be extended by building links between cancer networks and specialist mental health teams.

**5.67** In recognition of the particular issues faced by Black and Minority Ethnic populations in relation to accessing cancer services and their experiences of treatment and care, the National Cancer Action Team has established the National Black and Minority Ethnic Cancer Patient Advisory Panel to:

- > Give cancer patients and carers from a Black and Minority Ethnic background a voice and an opportunity to share their experiences; and
- > Provide the NHS with information and insights into various aspects of cancer and the experiences of people from Black and Minority Ethnic backgrounds.

**5.68** The work of the National Black and Minority Ethnic Cancer Patient Advisory Panel will inform the future activity of the NCEI.

## Developing the cancer workforce to promote equality

**5.69** A common theme in the visioning events was the importance of training for the cancer workforce, ensuring that all staff are able to recognise and address equality issues. Stakeholders reported that this needs to go beyond the diversity training which is currently provided in the NHS.

**5.70** Good commissioners will want to be assured that services for their population are providing appropriate training and support for healthcare professionals, ensuring that they are equipped to meet the specific needs of local populations.

**5.71** A remote learning package has been developed to improve person-centred communication skills in relation to end of life care. This package will be of benefit to many in the cancer workforce and its uptake should be encouraged.

**5.72** In addition to this, further consideration will be given to how the Connected advanced communications training programme for cancer clinicians might encompass training on communications in relation to equality issues.

**Box 11 – Training on equality and diversity**

NHS North West has developed an equality and diversity training programme which is for its own staff and staff from trusts in the region.

The SHA has also developed an online Health Equality Library Portal (HELP) to help regional staff get a better understanding of equality and diversity issues. HELP is NHS North West's central repository for up-to-date equality and diversity information. Its purpose is to:

- > Support the production of effective equality impact assessments of all strategies, policies, plans or activities;
- > Assist PCTs in achieving World Class Commissioning competency five: manage knowledge and assess needs;
- > Identify knowledge and evidence gaps;
- > Share good practice and policy material and prevent unnecessary duplication of effort; and
- > Help equality and diversity leads in their roles.

## Providing national support to the NHS in championing equality in cancer

**5.73** In addition to consideration of local action to promote equality, national support will be required to identify and spread good practice, highlight emerging equality issues and develop the evidence base.

**5.74** To assist commissioners, the equality metrics outlined above will also be accessible through the Cancer Commissioning Toolkit and will be incorporated in future versions of the Cancer Commissioning Guidance.

**5.75** Much of the action on equalities outlined in this document will be relatively new to large parts of the NHS. In order to stimulate thinking on the local activity identified, and to facilitate the implementation of good practice, a national cancer equality conference will take place on 22 March 2010.

**5.76** The Department of Health has a number of standing advisory groups which bring together stakeholders and experts to provide advice on different aspects of cancer. Such groups exist on different tumours (for example prostate cancer) and cross-cutting services (for example radiotherapy implementation). In future, as part of the NCEI, these groups will be asked to consider

whether there are particular equality issues of relevance to their remit and, if so, what action should be taken to address them. They will be required to report on progress on equality as part of the standard reporting process to the DH Cancer Programme Board.

## Tracking and reporting on progress

**5.77** It will be important to track progress on promoting all aspects of cancer equality, as well as to continue to measure reductions in inequality of outcomes. Moving forward, this will be a key role for the NCEI, which will provide annual advice to the Cancer Reform Strategy Advisory Board on the progress made in tackling cancer inequalities. As part of this process, cancer networks will be invited to provide updates on progress with local implementation.

# Appendix 1 – Membership of Advisory Group

Professor Sir Mike Richards	Co-Chair
Joanne Rule	Co-Chair
Jane Allberry	Department of Health
Dr Riccardo Audisio	University of Liverpool
Susan Barber	Cancer Research UK
Mike Birtwistle	Health Mandate
Suzi Butt	National Cancer Action Team
Matthew Capper	Department of Health
Dr Jennie Carpenter	Department of Health
Chris Carrigan	National Cancer Equality Initiative
Frank Chinegwundoh	Barts and the London NHS Trust and Chair, Cancer Black Care
Jessica Corner	Macmillan Cancer Support
TJ Day	NHS Cancer Screening Programmes
Jagtar Dhanda	Macmillan Cancer Support
Kathy Elliott	Cancer Action Team
Tim Elliott	Department of Health
Dr Julie Fish	De Montfort University
Anne Griffin	Department of Health
Dr Jane Hanson	NHS Wales
Jane Hatfield	Breast Cancer Care
Louise Hooker	National Cancer Team
Professor Mark Johnson	Mary Seacole Research Centre
Paula Lloyd	National Cancer Action Team
Clara Mackay	The Prostate Cancer Charity
Paul Mackenzie	Merseyside & Cheshire Cancer Network

Joe Magee	Northern Ireland
Joanne Marvel	Department of Health
Dr Carol Parkes	National Screening Committee
Julietta Patnick	NHS Cancer Screening Programmes
Dr Sarah Payne	University of Bristol
Margit Physant	Age Concern
Alastair Pringle	Scottish Government
Marina Raime	Betterdays Cancer Care
Dr Arif Rajpura	NHS Blackpool
Trudi Ratohwa	Barnet PCT
Surinder Sharma	Department of Health
Carrie Sykes	Beating Bowel Cancer
Ruth Thorlby	The King's Fund
Paul Trevatt	North East London Cancer Network
Professor Alan White	Leeds Metropolitan University
David Wilkins	Men's Health Forum



## Appendix 2 – Glossary

Active treatment	Treatment intended to affect the growth of the cancer by shrinking the cancer, stabilising it or slowing the spread of disease, and not given solely to relieve symptoms.
Cancer Awareness Measure	A validated set of questions designed to reliably assess cancer awareness.
Cancer Network	Cancer Networks bring together service providers and commissioners, to work collaboratively as a system, to plan and deliver high quality cancer services for a given population.
Cancer registry	Cancer registries collect information on patients diagnosed with cancer. There are eight regional cancer registries in England, each responsible for a particular part of the country. The health service runs cancer registries so that they can keep a count of cancer rates and monitor how effective their prevention, diagnosis and treatment strategies are.
Chemotherapy	<p>Chemotherapy is the use of anti-cancer drugs to destroy cancer cells.</p> <p>Chemotherapy may be used alone to treat some types of cancer. It may also be used with other types of treatment such as surgery, radiotherapy, hormonal therapy, biological therapies, or a combination of these.</p>
Co-morbidity	The presence of more than one unrelated disease or health condition in an individual at a given time.

Ethnicity coding	A system of recording the ethnicity of a person. The relevant code is selected from a list made up of different ethnic origins.
Incidence	Incidence refers to the number of people newly diagnosed with cancer and is usually expressed as the number of new cases which have been registered in a year in a specified area (e.g. in the U.K). The incidence rate is often expressed as the number of people newly diagnosed with cancer per 100,000 population and may be standardised to account for differences in population structure between areas.
Mortality	Mortality refers to the number of people who have died from cancer and is usually expressed as the number of deaths each year in a specified area (e.g. in England). As with incidence, the mortality rate is the number of people who die from cancer per 100,000 population and may be standardised to account for differences in population structure between areas.
Multi-Disciplinary Team (MDT)	Teams of healthcare professionals who have different areas of expertise.
Prevalence	Cancer prevalence is the number of people, or the proportion of the population, who are alive on a specified index date and have previously been diagnosed with cancer. As such it is an indicator of the burden of cancer and can help to inform health care service planning.

Primary Care Trust (PCT)	Primary Care Trusts are free-standing statutory bodies responsible for delivering better health care and health improvements to their local area. PCTs directly provide a range of community health services, such as GPs, and can commission services from hospital trusts. They have their own budgets and set their own priorities. However, much of their agenda is determined by directives from the Strategic Health Authority or the Department of Health.
Radiotherapy	<p>Radiotherapy is the use of high energy x-rays and similar rays (such as electrons) to treat disease. Radiotherapy works by destroying the cancer cells in the treated area.</p> <p>Radiotherapy treatment can cure some cancers and can also reduce the chance of a cancer coming back after surgery. It may be used to reduce cancer symptoms.</p>
Screening	Testing people for very early signs or precursors of a particular disease – usually before they have any symptoms. Can only be done if there is a reliable and simple test, such as the cervical screening test or mammogram.
Secondary cancer	Cancer that has spread away from the primary cancer site to another organ or part of the body. Secondary cancers have to be treated according to the type of cells it is made up of, i.e. the organ where the cancer originated. Secondary cancers are also called metastases.
Spearhead PCT	Spearhead PCTs are areas of the country with the worst health and deprivation indicators. The Spearhead group is defined on local authority data and consist of 70 local authorities that are then mapped onto primary care trust boundaries. There are 62 spearhead PCTs.

<p>Stage of cancer</p>	<p>Size of a cancer and how far it has spread. For most cancers there are four stages. Stage one is the smallest primary cancer while the highest stage is where the cancer has spread to another part of the body.</p>
<p>Strategic Health Authority (SHA)</p>	<p>Strategic Health Authorities manage the NHS locally and provide an important link between the Department of Health and the NHS. SHAs are responsible for developing plans for improving health services in their local area, ensuring quality and performance, increasing the capacity and ensuring national priorities are integrated into local health service plans.</p>

## Appendix 3 – Stakeholder organisations who contributed to the NCEI Visioning Events

- > Action for London Challenging Inequalities Group
- > The Afiya Trust
- > Age Concern England
- > Beating Bowel Cancer
- > Betterdays Cancer Care
- > Breakthrough Breast Cancer
- > Breast Cancer Care
- > Bowel Cancer UK
- > Cancer Equality
- > Cancer Research UK
- > Centre for Men's Health
- > Chinese National Healthy Living Centre
- > CLIC Sargent
- > Community Co-operative Action Limited
- > CYANA
- > De Montfort University
- > Football Foundation
- > Improvement Foundation
- > Institute for Child Health
- > Language is Everything
- > London School of Hygiene and Tropical Medicine
- > Leeds Metropolitan University
- > Macmillan Cancer Support
- > Men's Health Forum
- > National Alliance of Childhood Cancer Parent Organisations
- > National Council for Palliative Care
- > Paul D'Auria Cancer Support Centre
- > The Prostate Cancer Charity
- > RADAR
- > Roy Castle Lung Foundation
- > Sainsbury Centre for Mental Health
- > Teenage Cancer Trust
- > University College London
- > University of Kent
- > University of Leeds
- > World Cancer Research Fund International

In addition each event included a Department of Health representative and a range of NHS representatives, including the following;

- > Cancer Registries
- > Cancer Networks
- > General Practitioners
- > National Cancer Action Team
- > National Cancer Intelligence Network
- > NHS Trusts
- > NHS Cancer Screening Programme
- > Primary Care Trusts

# Annex 1 – Evidence to date on cancer inequalities in England provided by the National Cancer Intelligence Network (NCIN)



## Introduction

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

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

- > Summarises the evidence base on inequalities in cancer in England according to deprivation, age, gender, ethnicity, disability, sexual orientation and religion (although much more is known in some areas than others);
  - > Highlights the important messages which anyone considering commissioning or undertaking interventions to promote greater cancer equality should consider; and
  - > Signposts readers to sources of more detailed information.
- The advances that have been made in collecting evidence on cancer inequalities is a tangible demonstration of the importance of partnership working. Many of the analyses conducted since the publication of the Cancer Reform Strategy are a direct result of the partnership forged between the NCIN and the NCEI. This approach will continue as the NCEI moves into its next phase. In order to inform local action, it will be important that information on cancer inequalities should be available on as local a level as possible. Therefore this annex should be used in conjunction with the equalities portal ([www.ncin.org.uk/equalities/](http://www.ncin.org.uk/equalities/)) which will be an invaluable resource to inform local action, measure progress and compare performance on promoting cancer equality. The metrics contained in the portal will be updated over time and expanded as new data and analyses become available.



## Where does information on cancer inequalities come from?

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

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

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

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

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

## Information on equality groups

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

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

## Developing the evidence base

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

- > **Treatment** – to identify confidently equality issues in this area it is important to understand not just what treatment a patient received, but also how clinically appropriate the treatment was. This

requires information on both how advanced the patients cancer is (the stage of disease) and any unrelated diseases that may affect treatment (co-morbidities). Unfortunately, for most types of cancer, data on stage at diagnosis and co-morbidities are not available at a national level. A high priority for NCIN is working with the NHS to improve collection of this vital information.

- > **End of life care** – information on the services that patients from different equality groups receive near the end of their life remains limited. The NCIN is working with the newly created End of Life Care Intelligence Network, established as a result of the End of Life Care Strategy, to develop the evidence base in this area.

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

## Gender

### Key facts:

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

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

### Cancer incidence and mortality

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

However, these very similar headline figures mask some major differences in incidence and mortality once age is taken into account. Women live longer and could therefore be expected to have higher numbers of new cases and deaths. Once these figures are age standardised there is an excess incidence of 16% and an excess mortality of 38%

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

	Excess in men	
	Incidence %	Mortality %
All cancers except non-melanoma skin cancer (ex NMSC)	16	38
All cancers ex NMSC and lung	10	31
All cancers ex NMSC, breast and sex specific cancers	62	69
All cancers ex NMSC, breast, lung and sex specific cancers	61	71
Oesophagus	148	168
Stomach	148	132
Colorectal	54	56
Liver	121	99
Pancreas	27	27
Lung	64	65
Melanoma	-8	46
Kidney + 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

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

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 above<sup>1</sup>.

### **Cancer survival and prevalence**

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

Survival rates among males have been improving more quickly than for females over the past two decades and therefore this gap is closing (as shown in Figure 1). For cancers which affect both sexes, however, there was little difference between one-year survival from men and women in the period 2000-2004. For several sites male survival was slightly better and for bladder cancer one year relative survival was 77.4% compared to 65.7% for females. For women, higher relative survival rates were only seen for malignant melanoma, where one-year survival for both sexes was over 95%<sup>2</sup>.

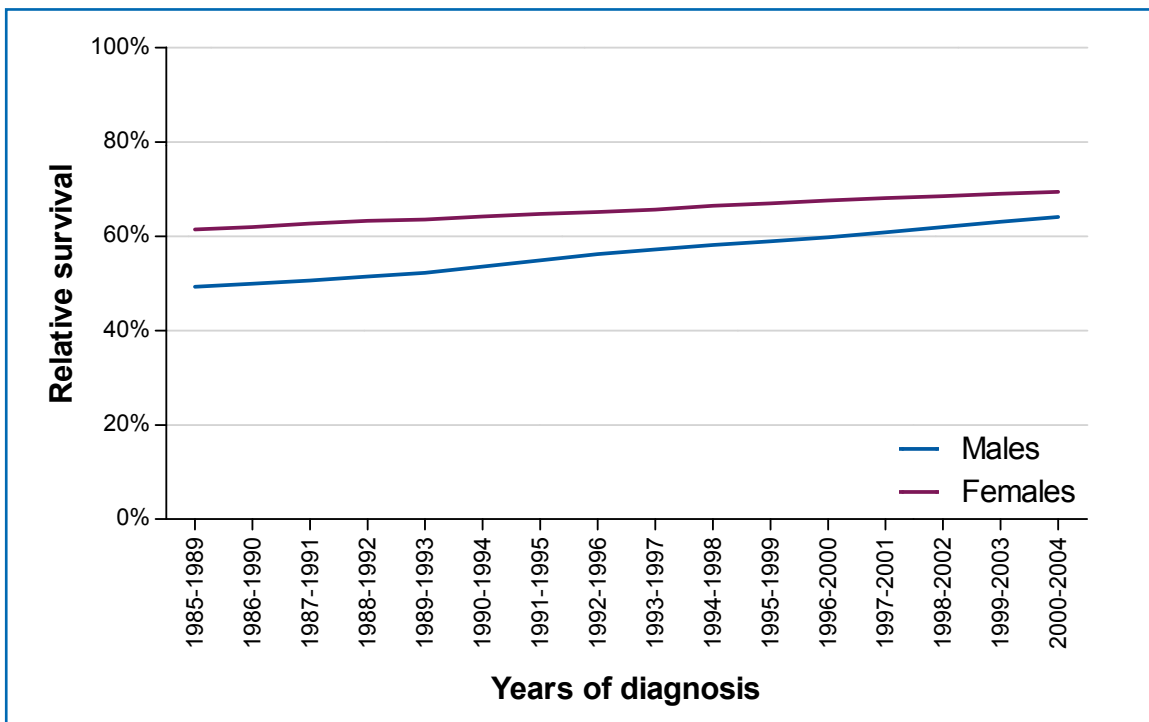
Overall, it is estimated that there were 1.6 million people alive with a cancer diagnosis in England at the end of 2008. Of these, around 60% were women. The most prevalent types of cancer are those with a relatively high incidence rate and a good prognosis. For example, the most prevalent cancer in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

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

It is widely assumed that men seek advice on symptoms which could be related to cancer later than women. However, a systematic review of the research literature found little evidence to support this assumption<sup>4</sup>. There is evidence from use of the CAM that levels of awareness amongst women and men vary according to cancer and knowledge of the warning symptoms and signs of cancer is somewhat lower amongst men than women. Men also anticipate a longer delay in seeking help than women but this may not reflect their actual behaviour<sup>5</sup>.

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

**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'<sup>2</sup>.

## Screening

Bowel cancer screening is the only national cancer screening programme which applies both to men and women. Uptake rates vary according to screening centre, but in both the pilot study<sup>7, 8</sup> and the initial rollout of the national programme have been somewhat lower in men than women<sup>9</sup>.

## Treatment

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

## Patient Experience

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

## End of Life Care

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



## Socio-economic deprivation

### Key facts:

- > The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups. A large part of this is likely to be attributable to lifestyle factors, and especially the higher smoking rates in deprived groups. The excess mortality may also be linked to later presentation/diagnosis in more deprived groups.
- > There is a clear survival gap between the most and least deprived. Survival rates are lower in Spearhead PCTs, although the rate of improvement is faster than for the population as a whole.
- > Health literacy is likely to be a particular problem for some socioeconomically deprived patients.
- > Awareness of the signs and symptoms of cancer is lower amongst socially deprived groups than the population as a whole and, for the cancers where there is a national screening programme, uptake of screening is also lower.
- > There is some evidence to suggest that otherwise similar patients from different socioeconomic groups receive different treatment within the NHS, although this requires further investigation to understand how much of this is due to later stage of presentation and co-morbidities.
- > People from more deprived social groups are less likely to die at home than those from more affluent groups.
- > **More information can be found in: Cancer Incidence by Deprivation<sup>14</sup> and Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001<sup>15</sup>**

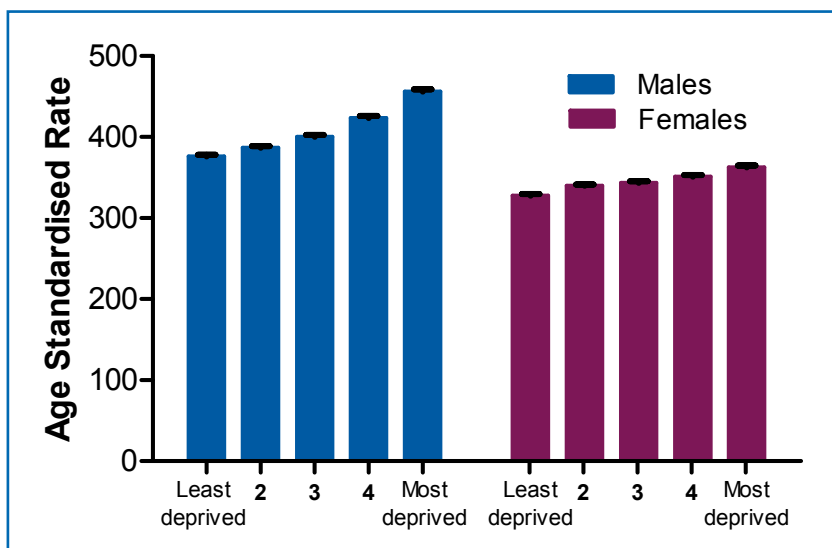
## Cancer incidence and mortality

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

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

There is a close association between deprivation and cancer risk factors including smoking, alcohol consumption, obesity and infections (*Helicobacter Pylori*/Hepatitis

**Figure 2 – Age standardised incidence for all malignant neoplasms (ex. non-melanoma skin cancer) by deprivation quintile, England, 2000-4**

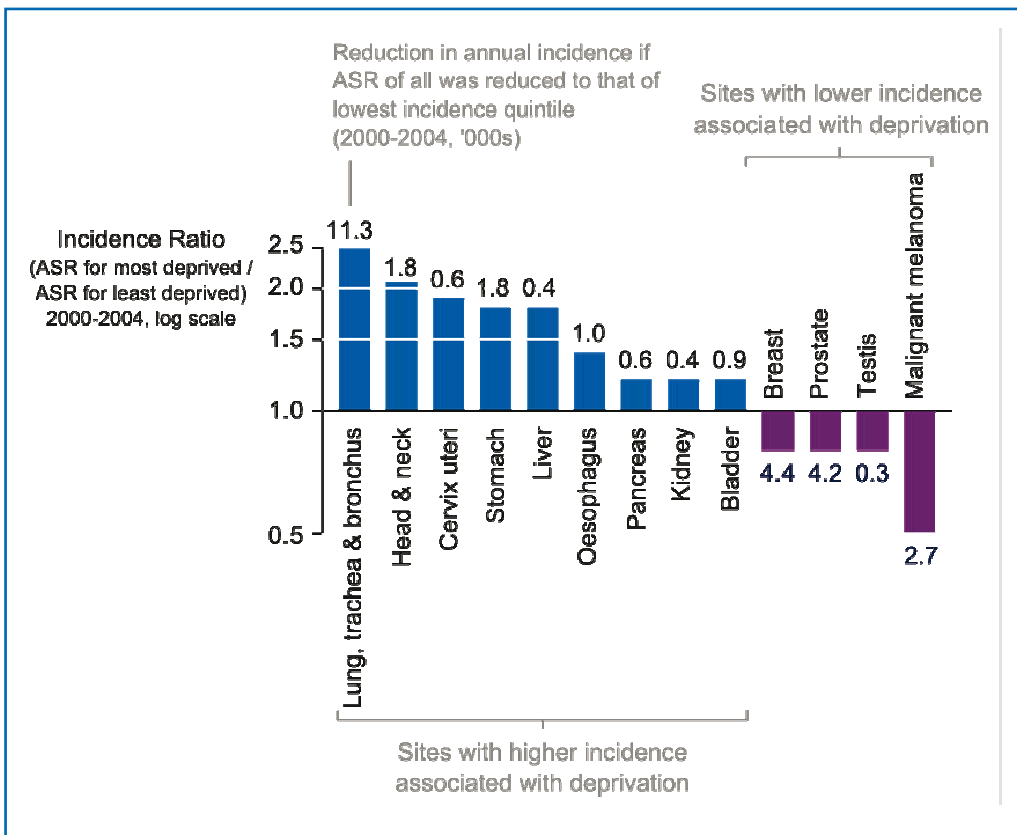


Reproduced from the NCIN report on 'Cancer Incidence by Deprivation'<sup>14</sup>. Error bars show 95% confidence intervals.

B&C)<sup>17-20</sup>. Reproductive factors, UV exposure and uptake of PSA testing also vary with deprivation but, unlike the previous set of factors, tend to increase incidence among the more affluent (although patterns of UV exposure are shifting)<sup>18, 21, 22</sup>. Figure 3 shows incidence ratios for the most deprived

compared with the least deprived for selected cancer sites. Figure 3 also shows the possible reduction in annual incidence if the age standardised rate for all groups was the same as the quintile with lowest incidence. The greatest opportunity remains a reduction in the incidence of lung and other associated cancers through smoking cessation programmes.

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



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

## Cancer mortality

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

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

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

## Cancer survival and prevalence

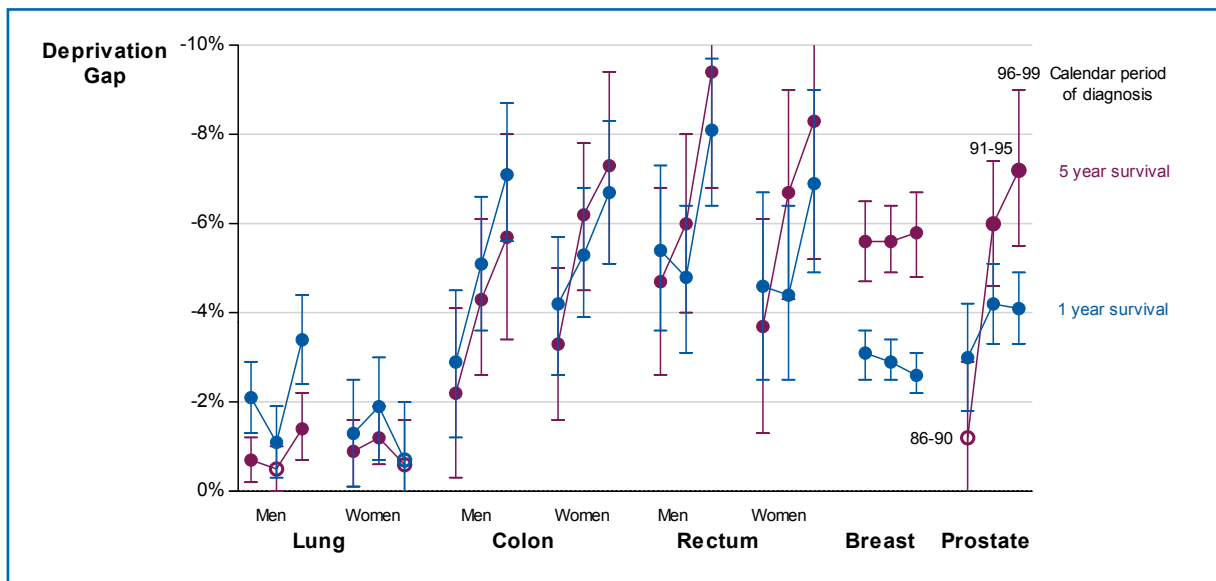
The most recent comprehensive analysis of cancer survival in England comes from a supplement to the British Journal of Cancer published in December 2008<sup>15</sup>.

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

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

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

**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'<sup>15</sup>.

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

		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

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

## Awareness and stage of diagnosis

For some cancers patients from socioeconomically deprived groups tend to present later than others and thus have more advanced disease and a worse prognosis. A recent systematic review<sup>4</sup> has shown a significant relationship between lower socioeconomic status and delayed presentation for men with prostate cancer and for patients with symptoms of upper gastrointestinal cancers. Lower levels of education were associated with greater delay for breast cancer and colorectal cancer. However, the pattern is not uniform across all cancers. Some sites showed no significant relationship between delay and socioeconomic status (colorectal cancer, gynaecological cancers, lung cancer) or educational attainment (urological cancers, gynaecological cancers, lung cancer).

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

## Screening

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

## Treatment

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

## **Patient Experience**

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

## **End of Life Care**

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



## Age

### Key facts:

#### Older people

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

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

#### Younger people

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

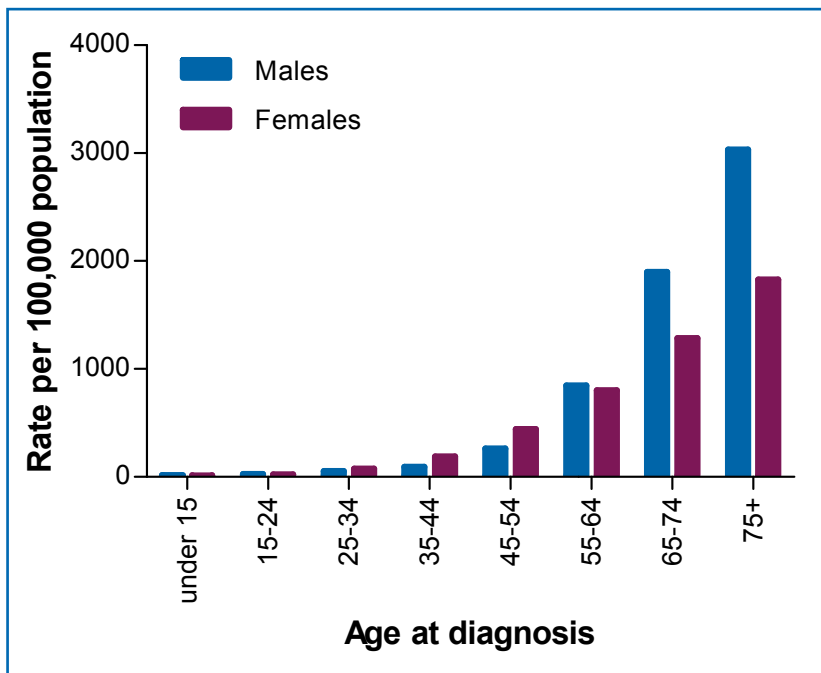
## Cancer and older people

### Cancer incidence and mortality

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

This trend is seen for each of the four most common cancers (breast, lung, colorectal and prostate), with 44% of all cases of colorectal and lung cancer occurring in patients age over 75 (see Table 3).

**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<sup>31</sup>.

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

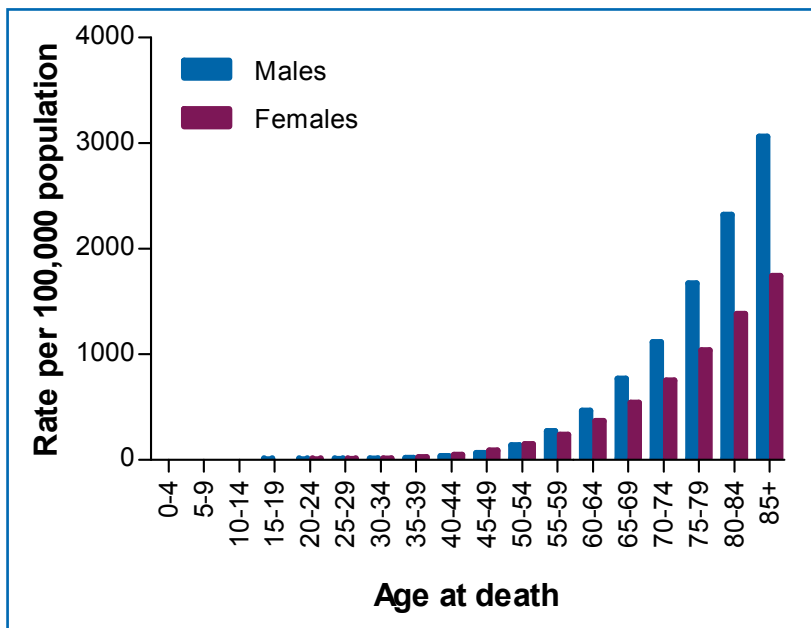
All cancers ex. NMSC	245,327	1	10	53	36
Breast (female)	38,048	0	19	56	24
Prostate	30,201	0	1	62	37
Colorectal	30,727	0	5	51	44
Lung	31,571	0	3	53	44

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

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<sup>31</sup>).

**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<sup>31</sup>.

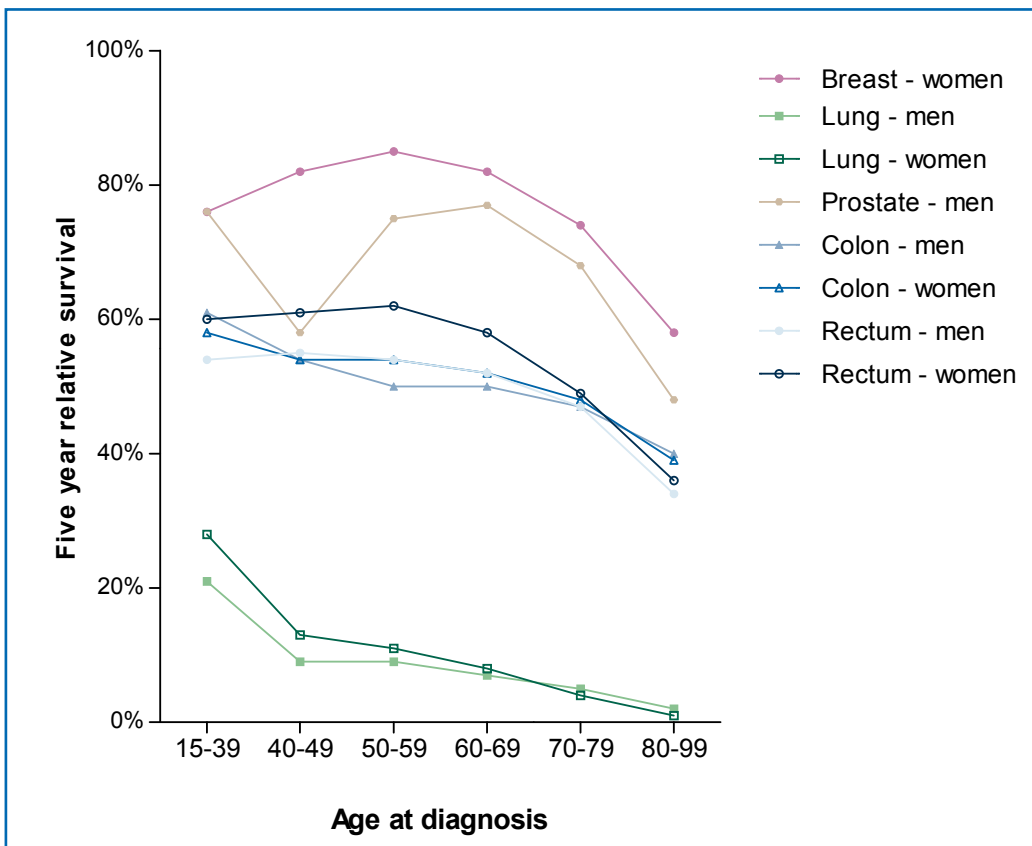
### Cancer survival and prevalence

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

12,661 for the over 65s, 538 for under 44 year olds and 4,990 for 44-65 year olds<sup>3</sup>.

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

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



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

### Awareness and stage of diagnosis

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

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

## Screening

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

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

'To take this recommendation forward, the Department of Health will use the opportunity for research provided by the planned extension of the breast screening programme to women aged 47-49 and 71-73. The extension is being randomised by screening batch so that half of eligible women will be invited at age 47-49 and half at age 71-73, creating natural control groups of those women not invited in

those particular age ranges. The Advisory Committee on Breast Cancer Screening has also recommended that the cohort of women being invited at age 71-73 should be re-invited for a further two screening rounds at ages 74-76 and 76-79. This would give sufficient numbers in the screened cohort and the control cohort to make decisions based on the benefits and harms of screening in this age range.

## Treatment

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

Detailed research studies have been undertaken on the treatment given to older women with breast cancer in the North West. These have shown that older women are investigated less intensively and are less likely to receive potentially curative surgery. Older age was shown to be the major factor determining treatment even when tumour characteristics had been accounted for<sup>43</sup>. A study on chemotherapy has also revealed

that age is a major factor in influencing clinical judgement, irrespective of other factors such as co-morbidities and tumour size<sup>42</sup>. More information is urgently needed in this area, but existing evidence indicates that under-treatment of older people with cancer may be a substantial problem. The NCIN's report on curative surgical will look for any differences between age groups.

### Patient Experience

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

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

### End of Life Care

The proportion of people dying in their own homes decreases with age and there is a corresponding rise in the number of deaths in old people's homes. The proportion of people dying in hospices decreases with age – almost a third of people who die in a hospice are under the age of 65, while only 2% of people age 85 or over died in a hospice<sup>13</sup>.

## Children and, Teenagers and Young Adults

### Cancer incidence and mortality

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

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

For teenagers and young adults (aged 13 to 24), the overall incidence rate of cancer was 224 cases per million persons each year in the period 1999-2003. Incidence increases with age and, as with children, has

increased over time. From 1979 to 2003, incidence increased by just over 1% in both the 13-14 and 15-19 age groups and by 1.9% per year for the 20-24 age group. Some of this change (for example increases in the incidence of melanoma and cervical carcinoma) may be due to behavioural changes and potentiality avoidable<sup>46</sup>.

The most frequent types of cancer in children and teenagers and young adults differ from those seen in older age groups. For children, leukaemias, central nervous system tumours, lymphomas and neuroblastoma are the most common types of cancer, although this varies between ages and sexes<sup>44</sup>.

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



## Cancer survival and prevalence

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

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

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

## Awareness and stage of diagnosis

Cancer in children and young people is relatively rare; it has been estimated that

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

## Screening

There are no screening programmes for cancer in younger people.

## Treatment

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

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

## **Patient Experience**

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

## **End of Life Care**

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

## Ethnicity

### Key facts:

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

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

### Cancer incidence and mortality

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

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

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

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

### **Cancer survival and prevalence**

Initial analyses of cancer survival by ethnic group have indicated that differences may exist, but due to data completeness, there is a high level of uncertainty in these results and therefore great care needs to be taken when interpreting them<sup>56</sup>. Black and Asian women with breast cancer have poorer survival rates, which may be explained by later presentation<sup>59</sup>. As ethnicity data collection improves, analysis of survival by ethnic group will become more reliable.

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

A recent survey using the CAM5 has shown that awareness of cancer is generally lower in Black and Minority Ethnic (BME) groups than amongst White men and women. A further survey focusing on ethnic minority groups<sup>60</sup> both reinforced the low awareness and showed significant differences between minority groups.

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

### **Screening uptake**

Uptake for breast<sup>62</sup>, cervical<sup>63</sup> and colorectal<sup>8, 64</sup> screening programmes is generally lower in minority ethnic groups than in the population as a whole.

## Treatment

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

## Patient Experience

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

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

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

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

## End of Life Care

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

## Sexuality

### Key facts:

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

### Cancer incidence and mortality

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

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

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

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

### **Cancer survival and prevalence**

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

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

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

It is possible that negative experiences with healthcare professionals lead to delays in presentation by lesbian, gay and bisexual people. One US study found that although lesbians were more likely, than heterosexual women, to find a lump themselves, the average timescale for a heterosexual woman to seek a doctor's advice was two weeks while for lesbians the timescale was 1.9 months<sup>75</sup>.

### **Screening uptake**

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

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

### **Treatment**

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

### **Patient Experience**

There is very limited recent evidence on differences in cancer patients' experience with sexuality. However, in cancer services and in healthcare environments more generally, there is a routine assumption of heterosexuality (widely known as heterosexism). Heterosexism in services means that there are few positive



representations of lesbian, gay, bisexual and trans people as patients. GPs may not always feel equipped to deal with their needs and are sometimes embarrassed to provide care for lesbian and gay patients<sup>77</sup>. One UK study of 5909 lesbian and bisexual women found that they were less likely to have come out to a healthcare professional (49% had not so disclosed) than in other public settings, such as the workplace, where in comparison 27% of lesbian and bisexual women had not disclosed<sup>78</sup>. These assumptions may have an impact on their access to social support: lesbians are less likely to report participation in a cancer support group than heterosexual women<sup>79</sup>.

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

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

### End of Life Care

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



## Disability

### Key facts:

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

### Cancer incidence and mortality

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

Patients with bipolar disorder have an increased incidence of respiratory cancer, but this can be explained by smoking and other risk factors<sup>81</sup>.

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

## Cancer survival and prevalence

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

## Awareness and stage of diagnosis

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

## Screening uptake

There is currently no central collection of information about differences in screening uptake for people with learning or physical disabilities or mental health problems. An audit of women in contact with the NHS Learning Disability Service in one Lancashire PCT found that uptake of breast screening was comparable with the national average but that uptake of cervical screening was much lower<sup>87</sup>. Other surveys have found similar patterns of low cervical screening uptake but higher levels of breast screening<sup>88, 89</sup>. There is also some evidence from the USA of barriers to screening attendance for those with physical disabilities<sup>90</sup>.

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

## Treatment

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

## Patient Experience

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

## End of Life Care

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

## Religion

### Key facts:

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

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

Some equality issues which are explicitly related to religion may be identified. Patients may find it difficult to access health services during religious festivals. One example cited to the NCEI was the impact that Ramadan can have on attendances at cancer clinics. It will be important that NHS services work with local communities to address these issues. Similarly, practices such as fasting may impact upon cancer treatment and interfere with medication regimes<sup>93</sup>.

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

# References

- 1 National Cancer Intelligence Network, Cancer Research UK, The Centre for Men's Health at Leeds Metropolitan University & Men's Health Forum (2009): *The Excess Burden of Cancer in Men in the UK*. London: National Cancer Intelligence Network.
- 2 National Cancer Intelligence Network (2008): *One Year Cancer Survival*. London: National Cancer Intelligence Network.
- 3 Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M et al. Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer*. 2009 101:541-7.
- 4 Macleod U, Mitchell ED, Burgess C, Macdonald S, Ramirez AJ. Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *Br J Cancer*. 2009 101 Suppl 2:S92-S101.
- 5 Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J et al. Public awareness of cancer in Britain: a population-based survey of adults. *Br J Cancer*. 2009 101 Suppl 2:S18-23.
- 6 Banks I. No man's land: men, illness, and the NHS. *BMJ*. 2001 323:1058-60.
- 7 UK Colorectal Cancer Screening Pilot Group. Results of the first round of a demonstration pilot of screening for colorectal cancer in the United Kingdom. *BMJ*. 2004 329:133.
- 8 Weller D, Coleman D, Robertson R, Butler P, Melia J, Campbell C et al. The UK colorectal cancer screening pilot: results of the second round of screening in England. *Br J Cancer*. 2007 97:1601-5.
- 9 Weller DP, Campbell C. Uptake in cancer screening programmes: a priority in cancer control. *Br J Cancer*. 2009 101 Suppl 2:S55-9.
- 10 Morris E, Quirke P, Thomas JD, Fairley L, Cottier B, Forman D. Unacceptable variation in abdominoperineal excision rates for rectal cancer: time to intervene? *Gut*. 2008 57:1690-7.
- 11 Airey C, Becher H, Erens B & Fuller E (2002): *National surveys of NHS patients: Cancer – national overview 1999/2000*. London: Department of Health.
- 12 National Audit Office (2005): *Tackling Cancer: Improving the patient journey*. London: The Stationery Office.
- 13 South West Public Health Observatory. *Analysis of Office of National Statistics mortality data*.

- 14 National Cancer Intelligence Network (2008): Cancer Incidence by Deprivation. London: National Cancer Intelligence Network.
- 15 Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001: population-based analyses and clinical commentaries. *Br J Cancer*. 2008 99 Suppl 1: S1-S120.
- 16 Noble M, McLennan D, Wilkinson K, Whitworth A, Barnes H & Dibben C (2008): The English Indices of Deprivation 2007. London: Communities and Local Government.
- 17 Jarvis, M. & Wardle, J. Social patterning of health behaviours: the case of cigarette smoking. In: Marmot & Wilkinson (Eds.) *Social Determinants of Health*. Oxford: Oxford University Press; 2005.
- 18 Gordon-Dseagu V (2008): Cancer and health inequalities: An introduction to current evidence. London: Cancer Research UK.
- 19 Law MR, Morris JK. Why is mortality higher in poorer areas and in more northern areas of England and Wales? *J Epidemiol Community Health*. 1998 52:344-52.
- 20 Zajacova A, Dowd JB, Aiello AE. Socioeconomic and race/ethnic patterns in persistent infection burden among U.S. adults. *J Gerontol A Biol Sci Med Sci*. 2009 64:272-9.
- 21 Kelsey JL, Fischer DB, Holford TR, LiVoisi VA, Mostow ED, Goldenberg IS et al. Exogenous estrogens and other factors in the epidemiology of breast cancer. *J Natl Cancer Inst*. 1981 67:327-33.
- 22 Clarke NW. Survival from prostate cancer in England and Wales up to 2001. *Br J Cancer*. 2008 99 Suppl 1:S78-9.
- 23 Romeri E, Baker A and Griffiths C. Mortality by deprivation and cause of death in England and Wales, 1999-2003. *Health Stat Q*. 2007 32: 19-35.
- 24 Department of Health (2009): Cancer reform strategy: achieving local implementation – second annual report. London: Department of Health.
- 25 Ellis L, Rachet B, Shah A, Walters S, Coleman MP, Cooper N et al. Trends in cancer survival in Spearhead Primary Care Trusts in England, 1998-2004. *Health Stat Q*. 2009 7-12.
- 26 Baker D, Middleton E. Cervical screening and health inequality in England in the 1990s. *J Epidemiol Community Health*. 2003 57:417-23.

- <sup>27</sup> Gatrell A, Garnett S, Rigby J, Maddocks A, Kirwan M. Uptake of screening for breast cancer in south Lancashire. *Public Health*. 1998 112:297-301.
- <sup>28</sup> von Wagner C, Good A, Wright D, Rachet B, Obichere A, Bloom S et al. Inequalities in colorectal cancer screening participation in the first round of the national screening programme in England. *Br J Cancer*. 2009 101 Suppl 2:S60-3.
- <sup>29</sup> Downing A, Prakash K, Gilthorpe MS, Mikeljevic JS, Forman D. Socioeconomic background in relation to stage at diagnosis, treatment and survival in women with breast cancer. *Br J Cancer*. 2007 96:836-40.
- <sup>30</sup> Crawford SM, Sauerzapf V, Haynes R, Zhao H, Forman D, Jones AP. Social and geographical factors affecting access to treatment of lung cancer. *Br J Cancer*. 2009 101: 897-901.
- <sup>31</sup> Cancer Research UK Statistical Information Team. CancerStats [Internet]. London: Cancer Research UK. Available from: <http://info.cancerresearchuk.org/cancerstats/>
- <sup>32</sup> Whelan J, Dolbear C, Mak V, Møller H, Davies E. Where do teenagers and young adults receive treatment for cancer? *J Public Health (Oxf)*. 2007 29:178-82.
- <sup>33</sup> Office for National Statistics (2009): Registrations of cancer diagnosed in 2007, England. Series MB1 No. 38. London: Office for National Statistics.
- <sup>34</sup> Spermon JR, Witjes JA, Kiemeny LALM. Difference in stage and morphology-adjusted survival between young and elderly patients with a testicular germ cell tumor. *Urology*. 2002 60:889-93.
- <sup>35</sup> dos Santos Silva I, Swerdlow AJ. Ovarian germ cell malignancies in England: epidemiological parallels with testicular cancer. *Br J Cancer*. 1991 63:814-8.
- <sup>36</sup> Kothari A, Fentiman IS. 22. Diagnostic delays in breast cancer and impact on survival. *Int J Clin Pract*. 2003 57:200-3.
- <sup>37</sup> Linsell L, Burgess CC, Ramirez AJ. Breast cancer awareness among older women. *Br J Cancer*. 2008 99:1221-5.
- <sup>38</sup> National Cancer Intelligence Network. Cancer eAtlas [Internet]. London: National Cancer Intelligence Network. Available from: <http://www.ncin.org.uk/eatlas/>
- <sup>39</sup> Department of Health (2007): Cancer Reform Strategy. London: Department of Health.

- 40 NHS Cancer Screening Programmes (2006): Breast Screening: Over 70? You are still entitled to breast screening. NHS Cancer Screening Programmes.
- 41 Carruthers I & Ormondroyd J (2009): Age equality in health and social care. London: Department of Health.
- 42 Turner NJ, Haward RA, Mulley GP, Selby PJ. Cancer in old age – is it inadequately investigated and treated?. *BMJ*. 1999 319:309-12.
- 43 Lavelle K, Todd C, Moran A, Howell A, Bundred N, Campbell M. Non-standard management of breast cancer increases with age in the UK: a population based cohort of women > or =65 years. *Br J Cancer*. 2007 96:1197-203.
- 44 Stiller, C. A., Kroll, M. E. & Eatock, E.M.. Incidence of Childhood Cancer 1991–2000 In: C. Stiller (Ed.) *Childhood Cancer in Britain: Incidence, survival, mortality*. Oxford: Oxford University Press; 2007.
- 45 Kroll, M. E. & Stiller, C.A.. Time Trends in Incidence 1966–2000 In: C. Stiller (Ed.) *Childhood Cancer in Britain: Incidence, survival, mortality*. Oxford: Oxford University Press; 2007.
- 46 Alston RD, Geraci M, Eden TOB, Moran A, Rowan S, Birch JM. Changes in cancer incidence in teenagers and young adults (ages 13 to 24 years) in England 1979-2003. *Cancer*. 2008 113:2807-15.
- 47 Bunch, K. J. & Stiller, C.A.. Childhood Cancer Mortality In: C. Stiller (Ed.) *Childhood Cancer in Britain: Incidence, survival, mortality*. Oxford: Oxford University Press; 2007.
- 48 Geraci M, Birch JM, Alston RD, Moran A, Eden TOB. Cancer mortality in 13 to 29-year-olds in England and Wales, 1981-2005. *Br J Cancer*. 2007 97:1588-94.
- 49 Stiller, C. A., Kroll, M. E. & Eatock, E.M.. Survival from Childhood Cancer In: C. Stiller (Ed.) *Childhood Cancer in Britain: Incidence, survival, mortality*. Oxford: Oxford University Press; 2007.
- 50 Birch JM, Pang D, Alston RD, Rowan S, Geraci M, Moran A et al. Survival from cancer in teenagers and young adults in England, 1979-2003. *Br J Cancer*. 2008 99:830-5.
- 51 Reulen RC, Winter DL, Lancashire ER, Zeegers MP, Jenney ME, Walters SJ et al. Health-status of adult survivors of childhood cancer: a large-scale population-based study from the British Childhood Cancer Survivor Study. *Int J Cancer*. 2007 121:633-40.



- <sup>52</sup> Reulen RC, Taylor AJ, Winter DL, Stiller CA, Frobisher C, Lancashire ER et al. Long-term population-based risks of breast cancer after childhood cancer. *Int J Cancer*. 2008 123:2156-63.
- <sup>53</sup> Feltbower RG, Lewis IJ, Picton S, Richards M, Glaser AW, Kinsey SE et al. Diagnosing childhood cancer in primary care--a realistic expectation? *Br J Cancer*. 2004 90:1882-4.
- <sup>54</sup> Ablett S, Pinkerton CR. Recruiting children into cancer trials--role of the United Kingdom Children's Cancer Study Group (UKCCSG). *Br J Cancer*. 2003 88:1661-5.
- <sup>55</sup> Fern L, Davies S, Eden T, Feltbower R, Grant R, Hawkins M et al. Rates of inclusion of teenagers and young adults in England into National Cancer Research Network clinical trials: report from the National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Development Group. *Br J Cancer*. 2008 99:1967-74.
- <sup>56</sup> National Cancer Intelligence Network & Cancer Research UK (2009): Cancer Incidence and Survival By Major Ethnic Group. London: National Cancer Intelligence Network.
- <sup>57</sup> Marchand LL. Combined influence of genetic and dietary factors on colorectal cancer incidence in Japanese Americans. *J Natl Cancer Inst Monogr*. 1999 :101-5.
- <sup>58</sup> Wild SH, Fischbacher CM, Brock A, Griffiths C, Bhopal R. Mortality from all cancers and lung, colorectal, breast and prostate cancer by country of birth in England and Wales, 2001-2003. *Br J Cancer*. 2006 94:1079-85.
- <sup>59</sup> Jack RH, Davies EA, Møller H. Breast cancer incidence, stage, treatment and survival in ethnic groups in South East England. *Br J Cancer*. 2009 100:545-50.
- <sup>60</sup> Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J et al. Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. *Br J Cancer*. 2009 101 Suppl 2:S24-30.
- <sup>61</sup> Jack RH, Davies EA, Møller H. Prostate cancer incidence, stage at diagnosis, treatment and survival in ethnic groups in South-East England. *BJU Int*. 2009
- <sup>62</sup> Hoare T. Breast screening and ethnic minorities. *Br J Cancer Suppl*. 1996 29:S38-41.
- <sup>63</sup> Moser K, Patnick J, Beral V. Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data. *BMJ*. 2009 338:b2025.
- <sup>64</sup> Robb KA, Power E, Atkin W, Wardle J. Ethnic differences in participation in flexible sigmoidoscopy screening in the UK. *J Med Screen*. 2008 15:130-6.

- <sup>65</sup> Davies E, Madden P, Coupland V, Linklater K, Møller H. Variation in place of death from cancer: studies in South East England. South West Public Health Observatory. Available from: <http://www.swpho.nhs.uk/resource/item.aspx?RID=50136>
- <sup>66</sup> Firth S (2001): *Wider horizons: Care of dying in multicultural society*. London: National Council for Hospice and Specialist Palliative Care Services.
- <sup>67</sup> Lee JGL, Griffin GK, Melvin CL. Tobacco use among sexual minorities in the USA, 1987 to May 2007: a systematic review. *Tob Control*. 2009 18:275-82.
- <sup>68</sup> Meads C, Buckley E, Sanderson P. Ten years of lesbian health survey research in the UK West Midlands. *BMC Public Health*. 2007 7:251.
- <sup>69</sup> Frisch M, Smith E, Grulich A, Johansen C. Cancer in a population-based cohort of men and women in registered homosexual partnerships. *Am J Epidemiol*. 2003 157:966-72.
- <sup>70</sup> Brandenburg DL, Matthews AK, Johnson TP, Hughes TL. Breast cancer risk and screening: a comparison of lesbian and heterosexual women. *Women Health*. 2007 45:109-30.
- <sup>71</sup> Dibble SL, Roberts SA, Nussey B. Comparing breast cancer risk between lesbians and their heterosexual sisters. *Womens Health Issues*. 2004 14:60-8.
- <sup>72</sup> Newnham A, Harris J, Evans HS, Evans BG, Møller H. The risk of cancer in HIV-infected people in southeast England: a cohort study. *Br J Cancer*. 2005 92:194-200.
- <sup>73</sup> Dougan S, Evans BG, Macdonald N, Goldberg DJ, Gill ON, Fenton KA et al. HIV in gay and bisexual men in the United Kingdom: 25 years of public health surveillance. *Epidemiol Infect*. 2008 136:145-56.
- <sup>74</sup> Fish J (2009): *Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods*. Leicester: De Montfort University.
- <sup>75</sup> Dibble SL, Roberts SA. A comparison of breast cancer diagnosis and treatment between lesbian and heterosexual women. *Journal of the Gay & Lesbian Medical Association*. 2002 6: 9-17.
- <sup>76</sup> Whittle S, Turner L & Al-Alami M (2007): *Engendered penalties: Transgender and transsexual people's experiences of inequality and discrimination*. London: The Equalities Review.

- <sup>77</sup> Hinchliff S, Gott M, Galena E. 'I daresay I might find it embarrassing': general practitioners' perspectives on discussing sexual health issues with lesbian and gay patients. *Health & Social Care in the Community*. 2005 13:345-53.
- <sup>78</sup> Hunt R & Fish J (2008): *Prescription for Change: Lesbian and bisexual women's health check*. London: Stonewall.
- <sup>79</sup> Matthews A, Peterman A, Delaney P, Menard L, Brandenburg D. A Qualitative Exploration of the Experiences of Lesbian and Heterosexual Patients with Breast Cancer. *Oncology Nursing Forum*. 2002 29:1455-62.
- <sup>80</sup> Tran E, Rouillon F, Loze J, Casadebaig F, Philippe A, Vitry F et al. Cancer mortality in patients with schizophrenia: an 11-year prospective cohort study. *Cancer*. 2009 115:3555-62.
- <sup>81</sup> Hippisley-Cox J, Vinogradova Y, Coupland C, Parker C. Risk of malignancy in patients with schizophrenia or bipolar disorder: nested case-control study. *Arch Gen Psychiatry*. 2007 64:1368-76.
- <sup>82</sup> Patja K, Eero P, Iivanainen M. Cancer incidence among people with intellectual disability. *J Intellect Disabil Res*. 2001 45:300-7.
- <sup>83</sup> Sullivan SG, Hussain R, Threlfall T, Bittles AH. The incidence of cancer in people with intellectual disabilities. *Cancer Causes Control*. 2004 15:1021-5.
- <sup>84</sup> Hill DA, Gridley G, Cnattingius S, Mellekjær L, Linet M, Adami H et al. Mortality and cancer incidence among individuals with Down syndrome. *Arch Intern Med*. 2003 163:705-11.
- <sup>85</sup> Sullivan SG, Hussain R, Glasson EJ, Bittles AH. The profile and incidence of cancer in Down syndrome. *J Intellect Disabil Res*. 2007 51:228-31.
- <sup>86</sup> Alborz A, McNally R, Glendinning C. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *J Health Serv Res Policy*. 2005 10:173-82.
- <sup>87</sup> Biswas M, Whalley H, Foster J, Friedman E, Deacon R. Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. *J Public Health (Oxf)*. 2005 27:344-7.

- <sup>88</sup> Pearson V, Davis C, Ruoff C, Dyer J. Only one quarter of women with learning disability in Exeter have cervical screening. *BMJ*. 1998 316:1979.
- <sup>89</sup> Stein K, Allen N. Cross sectional survey of cervical cancer screening in women with learning disability. *BMJ*. 1999 318:641.
- <sup>90</sup> Mele N, Archer J, Pusch BD. Access to breast cancer screening services for women with disabilities. *J Obstet Gynecol Neonatal Nurs*. 2005 34:453-64.
- <sup>91</sup> Werneke U, Horn O, Maryon-Davis A, Wessely S, Donnan S, McPherson K. Uptake of screening for breast cancer in patients with mental health problems. *J Epidemiol Community Health*. 2006 60:600-5.
- <sup>92</sup> Hogg J, Northfield J & Turnbull J (2001): *Cancer and people with learning disabilities: The evidence from published studies and experience from cancer services*. Kidderminster: British Institute of Learning Disabilities.
- <sup>93</sup> Tazi I. Ramadan and cancer. *J Clin Oncol*. 2008 26:5485.



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