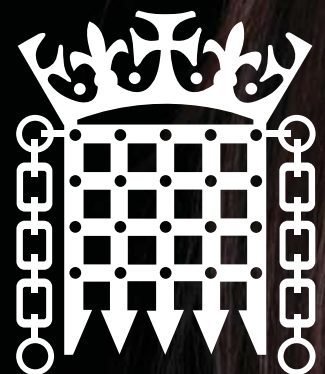


ALL PARTY PARLIAMENTARY GROUP ON CANCER



Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer



www.appg-cancer.org.uk

Contents

The All Party Parliamentary Group on Cancer

The All Party Parliamentary Group on Cancer (APPGC) was founded in 1998. The Group brings together MPs and Peers from across the political spectrum to campaign together to improve cancer services, to maintain a high profile in Parliament for cancer reform and to debate key issues affecting cancer patients and their families and carers.

Currently the officers of the group are:

John Baron MP	Chairman
Sandra Gidley MP	Vice Chairman
Dr Howard Steate MP	Vice Chairman
Dr Richard Taylor MP	Vice Chairman
Baroness Finlay of Llandaff	Vice Chairman
The Earl Howe	Vice Chairman
Lord Lewis of Newnham	Vice Chairman
Baroness Masham of Ilton	Vice Chairman

The Secretariat to the All Party Parliamentary Group on Cancer is provided by

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The APPGC is also supported by a group of stakeholder organisations: Breakthrough Breast Cancer, Cancer Black Care, Cancer Research UK, Marie Curie Cancer Care, the Men's Health Forum, the National Cancer Research Institute (NCRI), Teenage Cancer Trust and the Rarer Cancers Forum.

You can find out more information about the APPGC via www.appg-cancer.org.uk

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Foreword

My fellow officers and I are pleased to present the final report of the All Party Parliamentary Group on Cancer's Inquiry into cancer inequalities. We received evidence from a wide range of stakeholders including patients, clinicians, researchers, cancer charities, Primary Care Trusts (PCTs) and voluntary organisations. We are extremely grateful to all concerned and particularly to those cancer patients who gave evidence to us in person – their stories influenced us considerably.

Our Inquiry found clear evidence of unacceptable inequalities in both the experiences and outcomes of cancer patients. In response, we present a series of realistic recommendations to help correct these inequalities over time.

First and foremost, we believe the introduction of a one-year survival rate indicator for all ages will encourage the NHS to speed up early diagnosis and help to sharpen the focus on measuring outcomes. It will be a vital step forward in significantly reducing the numbers of people dying prematurely from cancer.

Other recommendations suggest how to get our message across to groups at higher risk of cancer, improve the patient's experience throughout the cancer journey and help people with rarer cancers. We also seek to plug what I call the 'black hole' which too often exists between the NHS, social services, financial support and education.

Finally, my fellow officers and I would like to thank the health and social care professionals, voluntary and charity groups for all they do in the battle against cancer. Our Inquiry was constantly reminded of their good work, particularly during our oral evidence sessions. Our thanks also go to Angus Baldwin and Lucy Grove from Macmillan for providing excellent support as the APPGC's secretariat during our Inquiry, and to Edmund Waterhouse for producing this report.

I hope our recommendations do justice to all concerned and help to move us forward in tackling this disease.



John Baron MP
Chairman, APPG on Cancer

Executive Summary

In April this year the APPGC launched an Inquiry into inequalities in cancer. Having reviewed written evidence from 90 stakeholders and listened to oral evidence from cancer patients, charities, cancer service providers and policy makers, we have identified eight priorities for action:

The eight priorities for action

1. Set a new indicator for one-year survival rates for all to encourage the NHS to:

- I. Raise levels of awareness of the early symptoms of cancer
- II. Promote early presentation and diagnosis
- III. Speed up the early referral system
- IV. Tackle the under-treatment of older people.

Earlier presentation and speedier diagnosis would both narrow the gap in survival rates between different groups and improve outcomes for all.

The one-year survival indicator would include people aged 75 and over for the first time. This would be a vital step forward in significantly reducing the number of people aged 75 and over who are dying prematurely from cancer – estimated to be around 15,000 a year [source: National Cancer Intelligence Network].

The indicator would also need to acknowledge the current variations in one-year survival rates by such factors as cancer type, age and region. The aim would be to eradicate such variations over time. We recommend that the National Cancer Intelligence Network (NCIN) takes on responsibility for developing this new indicator.

2. Introduce measures to improve prevention and early detection

a) We hope the Government's forthcoming National Tobacco Strategy is a successful attempt to change behaviour to prevent more people taking up smoking and to help those who do smoke to quit. To complement this strategy, we call on Ofcom to ensure the broadcasting code, which restricts smoking on television before the watershed, is properly enforced.

b) We would like the Department of Health to publish its review of the regulation of the sunbed industry by March 2010, with a view to introducing legislation as soon as possible to ensure that the use of all salon sunbeds is properly supervised and is limited to people aged over 18 years.

c) We also recommend that the Department of Health initiates a national television campaign, closely supported by targeted community-based outreach projects, to promote lifestyles and behaviours shown to reduce the risk of cancer and to raise awareness of the key symptoms of cancer among higher risk groups.

d) We look to primary care trusts (PCTs) and cancer networks to use the Cancer Awareness Measure (CAM) and, based on its findings, take steps to improve awareness and early presentation.

3. Collect more data on patients in order to enable PCTs and cancer networks to undertake a thorough assessment of the needs of their local populations. Comprehensive data – including ethnicity, sexual orientation, religion or belief, age and any disabilities – should be collected sensitively, confidentially, and only with the full agreement and understanding of the patient. Such data – which should be made publicly available – would help to determine whether there is inadvertent discrimination against particular groups and act as a spur for improvement. We look to the Department of Health to implement this recommendation.

4. Improve the patient's experience throughout the cancer journey.

We urge the Department of Health to speed up implementation of the Cancer Patient Experience Survey Programme [see glossary]. We are disappointed that two years on from the Cancer Reform Strategy this programme has still not been launched. Once introduced, the programme will enable providers to tackle inequalities in experience faced by particular groups of cancer patients. We would like the Patient Experience Survey Programme Advisory Group to report back on progress by February 2010.

5. Provide better quality information for all patients throughout their cancer journey

in ways which are tailored to meet their needs. We expect the NHS to provide *information prescriptions* [see glossary] for all cancer patients by 2010 at the latest. We look to the Department of Health to ensure this recommendation is met.

6. Provide more help specifically for people with rarer cancers.

a) Following the recent announcement that GPs will be given better access to diagnostics, a duty should be placed on the Department of Health to ensure GPs have adequate training in using these diagnostics effectively.

b) The National Awareness and Early Diagnosis Initiative's programme of regular audits of cancer diagnoses in primary care should be widened.

c) The Department of Health should continue to encourage the National Institute for Health and Clinical Excellence (NICE) to take a more flexible approach to the appraisal of orphan drugs (used in the treatment of cancers which affect approximately five in 10,000 people).

d) The commissioning of ultra orphan drugs – used in the treatment of cancers which affect fewer than one in 50,000 people – should be undertaken by the National Specialised Commissioning Group. Uptake of such treatments should be monitored through clinical audit.

e) Patients with extremely rare cancers for which there may be no licensed drug treatment should be able to gain access to appropriate 'near-label' treatments through a new national fund. The safety and effectiveness of these treatments should be evaluated through a national clinical audit.

f) The National Cancer Research Institute (NCRI) should review the balance of its research portfolio between the "big four" cancers (lung, prostate, breast and colorectal) and other cancers and publish this information in its annual report.

7. Promote further research into causes of inequalities in cancer

- including why:
- I.** Cancer mortality rates are higher among men than women for the same cancers
 - II.** The fall in cancer mortality rates for people aged 75 and over has not been as fast as for people under 75
 - III.** Certain interventions are effective in promoting early diagnosis
 - IV.** Young people make unhealthy lifestyle decisions which significantly raise their risk of cancer.

We would like the NCRI to take responsibility for this recommendation.

8. All cancer patients should receive a regular assessment of their care needs at key points in their cancer journey including at initial diagnosis, at completion of treatment and on relapse – as happens for people with other long term conditions. The aim is to ensure that services for people with cancer are better co-ordinated to meet their practical, emotional, financial and information needs from the point of diagnosis onwards. As a first step, the model for post-treatment assessment and personalised care planning currently being developed by the National Cancer Survivorship Initiative should be implemented at PCT and cancer network level as quickly as possible.

Next steps

We look to the Department of Health to accept our recommendations. We hope the National Cancer Equalities Initiative will build on our recommendations in its vision statement which is due for publication in January 2010. We shall also ensure this Inquiry report is presented to Professor Sir Michael Marmot's Strategic Review of Health Inequalities in England.

A one-year survival indicator would be a vital step forward in significantly reducing the number of people aged 75 and over who are dying prematurely from cancer.

Chapter 1

Introduction



1.1 In April this year the All Party Parliamentary Group on Cancer launched an Inquiry into inequalities in cancer with a view to:

- I.** Assessing the inequalities in cancer that currently exist
- II.** Seeking out examples of good practice in tackling inequalities
- III.** Considering what more can be done by 2012 and beyond to improve outcomes and create greater equality in cancer care
- IV.** Making key recommendations to Government, the National Cancer Equality Initiative (NCEI) and the NHS on tackling cancer inequalities.

1.2 The Call for Evidence invited people to respond to a set of questions about cancer inequalities. Ninety written responses were received. In addition, in July we took oral evidence from a number of witnesses, including from several cancer patients, and organised a roundtable discussion for patients, carers and family members affected by rarer cancers. A list of those giving evidence is at Appendix 1. This report is based on the evidence received.

1.3 Wherever possible we have tried to make sure that the work of our Inquiry assists and complements the work of the various bodies set up as part of the Cancer Reform Strategy to help reduce cancer inequalities:

I. The **National Cancer Equality Initiative** whose role is to develop policy and research proposals for tackling cancer inequalities. We hope this inquiry will help inform the NCEI vision statement which we expect to be published in January 2010

II. The **National Cancer Intelligence Network (NCIN)** – whose role is to improve the collection and co-ordination of data on cancer patients

III. The **National Awareness and Early Diagnosis Initiative (NAEDI)** – whose role is to co-ordinate activities and interventions, including at local level, aimed at raising public awareness of the early signs and symptoms of cancer and encourage people to seek help sooner

IV. The **National Cancer Survivorship Initiative (NCSI)** – whose role is to improve the care and support provided for people living with or after a cancer diagnosis.

1.4 Our Inquiry has also been informed by the Health Select Committee Inquiry into Health Inequalities, which concluded that health inequalities between social groups have widened in the last decade [source: Health Select Committee report, March 2009].

APPG officers received written evidence from 90 stakeholders and listened to oral evidence from a number of witnesses including cancer patients, charities, cancer service providers and policy makers. This report is based on the evidence we received.

Chapter 2

What are inequalities in cancer?



Cancer in context

2.1 Every year more than 290,000 people in the UK are diagnosed with cancer, and over 150,000 people die from cancer. It is the biggest cause of death in the UK, accounting for one in every four deaths [source: CRUK].

2.2 Although cancer survival rates have improved over the last two decades, England is still behind the European average when it comes to five-year survival rates.

Definition of inequalities in cancer

2.3 We regard cancer inequalities as the differences between individuals' cancer experience or outcome which result from their social-economic status, race, age, gender, disability, religion or belief, sexual orientation, cancer type or geographical location.

Inequalities in cancer by socio-economic status

2.4 From the evidence received, it is clear that socio-economic status is a fundamental determinant of inequalities in cancer outcome.

2.5 Survival rates for most types of cancer have been rising steadily for several decades. However, because they have increased faster among more affluent groups the inequalities gap has widened. As a result, for most types of cancer, survival rates are worse for the most disadvantaged groups [source: CRUK].

2.6 There is strong evidence that different groups have different perceptions about the risks associated with lifestyle factors such as poor diet and alcohol. These lifestyle factors are strongly associated with socio-economic status.

Smoking

2.7 Smoking is the main preventable cause of cancer. Far fewer people in affluent groups smoke (19 per cent) than in the most disadvantaged groups (29 per cent). Smoking has been identified as the biggest single cause of inequalities in death rates between rich and poor in the UK. It accounts for over half of the difference in risk of premature death between social classes [source: ASH].

2.8 The evidence shows that increasing the tax paid on tobacco is effective in reducing smoking rates, but there are also concerns that too high a rate of tax may be counter-productive – encouraging the growth of a black market in cigarettes.

2.9 We also heard powerful evidence of the value of providing help and support to those smokers wishing to stop.

Other lifestyle choices

2.10 The Cancer Reform Strategy outlined the research evidence on other preventable risk factors for cancer and identified obesity as the second most important. It listed a range of lifestyle measures intended to minimise these risks.

Inequalities in cancer by ethnicity

2.11 A large-scale study by the NCIN, published this summer, has shown that, when compared with the general population, Black Caribbean and African men have higher prostate cancer rates, South Asians have higher mouth cancer rates and South Asian women have lower breast cancer rates [source: NCIN: Cancer Incidence and Survival by Major Ethnic Group, England, 2002-2006].

2.12 Risk factors are also higher for some ethnic groups. For example, 40 per cent of Bangladeshi men smoke, compared with a national average of 24 per cent. Obesity rates are higher among Black African, Black Caribbean and Pakistani women. Fifty-six per cent of men and 36 per cent of women of Irish origin drink more than the recommended daily alcohol intake – respectively 11 per cent and 6 per cent more than the white population generally [source: CRS Equality Impact Assessment].

2.13 There is a lower take-up of screening among ethnic minority groups – independent of socio-economic status. Among women from minority ethnic groups aged between 50 and 70, 45 per cent have never attended screening. For PCTs, there is a clear correlation between lower than average screening coverage and high numbers of people from ethnic minorities [source: CRS EIA].

2.14 In its evidence to us, Cancer Black Care said that among ethnic minorities there was a much reduced awareness of the link between obesity and cancer, and between alcohol and cancer.

2.15 Cancer Black Care also drew attention to the fact that in some communities a diagnosis of cancer was seen as “the will of God” and in others the knowledge that a person had cancer could affect the marriage prospects of their children.

Inequalities by age

2.16 For most cancers, the risk increases with age but certain cancers (e.g. retinoblastoma) occur almost exclusively in childhood. Other cancers (e.g. primary bone tumours, testicular cancers, Hodgkin’s disease) peak during teenage and early adult life [source: CRS EIA].

2.17 More young people – 36 per cent – smoke, compared with 24 per cent of the general population [source: CRS EIA]. Eighty per cent of smokers start by the age of 19 [source: CRUK]. To combat smoking among young people, in its report *Forever cool: the influence of smoking imagery on young people*, published in July 2008, the British Medical Association called for all films and TV programmes which portray positive images of smoking to be preceded by an anti-smoking advertisement, and for film censors to take into account pro-smoking content when classifying films.

2.18 A Department of Health study of sunbed use found that nationally around 6 per cent of young people (11-17 year olds) had used a sunbed, although in Liverpool the proportion was 22 per cent – rising to 39 per cent amongst 15-17 year olds [source: CRS one year on report].

2.19 Recruitment to clinical trials often does not include those aged 14-25 or over 65 [source: Teenage Cancer Trust and CRUK]. At a 2007 conference for 500 young cancer patients aged 14-25, only 30 per cent reported they had had the opportunity to enter a trial.

2.20 Older patients may be offered less intensive treatments for cancer with a lower opportunity for ‘cure’. The national lung cancer audit found that older patients with lung cancer are less likely to receive radical treatment for their disease [source: national lung cancer audit]. Older women with breast cancer are also less likely to be diagnosed using the standard ‘triple assessment’ diagnostic method and less likely to receive primary surgery, axillary node surgery, radiotherapy or chemotherapy [source: Breast Cancer Coalition].

2.21 Despite this evidence, the Department of Health’s current target for reducing mortality from cancer excludes those aged 75 and over.

Inequalities by gender

2.22 For the ten commonest cancers affecting men and women, mortality rates are in each case higher in men. Every year 28 per cent of male deaths and 23 per cent of female deaths are from cancer [source: CRS EIA]. After excluding gender-specific sites of cancer and breast cancer, men have a 60 per cent increased risk of developing cancer and a 70 per cent increased risk of dying from the disease [source: NCIN].

2.23 Although more women are diagnosed with melanoma, the mortality rate is higher among men. The five-year survival rate for women is 90 per cent, whereas for men it is 78 per cent [source: CRUK].

2.24 Until the introduction of screening for bowel cancer, national screening programmes were available only for breast and cervical cancer [source: CRS EIA].

2.25 The causes of these inequalities are not fully understood. Differences in lifestyle (e.g. smoking) and occupational exposure to risk factors are likely to be major factors.

Inequalities by disability

2.26 People with a learning disability appear to have a lower risk for some cancers but a higher risk of leukaemia, oesophageal and stomach cancers. These differences are caused partly by genetic and partly by lifestyle factors.

2.27 There is evidence that people with disabilities, especially people with a learning disability and those with mental health issues, may have greater difficulty accessing screening services. According to Mencap, only 19 per cent of women with a learning disability take up cervical screening, compared with 77 per cent of all women invited; and only 33 per cent take up screening for breast cancer, compared with around 70 per cent of all women invited. Mencap also referred to “the poor diagnostic practice of doctors generally” when treating patients with a learning disability.

Inequalities by sexual orientation

2.28 At present there is little information relating to cancer by sexual orientation. It is known that gay men have a higher incidence of anal cancer and cancers related to HIV/AIDS. Lesbians may be at a higher risk of breast cancer. There may also be a perception among health professionals that lesbians do not need – or have a reduced need – to undergo regular cervical cancer screening [sources: CRS EIA; CRUK].

2.29 Smoking rates in gay men and bisexual people are also significantly higher – at 41 per cent – than for the general population.

2.30 The way in which information on prevention and early detection is presented may also contribute to inequalities. Stonewall told us that literature which depicted a man and a woman in a partnership may not be seen as relevant to the gay and lesbian community.

Inequalities by cancer type

2.31 There are wide variations in the incidence, mortality and survival rates of different cancer types. Of all new cases of cancer diagnosed each year in the UK, more than half – 54 per cent – are represented by the “big four” (breast, lung, colorectal and prostate). The “big four” also account for 47 per cent of all deaths from cancer. Lung cancer alone is responsible for around 35,000 deaths – more than 20 per cent of all cancer deaths.

2.32 Less is known about rarer cancers. Some have good prognoses (e.g. testicular), others less so (e.g. pancreatic). Diagnosis can be harder to achieve – especially where symptoms are non-specific – and there are often fewer treatments available. As a consequence there are frequently worse survival rates.

Inequalities by location

2.33 There is evidence that cancer incidence also varies geographically. People in rural communities access the NHS less often, yet a higher percentage of people from rural areas are admitted for cancer treatment than from urban areas [source: Commission for Rural Communities]. Distance exacerbates other problems: “you have to go 50 miles to your oncology centre to have a blood test, to come back and then go the next day to your chemotherapy, to come back to go the next day to see your counsellor” [source: Commission for Rural Communities].

Smoking is the main preventable cause of cancer. Far fewer people in affluent groups smoke than in the most disadvantaged groups. Smoking accounts for over half of the difference in risk of premature death between social classes [source: ASH].

Inequalities and the cancer journey

2.34 Cancer inequalities also affect people at different stages of the cancer journey.

Symptom awareness

2.35 It is known that, in general, the earlier a cancer is diagnosed and treated, the greater the chance of a successful outcome. There is evidence that awareness of cancer is lower in socially disadvantaged groups, in some minority ethnic groups and among men [source: NCEI].

2.36 We received evidence that a better understanding was needed of the extent to which levels of awareness vary between different groups – and why. To address this gap, NAEDI and CRUK have developed the cancer awareness measure which is currently being trialled in certain parts of the country. Using this measure it will be possible to assess the level of cancer awareness among different groups within the population.

2.37 Once there is a more thorough understanding of existing levels of awareness, research needs to be undertaken into interventions that are effective in raising awareness, whether population-wide or for specific groups. We note that new approaches are already being tested. For example, one initiative in London aims to increase the proportion of older women who present early with breast cancer by engaging in face-to-face interventions [source: NAEDI].

Screening

2.38 The NHS Cancer Screening Programmes told us that inequalities most often present in the form of reduced rates of acceptance of screening invitations. Research has shown that uptake of breast cancer screening is lower:

- I. In areas with high transient populations, where more people may not receive their invitations
- II. Among disadvantaged groups
- III. Among South Asians, and especially among Muslims.

2.39 The findings for cervical cancer screening are similar, although the decline in recent years in the number of younger women (aged 24-34) taking up screening has now been reversed, chiefly as a result of the publicity given to the case of Jade Goody.

2.40 For bowel cancer screening, there is evidence that ethnicity is a factor, with Asian people half as likely as others to take up screening. Bowel cancer screening rates are also lower among men [source: Men's Health Forum].

2.41 In view of the high incidence of prostate cancer, an effective screening programme would be invaluable in supporting early detection, treatment and survival. To date screening based on the PSA test has been controversial. A recent European trial indicates that PSA screening does reduce mortality, albeit at the cost of significant over-treatment. It remains extremely difficult to predict which prostate cancers will be aggressive and which will develop at a much slower pace. The Prostate Cancer Charity has made a good case for prioritising research into the development of a more accurate predictive test for use as part of a screening programme.

2.42 The low uptake of screening services among certain minority groups highlights important cultural differences between groups, such as the importance to people of being screened by or receiving treatment from a person of the same gender.

Early diagnosis

2.43 Delays in diagnosing cancer are a major reason why survival rates in England are worse than in other countries in Europe.

2.44 The reasons for late diagnosis appear to be a combination of factors: patients coming forward later, cancer diagnoses being missed in primary care, and GPs having limited access to diagnostic tests.

2.45 To understand better the relationship between these three factors NAEDI has developed a national audit of cancer diagnosis in primary care, so as to:

- I. Assess, for a range of cancers, the time taken from a patient's first presentation to the point when a diagnosis of cancer is reached
- II. Build up a better understanding of the process by which a cancer diagnosis is made
- III. Develop a baseline from which improvements in service can be measured
- IV. Develop a standardised tool for audit.

Delays in diagnosing cancer are a major reason why survival rates in England are worse than in other countries in Europe.



2.46 At present 18 of 28 cancer networks are taking part in the primary care audit looking at cancer diagnoses made in 2008/09. GP practices are being encouraged to take part in the programme. Once completed, the audits should identify those actions which tend to support early diagnosis of cancer in general practice.

2.47 In September, the Prime Minister announced that GPs in England are to get speedier access to diagnostic tests in order to help diagnose less clear-cut cases of cancer. The new scheme will initially be targeted at lung, colorectal and ovarian cancers although it is intended to extend the scheme to all cancers within five years. Once implemented, patients will have key tests within two weeks of seeing the GP – reducing to one week in due course.

Treatment

2.48 With regard to treatment, four main issues were raised:

- I. The need for more radiotherapy services to be made available
- II. The need to improve access to cancer drugs for NHS patients
- III. Provision of a cancer nurse specialist for all patients
- IV. Under-treatment of older people.

Radiotherapy

2.49 Professor Mike Richards, National Cancer Director, told us that the current shortage of radiographers was being addressed, and a programme of investment in radiotherapy equipment was under way which should enable

the NHS to meet its radiotherapy target for 2010. These developments should help to address some geographical inequalities in cancer.

2.50 In August the Department of Health announced that it was inviting hospitals to bid to provide proton beam therapy, which can cure tumours without damaging vital organs. The therapy is particularly helpful in the treatment of young people and people with rarer cancers.

Cancer drugs

2.51 In relation to cancer drugs, two concerns were raised:

- I. Difficulties in obtaining the drugs needed
- II. The appraisal process operated by NICE.

2.52 Difficulty in obtaining cancer drugs often arises because of different patterns of prescribing between different PCTs across the country. However, Professor Richards told us there had been a progressive reduction in variations across PCTs.

2.53 Professor Richards' own review of access to drug treatments, *Improving access to medicines for NHS patients*, published in November 2008, had led NICE to issue supplementary guidance aimed at improving access to more expensive drug treatments for end-of-life patients.

2.54 Professor Michael Rawlins, Chairman of NICE, told us that drug referrals were also now being made earlier. He said that by mid-2010 there should be no drug product where the gap between market authorisation and release of NICE guidance should take more than six months.

2.55 Yet despite this progress, David Cook, a patient with kidney cancer, told us: "There were no NICE drugs available for me. I had to take the PCT to appeal. It was the most stressful and harrowing experience of my life. These drugs are available to people throughout the United States and Europe." In other words, for some cancer patients, access to cancer drugs still remains a 'life or death' problem and the exceptional funding process (whereby a patient requiring drug treatment for a rare cancer not approved by NICE can apply for the costs to be met "exceptionally" by the local PCT) can be a major source of distress for cancer patients and their families and carers.

Cancer nurse specialists

2.56 Those providing evidence praised the work of cancer nurse specialists (CNSs). Not all cancer patients, however, had access to them. Angela Edgecombe, a secondary breast cancer patient, contrasted the ease of access to a CNS when she was treated for primary breast cancer with the difficulty of access when she was treated for secondary breast cancer.

Under-treatment of older people

2.57 In general, older people with cancer receive less intensive and less radical treatment than younger people. While some older people may in general be frailer, have other illnesses (co-morbidities) and may present later than younger people, others do not. In her evidence to the Inquiry, Joanne Rule, Co-chair of the National Cancer Equality Initiative (NCEI), pointed to the lack of a comprehensive assessment of older people to measure fitness for treatment. She added "the data suggests ageism as a hypothesis to explain the degree of under-treatment."

2.58 Detailed research in the North West among older women with breast cancer has suggested that – after taking frailty into account – they were investigated less intensively and were less likely to receive surgery than younger women. Researchers from the North West Cancer Intelligence Service (NWCIS) also concluded that over the last decade there had been little progress in reducing cancer death rates in people aged 75 and over in the UK. The gap in death rates compared to other countries was also widening.

This suggested that for people with cancer aged 75 and over there is likely to be a substantial issue of under-treatment in this country.

The patient experience

2.59 The Group received considerable evidence about the differences in the cancer experience of different groups of patients, including the findings from a large-scale national survey of cancer patients undertaken in 1999-2000 by the Department of Health and a follow-up survey carried out by the National Audit Office in 2004. Although both suggested that the experience of cancer patients was generally good, it is questionable whether the surveys gathered sufficient data about different groups or were sufficiently sensitive to differences in experience between groups.

2.60 John Neate, Chief Executive of the Prostate Cancer Charity, said that prostate cancer patients were half as likely as breast cancer patients to have had a discussion with their clinician about their treatment, and half as likely to have had access to a named nurse. Breast cancer patients were also five times more likely than prostate cancer patients to have been directed to support groups.

2.61 Cancer patients who gave oral evidence highlighted the importance of information to help empower them to make decisions about their care and treatment. They said that far too often this was lacking – despite the limited cost to the NHS in providing such information and support.

2.62 One witness, Kelly Denver, who had Non-Hodgkin's Lymphoma as a teenager, spoke about the inequalities she experienced because of her age. Because she was treated in a hospital unit for adults, health professionals did not take account of her specific needs, in particular her desire to continue with further education. It was difficult for her mother to stay with her overnight and her friends felt unwelcome in an environment geared towards an older age group.

The data suggests ageism as a hypothesis to explain the degree of under-treatment.

Joanne Rule, Co-Chair, NCEI

2.63 Another witness, Myrna Whiteson of the Teenage Cancer Trust, said that young people were more concerned about their fertility than with dying. Such issues were not always properly considered by health professionals.

2.64 As highlighted above, a number of respondents also emphasised the importance of the clinical nurse specialist as a source of emotional support and information, and as a coordinator of services.

Living with and after cancer

2.65 In their evidence, Macmillan Cancer Support said that for many people cancer was now a long-term condition. Despite this, a NCEI survey of NHS trusts found that projects to tackle inequalities were far more likely to focus on awareness and early diagnosis than living with and after cancer.

2.66 Many witnesses also drew attention to the fact that cancer patients require the services of different public agencies while living with and after cancer, whether for social care, financial advice and support, childcare, employment support or – particularly for young people – education. Where services were limited or poorly coordinated, the impact was felt most acutely by the most vulnerable and by those in socially disadvantaged groups.

2.67 The Commission for Rural Communities told us that people in rural areas often lacked the emotional support they needed from support groups because such groups had to cover much wider areas in the country and were therefore less accessible.

A NCEI survey of NHS trusts found that projects to tackle inequalities were far more likely to focus on awareness and early diagnosis than living with and after cancer.



Chapter 3

Conclusion – our priorities for action



3.1 It is clear that the impact of inequalities can be profound – not only in terms of incidence, mortality and survival, but also in terms of the patient's experience. The stories we heard from cancer patients themselves were heartfelt, sometimes harrowing, and always persuasive.

3.2 Over the past decade, cancer services have advanced significantly. The Cancer Reform Strategy represented a significant advance on the Cancer Plan 2000. We warmly welcome the partnerships that have been established to co-ordinate information on cancer, to tackle inequalities, to promote awareness and early diagnosis, and to support cancer survivors. We admire the initiative shown by many cancer service providers working at local level.

3.3 We believe the eight priorities for action set out in this report will complement the action already in hand. In reaching our views, we have been mindful that funds for cancer services are limited – and, in view of the wider economic pressures facing the country, the NHS will need to make some difficult financial decisions in the years ahead. We have sought to take this into account in determining our priorities, which we believe are realistic as well as ambitious.

**Priority action 1:
A new indicator for one-year survival rates for all**

3.4 Overall, the strongest message coming through the evidence was the importance of raising awareness of cancer and improving early diagnosis as the key to tackling inequalities in cancer outcomes. As this report makes clear, the causes of late presentation and diagnosis are complex – and are not fully understood. People in disadvantaged groups are however shown to be over-represented among those who present late.

3.5 Much excellent work is being taken forward by the cancer community, in the public and the voluntary sectors, and through a variety of partnerships and initiatives including those established by the Cancer Reform Strategy.

3.6 To give this work a fresh focus, we have concluded that the time is right to formulate a new indicator (or target) for one-year survival rates. The advantage that such an indicator has over five-year survival rates and mortality rates is that it is concerned with events in the immediate past. It also starts to shift attention away from inputs and onto outcomes. In time, a more outcome-focused approach may enable some of the current process targets to be downgraded.

3.7 The one-year indicator would, for the first time, apply to cancer patients of all ages. According to research published by the NCIN in June 2009, as many as 15,000 people aged 75 and over die prematurely from cancer each year. A one-year survival indicator for all would be a vital step forward in significantly reducing the number of people aged 75 and over dying unnecessarily.

3.8 The formulation of a one-year survival indicator would be difficult. It would need to reflect the current variations in one-year survival rates by such factors as cancer type, age and region. The aim would be to eradicate such variations over time. It would also be important that one-year survival rates for individual groups can be measured to enable the NHS to measure progress for all groups in society. It is recommended that the NCIN take on responsibility for formulating the indicator.

3.9 The adoption of this indicator would encourage the NHS to:

- I.** Raise all groups' awareness of the early symptoms of cancer which should never be disregarded by a patient or doctor
- II.** Promote early presentation and diagnosis
- III.** Speed up the early referral system
- IV.** Tackle under-treatment of older people.

Priority action 2: New measures to improve prevention and early detection

Smoking

3.10 Because smoking is shown to be the biggest preventable cause of cancer, and because it is strongly associated with inequalities, we have concluded that the Government must take further action to reduce the numbers of people who smoke.

3.11 By the time this report is published, we hope the Government will have published its new National Tobacco Strategy which we expect to cover four main areas:

- I. Reducing smoking rates and health inequalities caused by smoking
- II. Protecting children and young people from smoking
- III. Supporting smokers to quit
- IV. Helping those who cannot quit.

We hope this new strategy will be a radical attempt to reduce smoking rates – not simply to reduce cancer incidence but also to reduce inequalities in cancer.

3.12 Following evidence received about the importance of protecting children and young people from seeing images of smoking on television, the Group has reviewed the current Broadcasting Code and Guidance on smoking published by Ofcom (the independent regulator of the UK communications industries). The code states that smoking “must generally be avoided” and when shown “must not be condoned, encouraged or glamorised” in programmes broadcast before the watershed “unless there is editorial justification”. In our view the code is not being followed in all programmes broadcast before the watershed, such as soap operas, which are frequently viewed by children and young people. We think Ofcom has a duty to ensure the code is strictly enforced at all times. If necessary, we will consider recommending that smoking is banned in all programmes before the watershed unless there is strong editorial justification.

3.13 We would also like the UK Centre for Tobacco Control Studies to research further the reasons why young people take up and continue smoking; and in particular the impact of product packaging in encouraging young people to smoke.

Other lifestyle factors

3.14 A new strategy for smoking should be complemented by new measures to promote a balanced diet, physical activity and sensible levels of alcohol consumption. We look to the Department of Health to build on the measures outlined in the Cancer Reform Strategy.

3.15 In the Cancer Reform Strategy the Department of Health also said it would review options for the regulation of the sunbed industry and the use of sunbeds by young people. We would like the Department of Health to publish the results of this review by March 2010. However, since the Cancer Reform Strategy was published, the International Agency for Research on Cancer has decided to raise the classification of sunbed use (UV radiation) to its highest cancer risk category – at the same level as tobacco. As such, we think the Government should introduce legislation as soon as possible to ensure that the use of all salon sunbeds is properly supervised and is limited to people aged over 18 years.

National media campaign and local outreach projects

3.16 To give greater impetus to these measures, we also wish to see a new national media campaign, closely supported by targeted community-based outreach projects, to encourage people to adopt those behaviours and lifestyles which are known to minimise the risk of cancer and to raise awareness among higher risk groups of the key symptoms of cancer. These symptoms include unexplained weight loss, change of bowel habits, unexplained bleeding or a persistent cough.

Promoting the cancer awareness measure

3.17 We also support the adoption of the cancer awareness measure (CAM) as a tool to assess awareness and early diagnosis. We think all PCTs and cancer networks should consider using the CAM as the basis for their public awareness campaigns. We would also like those involved in the commissioning of cancer prevention and early detection services to encourage the use of the CAM in order to identify gaps in knowledge and to evaluate services. We look to NAEDI to share and encourage best practice.

Priority action 3: Better collection of data about cancer patients

3.18 Many of those giving evidence drew attention to the lack of information collected about cancer patients. Such information is essential in enabling PCTs to assess the needs of their populations and to commission services that are appropriate for those populations, above all for the most vulnerable and disadvantaged groups. This point was emphasised by a number of PCTs in their evidence.

3.19 With better information, it should be possible not only to identify the existence of different forms of inequalities, but also to measure the extent of those inequalities and find out why they exist.

3.20 We think a person’s gender, age, postcode (as a proxy for socio-economic status), ethnicity, religion or belief and sexual orientation should be routinely collected. Such data should be used to form part of the assessment which each PCT is required to undertake of the health needs of its population.

3.21 We recognise that all data on patients should be collected sensitively and confidentially. We think the reasons why the collection of data is needed should be fully explained to the patient and such information should be collected only with the full consent of the patient.

3.22 We recommend that the Department of Health commissions pilot schemes in order to determine the best approach to ensuring the collection of comprehensive data on patients.

Priority action 4: Speed up the introduction of the cancer patient experience survey

3.23 More information is also needed about patients’ experiences to enable providers of cancer services to see how well they satisfy the requirements of patients. Measures of patient experience can then be used to set goals for improvement. Where there is evidence of inequalities or inadvertent discrimination, service providers – and commissioners – can take steps to address it.

We think the Government should introduce legislation as soon as possible to ensure that the use of all salon sunbeds is properly supervised and is limited to people aged over 18 years.

3.24 The Cancer Reform Strategy agreed the development of a National Cancer Patient Experience Survey Programme in December 2007. We are disappointed that two years on this programme is still yet to be launched. We urge the Department of Health to redouble its efforts. We would expect the survey to be one of the main mechanisms for monitoring that the Cancer Reform Strategy is being properly delivered.

3.25 Crucially, the survey needs to be sensitive enough to pick up poor experiences among individual groups, and to allow comparisons to be drawn between individual cancer networks, PCTs and multi-disciplinary teams. We also hope the surveys will look at whether information can be gathered about the experience of the patient's family and carers who are often vital in determining the quality of the patient experience.

3.26 Surveys also need to be linked closely into trusts' quality performance measures and reporting requirements – such as 'quality accounts' [see glossary]. We hope this will lead directly to service improvement through better commissioning.

3.27 The Care Quality Commission [see glossary] should have a clear role in addressing poor performing trusts and teams and be alert for evidence of poor experiences among particular groups.

3.28 We would like the Department of Health's Patient Experience Survey Programme Advisory Group to report back on progress – addressing the issues raised here – by March 2010.

**Priority action 5:
Provide better quality information
for all patients**

3.29 Much of the evidence received identified the importance of providing better quality information for all disadvantaged groups in ways which are tailored to their requirements. As Cancer Black Care stated, if a community's primary manner of communication is by the spoken word, written information has little impact.

3.30 Good information, appropriately and sensitively presented for each target audience, should help to improve cancer prevention, promote awareness of symptoms and early diagnosis and improve the experience of cancer patients.

3.31 In the Cancer Reform Strategy the Department of Health made a commitment to roll out information prescriptions by 2009. We are disappointed that this deadline has not been met and call on those involved in both the Department of Health and the NHS to ensure that by 2010 at the very latest all cancer patients are given an information prescription at key points in their cancer journey.

**Priority action 6:
Provide more help specifically
for people with rarer cancers**

3.32 The Inquiry has concluded that a number of measures could usefully be taken to address the issues faced by people with rarer cancers.

3.33 First, the Prime Minister's announcement that GPs in England are to get speedier access to diagnostic tests will help with the diagnosis of less clear-cut cases of cancer. While this announcement is welcome, it is important to ensure that GPs have adequate training to recognise the main symptoms of cancer and, where symptoms are consistent with a possible diagnosis of cancer, to use these diagnostics effectively so as to ensure that the correct diagnosis is established as quickly as possible.

3.34 It is also important that all patients are aware that GPs will have speedier access to diagnostic equipment. More affluent groups are quicker in taking advantage of new developments such as this. To avoid the risk of exacerbating inequalities, the Department of Health needs to take steps to ensure the benefits are recognised and taken up by disadvantaged groups as well.

We are disappointed that two years on from the publishing of the Cancer Reform Strategy the Cancer Patient Experience Survey Programme has still not been launched.



3.35 To speed up diagnosis and referral still further, especially for rarer cancers, the Department of Health may wish to encourage the Royal Colleges, the pharmaceutical industry and others to explore the development of reliable and cost-effective algorithmic tools to assist GPs in identifying cancer. Such diagnostic tools, as they emerge onto the market, should be evaluated by NICE in order to ensure they deliver measurable benefits to patients.

3.36 Regular audits of cancer diagnoses in primary care are a key mechanism through which the management of the disease in primary practice can be improved. We recommend that NAEDI's programme of regular audits of cancer diagnosis in primary care is continued at local level and broadened to involve all cancer networks and all cancers. We also hope that the lessons learnt from these audits will be applied to all groups at a higher risk of late diagnosis.

3.37 We think that the Department of Health should continue to encourage NICE to take a more flexible approach to the appraisal of orphan drugs – used in the treatment of cancers which affect approximately five in 10,000 people – in accordance with the spirit of the Richards Review and the NICE guidance *Appraising life-extending, end of life treatments*. Despite the relatively high treatment costs per patient, we believe NICE should take fully into account the relatively small number of patients involved, and therefore the modest overall costs of making the drugs available. The appraisal process should take into account that patients with rare cancers often have few or no other options and therefore the proportionate health gain delivered by new drug treatments can be significant and extremely valuable.

3.38 In our view the NICE appraisal system is inappropriate for dealing with ultra orphan treatments (medicines which are used for the treatment of diseases that have a prevalence of fewer than one in 50,000 of the population). Equally, we consider it inappropriate to expect individual PCTs to have the expertise to effectively commission these drugs.

Treatments for very rare conditions, such as surgery for primary bone cancer, are currently commissioned through the specialised commissioning pathway. We therefore believe it would be appropriate for the remit of the National Specialised Commissioning Group to be extended to include the commissioning of all ultra orphan cancer treatments. It is essential that any new decision-making process must be transparent, fair and speedy; and that any variations in uptake are evaluated through clinical audit, drawing on the forthcoming NCIN chemotherapy dataset.

3.39 In addition, it would be helpful to set up new arrangements for funding and evaluating drug treatments for extremely rare cancers, for which there may be no licensed treatment. The Rarer Cancers Forum has described this as 'near-label' treatment. We support the establishment of a national fund for such treatment. It will be important that this is accompanied by rigorous national clinical audit to develop the evidence base on the safety and effectiveness of these treatments. Over time we would hope that this audit would generate sufficient evidence to enable some 'near-label' treatments to be commissioned through the national specialised commissioning arrangements.

3.40 There is a strong case for the pharmaceutical industry to contribute to the costs of such a national fund. We would therefore like the Association of the British Pharmaceutical Industry and the Department of Health to work in partnership to implement this proposal.

3.41 We would also welcome reassurance from the Department of Health that the latest directions on exceptional funding, published in April 2009, ensure that there is consistency in the decisions made by exceptional case panels, and that all patients are provided with the appropriate practical and emotional support they, and their families need, during what can be a traumatic experience.

3.42 We understand the concern that insufficient research capacity is given to rarer cancers. As with other issues, however, the starting point should be to find out how much resource is given to research into different cancer types. We would like the NCRI to review the balance of its research portfolio and set out in its annual report how much is spent on the "big four" and how much on other cancer types. Publication of this information would enable discussion to take place about the merits of shifting the balance.

Priority action 7: Promote further research into the causes of cancer inequalities

3.43 We are also persuaded of the need for more research into the reasons why inequalities exist. In particular, we would like the NCRI to look at four areas which we think would particularly benefit from further research:

- I. For cancers which are common to men and women, why are cancer mortality rates higher among men?
- II. Why is it that cancer mortality rates are not falling as fast for people aged 75 and over as they are for people aged under 75?
- III. In view of the importance of early diagnosis in determining cancer survival, what interventions can be shown to be effective in promoting early diagnosis among disadvantaged groups?
- IV. Why do young people make unhealthy lifestyle decisions which significantly raise their risk of cancer?

Priority action 8: Ensure all cancer patients receive a regular care needs assessment

3.44 We would like all cancer patients and survivors to have regular health and social care needs assessments – often called 'holistic needs assessments'. Individualised care plans could then be drawn up for each patient at key points in the cancer journey including at first diagnosis, on completion of treatment, and on relapse. The aim would be to ensure that services for people with cancer are better co-ordinated to meet the practical, emotional, financial and information needs of cancer patients from the point of diagnosis onwards.

3.45 Care plans would be similar in nature to the personalised 'after care' plans being developed as part of the National Cancer Survivorship Initiative. Timely implementation of post treatment care assessments and plans for cancer survivors at PCT and cancer network level would be an important first step, and should help to demonstrate the value of the approach for patients who are at an earlier stage in their cancer journey.

3.46 We also expect the Department of Health to ensure that its commitment – set out in the Final Report of the NHS Next Stage Review *High Quality Care for All* – to offer everyone with a long term condition a personalised care plan includes all cancer patients.

Next steps

3.47 In tackling inequalities in cancer it is important to build a momentum for change. We challenge Government to accept our recommendations and to develop a plan for implementing them, in partnership with other relevant organisations and agencies. In particular, we hope that the National Cancer Equalities Initiative will build on our findings in its vision statement which is due for publication in January 2010.

3.48 It is also important to build consensus. We will be working to secure support for our recommendations from all three main political parties. Indeed, as we approach the General Election, we trust that these recommendations will be given explicit endorsement in their manifestos.

3.49 We shall also ensure that this Inquiry report is presented to Professor Sir Michael Marmot's Strategic Review of Health Inequalities in England Post 2010.

Appendix 1

People who gave evidence

Oral Witnesses

Susan Barber, Cancer Research UK
 Melanie Brooks, Cancer Patient
 Frank Chinegwundoh, Cancer Black Care
 David Cook, Cancer Patient
 Beverley Dawkins, Mencap
 Kelly Denver, Cancer Patient
 Angela Edgecombe, Cancer Patient
 Professor Steve Field, Royal College of GPs
 Pat Higgins, Merseyside and Cheshire Cancer Network
 Ruth Hunt, Stonewall
 David Land, Commission for Rural Communities
 Paul McKenzie, Merseyside and Cheshire Cancer Network
 John Neale, The Prostate Cancer Charity
 Stella Pendleton, Rarer Cancers Forum
 Sir Michael Rawlins, NICE
 Professor Mike Richards, Co-chair NCEI
 Joanne Rule, Co-chair NCEI
 Professor Karol Sikora, CancerPartnersUK
 Myrna Whiteson, Teenage Cancer Trust
 David Wilkins, The Men's Health Forum

Written Respondents

Ashton Leigh & Wigan PCT
 Barking and Dagenham PCT
 Bayer Schering Pharma
 Berks East PCT
 Blackburn with Darwen PCT
 Bournemouth and Poole PCT
 Bowel Cancer UK
 Brain Tumour Research
 Brain Tumour UK
 Breakthrough Breast Cancer
 Breast Cancer Care
 Breast Cancer Campaign
 British Association of Surgical Oncology
 British Institute of Radiology
 British Lung Foundation
 British Neuro-Oncology Society
 Bromley PCT
 Ms Camilla Benincasa
 Cancer Research UK
 Central and Eastern Cheshire PCT
 Central Lancashire PCT
 Central South Coast Cancer Network
 Centre for Health and Social Care Research
 CLIC Sargent
 Mr Malcolm Cole

Commission for Rural Communities
 Dorset Cancer Network
 Dr Julie Fish
 Geoff Thomas Foundation
 Gloucestershire PCT
 Great Yarmouth and Waveney PCT
 Greater Manchester & Cheshire Cancer Network
 Dr Chris Hiley
 Heart of Birmingham Teaching PCT
 Hounslow PCT
 Hull PCT
 James Whale Fund
 Professor Janowski
 Professor Ian Judson
 Justice for Kidney Cancer Patients
 Kent and Medway Cancer Network
 Kirklees PCT
 Leeds PCT
 Lincolnshire Teaching PCT
 Macmillan Cancer Support
 Manchester PCT
 Mencap
 Men's Health Forum
 Merseyside and Cheshire Cancer Network
 Dr Tony Moran
 Myeloma UK
 National Cancer Equalities Initiative
 National Cancer Intelligence Network
 National Council for Palliative Care
 NHS Cancer Screening Programmes
 National Social Marketing Centre
 North East London Cancer Network
 North Lancashire PCT
 North of England Cancer Network

Northamptonshire PCT
 North Lancashire PCT
 North Staffordshire PCT
 Nottingham City PCT
 Novartis
 Pancreatic Cancer UK
 Peninsula Cancer Network
 Prostate Cancer Charity
 Prostate Cancer Charter for Action
 Rarer Cancers Forum
 Roche
 Roy Castle Lung Cancer Foundation
 Salford Teaching PCT
 Samantha Dickson Brain Tumour Trust
 Mr Bill Savage
 Sheffield University Academic Unit of Supportive Care
 Somerset PCT
 South East Essex PCT
 South West Essex PCT
 South of Tyne and Wear PCT
 Stonewall
 Sussex Cancer Network
 Swindon PCT
 Thameside and Glossop PCT
 Teenage Cancer Trust
 Thames Valley Cancer Network
 Tower Hamlets PCT
 Trafford PCT
 Wakefield District PCT
 West London Cancer Network
 Dr Michael Williams

We are extremely grateful to everyone who gave evidence to our Inquiry and particularly to those cancer patients who gave evidence to us in person – their stories influenced us considerably.

John Baron, Chair, APPG on Cancer

Appendix 2

Glossary

The **National Cancer Research Institute (NCRI)** is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research.

The **Care Quality Commission** is the independent regulator of health and social care in England.

The **NHS Cancer Patient Experience Survey Programme** was established by the *Cancer Reform Strategy* to collect regular information on patients' experience through surveys conducted annually.

Cancer networks bring together **providers** and **commissioners** to work collaboratively, in order to plan and deliver high quality cancer services for a given population.

Information prescriptions aim to guide people with long-term conditions or care needs, and their carers, to relevant and reliable sources of information.

The **National Clinical Audit Support Programme (NCASP)** has been developed to support the NHS in delivering national service frameworks and clinical governance.

Specialised commissioning: The treatment of some very rare diseases is highly specialised and is therefore commissioned nationally by experts in the relevant field.

Quality Accounts provide information on the quality of care a PCT provides.

ALL PARTY PARLIAMENTARY GROUP ON CANCER



The Secretariat to the All Party Parliamentary Group on Cancer is provided by

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The APPGC is also supported by a group of stakeholder organisations: Breakthrough Breast Cancer, Cancer Black Care, Cancer Research UK, Marie Curie Cancer Care, the Men's Health Forum, the National Cancer Research Institute (NCRI), Teenage Cancer Trust and the Rarer Cancers Forum.

You can find out more information about the APPGC via www.appg-cancer.org.uk