



# All Party Parliamentary Group on Cancer

## Response to the Review of the Cancer Reform Strategy

### Introduction

The All Party Parliamentary Group on Cancer (APPGC) welcomes the opportunity to respond to the Review of the Cancer Reform Strategy (CRS).

Our response to this consultation has been informed by the extensive inquiry into inequalities in cancer which the APPGC undertook in 2009. The APPGC held a number of oral evidence sessions in Parliament, and analysed over 90 pieces of written evidence from charities, public sector bodies, health professionals, PCTs and academics.

We published a report of this inquiry in December last year which concluded that there were a number of unacceptable differences in the cancer care and treatment received by certain groups of cancer patients which significantly affected their health outcomes and experiences. The report set out eight priority actions that, if implemented, would improve outcomes for all and reduce the unacceptable inequality which persists in England. The report was warmly welcomed by the National Cancer Director, Professor Sir Michael Richards.

### 1. Are there particular priority areas for action which need to be addressed if cancer outcomes are to be improved?

1.1. The CRS is to be applauded for the focus it placed on tackling cancer inequalities. The establishment of the National Cancer Equality Initiative (NCEI) was an important step forward; having a dedicated body to formulate guidance and investigate best practice is essential if we are to close the unacceptable gaps in cancer outcomes and experience.

1.2. The Government's refresh of the CRS presents an excellent opportunity to tackle cancer inequalities with renewed vigour. Following the NCEI 'vision', we need clear action on the ground. As a first step the APPGC urges the Government to establish outcome indicators and the National Institute for Health and Clinical Excellence to develop Quality Standards which encourage the implementation of recommendations from both the APPGC and NCEI reports. These steps will significantly reduce cancer inequalities and deliver improved health outcomes for all.

These include:

#### **An indicator for one-year survival rates for all**

1.3. A one year cancer survival indicator for all cancers and all age groups,



including people over 75, will encourage the NHS to raise awareness of the symptoms of cancer; develop mechanisms to boost earlier diagnosis and tackle the under treatment of older people. The APPGC is delighted by the recent progress made in this area by Professor Michel Coleman, the National Cancer Intelligence Network (NCIN), the Office of National Statistics (ONS); more details on the form of the indicator are given in paragraph 3.3 below.

- 1.4. In the Health White Paper, the Government makes clear its goal of improving the UK's one and five year cancer survival rates to be the best in Europe. During our inquiry we heard expert evidence which stated that if we can get people with cancer in the UK to survive one year their chance of surviving five years is similar to an equivalent European country. A one year survival indicator for all ages is, therefore, a critical step towards improving both one and five year survival rates in the UK.

#### **New measures to improve prevention and early detection**

- 1.5. Lifestyle factors, such as smoking, remain the biggest preventable causes of cancer. Local authorities need to undertake targeted community-based outreach projects to raise awareness of the risk factors associated with cancer, as well as cancer symptoms. The APPGC welcomes the recent announcement of a new £9 million campaign for 59 local areas to undertake such campaigns.
- 1.6. **All local authorities should be encouraged to use the Cancer Awareness Measure (CAM) to both inform their public awareness campaigns on cancer, and to measure the impact of these initiatives.**

#### **Better collection of data about cancer patients**

- 1.7. In their evidence to the APPGC's Inquiry, a number of PCTs highlighted the lack of data collected about cancer patients. While much progress has been made in this area, more needs to be done. For example, data on religion or belief and sexual orientation is still not routinely collected. This data could provide crucial information on possible inequalities and enable commissioners to design more locally relevant services.
- 1.8. The Government's vision, which we welcome, of an NHS judged on the successful delivery of outcomes rather than processes, **can only be delivered if comprehensive data is collected and used effectively.**

#### **Implementation of the cancer patient experience survey (CPES)**

- 1.9. The APPGC welcomes the progress made on the delivery of the CPES.
- 1.10. We are pleased that the 2010 survey includes a variety of questions



aimed at collecting equality data. The results must be used to inform local cancer services so that everyone's experience of care improves. The survey results should also be included in Trusts' and consortia Quality Accounts so improvements can be tracked and problem areas identified by the Care Quality Commission (CQC). By making this information publicly available it would also make commissioners and providers more accountable to their local populations, a central theme of the NHS White Paper.

### **Provide better quality information for all patients**

1.11. The APPGC welcomes the priority the Government has given to the role of information in the Health White Paper and is pleased that they are consulting on their information strategy this autumn.

1.12. Information and support is key to empowering patients to have choice over their treatment and care options, and improves experiences throughout the cancer pathway. If we are to improve outcomes for all, providing people with personalised and supported information in an appropriate format is of the utmost importance. Information Prescriptions (IPs) are a key mechanism for the delivery of such information and the APPGC is disappointed by the delay in their roll out. We urge the Government to launch the cancer IP implementation plan as soon as possible.

### **Provide more help for people with rarer cancers**

1.13. After calling for those with rarer cancers to have fairer access to treatment, we are delighted that the Government announced a £200 million drugs fund and the £50 million interim fund. We hope that cancer patients in the England will now have access to the same 'gold standard' treatments as people living in Europe and other equivalent countries. We very much hope the fund will target and support those with rarer cancers and that the commitment to £200 million will survive the Comprehensive Spending Review process.

1.14. We also hope these funds will allow access to treatments in a timely and stress free manner avoiding the current pitfalls of the exceptional funding system.[see paragraph 4.6]

### **Promote further research into the cause of cancer inequalities**

1.15. The research undertaken by the NCEI and the NCIN is to be applauded for beginning to uncover the extent of cancer inequalities and why they occur.

1.16. For the NHS to continue to tackle inequalities, we must have greater understanding of the causes. We particularly need research into



interventions which will promote early diagnosis amongst disadvantaged groups, the reasons why mortality for the over 75s is falling slower than the rest of the population, why mortality rates for men are greater than for women and the impact of post-treatment care on the life chances, experiences and long-term outcomes of different groups of cancer survivors.

- 1.17. Research should also be focussed on collecting inequalities data on the outcome indicators selected for the NHS Outcomes Framework. The Government's ambition to break down each indicator by equality strand is welcomed, and if effected, would provide a fantastic resource for measuring the success of the NHS in tackling inequality. However, unless significant resource is attached to ensuring the data collection for those indicators includes equality dimensions, this will not be achieved.

#### **Ensure all cancer patients receive a regular care needs assessment**

- 1.18. For many people cancer is now a long term condition yet many feel abandoned at the end of treatment. Cancer survivors often require many different forms of support such as social care, financial advice and support, employment support and education. During our inquiry we heard evidence from many cancer patients and clinicians who said that these services are often poorly coordinated.
- 1.19. All cancer patients should receive a post treatment assessment and care plan. We believe that care plans are key to improving long term outcomes and experiences for cancer survivors as well ensuring a reduction in unnecessary follow up appointments, emergency admissions and treatment for subsequent illnesses – such as heart disease or incontinence – caused by the original cancer or its treatment.
- 1.20. Such holistic care and planning will not only serve to make patients true partners in care – in line with the Government's policy of 'no decisions about me without me' – but will also serve to better integrate and coordinate all forms of support.

## **2. What opportunities are there for delivering efficiencies or saving money in cancer care**

### **Early Diagnosis**

- 2.1. Formulating a one year cancer survival indicator, for all cancers and all ages (as described in paragraph 3.3), and setting incentives around performance will focus the NHS on educating the public to the risk factors of cancer and will also boost early diagnosis and quicker referrals, saving money.



### After care

- 2.2. Many cancer patients could be empowered to manage their own condition. The National Cancer Survivorship Initiative (NCSI) has estimated that around 60-70% of cancer survivors could be better supported through self-management rather than the current NHS 'follow-up' model. Self care will reduce the need for unnecessary follow up appointments and reduce unnecessary hospital admissions.
- 2.3. Research led by Macmillan and Monitor Group in Manchester suggests that improving coordination so that a small percentage of patients are moved to a less resource intensive cancer journey; and improving key aspects of care for breast and lung cancer patients in Manchester could release savings in the region of 10% of the measured NHS costs for these patients.
- 2.4. The NCSI Vision Document described the need for a cultural shift in the NHS to deliver this innovative, effective and less expensive approach to after care.

### Screening – flexi-scope

- 2.5. There are a number of new technologies in the care and treatment of cancer patients which have the potential to save the NHS money over the next decade and beyond. For example, the flexi-scope test could prevent a third of bowel cancers and reduce death rates by nearly half<sup>1</sup>. Modelling work shows that for every one person who has a flexi-scope test, there would be a net cost saving of £28 (this is the cost of screening compared to no screening – including costs of diagnosis, treatment and follow-up over the life of the cohort).

## **3. How best can quality and outcomes in cancer care be measured?**

### One year survival rates

- 3.1. Survival rates are a crucial way of measuring both quality and outcomes. We are delighted that in the Outcomes Framework Consultation both one and five year survival rates have been recognised within the 'improvement area' of Domain 1 'Preventing people from dying prematurely'.
- 3.2. The one year survival indicator must cover patients of all ages and all cancers, including the over 75s. This data is already collected and should be used.** As set out in our inequalities report (p15) there is now clear evidence that older people are treated less vigorously than younger people. A one year cancer survival indicator covering all ages would encourage clinicians to address this issue.

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<sup>1</sup> Atkin et al 'Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial' *The Lancet*, [Volume 375, Issue 9726](#), Pages 1624 - 1633, 8 May 2010.



3.3. The APPGC warmly welcomes the progress made in this area in recent weeks. The ONS Report, *A cancer survival index for PCTs*, published on 6 September 2010, details PCT one year survival rates in the form of an index adjusted to take into account patients' age, gender and cancer type. It therefore provides a robust comparison by which to judge PCT performance. This data should be used to inform the one year cancer survival measure highlighted by the Government in Domain 1 of the Outcomes Framework. If we are to achieve the Government's aim of improving England's one and five year survival rates so that they are among the best in Europe, the APPGC recommends that it is necessary for PCTs, and consortia in the future, to be incentivised to reach an acceptable index score, above the current PCT average.

#### Cancer Patient Experience Survey (CPES)

3.4. The Health White Paper explicitly states that it will encourage more widespread use of patient experience surveys to measure quality. Domain 4 of the Outcomes Framework is entitled, 'Ensuring people have a positive experience of care'. **The CPES is a vital mechanism for gauging cancer patients' experience and therefore delivering on this domain, and should be conducted at least every two years and reported within domain 4.**

3.5. The information elicited from the CPES must be made public and used by PCTs, and in the future consortia, to develop improvement plans for services. Commissioners should be incentivised to develop such plans, for example, through financial incentive schemes which the NHS Commissioning Board establishes to ensure progress is made against the Outcomes Framework.

#### Audits of diagnosis

3.6. Audits of cancer diagnosis in primary care are critical to driving up quality. The National Awareness and Early Diagnosis Initiative (NAEDI) currently undertake these audits. These need to be expanded for all cancers and the lessons learnt from audits need to be shared across PCTs (and across GP consortia) to improve quality across the board.

3.7. Data on the stage of diagnosis is an area where progress is still required. Diagnosing cancers at an earlier stage, when patients usually stand a better chance of being successfully treated, is a key aim of current cancer policy. This data offers an immediate insight into the performance of providers in regard to early diagnosis, it is, therefore, crucial to showing which areas need to improve.

3.8. To promote the collection of this data by multi-disciplinary teams, commissioners should be incentivised, through measures such as Quality



Standards, best-practice tariffs, or other financial incentives, to develop systems to capture this data. Certain areas, such as the East of England Cancer Network, are already doing this – their processes need to be shared across the country.

3.9. Once this data is collected it must be used to improve referral and early diagnosis at the primary care level. GPs must have better access to diagnostic tools and be given adequate training to use these diagnostics effectively.

#### **4. What further action is required to improve patients' experience of treatment and care?**

##### Informed Patients

- 4.1. As recognised in the Health White Paper, patients who are informed of their treatment and options are more likely to have a better experience than those who are not.
- 4.2. Information prescriptions offer high quality personalised information and support at key points along the cancer journey and improve patient experience. They provide an effective way of supplying cancer patients with the information they require to make informed choices about their treatment. These need to be provided at key points along the cancer journey.
- 4.3. During the APPGC's inquiry, witnesses – including Cancer Black Care – stated that different groups in society absorb information in different ways. For all individuals to benefit from the increased provision of information we believe it should be delivered with face-to-face support from a healthcare professional or other experience information giver.
- 4.4. The NHS should be held to account on its provision of information through Domain 4 of the Outcomes Framework. An outcome measure could be set if the following data were collected through the CPES:
  - Percentage of people who say they were involved in decisions about their treatment and care
  - Percentage of people who felt they had access to the information and support needed
- 4.5. As well as information about their care, patients need to have access to information about providers before they start treatment. The Government has made clear that it aims to improve patient choice about providers, which is welcome. To enable patients to make informed choices, Quality Accounts should be standardised to ensure information is presented consistently in an easily digestible format by every provider of cancer services. Only by providing such consumer information can people really



make comparisons and considered choices about their care.

#### Access and equity to treatment and care

- 4.6. Too often people with rarer cancers have been denied effective treatments due to the inflexibility of the current NICE appraisal process or because of where they live. Patients who had been denied treatment told the APPGC that it can be a most distressing and harrowing experience.
- 4.7. With the establishment of the Interim and April 2011 Cancer Drug Funds it is hoped the experiences of those with rarer cancers will improve. For those with extremely rare cancers where there is no licensed treatment, the prescription of treatments in a 'near-label' setting is often the only option. Like the interim fund, the April 2011 Cancer Drug Fund should cover these treatments. If not, those with extremely rare cancers will again be left with no options. This is simply not acceptable.
- 4.8. It is essential to measure the effectiveness of the April 2011 Cancers Drug Fund to ensure it meets its aims. The implementation of the fund should be measured by an audit of all applications to the fund that would record: demographic information on the individual who is receiving the drugs, where they live and the reasons for their application. The overall value of this audit would be to determine whether the fund was delivering on its promise to improve access to treatments. The purpose of this audit would be to:
- Determine whether people affected by rarer cancers have the same access to drugs as those affected by more common cancers
  - If access is refused, determine whether it is on strong clinical grounds i.e. denied Herceptin on the grounds that they are HER2 negative
  - Determine whether there are geographical disparities in treatment access
  - Build up the evidence base for the use of these treatments to support future NICE applications, or license applications in the case of off-label drugs, so that in future patients with extremely rare cancers can access proven treatments
- 4.9. Radiotherapy is another area where equity of access needs to improve. Around 10% or 30,000 cancer patients are missing out on radiotherapy treatment<sup>2</sup> despite the clear evidence of its benefits. It is implicated in four in ten cases where cancer is cured and when added to other treatments it is estimated to improve five year survival by 16%<sup>3</sup>.

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<sup>2</sup> This figure is based on Williams MC et al 2007 Radiotherapy Dose Fractionation, Access and Waiting Times in the Countries of the UK in 2005. Clin Oncol, which showed that of an average 50% of patients who should be receiving radiotherapy as part of their treatment, less than 40% actually are.

<sup>3</sup> Barton MB, GebSKI V, Manderson C, Langlands AO. Radiation Therapy: are we getting value for money? Clin Oncol 1995; 7: 287-292.



## **6. What developments in prevention, screening, diagnosis, treatment or after care can be expected which will impact upon the way in which cancer services need to be commissioned or delivered?**

### Screening

6.1. During its inquiry the APPGC received evidence that illustrated that low uptake of screening amongst certain groups in society remains a significant issue. Asian people were half as likely to take up screening; men, generally, were less likely to access bowel screening; only 19% of women with learning disabilities, attend cervical screening, compared to 77% of all women invited. As developments in screening technology occur, as described in paragraph 2.3 above, commissioners and providers must ensure that all in society benefit from this progress.

### After care

6.2. As stated in paragraphs 1.16 and 2.2-2.4 delivering a survivorship model of aftercare will require a culture shift in both commissioning and the delivery of care.

## **7. Looking at the plans set out in the White Paper and associated consultation documents (to be published shortly), what are the issues and opportunities for delivering cancer services and improved outcomes?**

7.1. The Health White Paper details the most profound reform of our health system in a generation. As responsibility for commissioning moves to consortia of general practitioners it is crucial that they are supported to improve outcomes for all cancer patients and reduce inequality.

### Review of arms length bodies

7.2. In the consultation document *Report of Arm's Length Bodies* the Government states that it intends to remove duplication in data collection by centralising data returns in the Health and Social Care Centre.

7.3. The CRS established vital bodies who undertake much crucial data collection and analysis. The NCIN has brought to light many cancer inequalities and has collected and published one year survival rates for all PCTs, uncovering those trusts that need to make improvements in the early diagnosis of cancer.

7.4. The NCIN is critical to the effective collection of outcome data and the delivery of the Government's information strategy and should remain.

### Public health

7.5. Research suggests that many thousands of cases of cancer in the UK could be prevented by changes to lifestyle.



7.6. The forthcoming White Paper on Public Health provides an opportunity to increase investment in cancer prevention and health promotion strategies.

7.7. There is also a good opportunity to protect young people from the effects of sunbeds by bringing into force each of the powers provided for in the Sunbeds (Regulation) Act 2010.

#### Cancer Drugs Fund

7.8. The APPGC looks forward to the consultation on the new Cancer Drugs Fund and as mentioned in paragraphs 4.5-4.7 hopes that this will improve access for those with rarer cancers.

#### Information Strategy

7.9. As mentioned in paragraphs 1.11, 1.12 and 4.1-4.4, the Government has set out a clear agenda for information. We believe information prescriptions have a critical role to play in delivering the Government's Information Revolution.

### **8. As we develop work to improve cancer outcomes, how can we make sure that we continue to try and tackle inequalities in cancer care?**

8.1. Each answer given within this response has attempted to describe how inequalities in cancer care and outcomes can be tackled. Although we face tough financial times, we cannot afford to leave the most vulnerable in society behind as the NHS reforms. We must use this opportunity to take action against inequality with renewed vigour and resolve.