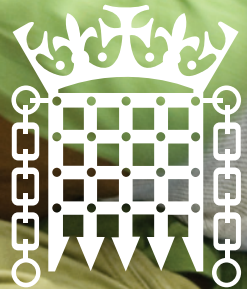




Tackling Cancer Inequalities – **one year on**



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Foreword

Following an extensive inquiry in 2009, the All Party Parliamentary Group on Cancer (APPGC) published a report last December on the unacceptable inequalities experienced by cancer patients in England, and made recommendations to address these inequalities. The report was warmly welcomed by the then Secretary of State for Health, Rt Hon Andy Burnham MP, National Cancer Director, Professor Sir Mike Richards, and the wider cancer community.



We were careful to ensure our recommendations were both ambitious and robust but also realistic. We kept one eye firmly on the financial constraints which we knew the NHS would be under for the foreseeable future. We firmly believe that our calls remain achievable even within this difficult economic climate.

Since publication, the APPGC has been working with the previous and current Government, Department of Health officials, the NHS, health sector experts, charities, patients and other cancer stakeholders to promote our findings and encourage implementation of our recommendations.

In this report, my fellow officers and I are pleased to present the excellent progress that has been made in tackling cancer inequalities in the last year.

Crucially, the new Government has embraced our most important recommendation – to establish a one year cancer survival rate metric to help focus the NHS on improving early diagnosis. My fellow APPG officers and I are delighted by this development.

There has also been considerable progress on a number of our other recommendations – from improving access to drug treatments for people with rarer cancers to support for care plans.

We would also like to use this report to thank the many people who have given such incredible support to our 2009 report, and to call upon the cancer community to continue the fight to ensure everyone affected by cancer, no matter who they are, where they live, or what cancer they have has access to the care and services they need.

With the new Government determined to reshape the health and social care landscape, we have a once-in-a-generation opportunity to reach our goal of ending inequalities in cancer care and services. We can make the experiences and outcomes of all cancer patients in England among the best in the world.

John Baron MP,
Chairman, APPG on Cancer

Introduction

The APPGC launched the report of its nine-month inquiry into cancer inequalities at the annual Britain Against Cancer conference in December 2009.



Drawing from 90 written submissions and oral evidence from patients, charities, cancer experts, service providers and Department of Health officials, we recommended eight priority actions to tackle the unacceptable inequalities experienced by cancer patients. **These were:**

- 1. Set a new indicator for one-year survival rates for all cancers and all ages**
- 2. Introduce measures to improve prevention and early detection**
- 3. Improve the collection of data about cancer patients**
- 4. Speed up the introduction of the cancer patient experience survey**
- 5. Provide better quality information for all patients throughout their cancer journey**
- 6. Provide more support for people with rarer cancers**
- 7. Promote further research into the causes of cancer inequalities**
- 8. Ensure all cancer patients receive a regular care needs assessment**

Implementing our recommendations

Over the last 12 months, APPGC officers, under the leadership of the Group's chair, John Baron MP, have worked tirelessly to keep cancer inequalities at the top of the political agenda and pushed for the implementation of the recommendations outlined in our 2009 report.



This work involved us collaborating with a range of cancer stakeholders. We received guidance and feedback from organisations including the National Institute for Health and Clinical Excellence (NICE), National Cancer Equality Initiative (NCEI), Care Quality Commission, National Specialised Commissioning Team, Pharmaceutical Oncology Initiative, National Cancer Intelligence Network (NCIN), and the stakeholder group of the APPGC.

APPGC officers also regularly raised our recommendations in Parliament and the Group responded to a number of health and cancer consultations, including the Cancer Reform Strategy Refresh.

Overall, we are delighted by the progress made on the implementation of many of our eight recommendations. However, the APPGC is keen for the Government, NHS and cancer community not to rest on their laurels. The recent wholesale reforms of the health system must be used as impetus for further action to reduce cancer inequalities and not as a reason to refocus efforts elsewhere.

The Cancer Reform Strategy Refresh, which we expect to be published in December 2010, gives the Government an ideal opportunity to make clear its commitment to continue this work.

Outlined in the rest of this report is a summary of the progress made over the past 12 months in delivering our eight recommendations and some proposed next steps.

1 Set a new indicator for one-year survival rates for all cancers and all ages to encourage the NHS to raise people's awareness of the symptoms of cancer; promote the early presentation and diagnosis of the disease; speed up the early referral system; and reduce the number of people aged 75 and over who die unnecessarily from cancer.



We are delighted that the Government has included one-year cancer survival rates as an improvement area for the NHS in the Outcomes Framework published in July 2010.

Crucially, the Government has also followed the APPGC's recommendation that survival rates should be measured for all ages, not just for those under 75. This will help address the under-treatment of older people.

The launch of the NCIN's Cancer Equalities Portal also represents significant progress. This has made cancer survival rates available to the public, revealing which primary care trusts (PCTs) have particularly poor cancer outcomes.

The NCIN, Office of National Statistics and London School of Hygiene and Tropical Medicine published *A cancer survival index for PCTs*. This details every PCT's one-year survival rates for 2006 in an index adjusted to take into account age, gender and cancer type of patients. This provides a fair way to evaluate and compare the performance of PCTs. The report shows that the best index score is

70.3% and the lowest is 56.3%. Overall, the one-year cancer survival index for England in 2006 is 65%.

Our 2009 report showed that if our survival rates matched the best in Europe, many thousands of lives could be saved each year.

Next steps

The adjusted cancer survival index scores of PCTs, and in the future, GP consortia, should be reported annually. All commissioners should be incentivised to deliver year-on-year improvements. The data should be presented as a performance table, rather than a league table.

The NHS Commissioning Board should review the performance of commissioners whose survival index scores are significantly below the best.

Another lever for improving early diagnosis is the routine collection of data for all cancers at the stage at which they are diagnosed. This will help to identify where improvements can be made.

2

Introduce measures to improve prevention and early detection, including increased action to prevent people taking up smoking, and helping those who do smoke to quit; better regulation of the sunbed industry; greater use of the Cancer Awareness Measure; and a national TV campaign and local outreach projects to promote lifestyles and behaviours shown to reduce the risk of cancer and raise awareness of signs and symptoms.



The Sunbed (Regulation) Act, banning under 18s from using sunbed salons, will become law in April 2011. We warmly welcome this legislation as a hugely positive development in the fight against skin cancer.

In our 2009 report, the APPGC called for a national media campaign, closely supported by targeted community-based outreach projects, that not only raises awareness of the key symptoms of cancer but also encourages people to adopt behaviours and lifestyles that minimise the risk of cancer.

As such, we are pleased with the Government's announcement that £9 million will be spent to support local campaigns that raise awareness and promote earlier diagnosis of the signs and symptoms of bowel, breast and lung cancer. We also look forward to seeing the evaluation from the two regions that are participating in centrally-led campaigns and how these campaigns will be developed at a national level.

The APPGC remains disappointed that programme makers are still not following the OFCOM broadcasting code on smoking.

It is unacceptable that programmes aired before the watershed continue to show people smoking with little or no editorial justification.

Next steps

We urge those organisations in England developing local awareness raising campaigns to fully consider the needs of more marginalised members of their communities. The charity sector, which has significant experience of developing awareness campaigns, should be called upon to offer expertise and advice. It is also important that the campaigns are evaluated so that lessons can be learnt and best practice shared.

The Government needs to ensure effective implementation of the Sunbeds (Regulation) Act 2010.

We continue to call on broadcasters to more closely observe OFCOM's guidance on smoking on television before the watershed.

3

Improve the collection of data about cancer patients, including information about ethnicity, sexual orientation, religion or belief, age and any disabilities. This data should help to determine whether there is inadvertent discrimination against particular groups and act as a spur for improvement.



In our inquiry the APPGC identified the need for more patient data to be collected. This will make it easier for commissioners to understand their local population, their likely needs, where the gaps in support are, and where there are significant inequalities in outcomes or experience.

The National Cancer Intelligence Network, working with the National Cancer Equality Initiative (NCEI), has led the way in collecting and publishing more information about cancer inequalities. The review of the National Cancer Dataset marks progress in this area.

The 2010 National Cancer Patient Experience Survey, which is expected to be published by the end of 2010, will also provide significant data to help us identify whether experience varies between different groups. For the first time, the survey also asked for information on sexual orientation and disability, which is very welcome.

Next steps

The NCEI's work to collect better and more extensive data should be actively supported by the Government in the Cancer Reform Strategy Refresh.

To ensure this occurs we call on more robust guidance for multi-disciplinary teams to collect equality data (sexual orientation, age, ethnicity and postcode) for all their patients, and for commissioners to be incentivised to develop systems to capture this data.

We also recommend that as better and more extensive equality data is collected, national cancer survival rates should be broken down and presented by each equality group.

4

Speed up the introduction of the National Cancer Patient Experience Survey to help healthcare providers tackle the inequalities experienced by particular groups of cancer patients.



We are pleased with the progress made on this priority action.

Following the publication of our 2009 report, the National Cancer Patient Experience Survey (CPES) was carried out over the summer.

We also praise the Government for placing an emphasis on patient experience in the Outcomes Framework for the NHS.

Next steps

The CPES is a vital mechanism for gauging the experiences of cancer patients. Therefore, it should be conducted annually and be included within the patient experience domain of the NHS Outcomes Framework. Results from the CPES should also be broken down by equality group as well as by cancer type.

Healthcare providers and commissioners should respond directly to the survey by drawing up action plans for improvement based on its findings.

The Care Quality Commission should also consider how it can use the survey's findings in its regulatory assessments of health and social care in England.

5

Provide better quality information for all patients throughout their cancer journey through personalised information prescriptions.



We called for every cancer patient to receive an information prescription (IP) by the end of 2010.

Although the roll out of IPs has begun, the APPGC is disappointed that our call has not been met and the delivery of IPs has been repeatedly delayed. At the time of writing we are still waiting for the publication of the DH implementation plan for cancer IPs. We hope this will be published soon with ministerial support.

The APPGC is pleased that the Government recognised the importance of IPs in its recent consultations, *An information revolution* and *Liberating the NHS: Greater choice and control*. However, IPs need to be more than just an 'option' for cancer patients. They are crucial in helping to ensure every cancer patient gets the information they need to understand their condition, treatment options and how to access support services.

We believe that IPs, delivered with face-to-face support from a health professional, have a vital role to play in delivering the Government's vision of 'no decision about me, without me'.

Next steps

Every cancer patient should be offered an information prescription by the end of 2012.

The NHS should be held to account over its provision of information to cancer patients through the Outcomes Framework. The performance of the NHS in this area could be measured if the following data was collected through the Cancer Patient Experience Survey:

- the percentage of people who say they were involved in decisions about their treatment and care to the extent they wished
- the percentage of people who felt they had access to the information and support they needed.

The delivery of IPs should be incentivised through their inclusion in measures such as NICE Quality Standards and the NHS Commissioning Board's commissioning framework.

6

Provide more support for people with rarer cancers by extending GP audits of cancer diagnosis so they cover more cancer types and all cancer networks; encouraging the National Institute for Health and Clinical Excellence (NICE) to have a more flexible approach to treatment appraisals; providing far greater access to clinically effective drug treatments; and improving the tools used by GPs to diagnose rarer cancers.



The Government's announcement that it will provide a £200 million per year Cancer Drug Fund and £50 million interim fund represents a huge stride forward in improving access to clinically effective drug treatments for all cancer patients. We now seek assurance that people with rarer cancers will be prioritised when the fund is implemented from April 2011.

We also welcome the Secretary of State for Health's commitment to move to a system of value based pricing. We hope this will ensure that more clinically effective drug treatments are available to cancer patients.

In its original report the APPGC also highlighted the importance of improved access to, and training on, diagnostic tools for GPs to help diagnose rarer cancers earlier. The APPGC was interested to learn that the National Awareness and Early Diagnosis Initiative's (NAEDI) audit of cancer diagnosis in primary care, which will be published later in the year, is expected to show that a lack of access to key diagnostic tools is delaying detection of cancer for many patients.

We continue to call for GPs to have access to more diagnostic tests – such as MRI or endoscopy – so they can refer and diagnose people as quickly as possible, and for cost-effective algorithmic tools to be developed to detect a greater number of rarer cancers.

Next steps

The Cancer Drug Fund must specifically help people with rarer cancers by making clinically effective cancer drugs far more accessible. The fund should also be monitored and audited to ensure people with rarer cancers are being prioritised and that there is consistent decision-making across all regions.

We continue to call for the NAEDI audits of cancer diagnoses in primary care, which currently collects data on 18,000 cases of cancer from 18 cancer networks, to be widened to cover all cancer types and all 28 networks.

The refreshed CRS must also support increased access to key diagnostic tests, and other decision aids, for GPs.

7

Promote further research into the causes of cancer inequalities, including why certain mortality rates are higher in men than women; why cancer mortality has not fallen as fast for people aged 75 and over as it has for people under 75; which interventions result in the early diagnosis of cancer; and why young people make unhealthy lifestyle decisions that significantly raise their risk of having cancer.



In March 2010, the National Cancer Equality Initiative (NCEI) published *Reducing cancer inequality: evidence, progress and making it happen*. It summarised the research that is being carried out to understand more about the causes and effects of cancer inequalities. The APPGC praises the work of the NCEI and is hopeful that momentum in this area will be maintained.

We also welcome the National Cancer Research Institute's (NCRI) commitment to work with the NCIN to prioritise additional equality research into lifestyle factors, early diagnosis and survivorship.

However, there is still much work to be done if the NCEI's goal of creating a substantial knowledge base on cancer inequalities by 2012 is to be achieved.

The NCEI identified that funding for research into cancer inequalities can be difficult to secure and that there are still unacceptable knowledge gaps.

There is also still little knowledge about why the reduction in mortality rates for older people is slower than for younger people, what action is effective in improving timing of presentation among more marginalised groups, and why mortality rates are higher in men than women.

Next steps

We want the NCRI, the National Cancer Research Network (NCRN) and research funders to prioritise the research areas identified in the NCEI's vision document. In particular, we continue to call for significant improvements in understanding around cancer inequalities by age and gender. We also want to see more research into the effectiveness of initiatives which aim to improve early diagnosis.

The NCEI should report back in 2011 on the progress made on increasing the body of research on cancer inequalities.

8

Ensure all cancer patients receive a regular care and holistic needs assessment at key points in their cancer journey to ensure that services for people with cancer are better coordinated to meet their practical, emotional, financial and information needs.



We commend the work of the National Cancer Survivorship Initiative (NCSI) in developing better support for people living with or after cancer. In particular, we support the NCSI's innovative approach to aftercare, which makes clear the need for post-treatment assessment and care planning.

In November, the National Audit Office reported that the number of cancer patients being admitted to hospital as an emergency doubled between 2000-2009. Many costly admissions through A&E could be avoided if the NHS better supported cancer survivors to manage their condition.

We warmly welcome the recent Government announcement in the Patient Choice consultation, *Liberating the NHS: Greater choice and control*, that everyone with a long-term condition should be offered a care plan.

We also praise the Government for supporting a more integrated approach to the delivery of health and social care, which should help ensure that the needs of cancer patients are better met, whatever stage they are at in their cancer journey.

Next steps

There is a range of things the Government can do to support the increased provision of care plans for cancer patients. These include:

- Including cancer in the Quality, Innovation, Productivity and Prevention (QIPP) programme of care plans for everyone with a long-term condition
- Including cancer in the long-term conditions outcome measure in the new NHS Outcomes Framework
- Ensuring the forthcoming Cancer Reform Strategy Refresh supports care plans for cancer survivors
- Ensuring care plans play a key role in the new NICE Quality Standards for cancer
- Ensuring the NHS Commissioning Board supports care plans in its commissioning framework.

Conclusion

When we published our *Tackling Cancer Inequalities* report last year we asked the Government and cancer community to support our eight priority actions and to work together to make sure every cancer patient receives the same high quality of treatment, care and service no matter who they are, where they live or what cancer they have.

This report has made clear the significant progress that has been made towards realising our vision during 2010. However, progress has not been wholesale and there are still many areas where action has not met expectation.

The APPGC will continue to champion the fight against cancer inequalities and we call on the Department of Health, NHS and other relevant organisations to use this report as a clear reminder of where there is still work to be done.

We cannot let the financial climate and the constraints on the NHS delay progress on the cancer equality agenda.

We firmly believe that now is the time to be bold and to tackle the unacceptable inequalities that persist in cancer care, services and outcomes with renewed purpose and vigour.

The NHS reforms cannot leave the most vulnerable people in society behind. We must use the opportunities reform presents to improve the experiences and outcomes of all cancer patients in England to be among the best in the world.

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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, National Cancer Intelligence Network, 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