



### Chairman's forward



John Baron MP Chairman, All Party Parliamentary Group on Cancer

If 2012 has been a year of transition for the NHS – with new philosophies and structures bedding down, and people in new posts – 2013 needs to be about delivery.

The All Party Parliamentary Group on Cancer (APPGC) hopes next year will mark the beginning of dramatic improvements across the country in the outcomes and experiences of cancer patients.

Last December, we launched our policy report Effective cancer commissioning in the new NHS. This set out our assessment of what needs to be done to improve the quality of cancer commissioning and, ultimately, ensure cancer outcomes continue to improve.

Throughout the year, the APPGC has been working hard encouraging the Government, NHS and cancer community to take action on these priorities. We held discussions with Ministers and other key officials at the Department of Health (DH) and the NHS Commissioning Board (NHSCB), as well as with our partners in the cancer community.

We have also campaigned in Parliament to keep these issues high on the agenda of Ministers. Our focus has been to ensure the Government does not take a step backwards by excluding the one and five year cancer survival measures from the Commissioning Outcomes Framework (COF) and by neglecting cancer networks. These campaigns are ongoing.

Our recommendations covered a range of issues, principally:

1 Ensuring commissioners deliver better cancer outcomes

2 Improving patient experience

3 Commissioning high quality integrated cancer services

4 Delivering better outcomes through improving public health

For this update report we have asked leading experts to assess progress against our priorities. The APPGC would like to thank those who have contributed: Sarah Woolnough, Executive Director of Policy and Information at Cancer Research UK; Mike Hobday, Director of Policy & Research at Macmillan Cancer Support; Mary Barnes, Director of Avon, Somerset & Wiltshire Cancer Network; and the Officers of the APPGC.

### 'Our focus has been to ensure the Government does not take a step backwards.'

They suggest that 2013 could see substantial progress being made. They also highlight specific areas, such as improving patient experience and ensuring cancer networks are at the heart of the NHS, where there is more work to be done. In this respect, the APPGC will continue to act as an ambassador for the cancer community in Parliament.

Finally, I would like to thank my fellow Officers for their hard work and dedication, and Macmillan for providing an excellent secretarial service.

John Baron MP

Chairman of the All Party Parliamentary Group on Cancer

## Ensuring commissioners deliver better cancer outcomes

In early 2011 the Government announced its ambition to save an additional 5,000 lives from cancer each year from 2014. For this to be achieved it is critical that the new NHS prioritises earlier diagnosis of all cancers and timely, effective treatment.

From April 2013, the NHS will be held to account on its performance nationally through the NHS Outcomes Framework, and locally through the COF. It is through these mechanisms that commissioners – from local Clinical Commissioning Groups (CCGs) to the NHSCB – will be motivated to take action to diagnose thousands more cancer cases early, and held to account for improving cancer survival.

The APPGC believes the first step to delivering better outcomes is to make sure the NHS is measured against the right benchmarks and milestones. That's why our 2011 recommendations focused on making the health service

accountability frameworks as robust as possible for cancer. We called for the NHS Outcomes Framework to incentivise improvements across all cancers and for the COF to encourage cancer outcomes to be a local issue.

More specifically we wanted to see NHS bodies, such as CCGs, measured against cancer survival rates. We also asked for proxy indicators for cancer survival, such as stage of cancer at diagnosis and cancers diagnosed as an emergency, to be included in the COF. These will provide a more immediate picture of what is happening at ground level.

'The first step to delivering better outcomes is to make sure the NHS is measured against the right benchmarks and milestones.'

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### 2012 progress

#### The Officers of the APPGC

We welcome the publication of the revised NHS Outcomes Framework which includes an indicator for one and five year cancer survival rates for all cancers, not just breast, lung and colorectal. This will provide an overview of progress in survival of all cancers and enable swift interventions for all groups of patients.

Progress on the COF has been more difficult and there is still considerable work to be done to improve it for cancer patients.

After falling in and out of favour with the National Institute for Clinical Excellence (NICE) COF Advisory Committee – the independent body appointed by the NHSCB to recommend indicators for the framework – one and five year cancer survival indicators were not recommended for inclusion in the first COF. Furthermore, indicators on stage of cancer at diagnosis and cancers diagnosed via an emergency admission have been left in the committee's 'potential indicators for future development' category.

If the NHSCB accept NICE's recommendation it will mean that CCGs will not be held to account for their performance on cancer survival in 2013/14.

The London School of Hygiene and Tropical Medicine has been commissioned to develop a composite measure for cancer survival at local CCG level. We believe that the development of composite indicators represents a significant step forward for people with less common and harder to treat cancers. However, many are concerned that by combining all cancer survival rates together, improvements for 'better performing' cancers could mask poorer performance elsewhere.

### Next steps

It's quite clear there is much work to be done in 2013 to strengthen the accountability frameworks:

The NHSCB should include one and five year survival indicators, covering all cancers, in the COF as quickly as possible.

2 A more detailed picture of the quality of cancer services at a local level is still needed. As such, stage of cancer at diagnosis should be included in the 2014/15 COF and

progress on developing an indicator on cancers diagnosed via emergency routes should be published.

The Government and NHSCB must make clear how the new composite indicators will work for rarer cancers and how the NHS will report against the indicator.

# 2 Meeting the needs of patients: improving patient experience

Improving survival rates has rightly been the focus of the NHS over the past decade. However, it is also vital that a better experience of care is secured for people throughout their cancer journey. This includes how care makes people feel, how responsive it is to people's needs and how supported people are at every stage of their journey.

In last year's report the APPGC put forward a series of recommendations which, if implemented, would go a long way to seeing patients put at the centre of decisions about their care. Included among these was a call for the National Cancer Patient Experience Survey (NCPES) to be conducted annually and used as an indicator in the NHS Outcomes Framework.

We also called for CCGs to show how they will involve patients in cancer commissioning.

We have continually raised these matters with Government and the NHSCB throughout 2012 to encourage them to place patient experience at the heart of their vision for cancer.

'It is vital that a better experience of care is secured for people throughout their cancer journey.'



### **2012 progress**Mike Hobday, Director of Policy and Research, Macmillan Cancer Support

People with cancer tell us about the central

importance of patient experience, including better communication, access to information and support, and being given the opportunity to make choices about their care.

Like the APPGC, Macmillan strongly believes that patient experience must become an integral part of the NHS. It must be regarded on the same footing as clinical outcomes, and seen as valuable in its own right. We are therefore pleased that important steps have been taken this year towards holding the new NHS bodies to account for their performance on cancer patient experience.

The NCPES is a valuable tool for measuring which hospital trusts provide a good experience to the cancer patients they treat, and where further progress needs to be made. While the 2011/12 survey results show that there have been improvements against most questions from 2010, there is still vast variation throughout the country in people's experiences of care. Significant development is needed in some key areas, such as care planning and information provision.

We were very pleased that the Government committed earlier this year to repeating the NCPES in 2012/13. This is a vital forum for patients' views to be heard and will allow us to measure and compare the performance of trusts across a number of years.

### Next steps

The new Health Secretary, Jeremy Hunt, has signalled his intention to prioritise patient experience, and we look forward to further progress being achieved in 2013:

1 Working with cancer charities, the Government must develop an indicator based on the NCPES for inclusion in the accountability frameworks. It will be vital that this indicator is relevant for a range of stakeholders, including commissioners, and that it accurately reflects what is important to people affected by cancer.

2 We also continue to support the APPGC's recommendation that the NHS Commissioning Board must commit to conducting the survey annually. This will ensure that the NHS is held to account for its performance on cancer patient experience on a regular basis and that continuous improvements are encouraged.



## Commissioning high quality integrated cancer services: the future of cancer networks

Our 2011 report called for both the newly created and existing NHS bodies to demonstrate how they would collaborate with each other in the reformed NHS. Integration between NHS bodies was a key principle of the health reforms.

Cancer networks have played a vital role in the integration of cancer care over the past decade. They provide expertise at every point of the cancer pathway and help to integrate cancer care at the local level.

The APPGC has worked with network directors to ensure that the structures are in place for their successful future. Last year we called on CCGs to demonstrate how they will collaborate with cancer networks.

We also stated that the role and responsibilities of cancer networks should be defined by the NHSCB. We have met this year with Dr Kathy McLean, who led the initial review of Strategic Clinical Networks (SCNs). It was an opportunity for us to reiterate our calls from last year's report and push for clarity for the many network staff affected by the changes.

'Cancer networks provide expertise at every point of the cancer pathway and help to integrate cancer care at the local level.'



**2012 progress**Mary Barnes, Director of Avoi

Mary Barnes, Director of Avon, Somerset and Wiltshire Cancer Network

2012 has been a difficult year for

cancer networks and their staff. In spite of the Government's commitment to fund cancer networks up to April 2013 and strengthen them beyond, there has been considerable uncertainty surrounding their future and funding over the past year.

In August 2012, the NHSCB proposed that from 2013 cancer networks would be established as SCNs. These SCNs will have centralised support teams in 12 geographical areas coterminous with the Clinical Senates across England. Each team will oversee a range of services including

cancer, cardiovascular, maternity and children, and mental health and neurological conditions. These teams will replace the condition-specific dedicated staff currently attached to individual networks.

The Single Operating Framework (SOF), published in November 2012, provides some clarity regarding remit and staffing of networks. However it is already evident that not many staff from existing cancer networks are being matched to the roles in the new structure. The resulting loss of knowledge of how to commission high quality cancer services is a significant concern.

### **Next steps**

It is clear that the changes to cancer networks pose a number of significant challenges for those concerned with ensuring that the highest quality cancer services are commissioned in the new NHS.

It is also evident that the new SCNs will need to work in a very different way to the current networks. They will cover a wider geography and be managed by a smaller team that includes a number of diseases and conditions. Fewer staff and a wider focus may have a negative impact on the quality of commissioning support provided in the new system, and avoiding this will be the key challenge for the NHSCB in the next year. Some practical steps to achieve this are:

The NHSCB must ensure that cancer networks have sufficient resources – both money and staff – to deliver their functions effectively.

2 Cancer-specific expertise must be retained in clinical networks, to ensure that cancer networks can continue to function effectively in the new system.

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# 4 Delivering better cancer outcomes through improving public health

The NHS reforms have seen a large overhaul in how public health services in England are organised and delivered. As we reported last year, an unhealthy lifestyle is the single biggest preventable cause of cancer. A reformed public health structure will help to tackle this and contribute to matching the UK's outcomes with the best in the world.

We also stated that the Public Health Outcomes Framework (PHOF) would set the context of the new system, and so it was imperative to include the right cancer indicators. Not only would this help to prevent cancer, it would also ensure that there is a consistent message across the three accountability frameworks.

Additionally, we called last year for collaboration between the new CCGs, Health and Wellbeing Boards (HWBs) and Public Health England (PHE) to ensure that the public health system was not fragmented.

'An unhealthy lifestyle is the single biggest preventable cause of cancer.'



### 2012 progress

Sarah Woolnough, Executive Director of Policy and Information, Cancer Research UK

Much has been achieved in public

health in 2012 but if the Government is to meet its ambition of saving an additional 5,000 lives a year from cancer from 2014, more must be done.

The APPGC and its stakeholder charities, including Cancer Research UK, successfully lobbied the Government to include cancer measures in the PHOF published in January 2012. In line with our recommendations, they included indicators for under-18 smoking, screening uptake and cancers diagnosed at stage one and two. These measures not only show that

tackling public health is a priority for this Government, but their inclusion in the PHOF will make a real difference when it comes to cancer prevention.

Of course, this does not mean that the battle against smoking is over. As PHE prepares to take centre stage in public health, we are delighted to hear that tackling smoking will be a priority. We were pleased that the Government also launched a public consultation on the plain packaging of cigarettes. The idea is to standardise all packaging to ensure children are protected from the 'silent salesman' of branded packs. This will give them one less reason to start smoking.

### **Next steps**

Despite this progress there remain many areas of uncertainty and a number of issues where action needs to be taken:

Directors of Public Health must detail how they will prevent cancer by tackling unhealthy behaviours in their localities. They must also explain how they will raise public awareness of the importance of early diagnosis of cancer.

2 In 2013 the Government must find parliamentary time for plain packaging legislation and move to implementation as swiftly as possible. There have been some strong steps taken to combat smoking in 2012, however in 2013 plain packaging needs to be a key focus of cancer prevention.

Finally, as the new statutory bodies take on full responsibility in April 2013, CCGs must demonstrate how they will collaborate with their local HWBs.

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### The way forward in 2013

Twelve months on from Effective commissioning in the new NHS, it is clear that there has been considerable progress towards establishing the new NHS landscape. We are pleased the recommendations we set out in that report, and our work throughout the year to convince Ministers and officials to implement them, has contributed meaningfully to securing some improvements.

As Sarah Woolnough highlighted, the PHOF now demonstrates a real commitment to preventing and tackling the causes of cancer. The shape of the NHS Outcomes Framework is also promising, with one and five year survival rates for all cancers now included as measures of NHS performance year on year. And as our Officers pointed out, work to develop composite survival rate indicators for the COF is underway.

But there remains a considerable amount of work to be done before we can be satisfied that the new NHS is set up to deliver world-class cancer services. Mary Barnes identified the difficult year endured by cancer networks, and the uncertainties surrounding their future. Whilst Mike Hobday called for extra focus to be placed on patient experience to ensure it is at the heart of all NHS cancer care.

What is clear from our experts is that the issues we raised in last year's report still remain pertinent in 2013. In some areas, progress from the Government and NHSCB has been impressive, in others more needs to be done for next year to be truly about delivery. The APPGC will continue to pressure decision makers in the NHS to prioritise cancer and ensure that effective cancer commissioning leads to world class cancer outcomes.

Huge strides have been made in cancer services in recent years, and the APPGC saw the NHS reforms as an opportunity to make further improvements.

What remains important of course is improving patient outcomes. That has always been the focus for the APPGC, and will remain our focus in 2013.



#### Get involved with the APPGC

Visit our website: www.appg-cancer.org.uk

Find us on Twitter: @appgc

And if you have a question for the group, you can

contact the Secretariat via sgould@macmillan.org.uk

#### ALL PARTY PARLIAMENTARY GROUP ON CANCER



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

## WE ARE MACMILLAN. CANCER SUPPORT

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